THE INVESTIGATING MEANING/PURPOSE AND CONNECTEDNESS (IMPACT) STUDY: A COMPARATIVE CASE STUDY OF PARENTS OF ADULT CHILDREN WITH SCHIZOPHRENIA

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by
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ABSTRACT

Schizophrenia is a chronic and disabling disease that causes significant stress for a family from the time of onset throughout the individual’s life. For families with members who live with schizophrenia, spirituality can be a source of support and help caregivers manage stress. While holistic nursing care of patients and families with schizophrenia includes addressing spiritual needs, spirituality is often not incorporated into nursing care due to a lack of understanding and confidence of nurses. There has been little research to understand the spiritual needs of parent caregivers of adult children with schizophrenia. The purpose of this comparative case study was to answer the question: “How do parent caregivers of adult children with schizophrenia renegotiate their spirituality, defined as life meaning/purpose and connectedness, in the years following the onset of the illness?” A comparative case study approach was used. Participants were recruited from the National Alliance on Mental Illness (NAMI) in Northeast Ohio and social media. Snowball sampling was also used to recruit participants. Eligibility criteria included the ability to speak and understand English, having an adult child with schizophrenia, and consenting to be interviewed via Zoom videoconferencing technology on a phone or computer. Three in-depth interviews were conducted with six participants, and artifacts were documented. Cases were analyzed individually using thematic analysis and across cases to identify similarities and differences. Three persons were interviewed, all white women between the ages of 57 and 73. When one participant was unable to complete the interview series, another was recruited. Primary themes from the interviews were conflict/peace, disconnectedness/connectedness, real/ideal, and despair/hope. Ancillary themes were related to the participants' personal values and beliefs and included the role of mother/parent/provider and personal religious beliefs. This study provided a deeper understanding of the process of renegotiating spirituality that can inform future nursing research exploring best ways to support for families with children who live with schizophrenia. This better understanding of family processes and needs can inform development of family-targeted, nurse-led programs to provide more individualized and holistic care to families.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Nursing and Health Studies, have examined a dissertation titled “The Investigating Meaning/Purpose and Connectedness (IMPACT) Study: A Comparative Case Study of Parents of Adult Children with Schizophrenia,” presented by Michelle Madeleine Clark, candidate for the Doctor of Philosophy degree, and certify that in their opinion it is worthy of acceptance.

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DEDICATION

This work is dedicated to all those who have cared for a family member with a serious mental illness. Remember that you are not alone, and support is out there. May all of us continue to fight against the stigma of mental illness.

CHAPTER 1

INTRODUCTION

The onset of schizophrenia is a catastrophic stressor for a family, as individuals with this severe mental disorder are unable to fulfill their expected societal roles and frequently live at home with their parents (Bademli & Duman, 2014). The parents can be overwhelmed by the burden of caregiving, the disruption of their supportive connections, and their sense of life meaning/purpose (Koutra et al., 2014). In the United States (U.S.) around 2.4 million people have a diagnosis of schizophrenia, and worldwide this disease affects 1.1% of the population (National Institute of Mental Health, n.d.). As such, schizophrenia is a leading cause of disability (Switaj et al., 2009). It is estimated that anywhere from one-third to one-half of homeless adults in the U.S. suffer from schizophrenia (Schizophrenia and Related Disorders Alliance of America, 2014). Because schizophrenia is a chronic illness that requires frequent psychiatric nursing care, schizophrenia carries a large economic burden, with an annual cost of $32.5 to $65 billion (Schizophrenia and Related Disorders Alliance of America, 2017).

Psychiatric nursing assumes a holistic approach to health care delivery, and as a result comprehensive nursing care of patients and families dealing with schizophrenia encompasses patients’ and their families’ psychological, physical, social, and spiritual well-being; yet, in current nursing care, spirituality is often overlooked, in part because spirituality is too often conflated with religion (Ramezani et al., 2014). But spirituality differs from religion. Spirituality is broader than organized religion and applies to a wider variety of contexts (C. C. Clark & Hunter, 2018). While religion is an organized system of beliefs, spirituality resides within each individual and pertains to a person’s beliefs about life’s purpose that shape how they relate to others and their experiences (Drury & Hunter, 2016). Spirituality can be addressed by focusing on how patients find meaning, purpose, and connectedness in their lives (C. C. Clark & Hunter, 2018). These core components of meaning/purpose and connectedness are the focus of the Investigating Meaning/Purpose and Connectedness (IMPACT) study.

Addressing spiritual needs is an essential part of nursing, since spirituality has been found to improve patient outcomes, including giving patients ways to cope with stress, a sense of control in life, and increased social supports (Koenig, 2012). While spirituality has been studied in relation to some mental health disorders, the majority of studies have been cross-sectional surveys assessing how important religion or spirituality is to caregivers and how it affects coping, caregiver burden, and quality of life (Gurak & Weisman de Mamani, 2016; Hsiao & Tsai, 2014; Jagannathan et al., 2014; Kate et al., 2013, 2014; Mantovani et al., 2016; Ong et al., 2016). These studies include research on burden, perceived stigma, and psychological distress among caregivers of patients with schizophrenia but not the experiences of spirituality of parents caring for adult children with schizophrenia and how this affects the caregiving process (Bonelli & Koenig, 2013). The IMPACT study, by addressing this question, aimed for better understanding of parents' spirituality. With this knowledge, we can empower nurses to address the spiritual aspect of health, thus enabling a more holistic approach to nursing care.

Background

The significance and purpose of the IMPACT study rests on two major premises: mental illness is a family crisis, and spirituality has health benefits. When a family member becomes ill with a severe mental illness, such as schizophrenia, research indicates that the resulting stress is experienced by individuals in a family and by the family unit as a whole (Gavois et al., 2006). Spirituality has been shown to be a helpful coping resource for families dealing with crises, one that can improve quality of life (Nolan et al., 2012). The IMPACT study addressed the need to understand how schizophrenia is a stressor for a family and how spirituality is a potential coping mechanism.

Mental Illness as Family Crisis

The societal understanding of how mental illness relates to the family unit has changed over the years. In past decades, families with a mentally ill member were blamed for the illness and labeled as dysfunctional (Doornbos, 1996). In the mid-Sixties, Lidz developed a theory that schizophrenogenic mothers caused schizophrenia in their child. According to Lidz, mothers who were dominating and self-absorbed could cause their children to develop schizophrenia (Lidz et al., 1966). Lidz's theory was widely accepted in the psychiatric community through the 1970s. As a result of this theory, parents of children with schizophrenia experienced a large amount of guilt and burden surrounding the illness and found little sources of coping (Brady & McCain, 2005). Now, the theory regarding schizophrenogenic mothers has been rejected, and there is a greater awareness of the biological factors that are involved in mental illness, resulting in a more clinical approach to treating mental illness (Doornbos, 1996). However, there is still much stigma and discrimination associated with mental illness, which can add to the stress that a family experiences (Gonzalez-Torres et al., 2007). Although there is now a greater understanding of the numerous factors involved in mental illness, dealing with mental illness continues to be challenging for families.

When faced with mental illness, the normal functioning of a family is disrupted. The onset of mental illness results in a crisis for a family (Gavois et al., 2006). There are two main types of stressors that families face–normative and non-normative stressors. Normative stressors are expected changes in the family cycle that do not cause significant distress, such as the birth of a child or the death of a grandparent (McCubbin & Patterson, 1983). Non-normative stressors are unexpected and traumatic (McCubbin & Patterson, 1983). When the family does not have sufficient resources to overcome non-normative stressors, then crisis occurs (McCubbin & Patterson, 1983). As such, severe mental illness is a non-normative stressor, and it has also been described as a catastrophic stressor, as it is a sudden and extreme threat to the family (Mo'tamedi et al., 2014). The crisis of mental illness is one that is both unexpected and overwhelming to a family.

Mental illness is a significant source of stress, because it causes disequilibrium within the family on many levels (Quah, 2014). Severe mental illness can cause the family to have difficulties with finances, employment, housing, marital relationships, other interpersonal relationships, and legal issues (Doornbos, 1996). Additionally, a family with a member that has a severe mental illness experiences caregiver burden, grief, guilt, shame, stigma, and difficulties communicating with the health care system (Crowe & Lyness, 2014). Families with a mentally ill member often face the additional challenge of being the patient's sole source of support, although few families feel adequately equipped to provide such support (Rose et al., 2002). Some research has indicated that the greatest impact on the family is the symptoms of the mental illness (Rose et al., 2002). Families have also reported that a central concern is living with the ambiguity of a mental illness (Rose et al., 2002).

Schizophrenia is a mental illness that causes severe stress on a family. The symptoms of schizophrenia can have a sudden onset and be extremely distressing for both patients and their families (Saunders, 2003). Due to the severity of the symptoms, people with schizophrenia typically experience severe impairment in functioning in various areas of life, such as social and occupational dysfunctions (Jablensky, 2010; Saunders, 2003). The sudden changes that come with the onset of schizophrenia can shatter family functioning and stability. Individuals with schizophrenia often live at home and are cared for by their parents, causing high levels of caregiver burden in families dealing with schizophrenia (Saunders, 2003). The family dynamics and coping mechanisms shift as parents deal with the stress and transition of re-taking on the roles of caregivers of their child, who is now an adult. Depression is common among caregivers of family members with schizophrenia (Koutra et al., 2014), meaning that parents must cope with the responsibility of caring for their adult children while also dealing with their own mental health issues.

An additional stressor is that parents of children with schizophrenia seldom get a respite from caregiving (Pattison et al., 1975). Parents have the responsibility of caring for their adult children almost constantly and providing for all their needs, and this can be extremely overwhelming. In a pilot study of parents of adult children with schizophrenia, a major reason why parents felt a need to provide constant care and supervision to their children was concern regarding their children’s safety (M. M. Clark, personal communication, 2016). Parents are often overwhelmed facing the burden of full-time caregiving and the disruption of their supportive connections and their sense of life meaning/purpose. Patients and families dealing with mental illness often struggle with isolation, as stigma and community rejection is a common reaction to the onset of mental illness (Ong et al., 2016). It is during these times of crisis, such as the onset of mental illness, that the family most needs supportive connections from outside the family, for only very resilient families are able to successfully navigate the threat of crisis while retaining very close connections. Most must reach beyond their immediate support system for outside assistance, such as from mental health counselors, clergy, and support groups (Mo'tamedi et al., 2014). The disruption of close ties and the changes in understanding of life meaning/purpose relate to issues of spirituality.

Benefits of Spirituality

The search for meaning/purpose and connectedness is an essential component of spirituality, which plays a central role in the life of many Americans. Nearly 60% of Americans are members of a faith community, and 86% believe in God or a universal spirit (*Religion*, 2017). Numerous studies have found an association between spiritual practices and positive mental health (Nolan et al., 2012; Weaver, Flannelly, Flannelly, Koenig, & Larson, 1998).

Spirituality has many benefits and has been shown to improve patient outcomes. When patients are involved in spiritual pursuits, such as searching for meaning and forming relationships, they have lower rates of depression and hospitalization and report increased satisfaction with life (McLaughlin, 2004). Encouraging patients to engage in spirituality can help reduce anxiety and put patients at a lower risk for committing suicide (Nolan et al., 2012; Rosmarin, Bigda-Peyton, Öngur, Pargament, & Björgvinsson, 2013). Spiritual coping is also related to less severe negative symptoms of schizophrenia (Tabak & Weisman de Mamani, 2014). When utilized in psychiatric care, addressing spiritual needs, such as searching for meaning and relationships, can bring about numerous benefits for patients and their families. Searching for meaning and relationships is a major way that people cope with psychiatric illnesses, but currently not much is known about how this happens in families during the months and years following the onset of mental illness in a family member. By learning more about the changing spiritual needs and experiences of families dealing with schizophrenia, we can provide psychiatric nurses with the tools to address aspects of spirituality that will help patients interpret and cope with their experiences with mental illness.

Purpose

The purpose of the IMPACT study was to explore the renegotiation of spirituality among parents of adult children with schizophrenia. The core aspects of spirituality are identified as life meaning/purpose and connectedness, since spirituality involves searching for an understanding of ultimate questions in life and seeking out supportive relationships (Huguelet et al., 2011; Menezes & Moreira-Almeida, 2010). Renegotiation refers to how the parents' spiritual needs shift and their understanding of their personal spirituality changes. Numerous studies have addressed the problem of caregiver burden and the negative impacts on the family dealing with schizophrenia. However, little research has been completed on the spiritual needs of the parents, the majority of whom are the primary caregivers of their adult children with schizophrenia (Bademli & Duman, 2014).

The IMPACT study investigated the spiritual needs of parents of adult children with schizophrenia utilizing a comparative case study approach. The case study method combines diverse data sources, including interviews, observations, and artifacts; allows for analysis of core experiences and shared dimensions; and includes comparison of common themes across cases (Patton, 2015). Due to its comprehensive, detailed look at individual cases, this approach allows for a more nuanced, in-depth view of how people behave, understand, approach, and interact with a phenomenon (Sandelowski, 2011). A comparative case study inquiry involves identifying and describing themes across cases (Patton, 2015). The comparison aspect allows an investigator to identify the salient themes that emerge out of the variation across the cases (Patton, 2015).

In the IMPACT study, the case study approach helped to discover the nuanced ways in which a parent caregiver's spirituality changed when faced with schizophrenia in an adult child. The in-depth understanding gained from this study can be used to inform future studies regarding spirituality, schizophrenia, and the family. Further research in meaning/purpose and connectedness among patients with schizophrenia and their families will be a useful contribution to the field of psychiatric nursing.

Research Question and Specific Aim

The central research question of the IMPACT study was: *How do parent caregivers of adult children with schizophrenia renegotiate their spirituality, defined as life meaning/purpose and connectedness, in the years following onset of the illness?* The specific aim of the study was to learn more about parent caregivers' renegotiation of spirituality after the onset of schizophrenia in their child using a comparative case study approach based on the construction and analysis of six individual cases based on life story interviews, interview observations, and volunteered archival objects, hereafter referred to as "memory objects."

Researcher's Voice

In qualitative inquiry, the background of the researcher plays an integral role in how research is generated, analyzed, and interpreted (Patton, 2015). In the spirit of qualitative research, I have chosen to make my research voice present in my dissertation. My research voice comes from my experiences and philosophies. My biographic influences, philosophic assumptions, and interpretive paradigms impact my research choices.

Biographic Influences

The research topic of the search for life meaning/purpose and connectedness within the experience of schizophrenia grew out of my personal biography, specifically my career path. I began my career in health care chaplaincy before becoming a psychiatric nurse. In chaplaincy, the focus was on assessing and caring for the spiritual needs of the patients. While I saw the importance of the spiritual aspect of health, I became interested in caring for the patients’ physical and mental needs, as well. This interest drew me into the profession of nursing. I see nursing as a holistic profession that encompasses all aspects of health and wellness, including spiritual, emotional, physical, mental, and social. When I became a nurse, I entered the field of psychiatric nursing, finding it had many similarities to chaplaincy, including the focus on emotional needs and the importance of therapeutic communication. As a nurse, I also heard patients express spiritual needs and concerns. I became interested in learning more about the intersection between spirituality and nursing care.

On beginning my PhD studies, I planned to focus my research on nursing and spiritual care. I encountered a challenge in that some nurses do not feel comfortable talking about spirituality and feel that it is not part of their role (Hilton et al., 2002). For some patients as well, discussing spirituality may not be comfortable. However, my personal understanding of spirituality, supported by numerous accounts of spirituality in literature, is that spirituality is a universal human experience that does not necessitate adherence to any faith tradition or even a belief in God (Fry, 1998; Koslander & Arvidsson, 2005; Menezes &

Moreira-Almeida, 2010). To make the concept of spirituality more accessible to both nurses and patients, I decided to examine the topic of spirituality in relation to the core concepts that emerged in my review of the literature, those of life meaning/purpose and connectedness.

My background also influenced my choice of the patient population. I work on an acute adult inpatient psychiatric unit. The unit patient population is predominately patients with psychosis, many of whom are ill with schizophrenia. In my experience with patients with schizophrenia, I have seen many express a need for finding meaning—by requesting Bibles to read, visiting with their ministers, or attending chaplain-led groups on spirituality. Although psychosis sometimes involves religious delusions, this does not mean that patients do not have spiritual needs. Patients still feel a need to find meaning in their lives and form important relationships with others. I wanted to learn more about the role that spirituality plays within the experience of schizophrenia. Learning more about what role spirituality plays for caregivers of patients with schizophrenia and those who care for them can help nurses better understand their needs and identify interventions that will be of benefit.

My biographical influences relate to how I situate myself in research. I am not approaching my research interests as a blank slate. Rather, my interests have influenced and been influenced by the career path I have taken and my understanding of spiritual needs and nursing care.

Philosophic Assumptions

In addition to the biographical influences that have affected the direction of my research, my beliefs and philosophic orientation, including ontological, epistemological, and methodological assumptions I make, impact how I understand the world and approach this research.

Ontology

Ontology deals with the nature of being and existence (Butts & Rich, 2015). My ontological assumptions impact how I understand reality. While some people believe there is one absolute reality that can be known through science and others believe there are multiple realities constructed through personal experiences, my ontological stance lies somewhere in the middle. I believe that there are some aspects of reality that are absolute and discoverable, such as pathophysiological processes and physiological responses. However, for some things, multiple realities may exist. Both in my work as a chaplain and a psychiatric nurse, I have seen how religion, spirituality, culture, and ethnicity can affect how people understand, experience, and respond to mental illness. When I think about the big picture of the nature of reality, I try to remember that while some things in life are certain, many things are uncertain and subjective. For me, it is important to be open to multiple interpretations and understandings.

Epistemology

In my research, I am seeking knowledge through a deeper understanding of others' perspectives. I believe that there is not just one answer to my questions. Each patient comes from a unique spiritual perspective and will have different answers for finding meaning and purpose in life and what constitutes a meaningful relationship. While some research questions are suited to quantitative analysis in a controlled setting, I feel that my topic is better suited to qualitative inquiry, as it deals with personal and subjective issues. In keeping with this epistemological perspective, I used inductive approach in the IMPACT study. I think that for my research area, I can best obtain knowledge through individual observations. At the same time, my interpretation of those observations will necessarily be affected by my understanding of research and theory in the fields of family burden and spirituality. In particular, I will bring to my analysis of cases assumptions borrowed from the theory of spirituality and health (Miner-Williams, 2006), discussed below, which will guide but not dictate my initial approach to analysis. In the end though, I want to understand the experience of schizophrenia from the perspectives of the individual family members. I do not think the knowledge gained through my research will be absolute—I question whether complete knowledge is possible—but what I find will add to a bigger picture that will help build a deeper understanding about how spirituality plays a role in the experiences of schizophrenia.

Rhetoric

In writing about my research, it was important to convey the voices of my research participants through frequent and sometimes extensive quoting. Individuals with mental illnesses are a marginalized group in society, so it is important to have their perspectives and the perspectives of those who care for them represented in the research. I also promoted author presence through the use of first-person in the writing of the research, because I think it is important to bring in my perspective—signified by my voice—and to keep my background in chaplaincy and psychiatric nursing in view.

Interpretive Paradigm

In keeping with my ontological and epistemological assumptions, the interpretive paradigm of constructivism guided my research. Constructivism rejects the idea of an absolute reality and understands that human relationships and perceptions affect how a phenomenon is understood (Patton, 2015). Constructivism is appropriate for the IMPACT study, since I am searching for participants' multiple realities through interviews with parents caring for adult children with schizophrenia. My goal is to be able to glean from the construction of individual cases a deeper knowledge of how the spiritual concepts of life meaning and relationships and how they are uniquely understood and experienced by families dealing with schizophrenia. Thus, my work took an inductive approach, as I analyzed the individual stories to bring together patterns and build interpretations to shed light on the experiences of schizophrenia and create the "case" or story of the participants' experiences. It is my hope that this work will be a helpful contribution to psychiatric nursing and improve nurses' understanding of needs, experiences, and values of families dealing with schizophrenia.

Definition of Terms

The following section defines the major terms used in this study.

Crisis

A crisis is a stressful event that causes an imbalance in the family. The family's normal coping resources are depleted, and to deal with this problem there must be changes in the family system (Staudt & Drake, 2002). Each family has a unique perception of the crisis situation that affects their ability to cope (Kolier, 1991). A crisis for a family involves the stressors, the family resources, and the perception of the event. Some families can recover from a crisis and quickly return to their previous level of functioning or perhaps an even higher level. However, other families take longer to work through the crisis and may not be able to return to their previous level of functioning (Patterson, 1988). The stressors that cause a crisis can take on a number of forms, one of which is the onset of serious mental illness (Witt, 2016).

Parent

For the purposes of the IMPACT study, parent will refer to an individual responsible for the care of the child that they are related to biologically or through adoption or marriage.

This is in keeping with other research in which the diversity of family structures has been acknowledged. In the U.S. in recent years, there has been an increasing number of children living in situations where the parents are divorced, separated, or have never been married. Additionally, more diverse parental structures are present, such as two mothers or two fathers caring for children (Wojtkiewicz, 1992). While there is diversity in regard to the types of parents that may be caring for children, all parents share similar roles and responsibilities. These include supervising children, showing affection, encouraging peer relationships, assisting children with everyday problems, disciplining children, and encouraging conformity to family and societal norms (Amato & Fowler, 2004).

Serious Mental Illness

Serious mental illness includes a variety of psychiatric disorders that can be debilitating for the patient and have significant impact on the family. Serious mental illness includes major depression, schizophrenia, bipolar disorder, panic disorder, post-traumatic stress disorder, and borderline personality disorder (Crowe & Lyness, 2014). A common aspect of these conditions is that they can cause alterations in thought, mood, and behavior (Rose et al., 2002). Serious mental illnesses are distinguished from other mental illnesses by the significant impairment in functioning they cause, which limits one or more life activities, including relationships, activities of daily living, care for self, recreation, and employment (Substance Abuse and Mental Health Services Administration, 2016).

Schizophrenia

Emil Kraepelin developed the diagnosis of schizophrenia in the early 1900s by integrating a number of clinical signs and symptoms, including loss of function, disorganized speech and behavior, hallucinations, and delusions (Jablensky, 2010). Schizophrenia includes both positive and negative symptoms. Hallucinations (false sensory perceptions) and delusions (false beliefs) are the main positive symptoms of schizophrenia (Menezes & Moreira-Almeida, 2010). The negative symptoms include apathy, social withdrawal, flat affect, lack of motivation, and lack of speech (Jablensky, 2010). The average age of onset of schizophrenia is between 16-25 years for men and 25-35 years in women. Having an earlier age of onset is associated with greater psychopathology, including earlier conduct problems, premorbid personality changes, greater cognitive impairment, and structural brain changes (Butjosa et al., 2016).

Spirituality

The root of the word spirituality is spirit, which originates from *spiritus*, the Latin word for breath (Online Etymology Dictionary, 2017). Spirituality is a universal dimension of human existence, although it is uniquely experienced and expressed (Koslander & Arvidsson, 2005). While religion and spirituality are closely connected, they can be differentiated. Religion is a formalized system of beliefs and practices related to the transcendent or sacred that is shared by a group of people (Clark & Hunter, 2018). While the definition of spirituality overlaps with religion, spirituality is generally considered the broader concept (Koenig, 2012). Not everyone may consider themselves religious, but most acknowledge that some form of spirituality is present in everyone. Spirituality is broader than religion because it is not tied to specific tenets or beliefs (as religion is). In general, spirituality relates to how people find purpose and supportive connections in their lives (Drury & Hunter, 2016). Spirituality functions for many as a source of strength when faced with a crisis or stressful life event, such as an illness or a death (McLaughlin, 2004; Murray & Zenter, 1989). Thompson (2002) asserts that spirituality affords comfort during times of stress, promotes self-meaning, and instills a sense of connectedness. As spirituality is thought to be present in nearly all people and has been connected to health benefits, it is an essential aspect of health for nursing to consider.

To arrive at a working definition of spirituality for the IMPACT study, I considered multiple definitions in the literature, shown in Table 1. As illustrated in Table 2, from the examination of the definitions of spirituality, I identified two main themes: a sense of meaning or purpose and a sense of connectedness.

Life Meaning/Purpose

Central to the concept of spirituality is the idea that there is meaning and purpose in life (Hammond, 2003). Spirituality is about the *search* for meaning and purpose in life, but it is also about the *source* of meaning and purpose in life (Miner-Williams, 2006; Thompson, 2002). Addressing ultimate questions regarding life meaning/purpose is a critical concern in spirituality (Huguelet, Mohr, Gilliéron, Brandt, & Borras, 2010). For people struggling with illness who may not be satisfied with medical explanations alone, spirituality can offer an additional viewpoint that brings meaning and provides a way to cope with difficult life circumstances (McCarthy-Jones et al., 2013).

Connectedness

The second theme common to most definitions of spirituality involves relationships and how one connects with others. The context of spirituality is intra/inter-relational in nature in that it embodies reflecting on how one relates to oneself, others, groups, and the transcendent (Nolan & Crawford, 1997). This includes connections with oneself, others, nature, and, for many, that which is transcendent or sacred (Fry, 1998; Menezes & Moreira-Almeida, 2010; Miner-Williams, 2006). This sense of connectedness provides a sense of supportive community to ease feelings of loneliness and isolation in times of crisis (Koenig, 2009). Combining the two themes, in the IMPACT study I defined spirituality as one's effort to find life meaning/purpose and connectedness. Spirituality names both the process and the result of a search for life's meaning and for supportive relationships with others, including but not exclusive to the transcendent (Huguelet et al., 2011; Menezes & Moreira-Almeida, 2010).

Chapter Overview

Chapter 2 presents both a review of the literature and a discussion of applicable theoretical frameworks. The review of the literature includes two major parts: first, an overview of changing views on spirituality and how spirituality has been addressed in research psychiatric nursing practice, and, second, a review of literature that focuses specifically on the effects of schizophrenia on the family and major concepts found in that literature on family caregiving. My discussion of theory includes consideration of the two main theoretical frameworks that will guide the study, family systems theory and the theory of spirituality and health.

Chapter 3 presents the methods to be used in the IMPACT study. The chapter includes elucidation of the study design, setting, participants, data collection plan, and data analysis procedures. I also discuss potential problems and how they were addressed and provide the timeline for study completion.

In chapter 4, I present the findings from the IMPACT study, including the individual case reports and the comparative analysis.

Chapter 5, the conclusion, outlines the general implications of this study, the potential next steps for future research to which it potentially points, and how its findings might be incorporated by nurses into their practice.

CHAPTER 2

REVIEW OF THE LITERATURE AND THEORETICAL FRAMEWORK

Review of the Literature

To review the literature on psychiatric nursing and spirituality, a search of relevant databases was performed using the date range 1987-2018. Databases searched include PubMed, CINAHL, and PsychINFO. Key search terms used included “nurses AND spiritual assessment,” “spirituality AND mental health,” “psychiatric nursing AND spirituality,” “psychosis AND spirituality,” “nursing AND spiritual AND psychotic,” and “schizophrenia AND religion.” The searches resulted in a total of 1549 articles. After scanning the abstracts for relevancy to the topic, 70 articles were downloaded for further review. Of those 70 articles, 56 were then included in the literature review. These articles were read, and the salient information was recorded onto a search strategy form and a matrix table. In reviewing the literature, I identified trends in the research over time as well as gaps in the body of literature that warranted further research.

The Changing View of Spirituality

Spirituality and psychiatric care have been connected historically, although this relationship has changed over the years. Before modern psychiatry, mental illness was seen as a malady of the spirit. In ancient times, when people displayed signs of mental illness, such as disturbed speech, behavior, and mood, it was attributed to supernatural powers, such as evil spirits (Porter, 2002). To treat these spiritual illnesses magical or spiritual remedies were used and people were often sent to religious centers, such as churches and shrines (Porter, 2002). Spirituality and psychiatric care were closely connected until the work of Sigmund Freud initiated their separation (Koenig, 2012). In his early work *Three Essays on* *the Theory of Sexuality,* Freud (1905) discussed how religion was a force of authority and prohibition that people both desired and feared. Thus, religion could become repressed in one's consciousness and become a source of hysteria in which psychiatric issues were manifest in physical symptoms. Although spirituality was initially viewed as an integral part of both nursing and psychiatric care, this viewpoint shifted within the past hundred years, which presents challenges for modern-day psychiatric nursing care. As is reflected in the research literature, the understanding of the relationship between spirituality and psychiatric nursing practice has continued to evolve in recent decades.

The Late Eighties and Nineties (1987-1999)

This period of literature explored how psychiatric nurses incorporated spirituality into their practice. Boutell and Bozett (1990), for example, conducted a cross-sectional survey of nurses to examine the extent to which they assessed their patients' spiritual needs. The results indicated that psychiatric nurses were more likely than other specialties to assess the spiritual needs of their patients (Boutell & Bozett, 1990). In a descriptive, correlational study, Pullen, Tuck, and Mix (1996) investigated the spiritual perspectives of psychiatric nurses and found that psychiatric nurses scored high on the Spiritual Perspective Scale (SPS), meaning their spirituality was very important to them and helped guide their nursing practice. A second study during this period also used the SPS scale to investigate how psychiatric nurses incorporated spirituality into their practice (Tuck et al., 1997). In this study, Tuck et al. (1997) found that while psychiatric nurses had high SPS scores and valued the use of spiritual interventions, few nurses reported using spiritual interventions. The authors proposed that nurses may have viewed spiritual interventions as outside their role (Tuck et al., 1997). However, as documented in a contemporaneous study by Weaver et al. (1998), the majority of psychiatric nurses viewed spirituality as important both personally and professionally and believed they were in a unique position to contribute to the spiritual well-being of their patients. In general, the early literature contained mostly qualitative, descriptive studies and focused on the experiences of the nurses rather than the patients. While the importance of spirituality in psychiatric nursing was stressed, there was a lack of studies looking at the patient experience.

The 2000s (2000-2009)

During this time, the literature on spirituality and psychiatric nursing began to focus on the experiences of the patients. Hilton, Ghaznavi, and Zuberi (2002) conducted a retrospective chart review to investigate religious and spiritual practices among acute psychiatric patients. Their study revealed that, while all patients had a documented religious preference, there was no information about their specific religious or spiritual beliefs or practices (Hilton et al., 2002). Based on these findings, the authors concluded that patients were not having their religious and/or spiritual beliefs met (Hilton et al., 2002). Tarko (2002) undertook a grounded theory study exploring the experience of spirituality among patients with schizophrenia and discovered a major theme, “spirituality as connection.” Tarko’s (2002) research explicated how individuals with schizophrenia experience spirituality as a search for connection with oneself, others, the larger community, and nature.

During the first decade of the new millennium, scholars doing work in mental illness also affirmed the benefits of addressing the spirituality of patients and the role of spirituality as a form of coping that leads to improved patient outcomes (Koenig, 2009). Studies that were conducted to investigate these ideas again found that spirituality was often not addressed by staff (Thompson, 2002). While spirituality is a useful form of coping, most mental health caregivers were not addressing issues of spirituality with their patients. According to one study performed during this period, while a majority of patients with schizophrenia felt their spirituality was an important aspect of their lives, only 36% mentioned their spiritual needs to their mental health clinicians (Philippe Huguelet et al., 2006).

One proposed reason for the lack of spiritual interventions by nurses was the lack of information and training in how to address spiritual needs. In her review of the literature on spiritual care and nursing, Ross (2006) concluded that nurses need more education on spirituality and spiritual care in order to provide comprehensive patient care. Koslander and Arvidsson (2006) conducted a phenomenological study of psychiatric nurses and found that nurses attempted to provide for the spiritual needs of their patients by being a “good carer,” and while nurses strove to recognize the spiritual dimension of the nurse-patient relationship they found it difficult to do so. Nurse researchers have investigated ways to equip nurses to address this spiritual dimension. Thomas Cox (2003), for instance, proposed that simple and brief spiritual interventions based on Martha Rogers’s nursing framework might be effective tools for addressing patients’ spiritual needs. Cox (2003) stressed that spiritual interventions must be performed in a non-intrusive manner that respects the privacy and personal spirituality of the patient. The literature during this period began to focus on *how* to better integrate caring for spiritual needs into nursing care. Although researchers saw that spirituality could provide patients with an increased sense of well-being and a way to find meaning to interpret their experiences, their studies continued to find that spirituality was overlooked in nursing care (McLaughlin, 2004).

The Present (2010-Present)

While the literature during the 2000s often focused on how nurses addressed spirituality with their patients, the current literature on spirituality and psychiatric nursing focuses more on patients with psychosis, such as patients with schizophrenia. In one study, for example, Menezes and Moreira-Almeida (2010) examined how spirituality and psychosis interact, how both feature similar experiences of feeling controlled by external influences and seeing and hearing things others do not see. Current studies have also looked at how culture influences both spirituality and delusions (Bassett & Baker, 2015; Earl et al., 2015; Gearing et al., 2011). These studies explored the connections between spirituality and psychosis and the way this connection can impact how psychiatric nurses approach issues of spirituality with psychotic patients (Bassett & Baker, 2015; Earl et al., 2015; Gearing et al., 2011; Menezes & Moreira-Almeida, 2010).

One of the central developments in the current literature is its focus on spirituality as a form of coping. Research in this vein has looked at the positive and negative effects of spirituality, with most concluding that the positive outweighs the negative (McCarthy-Jones, Waegeli, & Watkins, 2013; Mohr et al., 2010). In a recent study by Mohr et al. (2012), researchers examined spirituality and psychosis by seeking to understand the importance of spiritual coping among outpatients with schizophrenia. This study found that spirituality was helpful to 87% of the participants and harmful to 13% (Mohr et al., 2012). The positive effects of spirituality among the participants included a positive sense of self, use of spiritual resources to help them cope with illness, and a greater spiritual understanding of their illness which helped them become more accepting of their illness (Mohr et al., 2012). The harmful effects of spirituality included a negative sense of self, despair, increased delusions, depression, and substance abuse (Mohr et al., 2012). Although there is the potential for detrimental effects of spirituality, research more often indicated that spirituality is a helpful resource for mental health patients. Hammond (2003) examined specifically how spirituality can play a role in care plans of patients with a dual diagnosis (serious mental illness and substance abuse). This study found that spirituality could be a helpful addition to care plans for such patients and proposed that spirituality could be integrated into the treatment stages of engagement, motivation, active treatment, and relapse prevention (Hammond, 2003). In her review of the literature, Mohr (2006) concluded that as a holistic profession, nursing is obligated to address patients' spirituality. However, there are several ethical concerns that need to be considered when incorporating spirituality into psychiatric nursing practice. Ethical concerns for nursing included the imperative to avoid doing harm by not substituting spiritual interventions for evidence-based psychiatric interventions, and the imperative to avoid impinging on patient autonomy by imposing one's personal spiritual beliefs and practice on patients (Mohr, 2006).

Gaps in the literature

In the past 30 years, research on spirituality and psychosis has increased by 471% (Gearing et al., 2011). Despite the marked increase in this area of research, there remain gaps in the literature that warrant further investigation. While both quantitative and qualitative work that addresses spirituality in patients with serious mental illness has identified the benefits and core aspects of spirituality, there has been less research undertaken regarding how the benefits of spirituality are experienced and how the themes of spirituality are understood by family members caring for a member with serious mental illness. Spirituality can be a helpful tool for managing stress in patients with schizophrenia (Das et al., 2018).

More research is needed on spirituality and schizophrenia in order to help develop spiritual care interventions for patients and families (Ho, Wan, & Chan, 2016). The IMPACT study will help to better understand the spiritual needs of patients and families dealing with schizophrenia with the eventual goal of developing helpful interventions to improve patient care and outcomes.

Caregiving and Schizophrenia

Families who have a member with schizophrenia face unique challenges. Schizophrenia is a disabling disease, and those who experience it may struggle to fulfill their prior roles within society and within the family. Most individuals with schizophrenia need constant care and supervision which they receive from their families with little or no other support. As schizophrenia puts a heavy burden on the family, caregivers of individuals with schizophrenia often have high rates of anxiety and depression (Bademli & Duman, 2014). Additionally, the onset of schizophrenia is often sudden, and families are faced all at once with caring for their loved one as well as dealing with the stressors that come with facing the onset of schizophrenia: social isolation, financial burden, and concern for the future (Ozlu et al., 2015). With social isolation comes feelings of hopelessness, which contribute to anxiety and depression (Bülbül & Izgar, 2017). Researchers who have sought to explain the coping needs and practices of parents of adult children with schizophrenia have taken a number of approaches, including a process approach and the family burden approach.

Process of Caring

Muhlbauer (2002) has identified an eight-phase process of caring for an adult child with schizophrenia that families go through. This process includes struggling to frame the events as normal, seeking help, transformation of a loved child, living with constantly changing levels of hope, endless caring, gathering personal meaning, preserving identity, and knowing (Muhlbauer, 2002). Muhlbauer’s (2002) process has been used in a variety of studies to help understand the impact that mental illness has on the family. Barnable et al. (2006) found that siblings of patients with schizophrenia often find themselves in conflict with other family members regarding how to manage the illness. Ebrahimi et al. (2018) discussed how the stress of the onset of mental illness prompts a family to try to cope with the situation, and the process they go through can either help or hinder the coping process. Having any family member with schizophrenia can be extremely difficult, and many families suffer from family burden.

Family Burden

When a family member becomes mentally ill, the family is tasked with the responsibility of caring for the sick individual. Many families are reluctant to take on the caregiving role due to the large burden it carries, but most still do (Jonker & Greeff, 2009). This caregiving role can be a major stressor for the family. Caregivers are often treated with hostility by the family members in their care, because many people with schizophrenia deny that they are sick (Jonker & Greeff, 2009). In addition, dealing with the symptoms can be extremely difficult. Mental health professionals have labeled the negative impact of the mental disorder on the family as *family burden* (Kate, Grover, Kulhara, & Nehra, 2014). Family burden includes worry, fatigue, social isolation, limited recreational activities, and financial concerns (Rose et al., 2002). In a cross-sectional study by Kate et al. (2014), researchers found that among caregivers of family members with schizophrenia, negative symptoms and difficult behaviors contributed most to family burden. Mantovani et al. (2016) also conducted a cross-sectional study focused on patients with schizophrenia and their primary caregivers, and they found that higher family burden increases rehospitalization rates.

Types of Family Burden. Family burden can take many forms. Doornbos (1996) conducted a descriptive study to investigate the burdens of dealing with a family member with serious mental illness and the strengths that families have to cope. Doornbos (1996) discovered that families dealing with a mentally ill member experienced more stressors regarding intrafamilial relationships, occupational issues, finances, and legal stressors compared with families without a seriously mentally ill member. In their study of family burden among family caregivers of patients with schizophrenia, Jagannathan et al. (2014) identified both objective and subjective burden. Objective burdens are the challenges the family faces in their everyday life, such as altered relationships, financial problems, and loss of recreational time (Jagannathan et al., 2014). Subjective burden refers to the emotional costs faced by the family, like depression and stigma (Jagannathan et al., 2014).

Predictors of Family Burden. There are several factors that can affect the amount of burden experienced by the family. Jagannathan et al. (2015) investigated family burden through conducting interviews of family caregivers of patients with schizophrenia utilizing the Burden Assessment Schedule. The results from this study indicated that significant predictors of family burden were psychopathology, disability, duration of illness, and perceived social support (Jagannathan et al., 2014). Mantovani et al. (2016) conducted a cross-sectional study to investigate determinants of family burden among families of patients with schizophrenia. The results indicated that objective burden is predicted by negative symptoms, while subjective burden is predicted more by positive symptoms and age of onset of the mental illness (Mantovani et al., 2016). Kate, Grover, Kulhara, and Nehra (2013) conducted a cross-sectional survey to investigate the relationship between caregiver burden and a number of sociodemographic and clinical variables. The research found that family burden is higher when the patient is male and the primary caregiver is female, and perceived burden is higher when the caregiver is older, less educated, and from a lower socio-economic background (Kate et al., 2014). Zhou et al. (2016), examining caregiver burden in China, compared cohabitating and non-cohabiting families of patients with schizophrenia. Results from the study indicated that caregiver burden was highest among cohabiting families, as they experience more caregiver distress, disrupted routines, and increased needs to assist the person with schizophrenia (Zhou et al., 2016).

Family Burden and Coping. When faced with the burden of caring for a family member with mental illness, there are several coping strategies that a family may employ, such as hoping for a cure, wishing the illness would go away, and looking for hope within the crisis (Doornbos, 1996). Families that are able to arrange back-up or alternative care for the member with schizophrenia and locate supportive resources have increased ability to cope with family burden (Doornbos, 1996). Utilizing semi-structured interviews and quantitative questionnaires, Jonker and Greeff (2009) explored how families with a seriously mentally ill member deal with family burden. They identified internal and external resources that families utilize to cope with mental illness. Internal resources included religion and spirituality, personal attitudes, and intrafamilial support, whereas external resources included social support and community resources (Jonker & Greeff, 2009).

Family Strengths

Despite the potential family burden that caring for a loved one with schizophrenia brings, many families find sources of strength in this time of crisis. Although families with mental illness have more stressors than families without, many also have the skills of adaptability, flexibility, and conflict management (Doornbos, 1996). Utilizing a cross-sectional survey of families coping with serious mental illness, Crowe and Lyness (2014) discovered that families that are able to take a positive approach to the mental illness have better communication skills and better flexibility. Bishop and Greef (2015) conducted a mixed-methods study of resilience in families with schizophrenia. They discovered that the strongest correlation with family adaption is family *hardiness*, which refers to the family's internal strengths and durability (Bishop & Greeff, 2015). Hardiness gives the family increased ability to function during times of stress which in turn gives them a stronger ability to adapt when faced with a crisis (Bishop & Greeff, 2015). It is also important that families are committed to one another. This sense of family commitment enables the members to work together to overcome a crisis (Bishop & Greeff, 2015). Being faced with a crisis does not necessarily tear a family apart; many families are able to find strengths to help them successfully navigate the crisis.

Hsiao and Tsai (2014) investigated family strengths in caregiving by conducting a cross-sectional, descriptive, correlational study. They identified that one way that families can find strength in the face of crisis is to take a positive approach to caregiving. (Hsiao & Tsai, 2014). Caregiver burden is a genuine problem that many families face. However, some families are also able to find a positive perspective in the experience of caregiving (Hsiao & Tsai, 2014). The family can see caregiving as an opportunity to express their love for the person (Hsiao & Tsai, 2014). The family can also feel a sense of satisfaction in knowing they are able to keep the person safe and well-cared for (Hsiao & Tsai, 2014).

Spirituality and Schizophrenia

In the literature of the last decade, the benefits of spirituality in patients with schizophrenia have been explored in more depth. In a recent cross-sectional study by Das et al. (2018), researchers evaluated relationships between religion, spirituality, and coping skills in patients with schizophrenia. The findings from this study indicated that patients who identified as more religious or spiritual were better at managing stress, problem solving, and seeking social support (Das et al., 2018). In another recent study, Huguelet et al. (2016) examined meaning in life and relationships among patients with severe mental disorders. This study found that among patients with schizophrenia, those who considered their spirituality as an “essential” part of their lives had fewer negative symptoms, better social functioning, and higher self-esteem (Huguelet et al., 2016). As spirituality has the potential to positively impact patients with schizophrenia, having more information on the spiritual needs of caregivers of such patients would help to identify beneficial spiritual interventions.

While some studies have examined the positive benefits of spirituality, others have addressed the issue of the differing meaning and interpretations of spirituality among patients and health care providers. Using qualitative semi-structure interviews with 18 patients with schizophrenia, Rainbow and colleagues (2016) examined understandings and interpretations of spirituality. This study found that while patients and mental health professionals shared similar understandings of the meaning of spirituality, they had differing ideas regarding the role that spirituality could play in mental health recovery (Ho et al., 2016). Patients saw spirituality as an important way to both give and receive love and care, while mental health professionals viewed spirituality as a way to manage symptoms and receive social support (Ho et al., 2016). It is important for mental health professionals, including nurses, to understand the range of differing views on spirituality in mental health care. Having more information regarding spirituality among patients with schizophrenia and among their caregivers will broaden providers' perspectives on the ways that spirituality can benefit this patient population.

Despite differing views and interpretations of spirituality, most research involving spirituality finds certain common elements, such as hope. Coskun and Altun's (2018) recent descriptive, correlational study of 107 patients with schizophrenia using the Herth Hope Scale examined the relationship between levels of hope and recovery in patients with schizophrenia and found that patients with schizophrenia had moderate levels of hope, with the most influential dimension of hope being interconnectedness.

Having a loved one become ill with schizophrenia is a crisis for a family. This unexpected event causes disorder in the family, and the family struggles to find ways to cope, reorganize, and regain their level of functioning (Saunders, 2003). There are several phases that families go through as they struggle to make sense of their situation, seek healthcare for their loved one, and work towards a future together as a family (Pharoah et al., 2010). Families have the challenge of dealing with both the crisis (the unexpected event) and the burden of caregiving for the sick individual. Although it can be quite difficult, many families are resilient and able to find the strength to cope and navigate through the crisis (McFarlane, 2016). To assist in dealing with the crisis, it is important for families to have the support of mental health professionals, who can provide them with helpful tools such as psychoeducation and psychosocial interventions. Although dealing with schizophrenia does create a crisis for a family, it does not have to be an insurmountable crisis. With the proper support and education, families can reorganize, regain their functioning, and find ways to support and assist one another in coping with severe mental illness. It is important for mental health professionals working with such families to remind them that a family crisis does not last forever, and that healing and growth are possible.

Theoretical Framework

There are two main theoretical frameworks that guided the development of the methods for the IMPACT study and that were used in the data analysis process, as well as three related, ancillary theories that researchers have used to explain the changes that occur in the family after the onset of schizophrenia were relevant to how data were collected in this study were interpreted. Family systems theory was the overarching guiding theory for the IMPACT study, as it explains how the family functions as a system and is affected by and responds to a crisis. It is important to understand how, when one family member becomes ill, a number of changes occur that affect the other family members and the entire family system. The theory of spirituality and health was used in the development of the research question and interview guides and in the initial data analysis process to identify preliminary thematic codes. Prior to discussing these main theories , I will briefly describe three ancillary theories that were also important because they undergird basic processes and relationships in the primary theories, especially family systems. These ancillary theories are role theory, stress theory, and systemic theory.

Ancillary Theories

Role Theory

Role theory was developed to explain behavior patterns (roles) by looking at the social positions that each person holds that the associated expectations on behaviors based on those positions (Biddle, 1986). Role theory is applicable to a variety of social situations, including the family. According to role theory, each person has a certain position within the family. Having a person with mental illness in the family upsets these roles and causes disorganization in the family dynamics (Caqueo-Urízar et al., 2014). When someone in the family becomes a caregiver to the mentally ill individual, their new caregiving responsibility is an added obligation on top of the duties they performed in their previous role. This added obligation can cause the person to be overburdened, and then role distress can occur (Quah, 2014). Although not everyone may be aware of the role they have within the family, each person has one, and a crisis like a mental illness can upset those roles and cause problems both for the individual family members and the family system. When family members' roles change, this affects both how members relate to others within the family (connectedness) and their function in the family (meaning/purpose). A number of studies in the area of family caregiver stress and burden apply the frame of role theory, including studies by Burnette (1999), Major (2003), and Roff et al. (2004). Strengths of role theory include its ability to explain changes in family members that occur after the onset of mental illness, although the theory is limited by focusing on the family members and not incorporating external societal and institutional factors that affect family functioning.

Stress Theory

Another ancillary theory is stress theory. Stress theory was developed to explain how a family responds to stressors. According to stress theory, factors affect how much crisis a family may experience, including the nature of the stressful event, other family hardships, and the family's degree of vulnerability (McCubbin, Thompson, & McCubbin, 1996). A disorder in the family system creates chronic tensions that causes subjective burden for the family. This burden in the family system affects coping strategies and changes the family members (Caqueo-Urízar et al., 2014). Stress theory has proved useful to researchers working in the area of family caregiver burden who apply the theory to explain the relationship between sociodemographic factors, social support, and stress levels and how these factors contribute to caregiver burden among primary caregivers of chronic patients (Yigitalp et al., 2017). The stress and burden put on a family affects how they relate to others (connectedness) and what they find important in life (meaning/purpose). A process of renegotiation takes place as families adjust to the changes brought about by the crisis of mental illness.

Systems Theory

A third ancillary theory is systems theory. Systems theory explains how structural and functional components interact with each other and the larger environment (Kenny, 1995). There are four main elements in systems theory: input, throughput, output, and feedback (Kenny, 1995). As Bridgen (2017) explained, in systems theory, input is what is received from the environment, including matter, energy, and information. During throughput, the matter, energy, and information is modified within the system. Output is when things are released from the system. Feedback is the information about the environmental responses (Rychtáriková et al., 2018). Gunaratne (2008) wrote that, in order for a system to survive, it needs to find a state of balanced relationships, or equilibrium. Finding equilibrium can be challenging, because any change in one part of the system affects the system as a whole (Gunaratne, 2008). Systems theory has provided a number of researchers with a framework for explaining how mental illness impacts the family (Bickerton et al., 2014; Sanders et al., 2014; Sporer & Toller, 2017). In this research, the family is a system that relates to other systems within society, and thus it must be understood in its social context (Caqueo-Urízar et al., 2014). In short, a family does not stand alone. One strength of the theory is its focus on the reciprocal nature of change or stress within entities: other systems affect a family, just as the family can affect systems in the larger environment. The use of systems theory in research on family burden and stress highlights the various types of relationships that can influence the family and the family's evolving need to renegotiate these relationships.

Role theory, stress theory, and systems theory have been used in the literature to elucidate the impact of a crisis on the family system. These theories relate to the IMPACT study's focus on meaning/purpose and connectedness. The multitude of changes brought about by the crisis of mental illness force the family to change their own relationships and understandings as they struggle to cope.

Family Systems Theory

The ancillary theories of role theory, stress theory, and systems theory are all independent theories that researchers have used to explain changes that occur when a family faces a crisis. Each plays a role in one of the two main theories that guided the IMPACT study: Murray Bowen's family systems theory and Miner-Williams's theory of spirituality and health. Family systems theory was developed by Murray Bowen, a psychiatrist, in the 1950s, in order to explain how the family functions. Bowen researched families with a member with schizophrenia when he was developing his theory and its associated psychotherapeutic treatment (Regina, 2011). Family systems theory views the family as an emotionally interconnected unit. As the members are connected emotionally, each member can affect the feelings, thoughts, and actions of the other members. This interdependence can be both beneficial and detrimental (Regina, 2011). Having a connection within the family means that the family can work together as a team and successfully navigate crises. However, when one member experiences anxiety it can also cause stress in other members and in the family as a whole.

According to family systems theory, there are eight interlocking concepts that affect family functioning, including levels of differentiation of self, the nuclear family, the family projection process, the multigenerational transmission process, sibling position, triangles, emotional cut-off, and the societal emotional process (Bowen, 1966). Related to these concepts is the proposition that families are embedded in other systems, including the extended family and larger community systems. It can be very difficult for families to adapt to change, as families in general tend to resist change and attempt to maintain a level of homeostasis (Gurman & Kniskern, 2014).

Researchers working in the area of schizophrenia and the family have used family systems theory to guide their interventions, as studies have found that a family approach to treatment for schizophrenia can help to decrease symptom exacerbation and rehospitalization (Anderson et al., 1980). Anderson et al. (1980) developed family interventions aimed at increasing understanding of the illness by the family, reducing family stress, enhancing social networks, and addressing long-term issues that contribute to overall family stress. The treatment involved four stages: connection, survival skills workshop, reentry and application, and maintenance (Anderson et al., 1980). This family approach was found effective for long-term treatment of schizophrenia. Hogarty et al. (1986) also utilized a family systems approach in their study of relapse rates of patients with schizophrenia in the year following discharge from a psychiatric hospital. A family treatment approach in the year following discharge was found to delay relapse, although it did not actually prevent the occurrence of relapse (Hogarty et al., 1986).

Because caring for an adult child with schizophrenia causes anxiety in the family, family systems theory is applicable to the IMPACT study. Understanding how families manage the caregiving role and related anxiety relates to how the family functions, including how their spiritual needs and understandings change over time. Family systems theory has the advantage of examining the management of the caregiving process from both the perspective of the family as well as the individual family members. As the family is an interconnected system, to gain a holistic picture of the impact of the illness of schizophrenia, the entire family must be considered.

Theory of Spirituality and Health

While family systems theory was the guiding theory for the IMPACT study, Denise Miner-Williams's (2006) theory of spirituality and health more directly informed the development of the research question and interview guides for the study and was used to identify preliminary codes for data analysis. The theory of spirituality and health, developed by Miner-Williams (2006), a registered nurse, posits that nurses often lack a practical understanding of spirituality when planning and delivering patient care. Miner-Williams (2006) affirmed that spirituality is innate to every human being's existence and defined spirituality as a search for meaning through connectedness with oneself, others (e.g. people, animals, nature), and/or the transcendent (i.e. a deity). According to Miner-Williams (2006), spirituality is the essence of being human. Spirituality is specifically associated with health in Miner-Williams's theory, where health is viewed as wholeness or a unity of body, mind, and spirit.

In the conceptual model for her theory (Figure 9), Miner-Williams (2006) illustrated how values and beliefs affect the personal manifestation of spirituality. There is both a relational and behavioral aspect to spirituality. Relationally, spirituality involves finding and forming connections within oneself and in the larger world. In a behavioral sense, spirituality includes seeking out connections with others and finding what is meaningful and important in life. Spirituality results in emotions of love, hope, peacefulness, forgiveness, and comfort. There is an over-arching energy fueling the search for meaning, which is an integral part of health, and which Miner-Williams defined as the alleviation of suffering. Spirituality is not the same as religion. It does not matter if someone is part of a faith tradition or not, spirituality is about searching for meaning, purpose, or happiness in life (Miner-Williams, 2006).

Though Miner-Williams does not explicitly connect her theory to the nursing metaparadigm, connections may be traced between the theory of spirituality and health and the nursing metaparadigm of nursing, person, environment, and health (Kitto, 2014). The person is composed of a variety of different dimensions, including physical, emotional, and spiritual. Thus, nursing care assumes a holistic perspective, with an integral part of health being spirituality. Health includes how one is in relationship with oneself, others, and the larger environment (Kitto, 2014). The environment includes the external context of everyday life as well as values and relationships that affect the person. Holistic nursing care addresses the spiritual aspect of health and the meanings and relationships that are central to the person (Kitto, 2014).

Strengths

The theory of spirituality and health has several strengths. It describes spirituality as the quest for meaning/purpose/happiness that is an essential component of one’s journey towards health (Miner-Williams, 2006). The two major defining concepts this theory addresses are meaning/purpose and connectedness. As my review of definitions in the literature demonstrated (see Tables 1 & 2), the concepts of connectedness and meaning/purpose are in keeping with what other researchers have used to define spirituality. Miner-Williams's theory also upholds the universality and subjectivity of spirituality, that while spirituality is something that is part of being human, it is also something that each human may experience differently (Miner-Williams, 2006). Because of its combined universality and subjectivity, the theory of spirituality and health provided a framework for understanding the varied experiences of spirituality among families caring for patients with schizophrenia.

Limitations. Although the theory of spirituality and health has many strengths, such as universality and subjectivity, it is not without its limitations. For one, the theory focuses exclusively on the positive side of health (well-being) and does not incorporate the role of illness. This represents an important oversight when considering how patients and families cope with a chronic condition like schizophrenia. Perhaps the greatest limitation of the theory of spirituality and health, however, is its lack of application in the research. As a relatively new theory, introduced in 2006, the theory of spirituality and health has not been used as a guiding theoretical framework in nursing research. This may be due to nursing researchers' feeling more comfortable using established theories and/or the fact that this theory is not widely known in the nursing research community. The theory of spirituality and health is also a particularly parsimonious theory, as it attempts to present only the core components of spirituality. Due to this, some aspects of spirituality (such as spiritual distress) are not addressed, which may also affect its perceived usefulness by researchers.

Application to the IMPACT Study. Despite its limitations, the theory of spirituality and health was an appropriate choice for the IMPACT study. The theory of spirituality and health was applied to the IMPACT study, first, through the study's overarching conceptual understanding of connectedness (the relational aspect) and meaning as defining of spirituality. The IMPACT study's research question focused on these two aspects of spirituality—life meaning/purpose and connectedness. Second, the theory of spirituality and health informed the interview guides: the questions were designed to generate data regarding the parents' changing understandings of meaning/purpose and connectedness. Using questions that concern relationships, connectedness, and sources of meaning should reveal information about how participants' behaviors and relationships affect their personal manifestations of spirituality (Miner-Williams, 2006).

Third, the theory of spirituality and health provided a general framework from within which to guide analysis of data collected in the IMPACT study. Each case was first analyzed using a preliminary code list based on concepts from the theory of spirituality and health, including connectedness (with others, self, and the transcendent); interactions with others; values and beliefs; and hope. As discussed further in chapter 3, during data analysis, these codes were used to help identify relevant themes. Spirituality is a subjective experience, and although I posited, along with Miner-Williams, that spirituality has common elements (meaning/purpose and connectedness), I also acknowledged that the ways these would manifest in sentiment and behavior was likely to vary widely between individuals. Therefore, while the theory of spirituality and health influenced the construction of my preliminary code list, I was careful to remain open to emergent codes–and the themes and interpretations to which they pointed–as the data was read and reread during analysis.

CHAPTER 3

METHODS

Research Design

The design for the IMPACT study was a comparative case study. Case study is the in-depth analysis of a case or bounded system. This bounded system comprises various things, such as a patient, a family, a neighborhood, an institution, or an organization (Sandelowski, 2011). For a case study, information is gathered using multiple sources of data (Sandelowski, 2011) in order to gain a rich and in-depth understanding of the case (Patton, 2015). Comparative case studies examine certain phenomena of interest across multiple cases to look for similarities, differences, and salient themes (Luck et al., 2006). For the IMPACT study, six cases of parent caregivers of adults with schizophrenia were constructed and compared based on interviews, observations, and memory objects. As the aim of the study was narrow, a sample size of six was sufficient to achieve data saturation (Malterud et al., 2016). For each case, three separate interviews were conducted that each focused on different times in the participants' lives, giving ample time for exploration of the process of renegotiation of spirituality. Considering the multiple interviews for each case, which allowed time to generate in-depth information, I determined that six would be a sufficient sample size for this multiple case study. Small sample sizes in case study approaches are supported in the literature since case studies seek to give detailed, context-rich accounts rather than provide probabilistically generalizable conclusions (Marshall et al., 2013).

The comparative case study is a naturalistic methodology (Guba & Lincoln, 1986) in that it involves studying human experience in its natural context (Owen, 2008). Stake (2006) asserted that cases need to be observed in ordinary settings, because part of studying the case is to study its situation in the various contextual aspects that give the case its particular shape and meaning. Due to time constraints, I was unable to conduct interviews face-to-face in participants' homes; therefore, I conducted all interviews via Zoom video-conferencing technology, with participants being interviewed in their homes. Life story interview technique was used, because that method allowed the participants to share what was most meaningful and important in their life experiences. The life story technique captured the experiences of participants in their own words in a way that allowed for an in-depth understanding of their life events and the meanings those events had (Atkinson, 2002). The methods employed in this research design, including interviews, observations, and archival methods (artifacts shared by participants during the interview session), were aimed at generating data regarding how the parents renegotiated their understanding of life meaning/purpose and connectedness after the onset of schizophrenia in their adult children.

When utilizing a case study design, there are two major approaches. Robert K. Yin's work is associated with the postpositivist approach to case studies (Anthony & Jack, 2009; Yin, 2003, 2004, 2009, 2011, 2012), whereas Robert E. Stake's work can be said to represent the constructivist approach (Stake, 1978, 2000, 2005). Yin, a social science researcher, has done extensive work in case study methodology, writing several books and articles on his case study approach. In these works, Yin (2003, 2004, 2009, 2011) described reality as predictable and objective. According to Yin, the researcher should be detached and free from bias in the research process to capture an objective understanding of the phenomena of interest. For this reason, Yin (2012) argued that interviews, which he believed to be prone to bias when used as data, should be corroborated with other sources, such as documents and observations. Yin believed the researcher should look for logical cause-and-effect relationships (Yin, 2003), and he argued that findings from case studies can be generalized to theory but not to populations (Anthony & Jack, 2009).

Stake (1978, 2000, 2006) has also done in-depth work in case study methodology. Stake’s (1978, 2000, 2006) approach valued subjectivity as part of understanding and sought to understand the human experience by gaining a deeper understanding of the lives and perspectives of the people involved. Rather than trying to control for bias, Stake believed that biases and values were inherent in research and should be acknowledged and embraced as part of the research process. Stake’s (2006) methodology is naturalistic, and he promoted the idea that research should be conducted in real-world settings, allowing observation of participants in their everyday lives to gain a deeper understanding of their experiences. Stake believed the goal of case studies was not to generalize the findings but to gain an in-depth understanding of the particularities of the cases (Anthony & Jack, 2009).

The constructivist approach modeled by Stake was followed in this study, rather than Yin’s postpositivist approach, because studying the experience of meaning/purpose and connectedness among parents of adult children with schizophrenia called for a more subjective approach, one that was focused on the experiences of the parents and their ideas about meaning and purpose, data that were best recoverable through interviews that required interaction with and interpretation by the researcher. To access participant ideas most completely, a comprehensive approach to case construction, like the one Stake outlines in *Multiple Case Study Analysis* (2005), was applied. According to Stake’s approach, the research question is used to focus the study on the quintain or desired information about the phenomenon of interest. A case is studied because of what it reveals about the quintain (Stake, 2005). In this study, the quintain or overall focus was the parent’s renegotiation of life meaning/purpose and connectedness when their adult child became ill with schizophrenia. However, each case also had several subsections that were addressed to fully understand the case. For the IMPACT study, these subsections involved information that was generated during the interview process about the parents, the extended family, the healthcare system, and the faith community, if applicable.

Stake described several types of case studies. The two main types of case studies are instrumental case studies and intrinsic case studies. Intrinsic case studies are focused on the case itself, discovering all that can be discovered about a single instance. In instrumental case studies, the purpose is to go beyond the sole case. The case study design for this research project was instrumental comparative case study, because the focus extended beyond a single case to encompass comparison of multiple cases (Stake, 2005). The goal was to learn how the cases related to one another and to the quintain. Comparing the six cases helped to identify what was similar and what was different between the cases. It was also instrumental in nature because the purpose of the research went beyond gaining new knowledge for knowledge sake to applying new knowledge to nursing practice.

Case study is by nature a subjective process, with the analytic focus on both the process and the product of data collection (Stake, 2005). In keeping with the dual focus, I kept careful notes on my observations and experiences during the interviews. Through those process notes and the interview and artifact products (i.e., memory objects), I aimed at a comprehensive data collection. The case studies created in the IMPACT study should help to reveal the intricacies of a complex issue and provide a basis for a deeper understanding (Yin, 2003) as well as help map the landscape for future study (Riessman, 2008).

Sample and Recruitment

Sample

I recruited a sample purposefully focused on parent caregivers of adults diagnosed with schizophrenia. Recruitment aimed for a small sample of approximately six cases. This number was based on similar case studies from the literature, where sample sizes of between three and six are common (Dowlen, 2019; Gerdeman, Garrett, & Monahan, 2018; Ontong & Le Grange, 2018; Teng, 2019; Whitacre, 2015). The relatively small sample size is further supported by Creswell's argument that to achieve thick description of a phenomenon of interest in case study or other qualitative work generally requires five to six cases (Creswell, 2007).

The IMPACT study sought to use maximum variation in the selection of cases. In maximum variation sampling, cases representing a range of variation are recruited from a population that shares a primary dimension of interest (Stake, 2005). For the IMPACT study, the primary shared dimension was the experience of providing care to one's adult child diagnosed with schizophrenia. Variation in cases was sought by attempting to recruit parents who had cared for a child who was diagnosed at varying points of time in the past (under five years, between five and 10 years, and over 10 years), were of varied age (under 40, between 40 and 65, and over 65), and had attained varied education levels (high school education or less, some college or professional school, college graduate). The above variables were selected based on their connection with caregiver burden. Caregiver burden tends to increase with longer time of caregiving, increased age, and lower education level of the caregiver (Bademli & Duman, 2014; Jagannathan et al., 2014; Kate et al., 2014). One of the main ways that caregivers are able to cope with caregiver burden is spirituality (Jonker & Greeff, 2009).

All of the variables relate to how a caregiver would react to the process of caregiving and how the caregiving process would affect their spirituality. By attempting to build a sample that shared a role as caregiver of an adult child with schizophrenia but that varied in the amount of time they had provided that care, their ages, and their education levels, the IMPACT study, though it did not aim to be exhaustive, sought to capture a diversity of experience in renegotiating spirituality.

Recruitment

To recruit potential participants, flyers (see Appendix A) were displayed at National Alliance on Mental Illness (NAMI) locations in Northeast Ohio (Cuyahoga, Geauga, Lorain, Medina, Portage, and Summit Counties) and distributed at family support groups for three months. When, after three months, those means failed to attract any participants, I distributed internet recruitment flyers (see Appendix B) on social media platforms, which included Facebook, Twitter, Instagram, LinkedIn, the American Psychiatric Nurses Association (APNA) Member Bridge, and Ohio Nurses Association (ONA) Member Connect. Social media has been shown to be an effective recruitment method, such as in one study by Morgan, Jorm, & Mackinnon (2013) in which internet-based methods were used successfully to recruit participation in an online preventive depression inventory as part of the Mood Memos Study (Morgan et al., 2013). Social media has potential to reach a large number of diverse participants, including persons of various ages, races, and geographical locations (James et al., 2017; Williamson et al., 2018). In the IMPACT study, positive responses received via the above recruitment methods were followed by snowball sampling. Snowball sampling is a common qualitative research sampling method that involves having early participants refer other potential participants to the study (Griffith et al., 2016). Snowball sampling, specifically via social media platforms, is a recruitment method that has been effectively utilized in prior mental health research (Stomski & Morrison, 2018). How each participant learned about the study is found in Appendix C.

Persons recruited by any means were given information to contact the PI via email, text, or telephone call. After initial contact was made, the PI spoke to potential participants on the phone to screen for eligibility criteria, discuss willingness to participate, answer questions regarding the study, and collect demographic information (Appendix D). The call script is located in Appendix E. In order to promote retention, I had regular communication with participants via phone call, text, and email to build rapport and establish a good working relationship and conducted interviews via video-conferencing technology at times that were convenient for participants. According to the National Institute of Mental Health (2005), these strategies have been successful in facilitating retention in other studies.

Inclusion Criteria

Inclusion criteria for all caregiver/parent participants included:

1. having the ability to speak and understand English (determined during telephone screening interviews in the recruitment phase);
2. having an adult child with schizophrenia;
3. consenting to be interviewed in the home via Zoom video-conferencing technology on a phone or computer.

Data Collection Procedures

Setting

The setting for data collection in the IMPACT study was the participants' homes, which is where the participants were during the interviews. Cases need to be observed in ordinary or naturalistic settings, because part of studying the case is to study its contexts, including aspects of the physical setting that may have bearing on how social dynamics unfold or how power relationships are organized (Sandelowski, 2011; Stake, 2005). Aspects of a case such as family interactions, the physical setting where the majority of caregiving takes place, and the emotional environment were more visible using videoconferencing in the home compared with an audio-call or meeting or consultation room in a provider's office or at the hospital. Because of the potential to capture elements of relationship and meaning that are associated with place in participants' lives, research involving direct observation in the field is essential to understand the phenomenon (Patton, 2015).

Procedures

I conducted all interviews using a semi-structured interview guide (Appendix F). Participants were sent the list of interview questions prior to the interviews to give them the opportunity to reflect ahead of time. Participants were also invited to choose memory objects (artifacts) to share during each interview. Artifacts were objects that represented to them feelings and ideas they wanted to share during interview sessions. The use of artifacts in case study research has been described by Gubrium and Harper (2016) who argue that objects are evidence of events and conditions and point to an external narrative that can provide a rich source of data. Study consent included consent for photographing of memory objects for potential use in publications and presentations.

While interviews were conducted using videoconferencing, only the audio was recorded. The audio recordings were later transcribed for analysis. After completing each interview, I wrote a record of observations from the video-conference call, including reflections on the physical setting, the social environment, interactions witnessed, language and meanings, and nonverbal communications (Patton, 2015). An observation form is included in Appendix G. It was anticipated that each interview would last between 60-90 minutes. To encourage participant retention, the participants were contacted via phone or email the day before each interview session to confirm the time of the interview.

Data Analysis

After generating data from interviews, observations, and memory objects, the data were cleaned, organized, and analyzed. The audio recordings of interviews were transcribed using an automated electronic transcription service through NVivo qualitative data analysis software. I then checked transcripts for accuracy and corrected errors. The data was managed on NVivo, which has the ability to import images, audio and video files, transcripts, and notes of observations (*NVivo product range | QSR International*, n.d.). The data, including interview transcripts, observations forms, and memory objects, were entered into the NVivo database and analyzed for themes.

Analysis took place in the following steps:

1. initial coding of individual case data;
2. organizing codes into a matrix;
3. writing the case narratives;
4. using the case narrative and the codes to consolidate themes;
5. my dissertation advisor reviewed the case reports and the themes;
6. themes were compared across cases using the case reports and themes matrix;
7. based on the comparative analysis, a model was created for how parents caring for an adult child with schizophrenia renegotiate spirituality.

After coding each individual case, a matrix system was used to organize data from the interviews, observations, and visual methods into thematic categories. Themes were defined, following Graneheim (2004), as threads of meaning that occur in multiple domains. Additionally, ancillary themes related to values and beliefs were identified in the cases. Each case was examined individually, and individual case reports, including a case narrative and cross-case thematic analysis, were written based on the data generated from each case. Individual case reports were written to produce a descriptive and engaging narrative that characterized in-depth how the participant handled the renegotiation of spirituality (Stake, 2005). Next, the cases were compared, using the matrix, to identify how themes relevant to the renegotiation of spirituality occurred or did not occur across the cases (Patton, 2015). The last phase of the analysis was to compare the case findings with one another to create a model (Figure 8) of how parents caring for adult children with schizophrenia renegotiated spirituality during the years after onset of the illness (Braun & Clarke, 2006).

Protection of Human Subjects

Institutional Review Board (IRB) approval was obtained from the University of Missouri – Kansas City (UMKC). Following recruitment, I contacted the potential research participants via a telephone call to inform them about the study and consent them if they were willing to participate. All participants were given the opportunity at that time to ask questions about the study itself and the contents of the consent form. Participants were subsequently sent an electronic copy of the consent form (see Appendix I), which included their permission to audio-record interviews and photograph memory objects. Participants' confidentiality was maintained by using case numbers in research notes and assigning pseudonyms for reporting purposes. Cases were assigned a number 1 – 6 based on the order in which the participant joined the study. The sensitive and confidential data from the IMPACT study was protected during data analysis by using the NVivo qualitative data analysis software, which includes enhanced security of user passwords and profiles as well as encrypted storage. Regarding the interview recordings, video recordings of the Zoom interviews were deleted. The audio recordings, along with all study forms and data, were saved in in the UMKC licensed REDCap (Research Electronic Data Capture) database, to be stored and then deleted after seven years. REDCap is used by approximately 2000 institutions in over 100 countries and is considered to be a secure method of data collection and storage (Sole et al., 2018).

Trustworthiness of the Data

To produce trustworthy outcomes, following the definition of trustworthy given by Lincoln and Guba (1985), I included study elements that would enhance credibility of the connection between the data and the findings. I used thick description, triangulation, multivocality, and partiality (Tracy, 2010). To achieve thick description, which the cultural anthropologist Geertz (1973) first defined as a recording of facts, observations, commentary, and interpretations, I included an in-depth, written case narrative for each of the individual cases and a report identifying and discussing the data supporting the case comparisons. Data triangulation, which Guba and Lincoln (1986) have described as using multiple sources of data to validate conclusions was achieved through my use of multiple data sources, including the interviews, observations, and memory objects.

In addition, I kept an audit trail by maintaining process notes, a regularly updated study timeline, audio recordings from interviews, image files for artifacts, field notes from site visits, a record of correspondence with participants and others involved in coordinating the study, and notes on conversations with advisors—all of which were uploaded to REDCap. The audit trail was maintained to provide details of the research process that would establish transparency and study rigor by recording how the data was collected, analyzed, and interpreted (Wolf, 2003).

I also strove to preserve multivocality in the IMPACT study by retaining the voices of the participants in the research by constructing case narratives of the participants' experiences and including verbatim quotes. Multivocality is the use of various voices in the report and data analysis (Tracy, 2010). Dependability, or the stability of the data over both time and conditions (Polit & Beck, 2012), was enhanced by the audit trail, including my detailed and accurate records of the process of data collection and data analysis. During data analysis, I consulted weekly with my dissertation advisor, a PhD-prepared nurse researcher, who independently reviewed the data. These discussions and the further review of findings by my dissertation committee helped to establish confirmability, or the degree to which my interpretations would make sense to other readers (Korstjens & Moser, 2018). Transferability was enhanced by my providing ample descriptive data of each case. This approach was intended to give a reader sufficient information about how the study conclusions were reached to determine whether the findings were likely to apply to their population of interest (Tracy, 2010). Finally, the time I spent observing the participants' homes via video-conferencing technology and conducting in-depth interviews enabled me to write cases of sufficient detail to convey authenticity by presenting a descriptive account of the participants' lives; the major themes, values, and beliefs involved; and an accurate interpretation of the participants' experiences in order to help the reader grasp an holistic picture of the participants' life stories (Johnson & Rasulova, 2017).

CHAPTER 4

RESULTS

Schizophrenia is a devastating condition that affects the entire family. Adjustment to the changes that occur in a family can be extremely difficult, and many families struggle to regain their sense of equilibrium after such a crisis. While much is known about schizophrenia, family crisis, and caregiver burden, very little research has been conducted to understand how parents renegotiate spirituality after diagnosis of an adult child for whom they subsequently provide care. In this study, I constructed cases using data from in-depth interviews, memory objects, and observations with parent caregivers to better understand that process. This chapter presents my findings and includes 1) an overview of the themes; 2) presentation of individual cases; and 3) a cross-case analysis in which I synthesize convergent and divergent thematic patterns and interpret their meaning in light of the research question: *How do parent caregivers of adult children with schizophrenia renegotiate their spirituality, defined as life meaning/purpose and connectedness, in the years following the onset of the illness*?

Participants

I was contacted by six interested persons responding to social media ads over seven months of recruitment. All who contacted with interest in the study were screened and met eligibility criteria. Six initially agreed to participate, but one did not respond to my efforts to contact her following her first interview. Another participant was recruited. Three interviews were conducted with each of the six participants, for a total of eighteen interviews in the IMPACT study. All interviews were conducted via Zoom videoconferencing, allowing for observations of the participants in their home setting. Interviews ranged from 17 to 119 minutes, with an average of 44 minutes. Observations recorded for each interview included physical setting, social environment, interactions, language and meanings, and nonverbal communication. In keeping with what we know about caregivers in general being primarily female (Kate et al., 2014), all six participants were women. Participant demographics are recorded in Table 5. The participants ranged in age from 57 to 73 years, with a mean age of 64 years. The years since diagnosis of schizophrenia ranged from 3 to 33 years. The mean number of years since diagnosis was 18.7. High school was the highest level of education completed for one participant, with the other five participants having a bachelor's degree or higher. The participants came from various locations in the United States–three from the Midwest, one from the East Coast, one from the West Coast, and one from the Northwest. At the time of this writing, five of the adult children were still living, and one was deceased. Of the five adult children who were still living, two resided at home with their parent, and three lived elsewhere. One participant completed the first interview but could not be reached to complete the subsequent interviews, so another participant was recruited.

Themes

Cases were analyzed initially one-by-one for references to experiences, thoughts, or feelings directly or indirectly related to the spirituality and health codes (Appendix H) drawn from the theory of spirituality and health: connectedness (with others, self, and the transcendent), interactions with others, values and beliefs, and hope (Miner-Williams, 2006). In keeping with qualitative methodology, themes were added during analysis. After coding for themes and life events, I read each case two additional times to highlight salient quotes and record details for the case narrative.

In the analysis of individual cases, I identified four thematic dyads as most prominent and most related to the initial codes of spirituality: conflict/peace, disconnectedness/ connectedness, real/ideal, and despair/hope. These dyads related to the process of renegotiation of spirituality. Participants went through an iterative process with each of these dyads as they experienced moving from conflict to peace, disconnectedness to connectedness, real to ideal, and despair to hope. These movements between the dyadic elements happened over and over again, demonstrating that spirituality is something that is *re*negotiated.

The theme of conflict/peace referred to interactions with others that brought the women either a sense of ease, peace, or buoyancy, or a sense of being blocked, frustrated, or provoked. Interactions, or the mutual action between two individuals during which information is exchanged (Gummesson, 2012), are the basis for the formation and maintenance of relationships (Nota & Aiello, 2019). Conflict/peace was closely aligned with the second theme, disconnectedness/connectedness, which referred to experiences or expressions of finding, forming, or tending meaningful bonds with others—or, alternatively, experiences or expressions of isolation, alienation, disruption, or abandonment.

The third major thematic dyad, real/ideal, was evident in women’s expression of a sense of correspondence or disjuncture between what was actually happening (the real) and what they had expected or envisioned (an ideal). Segments that centered on the real/ideal theme highlighted the interviewees’ notions about normalcy, where expectations about what is or should be were defined, met, or, as was more often the case, were disrupted and/or reshaped. Because expectations are beliefs that one holds about what can happen; their fulfillment or disappointment can have a significant impact emotionally (Brudner et al., 2018). Shattered expectations were described in the interviews in this study with a range of emotional responses, including disbelief, anger, grief, and eventually relief and gratitude as unmet expectations were reframed to meet real possibilities.

Closely connected to real/ideal was the fourth theme, despair/hope. Hope is actively desiring a specific outcome, visualizing the desired outcome, and believing it is possible to achieve (Kwong, 2018). While hope allows one to strive towards a specific outcome, an essential part of hope is also the recognition that not all goals will be achieved. Hope is present when one feels empowered nonetheless to work to achieve goals (Kwong, 2018). Like hope, despair also involves reference to an outcome. However, in despair, disappointment in that desire to achieve an outcome drives one to a state of helplessness and hopelessness, and eventually in some cases to resignation. In despair, one relinquishes all belief that one can reach the outcome (Kwong, 2018; Meirav, 2009). This theme was identified in the places in the women's stories where descriptions of having nowhere left to turn dominated. In terms of renegotiating spirituality, despair is important since when one is in a state of despair it is difficult to decipher meaning and purpose in one's life.

These were the four main themes I identified in the women's accounts. Other themes emerged in the stories related to the participants' values and beliefs, and I discuss these along with the main themes in the thematic and cross-case analyses below.

Case Reports

Case 1–“Sharon's” Narrative

Before the Illness

Sharon became pregnant with her first child, Nathan, shortly after she turned 18 and moved out of her parents' home. After Nathan's birth, Sharon moved back in with her parents, but she was not allowed to have any contact with Nathan's father, Teddy, as they were not married. This living situation only lasted a short time before Sharon moved in with Teddy. Over the next few years, Sharon and Teddy had two other children. Sharon worked part-time for a few years and then started nursing school. While in school, Sharon and Teddy divorced, and Sharon and her three children moved frequently. She moved from the Midwest to the Southern United States as a new nurse. She then traveled several states away after marrying her second husband. This marriage only lasted for a short time. After her second divorce, Sharon moved to the East Coast and met and married her third husband, Ryan. Ryan had three children of his own. This was a difficult adjustment to make, having six teenagers under one roof. Sharon's recollections of Nathan during the period before his diagnosis included her description of Nathan as a child who "was an independent guy," her memory of Nathan's being a good student and active in the Boy Scouts, and her impression that Ryan did not like Nathan. During this period, Sharon sent Nathan to live with family friends, where he stayed during his high school years. Sharon described her state of mind during the before period as focused on her purpose of being a provider for her children while struggling with a series of broken relationships.

Becoming Ill and Being Diagnosed

When Nathan was 19, he moved several states away with his brother, Adam, to work on a construction job. When Adam and Nathan would come home to visit, Sharon noticed strange behaviors in Nathan, like Nathan's saying that he believed his stepfather was poisoning his food, or Nathan's describing communications he had had with his deceased grandmother. When the brothers left to go back to work, Sharon continued to hear reports of other concerning behaviors from Adam, like descriptions of Nathan's yelling at the television and talking about special connections with celebrities. Sharon finally persuaded Adam to bring Nathan home. When they arrived, Sharon took Nathan to the local emergency department to be evaluated, believing at the time that Nathan's behaviors were related to his drug use. The period leading up to diagnosis was dominated in Sharon's account of these incidents by expressions of uncertainty about what was happening and anxiety regarding Nathan's disturbing behaviors.

Getting Nathan the proper evaluation and treatment was challenging for Sharon. During the first emergency room visit, Sharon recalled that not a single physician talked to her, although she did talk to a nurse briefly. Nathan had several other hospitalizations during that first year of exacerbations. In each, Sharon faced the issue of Nathan's being an adult, which meant the healthcare team had to uphold confidentiality laws and could only release information to her if Nathan consented, which did not always happen. Sharon described feeling "hysterical" at times because she did not know what to do. A major support for Sharon in this first year was a parents' support group for families with members with serious mental illnesses. The group helped her understand, as Sharon said, that "it doesn't matter how well everybody seems, everybody's got some issues in their lives."

Life After Diagnosis

After Nathan's diagnosis, Sharon supported Nathan financially because he was too ill to work. Almost four years passed before Nathan was approved for and started receiving Social Security benefits. Sharon described how she would "say some pretty hurtful things sometimes" to Nathan out of anger and frustration because he would stop taking his medications, leading to frequent exacerbations. Nathan's uncontrolled psychotic symptoms resulted in repeated incarcerations and conflict within the family. Sharon indicated that

Nathan's psychotic symptoms and unkempt appearance caused him to be ostracized by family members who thought Nathan's appearance was "at odds with everybody else's" and were made uncomfortable by how "he would talk strange to them." Nathan's continued use of drugs and alcohol complicated matters. At one particularly low point, Sharon described the destruction by fire of a house she had purchased for Nathan, in which she learned Nathan and his friends were growing marijuana. There were also long periods when Nathan went missing and Sharon feared he was dead or in jail.

In the years following Nathan's diagnosis, Sharon experienced further challenges trying to reconnect Nathan with the family and help him to find a purpose for his life in light of his diagnosis of schizophrenia. At the time of the interviews, Nathan was in his early 40s, living at home with Sharon, who supported him financially, helped him run his errands, and reminded him to take his medications. Sharon worried about who would take care of Nathan when she was gone.

Sharon's Memory Objects

Sharon did not show me any physical objects during her interviews. However, when asked, she described a different object at each interview. In the first interview, Sharon described a kaleidoscope, which she likened to the changes in her life that occurred after the onset of her son's illness. In her second interview, she described a baby stroller that she used to transport her Nathan to visit his father when he was out late drinking at the bar. In the third interview, Sharon described homemade birthday cards her son would make and send to family members.

Themes in Sharon's Case

Analysis of Sharon's case revealed four thematic dyads related to spirituality: conflict/peace, disconnectedness/connectedness, real/ideal, and despair/hope. The most prominent dyad in Sharon's case was disconnectedness/connectedness. In addition, Sharon highlighted four values and beliefs that impacted her spirituality. These included resilience, work ethic, being a provider for her family, and seeing the worth in her adult children.

Conflict/Peace. The thematic dyad of conflict/peace emerged in Sharon's case through her emphasis on how interactions with others affected her ability to achieve and maintain equilibrium. Conflict/peace arose as a theme in interactions or communications that Sharon described between herself and others and the effects that interactions between Nathan and others had on her. The theme of conflict/peace was apparent in interactions with family members, social connections, law enforcement and legal systems, and health care agents and agencies. The most central evidence of the conflict/peace theme in Sharon's account concerned interactions with health care. As many parents of adult children with schizophrenia experience, Sharon faced the exasperating challenge of trying to obtain crucial health information about her adult son's treatment when confidentiality laws barred the hospital staff from disclosing that information. Sharon described five separate instances that featured frustrating *non*-interactions with healthcare staff who excluded her from discussions about her son's treatment. Sharon described for instance how she "felt like I really didn't have any information whatsoever" when hospital staff informed her that Nathan would be going home with her after discharge but refused to give her information about his diagnosis or details about his treatment. Interactions like this one left Sharon conflicted, wanting to help Nathan but angry with the situation and system, having "to find out information on my own.” Her descriptions including feeling excluded, frustrated, and helpless. Sharon recounted how, at one particularly low point when she had run out of solutions, she found herself telling her son, “Nathan you might as well just go kill yourself. You're killing yourself anyhow.”

Sharon described how Nathan’s progressively strained interactions with others created conflict for Sharon. Family members started excluding Nathan from important occasions, causing discord within the family. In one example, when Nathan’s brother, Adam, got married, he did not invite Nathan to the wedding. As a result of this conflict, Sharon felt torn between her children. Sharon described Nathan’s arguments with family members, including one “episode of violence” that prompted her to call for police intervention.

While Sharon’s descriptions of interactions with others were primarily negative, she also reported occasional positive interactions, including interactions she had with both her father and her sister-in-law. Sharon described taking her children to visit her father regularly. On those visits, Sharon described a sense of harmony between herself, her children, and her father, who was very supportive of her and Nathan. Sharon and her sister-in-law had children around the same age, and they would often go on trips and spent time together with their children. These interactions helped Sharon to maintain a sense of peace within the family. As Sharon said, “they [my sister-in-law and her family] would help out so much.” Sharon also had occasional positive experiences interacting with some healthcare institutions, as when a local care services organization that assisted individuals with disabilities took over the management of Nathan’s finances, an arrangement that “solved a lot of problems [since Nathan] would argue with them not me.” Sharon’s descriptions highlighted the relief she felt when she no longer had to supervise Nathan’s finances, since, as she said, she and Nathan “used to fight all the time about money.”

Experiences of conflict/peace are central to understanding Sharon's renegotiation of spirituality in light of Nathan's illness. As Sharon put it, her role in the family after Nathan's illness was to be a peacemaker, as she "mostly trying to keep him out of trouble." In this way, interactions served as a precursor to connectedness. Experiences that produced conflict, such as family members' excluding Nathan from activities and Nathan's drug use and illegal activities, contributed to spiritual distress, making Sharon feel like both she and Nathan "went through a lot of loneliness there." In contrast, other interactions were described by Sharon as leading to feelings of ease where she could be "accepting of the way things are." Finding peace was linked in Sharon's case to the sense of nurturance that provided a ground for positive relationships, such as Sharon's relationships with her parents and her siblings or the equilibrium she described as part of her interactions with the mental health support group. Throughout Nathan's illness, Sharon had experiences of both conflict and peace. She was able to focus on those positive interactions to help her cope, such as when she described being made happy in recent years by the fact that Nathan had been able to help out on the farm, even if she was also sometimes frustrated that he did not complete all the errands she assigned to him. Focusing on interactions that gave her a sense of ease and peace provided an opening in which Sharon found the energy and opportunity to begin her renegotiation of spirituality.

Disconnectedness/Connectedness. In the interviews, the women depicted connectedness as a sense of spiritual fulfillment, while feelings associated with disconnectedness (i.e. isolation, abandonment) were often linked to descriptions of spiritual distress. Much of Sharon's experience of coping with Nathan's illness was organized around her accounts of successful or failed connections with others. For most of the early part of her account, Sharon described connections that were disrupted or broken, including relationships with Nathan, her husband, her elder son, and her grandchildren. For example, after Nathan became sick, Sharon's husband, Ryan, whom Sharon said, "always kind of resented the help I gave Nathan," began spending more time alone in his woodshop and less time with the family. Sharon's connection with her granddaughter, Nathan's own daughter, who went to live with her mother, was also disrupted, because after Nathan became sick "the family treated us differently and [now] we don't really have a relationship." Although Sharon's case exhibited numerous instances of disconnection, she also reported times when she felt connectedness with others. Sharon experienced a great feeling of connection during her involvement with a parent support group, describing how before her involvement with the group she "didn't know anybody whose kids had mental problems."

Sharon's account stressed the multiple lost connections with others that occurred over time as she attempted to care for Nathan. These were mirrored or even exacerbated in her narration by disrupted relationships her son also experienced, including with his stepfather, his brother, his daughter, and his nieces and nephews. Yet, perhaps the most prominent was the central disrupted relationship Sharon described between herself and Nathan. Sharon first talked about losing close connection with Nathan when he moved out of the house and dropped out of high school. Nathan's legal issues affected their connection, especially when he went to prison for four years. Early on, Nathan developed paranoia and became mistrustful of Sharon, refusing to eat food in her home because he believed his stepfather was trying to poison him. Although Sharon's connection with Nathan was broken on several occasions, toward the end of her narrative Sharon described how in recent years their relationship had grown stronger. At the time of the interviews, Nathan had moved back in with Sharon and had been stable on medications for about four years. Sharon described spending a lot of time with Nathan and feeling a sense of assurance in their rebuilt connection, relieved that she knew where Nathan was and did not have to worry about him as she did formerly.

The theme of connection was also apparent in Sharon’s understanding of herself as a connector *between* Nathan and others. As Nathan’s mother, Sharon said one of her major family roles was trying to keep the family together and preserve their connectedness. At one point, Sharon described how she “was just treading water and trying to figure out and keep peace with everybody–keep peace with the husband, keep peace with the brother that was mad at him.” Sharon recalled how she was often frustrated in this role. While she always felt a connection with her son, she indicated that that was not the case for all members of the family, commenting on how “[n]obody really wants to accept him where he's at when he’s really sick.” Nathan’s schizophrenia initially produced disconnectedness for Sharon in her relationships with Nathan, her elder son, her husband, and her grandchildren, but Sharon recounted how she was persistent and eventually rebuilt those bonds. She received help, she said, through involvement in a parent support group and by staying focused on what she believed was her purpose in her family–nurturing relationships between family members. Despite the challenges staying connected posed, when asked what was most meaningful in her life, family connections were what Sharon identified first.

Real/Ideal. Another important and recurrent theme in Sharon’s interview was the real/ideal dyad, which referred to experiences of a loss of normalcy and shifting of expectations for the future. Finding out that one’s adult child has schizophrenia can result in the shattering of multiple expectations, as Sharon demonstrated.

When Nathan first began having symptoms of schizophrenia, Sharon thought his behaviors were related to drug use. She thought, “if he didn't take drugs, he wouldn't do this kind of stuff,” that the odd behaviors would stop, and he would be like he had been before. Sharon’s expectations regarding Nathan’s future were shattered when she continued to see troubling behaviors even after he stopped using drugs and alcohol. The disillusionment deepened when Sharon first heard a label of mental illness used regarding her son: “[W]hen they finally got the word *schizophrenia*, all my expectations for him, they just completely changed.” Gone were Sharon’s expectations of Nathan’s going to college, getting married, and having a family of his own. She said she moved at that moment from what was an ideal in her mind to the real of Nathan’s situation, that someone with such a severe mental illness would never live, as she put it, “a normal life.”

With Nathan diagnosed with schizophrenia and likely not able to live up to her envisioned future for him, Sharon struggled to find more realistic expectations for Nathan. Sharon described that process using a metaphor of life as a kaleidoscope:

> When you look at something it’s all pretty and it's all perfect, and it's all there in one big flowery shape, and the next thing, it just all falls apart (…) Sometimes you have a vision and things are looking so good and beautiful and great and shapes all are aligning perfectly, and then something happens, and they all fall apart. There's an opportunity to make it whole again, and you can change it by which way you crank it. (…) I think sometimes it's how you look at it and which way you're turning it.

The conflict between real/ideal was powerfully expressed by Sharon as a sense of evolving expectations, the new patterns leading Sharon to reevaluate what she found meaningful and purposeful about her son’s life. Sharon also had to shift her view of her own purpose as a parent. She no longer focused on encouraging Nathan to go to college and start a family. She learned to be open to other kinds of opportunities. Sharon's life with Nathan continued to be challenging, but she found hope in the idea that, like the turning of a kaleidoscope, the continually changing view and shifting patterns could turn up something new and beautiful, even if it was not the ideal with which she began.

Despair/Hope. The theme of despair/hope referred to moments in Sharon's interviews when she described feelings of complete hopelessness, most of which were then followed by a renewal of hope. Thus, while despair was present in Sharon's discussion of the breakup of her second marriage and her struggle to get proper treatment for Nathan, Sharon's narrative also included prominent swaths of hope, including her accounts of how Nathan was able to complete a certificate to work a trade, Nathan's beginning to help out on the family farm, and finally getting Nathan on a medication that she believed might give him long-term stability.

In Sharon's account, the theme of despair was prevalent in descriptions in which Sharon expressed helplessness and resignation. For example, after his first admission, Sharon was told Nathan's antipsychotic medication, olanzapine (Zyprexa), was going to cost $900/month, a price well beyond what she could pay. Sharon said she was left reeling, "wondering how I was going to come up with that money." Sharon could not see any way forward and had no idea how she could take care of Nathan when she could not afford his medication. A different face of despair emerged when Sharon answered a question about how she felt about being a mother after Nathan became sick and Sharon said, "I guess I was resigned to it." Resignation occurs when one feels so helpless and hopeless that they accept a situation rather than resisting or trying to control or change it. Sharon's account showed both a kind of helpless frustration, as when she described “coming home and feel[ing] like I'm still at work,” and resignation, as when she came to the full realization that Nathan might never come to demand less of her time and attention and that there was not much she could do to help him become more independent.

That sense of giving up was most evident in an episode that occurred several years after Nathan initially became ill. At the time, thinking she could support Nathan in living independently, Sharon had a house built for Nathan close to her own. There, she thought, he could live, and she could monitor him and offer assistance. Not long after, Sharon discovered that the house was being torn apart from the inside by Nathan and his friends and turned into a grow house for marijuana. In response, Sharon said, she shut down. She simply stopped going to the house, stopped thinking about it. Feeling she had done all she could to care for her son and unable to see any hope for the future, Sharon turned away in despair, resigned to let matters fall out as they would. The house was eventually destroyed in a fire.

While despair describes a closure of the future that arises in moments of lost control and an absence of answers and assistance, hope is an opening of future possibility that arises with the belief that a desired outcome *is* possible. Despite the challenges that Sharon faced when Nathan became ill with schizophrenia, she was able to find hope within the crisis. For instance, early on in Nathan’s illness, Sharon set her sights on medicine as the best hope for Nathan to gain control of his illness. She thought that if he took his medicine regularly, it would keep his symptoms under control. Then, Sharon realized that Nathan would always have exacerbations of his illness. But, having a long-acting injectable medication for Nathan did give Sharon a better sense of hope for the future. Sharon also found hope in Nathan’s renewed involvement in family life and expressed how she appreciated when he was able to help out with chores on the family farm (“he does the best he can—he wants to do the best”).

The theme of despair/hope was integrally related to the spiritual component of life meaning and purpose. When Sharon was in a state of despair due to her divorce and Nathan’s uncontrolled symptoms, she could not see a positive outcome for the future or find any purpose in her actions. Alternately, when Nathan was started on a new medication and could take on a more purposeful role in the family, Sharon was able to find hope and envision a positive outcome. Sharon fluctuated between hope and despair, but she was usually able to create meaning and purpose through the activities of caring for Nathan and in encouraging his involvement with the family.

Values and Beliefs. Additional themes arose in Sharon’s interviews that clustered under the category of values and beliefs. Values are what one deems important in life and can serve as a source of motivation to drive one to accomplish goals (Hayes, 2018). Beliefs are how one thinks and feels about the world and what they accept as true (Forgas, 2012). Values and beliefs together influence how one finds purpose in life. In Sharon’s story, prominent values were resilience, having a work ethic, and providing for the family. Sharon also emphasized her belief in the importance of seeing the unique worth in each of her adult children.

Sharon observed early in the interviews that her parents had instilled in her a sense of resilience and a problem-solving mindset that helped her cope with Nathan’s illness. Sharon described a strong work ethic, ascribing to that value her efforts to maintain job security and provide for her family no matter what else was happening. Sharon equated the provider role with being a good parent and identified as her major purpose in life being a support to her children. Sharon’s sense of responsibility to her family motivated her to complete her education: “I quickly learned that I had better get to college. Nursing paid the bills.” The value placed on her family’s welfare influenced how she formed and conducted romantic relationships: “[You can’t] divide yourself up between the [romantic] relationship and your relationship with your kids.” It governed how she spent her time, evident in her frequent reference to taking her kids camping and to museums. When asked what was most important in her life when her children were little, Sharon said, “giving them experiences.”

Sharon also discussed her belief in the importance of valuing the role of her adult children in her life. She spoke of her pride in her son Adam and his wife, who ran the family farm. Although Nathan did not have such a responsibility within the family, Sharon still saw his worth and talked about how Nathan “does his best” and how he helped out as he could. While Sharon upheld hard work and family responsibility, she also understood how the ability to contribute to the family varied between her children, and what mattered was the individual effort that each put forth.

Sharon’s values and beliefs related to her spiritual understanding of what was meaningful and purposeful in her life. She was very focused on her purpose of being a hard worker and providing for her family despite obstacles. She also thought it was important to find distinctive meanings in her relationships with her sons, recognizing that each person may serve a different purpose within the family and that their purpose might change. After Nathan became ill, Sharon reformulated her ideas for what it meant for Nathan to be a contributing member of the family.

Case 2–“Ruth’s” Narrative

Before the Illness

Ruth dropped out of high school at age 18 and married her high school boyfriend. Her first child was born shortly after. Her daughter, Christy, arrived two years later. And another daughter was born a few years after that. Ruth was very involved in La Leche League, and she worked part-time as a childbirth educator when her children were young. When Christy was four, Ruth and her husband divorced.

As a single mother, Ruth struggled to support her children. She also became responsible for her 15-year-old sister who moved in with her. It was a difficult and stressful time for Ruth, although she did manage to complete requirements for her high school diploma. Ruth briefly lived with a friend, another woman who was divorced with kids, before moving to another state, where Ruth heard there were more resources available to single mothers. After moving, Ruth met and married her second husband, to whom she had been married 47 years at the time of our interviews. Ruth and her family moved numerous times when the children were young. They lived in the first state for three years, where Ruth had another child. When this youngest son was 18 months old, Ruth went back to school full-time to pursue her dream of becoming a nurse. After completing the prerequisite courses, the family moved to the South where Ruth attended nursing school. The family lived in the South for 10 years before moving back to the West Coast.

Becoming Ill and Being Diagnosed

In keeping with her upbringing, Ruth expected all her children to become independent when they turned 18. Her daughter, Christy, worked during high school and moved out shortly after graduation. Sharon thought Christy was doing well on her own at first, until Christy was 20 when Ruth noticed a change. Christy, who was never very emotionally expressive, started calling Ruth repeatedly, crying and complaining about her roommates. Ruth was not sure what was going on but suspected Christy was abusing drugs. Christy continued to get worse and eventually moved back in with Ruth. When Ruth took Christy for treatment, the doctor said she had a problem with drugs and alcohol, referred Christy to outpatient treatment, started her on medication, and recommending that she attend Alcoholics Anonymous (AA) meetings. Ruth dropped Christy off at the meetings but soon learned that Christy would leave before the meetings even started. One day, Ruth came home from work and found an empty medication bottle on top of the refrigerator. Christy had taken all her medication at once. Ruth took Christy to a local emergency department, where she was triaged and then hospitalized in the inpatient psychiatric unit. She was discharged from the hospital a few days later with no definitive diagnosis.

Ruth described how Christy went through six hospitalizations before she was diagnosed with schizophrenia. In total, she had about 15 hospitalizations over the course of her illness. Several of these admissions were prompted by extreme agitation and aggression at home, including incidents in which Christy physically attacked her sister and Ruth herself. Eventually, Ruth changed the locks at home and refused to be alone with Christy for fear of being attacked.

Life After Diagnosis

Ruth became a grandmother when Christy, at age 23, gave birth to a son. Because of the pregnancy, Christy’s medications were decreased, and shortly after her son’s birth, Christy had another aggressive outburst at home. Ruth had to call 911 to have Christy taken to the hospital. Ruth said she believed this was the worst that she had seen Christy after she became ill, and the symptoms improved after this. But Ruth now had legal issues to deal with, since Christy was incarcerated in jail several times, the longest incarceration lasting nearly a year. Two weeks after being released from jail, Christy went to live in an independent living center. Ruth was optimistic that Christy would improve. When she got a phone call from the staff at the center, Ruth expected to hear that Christy was aggressive and acting out. She instead learned that Christy had gone into cardiac arrest and had to be placed on life support. Christy remained on life support for 48 hours before she died.

Ruth's Memory Objects

Ruth shared five memory objects during her interviews. The grief bowl was a gift from a friend that Ruth received at the time of Christy's memorial. Grief bowls are vessels in which one can symbolically place their grief. The friend made the bowl herself and included a special inscription, "It's that special day in all our lives," the words with which Christy would announce her birthday each year.

Figure 1

Front and Back of Grief Bowl

Another object that Ruth shared was a set of stuffed kangaroo dolls, part of what Ruth described as a vast collection. Over the years, Ruth and Christy would exchange kangaroo stuffed animals with one another as gifts on various occasions.

Figure 2

Stuffed Kangaroos

Ruth also shared a book entitled *Da Jesus Book*, which was a version of the Bible written in a native Hawaiian dialect. Ruth purchased this for Christy before her death.

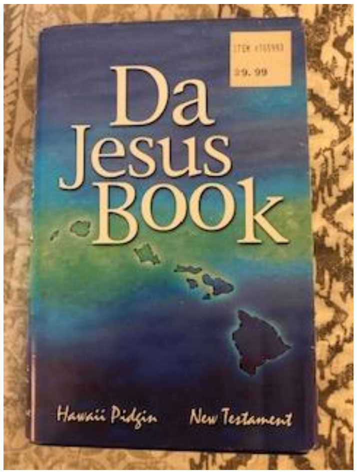

Figure 3

A Bible Written in a Native Hawaiian Dialect

Ruth also shared a framed photograph of Christy that was taken after Christy became ill. Christy was smiling in the photograph. Ruth keeps the framed photograph on her desk.

Themes in Ruth's Case

Conflict/Peace. In Ruth's case, feelings of both conflict and peace arose primarily around interactions with the healthcare system and were primarily negative. Difficulty with the healthcare providers who treated Christy was something that Ruth struggled with from the time Christy started exhibiting signs of illness. When Ruth would take Christy to the hospital, the staff relied on her to provide information. It was Ruth who had to tell everyone about the course of Christy's illness. Yet, after the initial triage in the emergency department, Ruth was neither asked for nor given information. While acknowledging that the staff was "courteous," Ruth expressed her frustration with such interactions, especially one episode in which nursing staff assumed that Christy, who was brought in after violently attacking Ruth, would go home with Ruth after discharge but refused to give her any information about Christy's treatment. As Christy's primary caregiver and sometimes-target of her aggression, being left out of Christy’s care plan was both frustrating and frightening for Ruth and left her feeling angry and conflicted with those who provided care.

Disconnectedness/Connectedness. The most prominent thematic dyad in Ruth’s case was that of disconnectedness/connectedness. The theme of disconnectedness arose in reference to experiences in which Ruth described herself as isolated or alone, while connectedness was exemplified in a number of meaningful personal relationships that Ruth formed or maintained. Ruth related feelings of disconnectedness from her mother and more generally from social contacts—friends, neighbors, coworkers, acquaintances. In contrast, Ruth found a sense of connectedness through her relationship with her husband, her siblings, her Bible-study book club, a particular business associate, and NAMI.

Of special note was Ruth’s relationship with her parents. Ruth described how going to her parents for support during the early stages of Christy’s illness was not an option. Like others of their generation, Ruth said, her parents believed once children turned 18, they should not be dependent. Ruth recounted how she and her sibling all moved out and married at young ages, after which their parents were not really involved in their lives. From her parents’ perspective, continuing to depend on a parent signaled a failure of both the child and the parents. Ruth said she knew that if she asked her parents for any assistance with Christy, they would consider her a failure and would feel they had not raised her to be self-reliant.

Other connections in Ruth’s account were similarly weak or subject to rupture. While Ruth claimed to have important connections for support throughout her life, she also described ties to others that changed radically when Christy became sick. About the period in which Christy started showing symptoms, Ruth observed, “I can't overstate how hard that was. All of my regular supports that I ordinarily would have completely vanished.” The sense of disconnectedness to siblings and friends posed challenges for Ruth, as she faced the crisis of her daughter's becoming seriously mentally ill without many of the social supports on which she previously relied.

A key element in the theme of disconnectedness/connectedness for Ruth was empathy. Ruth made it clear that the connections she expected to sustain with her friends failed in part because many with whom she had been close could not comprehend what she was going through. She eloquently described how friends and family

> [d]idn't understand it. I'm the most knowledgeable person—and *I* don't understand it. They didn't know how to help me. They didn't know how to help her. And it looks so catastrophic and so bad that they then stopped even asking about her.

In the end, for Ruth, connectedness did not mean leaning on those she already knew and loved but actively finding people who had had experiences of their own that gave them a basis for understanding. This happened in two ways, first, through Ruth's introduction to NAMI, and then through her chance introduction to another woman who had a child with serious mental illness.

In NAMI, Ruth found a community of people who could handle hearing about the bad stuff and could help her put it into perspective. She described how those in the group supported one another through their shared experience:

> Even if with others outside of that experience it looks too devastating to survive (. . .) among ourselves, we know you *do* survive. (. . .) So, we're not just like, "Oh woe is me." We're like, "Well, what's going on *now*?" We know this is just part of our life.

The empathetic support Ruth found in NAMI enabled her to feel a connection with others experiencing similar situations; she no longer felt isolated and alone. NAMI also helped normalize Ruth’s experience with Christy. She learned from NAMI that her situation and feelings were something many people shared. Ruth also found a sense of optimism in the assurance that, although she would face many challenges, she would be able to persevere just as others had done.

A second and unexpected source of connection came from a discussion Ruth had with a business associate. Ruth described how she was informed by a business associate that his administrative assistant, Kate, was also caring for an adult family member with mental illness. Kate was not, as Ruth put it, someone with whom she would ever have expected to find a connection. To her great surprise, however, Kate turned out to be a tremendous source of fellowship and support. Because Kate was experiencing many of the same stresses, an empathetic connection formed between them:

> This woman was gold. She really became my confidante. The one I could really pour it out to (…) the full range of emotions that you have when you're having to deal with a thing like that (…) You could really be honest.

Ruth’s account indicated that, for her, having a few strong connections with people who understood her situation was more important than having many connections with people who, though they might genuinely love and want to support her, lacked a basis for empathy and were thus more likely to avoid her out of fear than to stand by her with true understanding and acceptance.

Ruth also found connectedness through the only group that she described seeing regularly for support–her Bible study book club. This group represented a safe place to discuss whatever was on her mind. Ruth explained that “They pray for each other. They do, you know, all those wonderful things—keep[ing] tabs on how everybody is. It's really a safe place [where] you can dump it all out there." The women in the book club listened to and supported one another and helped Ruth feel like she had people to rely on whenever she needed. Ruth described the connections she gained in the book club as one of her greatest ongoing supports.

Other key sources of connectedness Ruth identified included her husband and her siblings. Ruth's strongest, most reliable source of connectedness was her husband, with whom she described having weathered numerous life challenges: multiple moves to multiple states, the completion of advanced academic degrees (both of them), and Christy's illness. In describing their relationship, Ruth used the term "incredible" and underscored the companionate quality of their marriage by remarking that they are "wonderful playmates." Ruth's also found connectedness in her relationships with her siblings. Ruth made it clear that she has relied on these relationships, observing that "my brothers and sisters were really, really important to me. I was super connected to them—more than to my parents."

For Ruth, the onset of Christy's illness caused many of her normal connections to be disrupted. She was fortunate to have good relationships with her husband and siblings and described finding several new and valuable connections to support her as she learned to care for an adult child with schizophrenia. Being able to make connections was central to Ruth's spiritual journey.

Real/Ideal. The theme of real/ideal related to how Ruth's sense of normalcy was disrupted and her expectations for the future were reshaped. When Christy began exhibiting signs of schizophrenia, Ruth began to see her daughter in a completely different way: "She was just becoming a different person. She was just like a different person entirely than I had ever known." Then, when Christy's illness continued to worsen, Ruth realized that Christy would never be the daughter she had before. Ruth described in blunt terms what coming to such recognition was like, narrating how Christy "lived on her own. She's worked since she was 14 years old. And now, she'll get in the shower and have a bowel movement right [there]." As Christy reached a point where she could not be independent and support herself and even required assistance with basic activities of daily living, Ruth found her expectations, the idea that her daughter would become a self-directed and fully functioning adult, shattered. That disillusionment came to a head when Ruth attended a NAMI conference:

> I look across the meeting, and it's all people with gray hair. And it was the first time it really struck me. This is a lifelong problem. These people are talking about their children who are 45, 50—I didn't realize that. For my generation of people, you pretty much thought you were done [being parented] at 18 or 20 for sure, because in our generation we were done. Our parents never did anything for us after that. You didn't think you had to do anything for kids past that certain point. So that was very confusing and hard. It is such a thing of parental failure. That was when I personally came to that realization: you wished your child would be a drug addict rather than have schizophrenia.

Not only were Ruth's expectations for her daughter's independence shattered, but she also had the added burden of feeling like she had failed as a parent. If Christy were a drug addict, at least there would be hope of a recovery. With schizophrenia, Ruth knew that Christy would never be the same again. Ruth explained how she dealt with this realization:

> People come to me often for wisdom or advice, “How am I to live through this? How am I going to make it through that area?” I guess I have a joking phrase, “When all else fails, lower your standards.”

Ruth’s philosophy was that, when her expectations were shattered, new ones had to be formed that took into account the more realistic goals for her daughter. Being a fully functioning and independent adult could no longer be an expectation for Christy, so Ruth reframed new and more attainable expectations for her daughter: “You lower your standards, for those new standards become great.”

The conflict between real and ideal related to the spiritual concept of how Ruth understood meaning and purpose in her life. She thought her parental purpose was mostly complete as Christy entered adulthood. But all this shifted when Christy became ill and was once again dependent on her. Ruth also struggled with finding purpose for Christy. She could not expect the same things from or for her anymore. Ruth had to reshape expectations she had for what Christy might be able to attain and the standards to which she held her, recognizing that as someone with a serious mental illness, Christy could not be expected to accomplish what Ruth once thought she could.

Despair/Hope. In Ruth’s narrative, feelings of despair emerged when aspects of Christy’s behavior or her situation left Ruth feeling as though there she was out of options, with no way forward. In contrast, the other face of the dyad, hope, was apparent in those moments when Ruth reported an opening of prospects, new sources of support, and surprising sources of joy.

Ruth experienced despair at several points in the course of Christy’s illness. When Christy was initially diagnosed with a drug and alcohol problem, Ruth was responsible for taking her daughter to the prescribed AA meetings. When Christy did not attend, failing to follow her recommended treatment, Ruth recalled being at a loss, having no idea "where to turn, what to do." The feelings of helplessness—not knowing what to do—were bad enough, but the lack of control over events would later amount to despair, when Ruth found herself unable to see any positive outcome for the future. One example occurred in Ruth's description of an important moment in the progression of Christy's illness, her ingestion of an entire bottle of medication. The incident prompted an emergency department visit:

> And I remember just being so fucking fed up. I was just—"You're killing me here! Can't I get *out*? You're killing me!" I was so beside myself.

Ruth sense of exasperation ("so fucking fed up"), entrapment ("Can't I get out?"), and panic ("You're killing me here!") made it clear that her daughter's suicide attempt had pushed Ruth to the edge of her capacity to cope—pushed her, as she says, "beside myself." Being thus overwhelmed, it was no wonder that Ruth had trouble seeing past the low point of Christy's present position to any chance of gaining traction, any chance of a better tomorrow. As Christy continued to experience exacerbations of her illness, so too did Ruth continue to have periods of despair. These reached another crisis point in one instance in which Ruth and her husband were driving to a wedding. She described:

> I'm crying—the entire way. No, you don't get it. I am going down for the count. I can't do this. I do not know what to do. It was too much. [My family] didn't understand it. I'm the most knowledgeable person, and *I* don't understand it. They didn't know how to help me. They didn't know how to help her. And it looks so catastrophic and so bad that they then stopped even asking about her.

What was clear at this moment was how totalizing Ruth's anguish was—how adrift, without support or solutions, she felt. Ruth's family had been there for her in the past, but at this point, they no longer even asked how Christy was doing. Ruth found herself, a woman who was used to being rich in support and ready with answers, alone with no idea where to turn. This was "too much." Notably, in hindsight, Ruth attributed her family's fear and silence about Christy to their lack of understanding, not their lack of feeling. As she implied, they might have been, as she was herself, overwhelmed: "it looks so (…) bad" that they had to turn away. Incomprehension was something she could empathize with. As Ruth reasons in the interview, when *even* she, a psychiatric-mental health nurse, could not make Christy's "catastrophic" condition fit into her schemas of family relations and everyday life, how could her family be expected to respond? In recollecting this moment of despair, the awful unknowing and uncertainty *joins* her (in imagined shared experience) to her family again. At the time though, Ruth's narrative makes clear that the perceived lack of family communication and support contributed to her sense of helplessness, abandonment, and, eventually, despair.

In Ruth's narrative, despair frequently found its match in hope. Although the disruption of old connections was very difficult for Ruth, she continued to form new connections. These gave her a sense of hope and a ground from which to remain open to the eventual healing and renewal of the old support system as well:

> The[re is] disappointment that comes from not having those people that you think you would rely on to be the most helpful, the most supportive, the most solicitous, the most instrumental [assisting], the most optimistic and hopeful. They're not. They are probably not going to be the ones. There's really a sense of loss in that those people

> are not there for you at your times of greatest need. Don't be worried about that. There is going to be other ones that come forward. Be open to the help and support and encouragement and hopefulness that really is out there. And it *is*. I think it is. But you have to be open to that and [also] know that, in time, friends come around. Family comes around. They learn to accept you to whatever degree they do.

Not only did Ruth find a connection in new friends and support systems but her family and friends eventually became more accustomed to Christy's illness and Ruth's caregiving role. For Ruth, hope might be summed up in her claim that support often comes "from places that you would never dream will be of support," which meant that no matter how bad things looked and how isolated she felt, Ruth realized that "[p]eople will emerge. People will appear from places that you would never dream and provide something to you that you just would have never dreamed could come from there."

Allowing herself to be open to surprising sources of joy was a major way that Ruth found hope. Seizing joy contributed to a more positive mindset, empowering Ruth to visualize a positive future. Ruth embraced joy in seeing the humor in absurd situations. In one instance, Ruth and her two young granddaughters found themselves driving slowly around the streets of San Diego, scanning groups of homeless people to find Christy who had been living on the streets. Ruth related how suddenly she recognized the absurdity of the spectacle they made: she and her seven- and eight-year-old granddaughters, cruising around, yelling Christy's name out the windows. In another instance, Christy was in police custody when Ruth arrived at the courthouse for her hearing. On catching sight of Ruth, Christy, in bright orange jumpsuit and shackles, was so happy to see her she began to yell, "Mom!" like a child on stage in a school play. Though Christy was no child and jail no proud performance, Ruth described how the scene gave way to humor and a small spot of joy arose from an otherwise low moment. For Ruth, remembering that—no matter what—"there will be joy" enabled her to find surprising sources of hope.

Ruth transcended despair by becoming open to new sources of hope, both in connections with others and in finding joy despite the circumstances. Hope enabled Ruth to envision a positive outcome for Christy, which empowered her in finding meaning in her experiences and a purpose in her efforts to care for her daughter.

Values and Beliefs. Ruth's account returned often to aspects of her role and self-perception that reflected her values. Two of the most prominent of these were being a good mother and being a good Christian. Ruth also emphasized the value of gratitude. Prominent beliefs related to Ruth's story centered on her religious faith. An important part of renegotiating spirituality in Ruth's narrative revolved around her efforts to maintain or adapt her core values and beliefs to the shifting demands of Christy's illness.

Early in her story, Ruth discussed the importance of her role as a parent, both in what she did and in how she was seen doing it by others:

> I wanted to look like a good mother. I wanted to look like I had my act together. That meant a lot to me—to be seen as having expertise and as knowing what I was doing. I wanted to do it, but I wanted to be seen as doing it, too. I wanted to be viewed as doing that. That is *so* not my deal now.

Rather than relying as before on external validation from others, at the time of our interviews, Ruth said she had become more focused on internal supports and relied "tremendously on my faith." But being Christy's mother had been no easy road for Ruth. Christy's illness challenged Ruth's understanding of what she could and should do for her daughter whose illness at times manifested in violent and aggressive outbursts, many of which focused on Ruth. At one point, Ruth described needing “six people to pull her off of me.” Ruth was concerned enough for her safety to change the locks and bar Christy from the house. Ruth’s fear for her safety continued for years so that “not more than one or two times ever did I allow myself for the next eight years to be somewhere with her that was either not in a public place or with other people around.” Ruth had to find alternative ways to be a good mom to Christy.

Certainly, Christy’s illness had challenged Ruth’s beliefs about the role of a parent in general. As described above, in the 1970s, “You didn’t prod kids into their life destinies.” Instead, parents let children find their own way. Having a self-reliant adult child was an indicator that one had succeeded in their role as a parent. Having to renegotiate her beliefs about what made for good motherhood as she parented Christy eventually led Ruth to realize that being reliable was the most important thing she could do for her children.

Whatever the difficulties, Ruth was clear about her identification with motherhood and her belief in the special bond she had with her child. One of Ruth’s memory objects, in particular, embodied that bond for her. She described how she and Christy used to exchange gifts of kangaroo stuffed animals:

> It really became very symbolic of “I know you love me. I love you too,” just our overall closeness. I knew that always, no matter, even if her behavior was beyond bizarre. The kangaroos—they’ll always be the thing that reminds me. I knew in the bad, tough, very hard things to go through, she didn't doubt my being there for her.

By focusing on being an unwavering source of support for Christy, even in the most difficult of times, Ruth was able to see the value in her maternal role.

Other values such as gratitude and spirituality also sustained Ruth. When her children were little, Ruth was a single mother. She recalled a time when her church unexpectedly came to her assistance and reminded her of the importance of gratitude:

> The church would always adopt a few families right at the holidays to give Christmas trees and presents. They pick[ed] me as one of their holiday meal [beneficiaries] to receive the blessing of that. It was such a gift. My kids were little. I never forgot what it felt like to be on the receiving end of that. I think it takes having been in that position to really get the meaning of what that means to you when you give back, and what a gift that is when you're in those very difficult times [thinking] how are you going to pay for this.

Ruth noted how later in life the memory of this time encouraged her to give to others in need, explaining how once she and her husband came to be better off financially, they bought all the school clothes for their grandchildren each fall because they understood what it was like to be struggling parents trying to provide for children.

Ruth’s religious beliefs played an important role in her story and undergirded her renegotiation of spirituality. Ruth and her husband were both religious, though they followed different faith traditions. In the home, the family observed two religious traditions: Christianity (Episcopalian) and Judaism. The family also lived in several faith-based communities in three different states, where Ruth encouraged her children to be involved in local religious activities. But wherever the family moved, Ruth attended services of the Episcopal church. Ruth explained, “There's always an Episcopal church everywhere. So, I could always find somewhere with your music, familiar viewpoints, familiar prayers. I did always feel a connectedness in that way.” Ruth held tightly to her Episcopalian beliefs and traditions, including attending church regularly and participating in Bible study, where she found a great source of support in her struggles with Christy's illness. But Ruth's religious beliefs also impacted her spiritual journey in a more personal way exemplified by a spiritual experience she had while in prayer at an Episcopal Church.

> I had this revelation of God's voice: "OK Ruth, I have tried everything. I got you a scholarship to do all of your mental health work. I got you this job. I didn't know how to get your attention, to get you back into mental health. I'm sorry I had to go to this, but now will you work in mental health?" And it was a calling, because I always felt [mental health nursing] was a pretty much my calling. I think my faith and all these various different avenues helped me to go back to that, to have a bigger sense of purpose and a larger sense that there's things to be gained from everything.

For Ruth, having what she experienced as a direct communication from God pointed her to a new purpose for herself in light of Christy's illness. God was calling her back to work in the mental health field, something for which she had trained but had not pursued. Although having a daughter with schizophrenia was in many ways devastating for Ruth, disrupting her relationships and her self-understanding as a good mother, the spiritual revelation to which it led helped Ruth recognize a new purpose and role in which she could use her education and what she learned with Christy to help others struggling with issues of mental health.

When Ruth found a new purpose in supporting others, she also achieved a sense of forgiveness toward those people in her life whose support for her dissipated after Christy became ill. She came to recognize how compassion and faith provided the means to forgive those who could not be there for her. Ruth described how family members, in particular, might disappoint a person going through the experience of caring for a child with schizophrenia. Ruth’s compassion for and forgiveness of her family was evident when she acknowledged how overwhelming mental illness in a family member could be to those who might genuinely want to help but simply could not shoulder the “extra burden.” As Ruth pointed out, “that's where faith can come in,” since it was through her faith and the support of her religious connections that Ruth was able to maintain her balance as a parent caring for Christy while also coming to terms with her family’s limited ability to help. Ruth described what she learned about the difference between support from her family and her religious community and the allowances that she found must be made for the former:

> Be forgiving of your friends and family and loved ones, even though they might be disappointing you. That's because that's an extra burden. And that's where faith can come in. A lot of times, people who are not plugged into your individual circumstance can be super generous. They’re praying for you. They're jumping right in there. They'll hear out every story. They'll let you say it over and over. They'll applaud every victory. They'll just be right there for you.

To Ruth, achieving forgiveness through her faith was key. Holding on to disappointment meant an extra burden that *she* was putting on herself. Forgiveness was a kind of opening-up, in which Ruth learned to accept the limited capabilities of those friends and family members who had disappointed her, while also opening her eyes to sources of support in unexpected quarters. Ruth thus claimed that her greatest strength was “faith and my ability to kind of recognize the gifts of support and be open to it.”

Faith and an openness to the gifts it created was bidirectional for Ruth—involving both acceptance of support from others and receptivity to the idea that she had something to give. Ruth described how the NAMI group in which she participated provided a forum for these values, since it was there that she learned that “opening up to other people is very big. Being open to other people and seeing how sharing your own experience, even if you're only an inch further along than they are, can provide a measure of hope and optimism. And that kind of thing is a gift.” Participation in the NAMI group gave Ruth an important source of connection and a sense of purpose as she shared her experiences to help support others in similar situations.

Finally, in the course of dealing with Christy’s illness, Ruth went through a process of evaluating what she believed was important in life. Taking into account the severity and course of Christy’s illness, Ruth found that things she once valued no longer seemed important:

> When people ask me, “What did you want for your children? Did you want them to go to college? Did you want them to do this?” (…) And I always say, “I want them to be alive!” I want them to be alive, because everything else can be fixed.

In renegotiating purpose and meaning, Ruth concluded that the external indicators of success and achievement paled next to the simple hope of having one’s child alive. For Ruth, it was like she lost Christy twice: first when she became like a different person after diagnosis and then when she died unexpectedly.

Case 3–“Maggie’s” Narrative

Before the Illness

Maggie and her husband raised their four children—three sons and a daughter—in the country. Maggie was a stay-at-home mom who cherished the time and attention she was able to spend with her children. Maggie’s own mother lived about an hour away, and Maggie made sure that her kids shared a close bond and spent time with their grandmother. The kids loved being able to play outside almost every day, and Maggie described how much she enjoyed taking them to playgrounds, parks, and playdates at their friends' houses.

Even though this period was characterized by Maggie's narration as full of bright spots, there were also signs of trouble. Maggie's husband was mentally and physically abusive to Maggie and their sons. As the children grew older, her husband developed a drinking problem and his abuse towards the family escalated. Though her husband worked 12-hour days, when he was home, "he would start on the boys." As the stresses of her husband's worsening mental illness and the abuse of her and her children increased, Maggie described trying to give her children stability, love, and a warm home life. Her husband was often not involved in family activities, but Maggie and her mother shared a close connection and they "did a lot together with the kids. We had a lot of good times." Asked about her purpose at that time, Maggie responded, "Number one was my kids. I wanted to see them happy."

Becoming Ill and Being Diagnosed

Brian was Maggie's middle son. It was when Brian as in high school that Maggie began to notice strange behavior in Brian, who told Maggie around that time that he just "never felt right," that he saw things other people did not, like a figure he described as the Grim Reaper. Maggie heard reports from Brian's older brother about Brian's acting strangely at school. She heard from his teachers that Brian got into fights and sometimes did not go to school at all. Maggie eventually sent Brian to a drug rehabilitation facility, where he spent only a short time before leaving to complete his senior year of high school at a vocational school.

After high school, Brian held a couple of different jobs with his brother David. Maggie heard from David of Brian’s increasingly odd behavior at work. Meanwhile, at home, Brian began to be violent. When Brian threatened to kill her, Maggie reached out for help and Brian was taken to the emergency department where he was diagnosed with schizophrenia. Despite the diagnosis, Brian continued to be impulsive and violent at home. It would take over two years and four hospitalizations before Brian’s symptoms were under control and Maggie was able to have an informative conversation with healthcare providers about what was going on with her son.

Life After Diagnosis

At the time of our interviews, Brian was 24 years old and living at home with Maggie and his younger sister Angie. Brian’s symptoms were well-managed with a long-acting injectable antipsychotic medication. Maggie and her husband were divorcing, but Brian’s father continued to be active in his life and had assumed the responsibility of taking Brian to his monthly psychiatrist appointments. Maggie described the close connection she felt to all her children and expressed satisfaction that she could be a source of support for Brian. She encouraged Brian to be as self-sufficient as he could be. Maggie believed that her purpose as a parent was to look after her children, even into adulthood. As Brian’s primary caregiver, Maggie’s described her concern about Brian’s future when she foresaw that she would not be there to care for him.

Maggie’s Memory Objects

When asked to share memory objects, Maggie narrated how one Christmas, the children begged her for a Thomas the Train playset. This was an expensive request, costing over $500. To earn extra money for the set, Maggie worked part-time at a store that specialized in personalized gifts, earning enough money to purchase the train set and a personalized blanket for each of her boys. Maggie described how Brian cherished his blanket throughout his childhood. Maggie's other memory object was a handful of soda can tabs that Brian compulsively collected in high school about the time when Maggie began to notice changes in his behavior. Brian, she said, had the tabs all over his room, made them into necklaces, and stacked them on one another like little shrines. Maggie also described how Brian would similarly collect cigar wrappers, although she did not share an image of them.


[redacted]

Figure 4

Personalized Blanket Given to Brian as a Child

Figure 5

Pop Tabs Brian Collected

Themes in Maggie's Case

Conflict/Peace. Conflict/peace was the most prominent theme in Maggie's case. Maggie's experiences of conflict and peace emerged in interactions she described having with others, including her husband and various health care providers and staff. Conflict especially characterized interactions with Brian's father whom Maggie described as an abusive alcoholic and a divisive force between his children. Although Maggie also experienced conflict and frustration when interacting with healthcare providers, whom she felt did not communicate with her, the one truly positive interaction described by Maggie was with a nurse in whom Maggie found a rare moment of comfort and validation.

At home, Brian's father struggled with alcoholism and mental illness (which Maggie believed was also schizophrenia) and physically and emotionally abused Maggie and their children. The husband worked seven 12-hour shifts each week, keeping him away from home most of the time, but when he was there, the husband would provoke argument and cause division between his sons. Maggie recounted how he would point to one son one day and say, “You’re my favorite,” and on another day tell the same thing to a different son. Interacting with Brian’s father was a major source of stress for Maggie and the family as a whole. As Maggie put it, “It was like walking on eggshells around here for everyone.”

Much of Maggie’s home life and marriage were defined by conflict, often violent, and by her account, she did not have much life outside the home. Other than the one year when she worked in a gift shop, Maggie said she never worked outside the home. She was not a member of a church. She interacted with few friends, and her mother passed away when Maggie’s children were young. The other source of support that could have smoothed Maggie’s way some would have been her increasing interactions with the health care system. But the most characteristic quality of those interactions was their absence. Maggie several times noted the lack of communication from doctors in the early years when Brian was being seen for and finally diagnosed with schizophrenia. This lack of contact and communication was true despite Brian’s having signed authorization to release information to Maggie. Unfortunately, when interactions did occur with healthcare staff who might have supported her, most of these were negative. During Brian’s first hospitalization, Maggie recalled that she did not even see the doctors until the day her son was discharged. Brian signed authorization to release information to her, yet hospital staff were still reluctant to give her information about her son, even though he lived with and would be returning home with her at the time.

Although silence or strife characterized most of Maggie’s interactions with others, leaving her feeling stressed out and alone, she reported one exceptional exchange with a nurse who took time to talk her about Brian. A couple of days before, Maggie had left the hospital crying after Brian, at the time an inpatient, told her that “he didn't want to see me ever again because he would hurt me.” When she arrived for the next visit, Maggie was approached by a nurse of 30 years’ experience, who said, “We’re going to sit and talk with you,” and then did just that:

> [The nurse] was a miracle. She was an angel that came out of nowhere and she saved my son. She got him to try the Invega—because he wouldn't have a needle in him—and she talked him into it. And that was the turning point of everything. I don't think she knows what she did for me. But she really cared. She was the first person I met in two years that cared enough to try to help my son.

For Maggie, the interaction with the nurse was a blessing and the conversation a turning point. Probably less than 15 minutes’ duration, the exchange provided Maggie with a sense of feeling cared for, a moment of harmony, and a sign that she and her son were worth someone’s going “that extra distance.”

Disconnectedness/Connectedness. Threaded throughout Maggie’s case were descriptions of Maggie’s feeling isolated from others. She also described several sources of connection. In general, the onset of Brian’s illness exacerbated the disconnectedness within the family as a whole. Eventually, however, Maggie was able to form a bond with Brian and find connectedness through her experiences with NAMI.

Relationships within the family suffered before Brian’s illness as a result of Maggie’s husband. Brian’s father was a divisive, violent figure known for splitting family members. During the period before Brian’s diagnosis, Maggie said she often took the role of moderator and diverter, the one who tended relationships. She described how she drove hours each week to keep her children connected to her mother and how, in the context of her husband’s drinking and violence, she "tried to keep the peace around here. Even if I had to step in the middle, I always did. That's what really was important to me."

When Brian became ill with schizophrenia, his behavior also became threatening, violent, and unpredictable, and Maggie had to find different ways to manage family connections. Because Maggie feared for the safety of herself and her other children, particularly her youngest child Angie, she was placed in the unfamiliar position of enforcing *dis*connection:

> I was scared, because I was his target for some reason. Women were his target. His sister was his target. So, I would always tell her to stay away from him. I had her in dance seven days a week, and I kept her out of here. And I worked.

Maggie recalled other particular moments of disconnection, as when Brian banished her from his presence, announcing that he could not see her anymore or he would have to kill her. Because of the disease, his trust in her was disrupted, and her trust that he would do her no harm was undermined.

Disconnection also thematized Maggie's description of her role as a mother. As she said, "I lived my life for my kids. You know, being a mom and a wife and doing all that. That was my life." As mothering Brian became increasingly challenging, Maggie's description of a lack of personal support underscored how alone she was in coping with those challenges. She described how:

> I didn't really have a lot of friends. I kept in touch with old friends, but a few of them never had children, so, it was pretty much me on my own (…) I never really established a friend base.

The repeated “on my own” highlighted Maggie’s sense of disconnectedness from friends who might have been able at the very least to lend an ear. Instead of friends, when pressed about where she found feelings of connection, Maggie referred to NAMI and to a book she had read.

Eventually, Maggie was able to build relationships, both with persons in her life who could give her support and with Brian himself. Maggie said that over the past few years she had been able to regain mutual trust with Brian. She described how “I'm pretty close to him. Just going through that whole situation with him brought us closer. And he knows he can depend on me always. I’m his mom. I never let him down.” Other family connections remained tenuous, and Maggie described her fears that without her Brian would be utterly without caring relationships. But Maggie expressed satisfaction with her and Brian’s having worked through his illness together in a way that enabled a rebuilding of trust and repairing of their broken tie.

Also important to Maggie’s sense of connectedness, after Brian’s initial hospitalization, Maggie reached out to her local NAMI chapter for support and completed a 12-week course for families with children with serious mental illness. Participating in the group helped Maggie cope during the early period of crisis. Later, Maggie received support from a family friend who grew up with her children and was like a brother to them. Maggie described a sense of connection and comfort in being able to talk to him.

Values and Beliefs. Values of motherhood and beliefs in inner strength and determination were key themes that arose in Maggie’s description of learning to deal with Brian’s illness. Throughout her narrative, Maggie affirmed how strongly she valued her role as a mother, stressing that as a “good” mother, she felt it was her duty to keep her children happy. That meant making sure they had time to play, either outside or in their home; had a relationship with their grandmother and were safe from violence. While her role as a mother gave Maggie a sense of purpose, that single, intense focus did not facilitate the formation and maintenance of connections with other adults who could help her feel supported when a crisis occurred.

Though "pretty much on my own," Maggie was able to draw on her identification with her role as a mother and her inner sense of strength to get through the tough times. As she explained, a key personal support for her was her inner strength: "I'm not a quitter. I'm a worker. I just have that type of personality. I was brought up that way—to be strong." By focusing on the values of being a good mother for her children and a self-supporting, strong person, Maggie created meaning in her life and persevered through the crisis of Brian's battle with schizophrenia.

Case 4–"Julie's" Narrative

Before the Illness

Julie gave birth to Annie at home, assisted by a midwife. At the time, Julie and her husband, Carey, had three older children. Annie's birth was traumatic for Julie because Carey physically attacked her a few hours after she gave birth. This abuse, which often occurred in the presence of her children, led Julie to move with her children several times when they were young. No matter where they lived though, Julie said she always made sure they had the opportunity to play outside and be in nature. Julie described family hikes, fishing, trips to the beach, and berry-picking. It was important for Julie that her children had positive experiences and felt connected to nature.

Although Julie and Carey separated, Carey continued to have visitation with the children. On one visit, when Annie was 4, he took his daughter out for ice cream and did not bring her back. Julie described this as a kidnapping, although the police did not recognize it as such because Julie and Carey had no formal custody agreement. For the year Annie was gone, Carey sent Julie periodic updates, but most of the time Julie had no idea where Annie was. Julie's year-long separation from her daughter ended when Julie got a phone call from child protection services in another state where Annie had been in foster care for two weeks. Carey had left Annie in a parking lot, in a camper, while he drank at a bar, and a concerned bar patron notified the police who took Annie into protective custody. Because Carey then lied about Julie's whereabouts, it took the police two weeks to find her. After this incident, Julie gained full custody of Annie. Julie described how she tried to provide for her children but admitted that it was difficult as a single parent. Julie remembered, "wishing I had more help" since, although she received public assistance financially, she had little social and emotional support. Julie reported nevertheless feeling the satisfaction that she was able to give her children a reasonably happy childhood.

Becoming Ill and Being Diagnosed

Julie began noticing a change in Annie's behavior around age 16. At that time, Annie was using drugs, staying out all night, and eventually dropped out of high school. Julie's first step in addressing Annie's troubling behaviors was to try to take her to a counselor, but Annie refused to go. Instead, Julie ended up bringing Annie to the local emergency department during one episode when Annie's behavior became manic. The hospital staff believed Annie had bipolar disorder, but Julie disagreed. Although there was no psychiatric diagnosis made then, the providers determined that there was probably both mental illness and a drug problem driving the behavior. Annie was admitted to an intensive program for adolescents dealing with mental health issues. Annie did well in the program, but once back home she refused to go to follow-up appointments or take medications.

Over the next year, when she was 18, Annie had several psychiatric hospitalizations. Julie was frustrated with the treatment overall and described advocating for her daughter but not being listened to. Annie was taken to the hospital several times. Most of the stays were brief because Annie refused to be admitted voluntarily. Julie was eventually able to convince a doctor to commit Annie to the hospital for 60 days with forced medication and had hopes that this hospitalization would begin Annie on a path to long-term stability. Things did not turn out as she hoped. Carey appeared in town shortly after and suggested that Annie live with him, an invitation that Annie, now an adult, accepted. Julie described the event as "heartbreaking."

Life After Diagnosis

After Annie went to live with Carey many states away, Julie had more to worry about. Once, for instance, when Julie was at work, she received a call from paramedics informing her that Julie had been out wandering at night and was hit by a truck. The paramedics then reported that Annie was refusing treatment. Though Julie pleaded with them to treat Annie—that she was mentally ill and not able to think clearly about the situation—the paramedics insisted that Annie had the right to refuse treatment. Julie remembered, "getting off the phone and crying. She [wouldn't] come home."

Over the next two years, Annie moved back and forth between Carey and Julie. And her behavior continued to be aggressive and unpredictable. At one point, she wanted to live with Julie but insisted on living in the backyard in a tent. About then, Julie's older son started using heroin and Julie lost her job and fell behind on her mortgage. Julie described turning to her faith for support and being given unexpected assistance from friends and neighbors. After a few months, Julie found a new job and was able to regain financial stability and again provide for her family.

At the time of the interviews, Annie was 26 and living with her dad. Julie identified that her purpose as a parent was to be available for Annie, even though they lived thousands of miles apart. Julie said she kept in frequent contact with Annie, that she texted her daughter often, and that she talked to Annie on the phone for a few hours at a time every two weeks. While Julie strived to maintain a connection with Annie, she admitted that it was difficult, even when she visited Annie in person. But Julie said that Annie knows “I'm always here for her. She can count on me.” Julie said she periodically offered to move Annie back home to live with her, but Annie always chose to stay with her father.

Julie’s Memory Objects

Julie’s memory objects included four photographs and one book. The photographs included one of three of her daughters in a butterfly garden before Annie became ill. She also shared a photograph of the three girls when Annie began to show symptoms of schizophrenia. The last photograph was of her daughter on the deck of her apartment after she became ill and had been diagnosed.

Julie shared an image of the book *A Bag Full of Nothing*, which she also read out loud to me. This was a favorite childhood book of Annie’s.

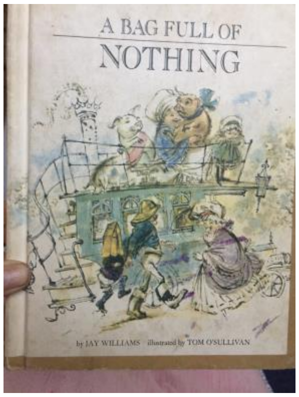

Figure 6

A Favorite Children's Book of Annie's

Themes in Julie's Case

Conflict/Peace. Julie described numerous instances in which interactions with others brought her a sense of conflict, moments where she felt blocked by the way others responded to her own and what she perceived to be her daughter's needs. Less frequent were descriptions of positive interactions in which Julie felt an exchange with others brought her a sense of peace or harmony. Situations that produced conflict for Julie included interactions with healthcare staff by whom she felt her concerns were unheard and her intentions misunderstood. Interactions that brought Julie a sense of peace included those with a friend who was also a family therapist and her co-workers.

During Annie's illness, interactions between Julie and healthcare staff often left her feeling in conflict, usually blocked or misunderstood. Julie told the story of a psychiatrist who refused to commit Annie to the hospital with a forced medication order:

> I begged her to file. You can do 30 or 90 days committed with meds, and she said to me, “Julie, she is trying to exert her independence,” and I remember being like, “She’s *sick*. She needs *help*. She's gravely disabled.”

In this interaction, Julie underscored how conflict could arise even when both parties were committed to helping Annie. The doctor interpreted Annie’s situation from a different perspective and disagreed with Julie about the severity of the situation. This was exasperating to Julie, who was trying to get adequate help for Annie and felt she had to fight to have Annie’s worsening symptoms recognized and addressed.

In another instance of conflict, Julie found herself dismayed by the mental health care providers’ critical interpretation of a rare moment of bonding with Annie. In this incident, discussed in more detail below, the grown Annie surprised Julie by crawling onto Julie’s lap to cuddle during a visit at the hospital. Though Julie was thrilled to have had this unusual moment of closeness with her daughter, the hospital team reported the behavior differently. What was a moment of uncommon harmony with her daughter was recast as problematic to Julie’s indignation:

> But when she was discharged, I got all of her discharge notes and in there it said: “Inappropriate display of affection with her mother—sitting on her mother's lap.” A grown woman sitting on her mother's lap! I remember being hurt. How could they think that was a bad or an inappropriate thing?

Though she often found herself at odds with the interpretations and decisions of those who provided care to Annie professionally, Julie also reported more positive interactions, including some with administration and management at the hospital where she worked. Julie described a kind of stoicism for example in how fellow staff members normalized her experience, helping her to feel less conflicted and more understood and accepted:

> They weren't at all like tiptoeing around it and just took like a normal thing. I've seen it with other people who have family members that work there. I guess they do what they have to do, [and don't bring it up] unless you go to them to talk to them about it straight on.

In the psychiatric hospital where she worked, Julie was surrounded by co-workers who knew how to minimize the stigma attached to her daughter's illness. Julie appreciated this, since it made her feel more in tune with those around her and as if she could go to them for support if she needed to. Julie also recounted her first trip with Annie to the emergency department, where Julie described meeting with a family therapist, who expressed understanding of the situation, acknowledged Julie's concerns, and agreed with Julie that something was seriously wrong with Annie. Julie appreciated that she was "helpful and understanding" and identified her as the only supportive interaction that she had in the emergency department. Finding validation in interactions with coworkers and mental health professionals helped Julie feel more at peace with the difficult struggle of getting Annie diagnosed and treated.

Disconnectedness/Connectedness. Julie depicted many situations that featured the theme of disconnectedness/connectedness. These were moments in which Julie described relationships that were disrupted or diminished as her daughter's illness worsened. These included her relationship with Annie, her relationship with other members of the family, and her social relationships as a whole. Julie's feelings of sustained or renewed connectedness focused on her co-workers and two close friends.

Julie’s connection with Annie herself significantly changed when Annie became sick. As her daughter became more difficult to interact and communicate with, Julie’s feelings of closeness with Annie suffered. This started early in the course of Annie’s illness:

> I don't know really how to describe it. When she first got sick, I remember trying to go for a walk with her, and I would try to get her to talk to me. I would try to walk with her, and I would try to draw her out and get her to talk. It was just no good. It wasn't working.

As the illness intensified, Julie’s few moments of feeling connected to Annie were in sharp contrast with the many more instances of alienation and distancing. This was true, for instance, of Julie’s description of the hospital visit in which Annie climbed onto her lap. Julie recalled how gratified she felt finally to have a moment in which she again felt connected to her daughter, a momentary respite from what Julie described as “two years of no physical contact, not seeing her, not hugging her. I'd see her but no interaction, no connection, nothing. She [was] just out there.” In the context of Annie’s illness, Julie’s relationship with her daughter became, as Julie termed it, “much more nebulous” and unpredictable.

When Annie became ill, connections within the family were disrupted. Annie required more attention and care from Julie than before, and Julie’s focus on caring for Annie put a strain on the whole family:

> Well, basically the relationships—like everybody's relationships—was different then. Because she was different. Her personality as we knew her was gone. So that to me that was the biggest change. I think it was more stress in the family. I was more stressed. I think maybe I wasn't emotionally available for my other kids for a while.

Annie's illness led to alienation from the rest of the family causing Julie to become less emotionally available to her children. This emotional distance resulted in a weakening of family bonds and disconnection within the family. However, Julie also described how the family was able to form new connections with Christy: "Even though [Annie didn't] seem like [herself] anymore, they still are that person, just in a different way. They just have a sickness, that's all." As the stress level was reduced, the family was able to rebuild their relationships and their sense of connectedness.

Two important connections that Julie drew strength from during the time Annie became sick were with friends and co-workers, Bridget and Dina. Julie enjoyed a close connection, built on empathy, with Bridget, a travel nurse who came to work at Julie's hospital. Bridget had an adopted son with serious mental illness, who, as an adult, left home and went to live on the streets. Julie described how, in talking to Bridget about the situation with Annie, she felt Bridget listened to her and understood what she was going through:

> She said something [about how] you can't drive yourself crazy about their illness. And I know that feeling. She said, "Sometimes, I used to wish—I thought it would be better if he did die." I remember that. To me, [Annie's] dying almost would've been a better thing than getting that diagnosis at that moment.

Julie was able to connect with Bridget, who understood firsthand the burden of having a child with schizophrenia. Both women had the experience of such constant, heightened worry about their children that they wondered if it would have been easier to deal with the death of their children than watching their child suffering through years of severe mental illness. Having a friend who shared her experiences and worries gave Julie a unique sense of empathic connection with someone who truly understood her situation.

Dina, another nurse who worked with Julie, brought Julie a sense of connection by being a supportive listener. Julie described how “Dina just listened,” leaving her free to say anything, “no matter what it was, no matter how bad or horrible.” The connection with Dina was important, because Julie felt like she could be honest and open about her feelings. As Julie also went on to say though, Dina was not just a sounding board but was always able to respond in “some therapeutic way” to help Julie feel supported. The open, caring communications with Dina were key to their close connection and friendship.

Real/Ideal. The theme of real/ideal related to the disruption and reshaping of Julie’s expectations about the future. Julie discussed how her hopes for Annie’s future changed with the onset of schizophrenia, because she knew Annie would never fulfill her expected role as an adult member of the family. Julie described grappling with the reality of Annie’s condition, when her daughter, whom she had expected to grow into a responsible, independent adult, became childlike again:

> I went in to visit her in the hospital, [and] I remember she had this orange, and she's pretending like she's going to throw it. And I said, “If you throw that orange, visit's over.” So, I stood up (…) and I said, “OK we'll see you next time. I hope you can behave.”

In examples like this, Julie indicated how expectations that Annie would fill her adult role were disappointed, causing Julie to adjust her parenting style.

Julie also described how she was forced to relinquish an ideal vision of Annie’s future, a process that left Julie “very severely depressed, realizing it’s kind of the end of her life how she had pictured or wanted it, or how I had pictured her life.” The loss of an idealized or imagined future for Annie felt like losing *Annie*: “I just remember being severely depressed about it, mourning her, grieving her loss of normalcy.” Julie added that she would not be able to create any new expectations either, that she felt she had to let go of the illusion of control over the future altogether. Without that control, it was difficult for Julie to find meaning in what Annie was experiencing or to decipher a purpose for her future.

Despair/Hope. Julie discussed alternating feelings of despair, in which she found herself unable to see a way out of her situation, and hope, in which she could visualize something like a positive outcome that she could achieve. The key moments of despair were focalized on the abusive relationship with Annie’s father and in struggling to provide for her children. Even with these barriers, Julie described being able to find hope in her personal faith.

Julie first described feelings of despair related to the abusive relationship with Annie’s father. It was difficult for Julie to get out of that relationship, and it continued to be an issue for years: “Looking back, I don't think I was too smart. I think I should have gotten him out of her life. But I guess I really didn't know how, and he wouldn't leave us alone.” Despite knowing she needed to get away from Annie’s father, it was hard for Julie to see a way out. But once Julie was able to separate herself from Annie’s father, she was able to find hope in the midst of her despair as she struggled to find a way to provide for her children:

> I did go back to cleaning houses part-time, and I remember one time I had Annie on my back, and I think Robert was a toddler (…) I was cleaning the toilet and all of a sudden, I just started crying. (…) I remember Robert, “Are you okay Mom?” (…) And I just put the toilet brush down. I remember I said, “That's it. I'm not doing this anymore. I'm going back to school.”

This event was a turning point for Julie, who had been unhappy with how she was earning a living, and she was motivated to continue her education to find a better way to provide for her children.

Julie’s Christian faith instilled a sense of inner strength and hope that helped her handle the stresses associated with Annie’s illness. To have this sense of hope despite her circumstances, it was important for Julie to focus on those things in her life that she could control and let go of the rest: “It's kind of like the Serenity Prayer. I guess changing what I can change and letting go of what I am not. I think that is my greatest strength, and it has gotten stronger since Annie got sick.” When Julie was worried about everything that was going on, including those things that she could not change, it was overwhelming. Letting go of some of the stress helped Julie to focus on what was most important and find a sense of hope going forward. To relinquish this control, Julie said she turned to prayer. Julie described gaining a sense of hope from a spiritual experience during prayer in which she felt God lift her burden from her. Over time, she felt “lighter” and was able to find a better sense of hope moving forward. Finding hope allowed Julie to focus on her purpose of being a provider to her children and a caregiver to Julie.

Values and Beliefs. Julie’s values and beliefs were the most prominent thematic element in her case. Throughout her interviews, Julie’s personal religious beliefs were central to her story. Julie also discussed how she valued herself as a provider for her children.

Julie’s religious faith affected her life in numerous ways. At one point in the midst of dealing with Annie’s illness, finding out her son was using heroin, and losing her job, Julie said she felt extremely depressed and contemplated suicide, but went on to say that “my faith in God, my belief in God would never let me.” Julie described turning to prayer often, a spiritual practice that helped her cope with the stressors in her life. Although her faith may have faltered at points, it was a driving force in her life: “And my faith wasn’t that strong, but I still had it. (…) I have the faith, but I do have doubts. I have the faith of a mustard seed.” Holding tenaciously to her religious faith allowed Julie to maintain a sense of connection with a power greater than herself.

Julie found value in her role as a parent to provide and care for her children and saw her purpose as being a mother and creating a stable home for her kids. This involved providing a fun and loving environment for the children and teaching them to be responsible and caring. Julie wanted the kids “to be confident in who they were, to keep their spirits alive.” To do this, she taught them about nature, God, and how to treat others respectfully. Julie also wanted to instill a sense of purpose in her children: “[I wanted to] help them gain a sense of who they are and what they want to do with their life.” As part of her purpose as a parent, Julie believed it was her duty to encourage her children to grow up into responsible adults: “That’s the ultimate goal, that they’re independent and you have an adult relationship with them.” In light of Annie’s illness, Julie’s ideas about that ultimate goal and what an adult relationship would look like had to be revised. For Julie, her personal life meaning and purpose was strongly tied to her role as a parent and provider and the connections she had with her children.

Case 5–“Geraldine’s” Narrative

Before the Illness

Geraldine raised her children in a small house in a city in the Midwest. Her husband was in medical school in South America and was only able to come home for a few months each summer. Geraldine was the provider for her family, working a full-time job and occasionally picking up overtime as well. Geraldine's work schedule and her husband's schooling resulted in her not having much time to spend with the rest of her family. During most of the year while her husband was out of the country, Geraldine relied on her father to help out with childcare. He would come over before and after school every day to care for the children while she was at work. Geraldine's time with her children was limited to the weekends and a few hours in the evenings during the week.

Geraldine had three sons and a daughter. Her oldest son, Sebastian, was a colicky baby who threw tantrums. As she put it, "We spent a lot of hours not sleeping." But as he grew up, Sebastian became a well-behaved and happy child. Geraldine said she believed that part of her purpose as a mother was to ensure her children all received a good education and so she required a formal homework time each evening. At school, Sebastian, like his siblings, "was very driven, very motivated. Loved to study and learn. He was very good student." Geraldine said she wanted her children to have strong family connections and friendships at school, and she "always asked at school whether or not they got along with the other kids. That was important." Looking back, Geraldine did not see any odd behaviors in Sebastian as a young child and believed he had a normal and happy childhood.

Becoming Ill and Being Diagnosed

As Sebastian became older, Geraldine noticed changes in him. Between Sebastian's junior and senior year of high school, he began exhibiting signs of depression. He suddenly wanted to give away a book collection—one of his prized possessions. Another bizarre behavior that Geraldine noticed was how readily Sebastian would do anything she asked. She thought he was "too obedient" for a teenager. Geraldine also reported that Sebastian, who had been an excellent student, was becoming distracted: "He would sit at the table and roll his pencil back and forth instead of doing his [home]work." Shortly after this, Geraldine received a note from one of Sebastian's teachers that he was acting strangely at school. Then, Sebastian was sent home from a public service school project at a local hospital after his speech became incoherent. That was two weeks before he would end up in that same hospital's emergency room for a psychiatric evaluation. Geraldine was not sure what was going on, but she wondered if Sebastian was using drugs.

When Geraldine took Sebastian to the hospital that first time, he was involuntarily committed to the psychiatric unit for 60 days. After leaving the hospital, Sebastian continued to exhibit odd behaviors, which, Geraldine said, frightened her other children. She struggled to maintain connections between her children while also acting as the sole provider for the family. Additionally, she was now Sebastian's main caregiver. During this time, Geraldine said she was "grieving and angry" as she thought about Sebastian's future and the lack of helpful treatment.

Life after Diagnosis

Although Sebastian was not diagnosed for three years after becoming ill, Geraldine suspected schizophrenia early on, because one of her cousins had the same illness: "I knew some of the things that she went through, and I knew that this was pretty much the same." After Sebastian was diagnosed, Geraldine wanted to ensure that Sebastian would be able to get good care, so she began to work on getting Sebastian on disability.

At the time of this study, Sebastian lived in a house that he rented from Geraldine. Geraldine believed it was important to maintain a close relationship and spend time with Sebastian; she helped him clean the house and do his shopping. Geraldine said she was pleased that Sebastian had been able to maintain a part-time job at the library, that "It gives him a reason to get up in the morning." Although life did not turn out for Sebastian the way that Geraldine had expected it to, she was glad to have a good relationship with her son and to see him engaged in meaningful work.

Geraldine's Memory Objects

Geraldine shared six photographs. These included a framed copy of her son's high school graduation picture. She also shared a photograph from her son's childhood in which the children were dressed up in South American-themed costumes for a cultural festival. The other photographs captured her three sons, Sebastian and his father, and all her children with their parents and grandparents. She shared one photograph of Sebastian after he was diagnosed with schizophrenia.

Themes in Geraldine's Case

Conflict/Peace. During Sebastian's illness, Geraldine experienced both conflict and peace in regarding her interactions with others. During times of conflict, Geraldine felt blocked and frustrated. These experiences typically related to the lack of information she received from healthcare staff. Positive interactions resulted in Geraldine's feeling a sense of peace and ease and usually occurred in interactions she had with Sebastian's teachers and the few healthcare staff members who took the time to communicate with her.

During Sebastian's first inpatient hospital stay, Geraldine experienced frustration with healthcare staff who were "very nice" but, aside from the physician, "can't really tell you anything." Because Sebastian was 18, the psychiatrist was also restricted by privacy laws from discussing protected health information with Geraldine. Geraldine felt uneasy with the lack of communication, since she was Sebastian's primary caregiver. The sense of being blocked in interactions with health care personnel continued throughout Sebastian’s outpatient treatment.

While her experiences with the healthcare providers were primarily marked by conflict, Geraldine reported positive interactions with the teachers at Sebastian’s school. When he started exhibiting signs of mental illness in high school, Geraldine reached out to Sebastian’s teachers to discuss his change in behavior: “I called one of the teachers, and I said, ‘Sebastian was acting kind of strange. Can you just look in his locker and see if he's got any drugs?’” Geraldine appreciated that the teachers listened to and addressed her concerns, but after they found no evidence of drug use, the issue went no further at school.

After this time, Sebastian’s behaviors at home increasingly worried Geraldine, who was eventually prompted to take him to the emergency department for evaluation. When Geraldine initially sought treatment for Sebastian, she had encounters with a nurse and a physician that left her feeling reassured and supported. Geraldine recalled being supported by a nurse at Sebastian’s dermatologist’s office whom Geraldine called to see if Sebastian’s behavioral changes could be a side effect of his acne medication. The nurse, a former psychiatric nurse, recognized signs of mental illness in Geraldine’s description and encouraged her to speak with Sebastian’s primary care physician. In another instance, Geraldine described finding comfort in an interaction with the emergency room physician who admitted Sebastian for his first psychiatric hospitalization. This physician took the time to speak individually with Sebastian. Geraldine described the physician’s saying, “This kid is not going anywhere.” To which she responded, “Thank you so much!” Because her concerns were heard and Sebastian seemed finally to be getting the treatment he needed, the interaction left Geraldine with a sense of peace that was unusual for her at that time.

Disconnectedness/Connectedness. Geraldine described distinctive instances of disconnectedness in her interviews surrounding the lack of support she felt when Sebastian was becoming ill. In several moments, she also described feelings of connectedness, where she formed and nurtured important relationships with others. For Geraldine, feelings of connectedness came as a result of her involvement with NAMI and her relationships within her family.

During the period when Sebastian first became ill with schizophrenia, Geraldine struggled to find a sense of connectedness; at first, she felt she had no support system: “At that time when he first got sick, I had no support system, and I didn't know what to do.” A lack of supportive connections left her feeling lost, unable to see how she could care for Sebastian. Eventually, after another hospital admission, Geraldine began to participate in a NAMI chapter that had meetings at the hospital. This group gave her a sense of connectedness and supported her during that difficult time. There, Geraldine said she “found a lot of good friends who also had children with disabilities and of different types.” Geraldine felt a sense of empathy with that group, as the people there all shared the experience of having an adult child to care for. Involvement in NAMI also gave “purpose” and brought her to see the importance of “advocat[ing] for my son, because I knew he wasn't going to be able to take care of himself and to see his own issues.” The feelings of connection and sense of purpose Geraldine found in NAMI were described as great supports to her.

After the initial crisis of Sebastian’s illness passed, Geraldine and her husband also found meaningful ways to rebuild and maintain connectedness within their family. Geraldine described how they visited older relatives in the family to nurture those connections: “We think it's [important] to keep up connections with people and a lot of older people, they can't get out [and] come visit us." Maintaining family connections with older relatives has been an important way that Geraldine and her husband have maintained a sense of meaning and purpose in their lives.

Real/Ideal. The theme of real/ideal manifested itself in Geraldine's story in her shifting expectations or ideals for Sebastian in light of the reality of his illness. Geraldine's narrative included frequent references to moments when she realized she had to change her views about Sebastian's role in the family and to adjust her expectations for Sebastian's future. This was because Sebastian's personality and interactions with the family were so markedly different after he became ill. As Geraldine put it, the family had to "adjust to an entirely new set of rules in the family. It was completely upside down." When asked what specifically had changed as a result of Sebastian's illness, Geraldine said, "It's almost easier to think of what hasn't changed."

Alterations in Sebastian also caused Geraldine's expectations for Sebastian's future to shift. Geraldine valued education highly, recognizing it as the key to Sebastian and his siblings' future success. Now that Sebastian had schizophrenia, Geraldine could no longer expect him to use his education to pursue a profession and start a life for himself, which made it seem as though she had lost him and that he had lost all that he had accomplished up to that point. As Geraldine said, "I think we were all devastated in a way. I knew everything he had done up until then was over." Realizing that Sebastian would not be able to fulfill her expectations about his future, Geraldine had to reframe her understanding of what it meant for Sebastian to live a meaningful life. She came to realize, for example, that "[s]chool is not the most important thing in the world," a difficult admission for her since "that was what everyone in the family was brought up on." While some expectations regarding her children changed, Geraldine repeatedly affirmed that an important part of her role as a mother was to help her children find happiness and purpose in life.

Despair/Hope. In her interviews, Geraldine described both experiences of despair and hope. Despair characterized those moments when Geraldine described feeling helpless, as if she had no support system to help her deal with Sebastian's situation. Hope was discernible in moments when Geraldine gained a larger perspective and found herself able to imagine positive outcomes for Sebastian, even if they were not the ones she previously cherished. When Sebastian first became sick, Geraldine felt she had no answers and no resources. She described feeling helpless, being "angry" and "grieving." The healthcare system was confusing to her, and she was disappointed with the support available from the healthcare staff. When asked what was most helpful during Sebastian's first hospitalization, Geraldine responded: "Nothing." Despite Geraldine's determination to get proper treatment for Sebastian, which she did eventually, at this point, she was unable to see how to do so. After this first hospitalization, Sebastian began seeing an outpatient psychiatrist and taking medications that helped his symptoms. This psychiatrist communicated regularly with Geraldine regarding Sebastian's care, and she became hopeful that Sebastian would improve.

Values and Beliefs. Geraldine's values were the most prominent theme in her case. Geraldine referred in her narrative to a couple of values that particularly motivated her, including the importance of parenthood and education. She was emphatic about the value of being a good parent to her children and how it remained central to her, even as experiences with Sebastian's illness caused her to shift her views about how good parenting might best be accomplished. Geraldine defined her purpose as a parent to be that of helping her children "have a happy life." With Sebastian's illness, this role became "very hard" since, as she said, "the things that I had to deal with changed a whole lot." The necessity of being flexible was especially evident in how Geraldine undertook to instill her appreciation for education in her children. Education, the other key value in Geraldine's narrative, was central to her family before Sebastian's becoming ill, since Geraldine saw education as the path to future success. Education was a value that was displaced though, "when my son got sick overnight, [and] I had to change what I thought was most important." In the context of severe mental illness, education and its rewards no longer seemed like the highest end to Geraldine. Instead, as she said, she came to find greater meaning and a better goal for her children to lie in "the way you treat people."

Case 6–"Donna's" Narrative

Before the Illness

To Donna, her second child Derek's entrance to the world dramatically affected the rest of his life. Derek suffered from birth trauma due to being stuck in the birth canal. The physician used high forceps during the delivery, and both Donna and Derek suffered injuries. Donna attributed Derek's development of schizophrenia later in life to that birth trauma.

As Derek, grew older, Donna began to notice odd behaviors. He would sometimes refuse to hold her hand to cross the street. He used unusual words when speaking and refused to talk at all for the first two weeks in kindergarten. Donna described feeling "concerned" and convinced that Derek's behavior was "more than shyness." At the same time, when Derek was about 5 years old, Donna's marriage began breaking up. Her husband, an abuser and an alcoholic "was getting more out of control and becoming less tolerable." Donna recalled that she wanted to protect her children and so made the decision to divorce.

Donna primarily raised her children as a single mother. She had a business in her home that enabled her to spend time with her children while she attended nursing school. Donna described herself as “a committed student, committed parent.” She recalled being busy but driven by the knowledge that her hard work would allow her to provide for her family’s future. Eventually, Donna graduated from nursing school and worked as a nurse as her children were growing up.

Becoming Ill and Being Diagnosed

When Derek went away to college, Donna was pleased that he did well in his premed program. She soon became concerned however when his roommates called her to report odd behaviors. One of Derek’s roommates described how Derek suddenly quit his job and refused to leave his room for two days. Donna and a friend intervened and took Derek to the emergency room for evaluation. This was Derek’s first and only inpatient psychiatric hospitalization. He was there for two weeks. A month after the hospitalization, Derek’s psychiatrist diagnosed him with schizophrenia. Donna was “stunned” when she heard the news.

Life After Diagnosis

After diagnosis, Derek went to live in his father’s unfinished basement. Donna did not think this a good environment for Derek, and she worked to find him a different place to live. At the time of my interviews with Donna, Derek was living in an apartment for people with disabilities in the town in which he grew up and about 60 miles from where Donna lived. Donna’s two sisters, a few other relatives, and Derek’s father all still lived in the same town, and Donna made sure Derek was checked on frequently. She described finding comfort in knowing that “there are people close by that are able to check on him frequently.”

Donna's Memory Objects

Donna shared three memory objects during her interviews. These included a childhood photograph of Derek and his brother in Halloween costumes and two things Derek made during his childhood. In describing Derek's odd behaviors as a child, Donna described a piece of artwork Derek brought home from school in eighth grade, a picture he said that showed how his brain worked.

Figure 7

Picture Derek Drew in 8th Grade

Donna also read aloud a story that Derek wrote in seventh grade that described how he could see through objects, a story Derek insisted was true.

Themes in Donna's Case

Conflict/Peace. In Donna's descriptions of her interactions with others, she described both experiences in which conflict was a prominent feature and those that emphasized comfort and peace. In general, Donna found interactions with healthcare staff to be stressful and non-productive. It would be a month after Derek's hospitalization before the treating psychiatrist called Donna to arrange a family meeting to discuss Derek's situation. When they did meet, the psychiatrist told the family bluntly that Derek had schizophrenia, the first that Donna and her family had heard of the diagnosis. As Donna described, "He just laid it on us." As for a plan of care, all the psychiatrist said was that they were going to trial Derek on different medications. He did not allow the family to ask any questions, although they all had a lot on their minds. Donna said she felt "dejected" after this. In other moments throughout Donna's narrative, she referred to feeling frustrated because, "I was never really provided resources."

Not all of Donna's interactions were negative. Although Derek's initial treatment was marked by experiences of conflict, Donna's experience of obtaining treatment for Derek included some positive interactions that made her feel supported and gave her a sense of comfort. When Derek became sick while away at school, for instance, Donna initially sought help by reaching out to her friend, Marvin, a professor at the university who coincidently lived across the street from Derek. Marvin was able to build rapport with Derek and convince him to leave his room and go to the emergency department. Knowing that Marvin was with Derek until she could meet them at the hospital eased Donna's mind in an otherwise stressful situation. Another time when peace or comfort was prominent in Donna's interactions included a discussion with her ex-husband in which they both agreed that Derek's mental illness may be related to his birth trauma: "I remember my ex-husband looking at me at the time and saying, 'Bingo.'" Although Donna and her ex-husband were no longer together, she was comforted in knowing that they shared a mutual understanding of Sebastian's illness. Despite the earlier conflictual interactions between Donna and her ex-husband, their involvement in their son's care and treatment planning helped them to have more peaceful interactions, as they both were concerned for Derek and wanted to ensure he received good care.

Disconnectedness/Connectedness. While Donna did not mention any specific struggles with feeling disconnected, there were several key examples of connectedness that emerged in Donna's descriptions of dealing with Derek's illness. These included Donna's recollection of family, husband, and co-workers' relationships and her evolving feelings of connectedness with Derek himself as a result of his illness.

When Derek was growing up, Donna said her most important connections were with her husband, her parents, and her two sisters who were "very close" and visited each other often. Family connections were important to Donna who said that part of her purpose as a parent was to keep her family connected and involved in family activities. Also important to Donna was the bond she had with her husband, also a nurse. An empathetic connection with her husband was a key source of comfort to Donna when faced with Derek's illness. Donna said she felt her husband's professional background gave him a unique perspective on Derek's illness and that "he understood the impact of that diagnosis immediately." In general, Donna expressed her sense that Derek's illness had deepened connections within the family. Donna described how, after Derek became ill, the family found a new purpose in caring for Derek, talking about his care, and showing their concern. Those experiences, she said, strengthened their connectedness to one another.

Donna also found connection and support in her co-workers. As she recounted, "I've come across co-workers that have had a similar situation in their family. And that's where I really find most of my camaraderie. [They] understand what's going on." The common ground helped Donna since she believed that those who had confronted similar challenges with family members could better relate to the experiences she was having.

Real/Ideal. The theme of real/ideal emerged in Donna's story as she described how Derek's illness changed the expectations that she and her family had for Derek. Donna described her "devastation" when she heard the diagnosis of schizophrenia, since she realized this would irrevocably change her life and that of her family: "I felt like I was getting a terminal diagnosis. There was so much sadness on my part and grief. I still grieve of how much he will never have." The shock of a diagnosis of schizophrenia centered on Donna's realization of what Derek would "never have," the life she previously imagined for him.

Despite the initial devastation, over time Donna was able to work through her heartbreak and envision a different future for Derek in light of his schizophrenia: "It hasn't been as bad as I thought that it would be. It's not [that] severe—I was ready for the worst, but it hasn't been horrid. It's been manageable." Donna and her family have different expectations now, knowing what Derek is dealing with. But Derek struggles with his own shattered expectations. Donna described how difficult it was for her to hear Derek talk about his future dreams of starting a family and working in the healthcare field, knowing that his illness would prevent him from being able to achieve those goals:

> He'll talk about things like, "If I was going to get married or if I had kids." Those are things he wants like everyone else. But it's very unlikely any of those things will ever happen for him.

Donna continues to struggle with the disjuncture between Derek's real and the dreams they both had for his future. In light of Derek's illness and what it spells for his future, Donna described continually having to readjust her understanding of both her sense of purpose as a mother while helping manage Derek's sense of purpose as well.

Despair/Hope. Despair/hope was the most prominent theme in Donna's case. Donna struggled with despair when she was unable to see any hope of a positive future for Derek, and she also experienced moments of hope as she came to believe that positive outcomes could be achieved, though they might look different from what she previously envisioned.

Despair was the main focus of Donna's early experiences with Derek's illness. When she was first informed that Derek had schizophrenia, she explained that she, "was not surprised to hear the diagnosis, but I was still stunned. My stomach had dropped to my lap. It wasn't what I wanted to hear. We all left pretty dejected." The diagnosis was followed by the psychiatrist telling the family that they would be trialing Derek on some medications, but at the time Donna said she did not find this "comforting" and was not hopeful that the medication would be helpful.

Derek's medication adherence was a major struggle throughout his illness. Derek's symptoms would improve when he took his medications. Then, "He would stop taking the meds but not tell anyone until a couple of weeks later when he's—[when] we're scraping him off the bottom again." Derek went through several cycles of being on and off medications before he started a long-acting injectable medication. Getting Derek started on this new medication helped Donna find hope in the midst of that situation. Knowing that Derek's schizophrenia would be managed was, as Donna said, "the best thing that ever happened to us." Long-acting medication meant Derek's symptoms could be controlled, which would enable Derek to gain back some control and maintain some stability despite the schizophrenia.

Values and Beliefs. In Donna's interviews, she discussed how her values and beliefs influenced her life experiences related to dealing with Derek's illness. Two values that motivated her were the importance of fighting against the stigma of mental illness and her role as a parent. Donna also discussed how her personal religious beliefs shifted after Derek became ill.

Donna said that her greatest value and priority was her children. She described how being focused on being a good parent to them gave meaning to her life. When her children were young, Donna started a business at home so that she could be a stay-at-home mother. It was not until Derek was older that Donna went back to school to become a nurse, which took her outside the home more. Even then, Donna indicated that the maternal role was her priority. She described that role as peacekeeper, "keeping harmony in the home" and maintaining meaningful connections with her children, and frequently referred to the centrality of motherhood in her life.

Also of primary importance to Donna was the value she placed on her role as an advocate, speaking out against the stigma of mental illness. In the interviews, Donna described incidents in which she challenged the stigma of mental illness. In one, she recounted a discussion with her sister, in which the sister said she thought Derek should not be allowed to get a pet cat because he might hurt it. Donna described having to "defend" Derek and educate her sister that people with schizophrenia are not inherently violent. In another instance, Donna described becoming "livid" on hearing the term schizophrenic used to criticize an entrée on a televised cooking show. She promptly sent a letter to the show's producers explaining the hurtful use of language and how it contributes to stigma around mental illness. Donna observed, “there's so many, so many delusions out there about what schizophrenics do,” and affirmed her purpose to fight against stigma wherever she saw it.

Religion was also a factor for Donna, though less so over time. She recalled how when children were small, religion had been an important part of their family life. As her children grew up and particularly when Derek began to be sick, Donna said, her religious values and beliefs faded:

> The lessons I was learning in religion weren’t adding up. I was having more questions and becoming more of a disbeliever. I was no longer getting the contentment or the peace. It wasn't fulfilling. My sense of spirituality became less important.

Although Donna’s beliefs about religion changed and the family stopped going to church, Donna described renegotiating spirituality by finding connectedness and hope and through reaffirming her meaning and purpose as a mother and advocate.

Comparative Analysis

In the cross-case thematic analysis of memory objects, major life events, themes, and participant-selected lessons from each of the six cases, I focused on convergent and divergent patterns related to spiritual renegotiation: conflict/peace, disconnectedness/connectedness, despair/hope, and values and beliefs.

Memory Objects

Before each of their three interviews, I asked the participants to choose a memory object to share during the interview—something that reminded them of their child during the time covered by that interview (i.e., before diagnosis, time of diagnosis, after diagnosis). There were 23 memory objects shared during the interviews (Table 3), and these included 18 objects that the participant showed me (Appendix J) and five objects that the participant described. The memory objects shown to me included 11 photographs, stuffed animals, a grief bowl, pop tabs, a baby blanket, two books, and a drawing. There were four photographs of the child alone, five photographs of the child with siblings, one photograph of a child with their father, and one photograph of a child with their parents, siblings, and grandparents. The five objects that were described were a kaleidoscope, a baby stroller, birthday cards, cigar wrappers, and a story written by a participant's child. Eight of the memory objects were things valued, made, or collected by the child. Five of the items were gifts to, from, or about the child. Of the 23 total memory objects shared, 12 reminded the participant of good times with the child, six reminded the participant of tough times, and five objects reminded the participant of a mix of both good and tough times. Fourteen of the memory objects were displayed or outwardly treasured in the participants' home, while five were privately treasured by the participant. The participants gave different kinds of explanations for the objects. Eighteen objects were given a descriptive explanation. Four objects were explained metaphorically, and one object was explained commemoratively. More on the meanings ascribed to the objects by participants appears below in the comparative thematic analysis.

Observations

All interviews were conducted via Zoom videoconferencing, allowing me to observe the participants in their settings throughout the interviews. Interviews ranged in length from 17 to 119 minutes, with an average interview length of 44 minutes. Observations recorded for each interview included information about the physical setting, social environment, interactions, language and meanings, and nonverbal communication.

Physical Setting

All participants were asked to interview at home via videoconferencing. Five of the six participants were in their home during all three of their interviews. One participant went out of her house during her interviews to sit in her car, stating that she needed to do so for privacy, since she had children in the house. Of the participants who interviewed in their homes, four were on a couch or recliner in their living rooms, while one participant sat at a computer desk in her bedroom.

Social Environment

During several of the interviews, other individuals were briefly present in the environment, usually while walking through the room. One woman had her pet poodle on the couch with her during all of her interviews.

Interactions

In all but one of the interviews, when a family member entered the room, the participant did not interact with them, although several of the participants interacted with family members at the beginning of one or more interviews to help get the Zoom technology working properly.

Language and Meanings

Four participants were psychiatric-mental health registered nurses. During their interviews, it was clear that they had expertise in this area, as they were familiar with psychiatric nursing lingo, knowledgeably using such terms as “Trilafon,” “HIPAA,” and “catatonic.” All the participants also used legal language regarding the intricacies of involuntary commitment procedures, especially terms like “*ex parte*,” “forced medications,” and “guardianship.” Five of the participants used language signifying their familiarity with support groups. Terms such as “facilitator” and “community resources” were most typically applied in descriptions of participants' experiences with NAMI. One participant, who struggled particularly with the stigma associated with her son's mental illness, spoke in an especially animated tone whenever she spoke about "defending" her son throughout her three interviews.

Nonverbal Communication

The nonverbal communication of the participants varied. Most participants appeared at ease during the interview process, being openly expressive, smiling, and sometimes laughing in their interviews. However, one participant gave signs of discomfort. This latter seemed guarded throughout her interviews, often looking away from the camera and displaying little emotional expression.

Life Events

Significant life events (Table 6) described by two or more participants included: family history of mental illness (6 cases), domestic violence (3 cases), divorce (6 cases), frequent moving (5 cases), child's drug use (5 cases), and child's criminal justice involvement (5 cases). Events that were common to all six cases included divorce and family history of mental illness.

Themes

The initial code categories for the IMPACT Study were drawn from the theory of spirituality and health (Miner-Williams, 2006) and included interactions, connectedness, hope, and values and beliefs. Through inductive coding, thematic categories were identified, and the themes consolidated into four dyads and two additional themes. These included conflict/peace, disconnectedness/connectedness, real/ideal, despair/hope, and a values and beliefs category.

Conflict/Peace

The theme of conflict/peace evolved from the spirituality and health code of interactions. Across the six cases, there were two repeated conflictual interactions that emphasized participants' frustration, exasperation, and distress. These generally involved exchanges with either hospital staff or family. All six participants reported exasperating interactions with hospital staff. Conflict with staff could include poor communication, as when one parent said that, when she spoke to the psychiatrist, she felt he did not understand the severity of her child's illness (case 4). Another participant was criticized by the hospital staff when she said she did not feel safe having her daughter return home with her after being hospitalized following a violent episode (case 2). Another parent reported that staff members were generally "nice" to her but did not provide information about her son (case 5). In one case, a psychiatrist imparted information but never allowed the family to ask questions (case 6). The sense of exasperation and distress was even more evident in participants' descriptions of *non*-interaction, where there was a complete lack of contact between providers and family (case 1) or interactions left the family feeling excluded from the child's care (case 2). One parent reported that the hospital staff would not speak to her *at all* until the day her child was discharged (case 3).

Interactional conflict as a theme was also prominent in participants' descriptions of interactions with family. Whereas conflict with providers and the health care system tended to cluster in the mid phases of the case chronologies—during the general period of diagnosis—conflict as a quality of family relations was more global, occurring at all points. For example, in several cases, conflict including abuse was a key feature of participants' relationships with intimate partners prior to diagnosis (cases 3, 4, 6). The presence of conflict within families also manifested in interactions between participants and their siblings and parents after diagnosis. One participant reported frustration with family interactions, because while there were other family members with schizophrenia in the family, there was an unspoken rule that no one in the family would acknowledge or talk about the illness (case 2).

Finally, conflict was a chief characteristic of all six participants' descriptions of the relationship they had with the child who developed schizophrenia. In most cases (1, 2, 3, 4, 6), the participant traced a trajectory that began with a happy before-time, when interactions between parent and child were generally harmonious, to later, conflict-ridden phases in which physical and verbal violence was a dominant feature of exchanges with the child. This idea was reflected in the memory objects, with several participants (cases 4, 5, 6) sharing and reflecting positively on photographs before their child became ill. Participants also shared photographs after their child became ill and discussed how interactions were more strained after the onset of the illness (cases 2, 4, 5). In cases 1, 2, 3, and 4 participants described specific interactions with their child that included physical threats of violence or actual attacks. Other interactions, though less physically or overtly conflictual, produced distress or dismay in participants (cases 5, 6). Of these more subtle discordances, for example, one participant described taking a walk in an effort to achieve the former easiness she felt with her child, only to be disappointed in the complete absence of harmony between them (case 4).

The interaction dyad included peace, because most of the cases also included significant moments when participants' exchanges with others did provide a sense of harmony or concord. While all the participants reported conflict-focused interactions with healthcare staff, half of the participants also described memorable moments of positive interaction, moments that brought them a sense of support, understanding, or community. One parent described how her first visit to the emergency room with her child was marked by an interaction with a physician who spoke with her at length and made her feel her needs and fears were genuinely heard (case 5). Another parent described an interaction with a nurse "angel," who not only brought the participant a sense of peace by providing supportive, informative communication but created such good rapport with her son that he was persuaded to accept a long-acting injectable antipsychotic medication despite his belief that injections would poison him (case 3). Peace or harmony as a quality of interactions was less prominent than conflict across the cases, but it was a present and often notable element of interactions in the last phase of the interviewing where participants reflected on how interactions with groups or individuals—including the child—became less conflictual over time as they acclimated to the challenges of life with a child managing a severe mental illness.

Disconnectedness/Connectedness

Also borrowed from the literature on spirituality and health was the theme of connectedness. With its inverse, disconnectedness, this dyad was found in all six cases and was the most prominent theme in two cases (cases 1, 2). Connectedness dominated participants' descriptions of relationships with support groups, immediate and extended family, friends, and co-workers. Nearly all the participants referred specifically to how their involvement in NAMI helped them feel connected to and understood by others (cases 2, 3, 5, 6). Another participant referred to a "support group" but did not specify what group it was (case 1). Al-Anon was mentioned as an important source of connection and support by a member whose child also struggled with issues of substance abuse (case 2).

Connectedness characterized participants' descriptions of relationships with immediate and extended family, including close bonds with a spouse (cases 2, 6), siblings (cases 2, 6), parents (case 3), and extended family (cases 1, 5). All of the participants shared memory objects that symbolized close family connections. Finding a sense of connectedness with co-workers was reported in cases 4 and 6. One noteworthy pattern found in two cases was the discovery of connection with near-strangers whose ability to empathize or provide non-judgmental or unassuming support gave participants the opportunity to form surprisingly sustaining bonds that lay outside their usual networks (cases 2, 4).

Disconnectedness was the other face of this theme and also occurred in all six cases. Disconnection was often cited concerning connections that changed, for instance during the phase in which a child became ill with schizophrenia. Half of the participants (cases 1, 3, 4) described family connections that were lost, disrupted, or destroyed due to the child's illness. These breakdowns were in some cases connected to a child's increasingly troubling behaviors and speech. One participant reported how family members deemed the child with schizophrenia to be "strange," and maneuvered to exclude the child from family gatherings (case 1). Distancing or disconnection from family members, neighbors, friends, and co-workers left participants feeling isolated, alone, and abandoned. In relation to disconnectedness, one woman described how her normal supports had "vanished" (Case 2), and another said she felt "on my own" (case 3).

Similar to the examples of conflict above, some participants described increasing feelings of disconnectedness specifically with their child. Cases 2, 4, and 5 shared memory objects related to this theme of disconnection with their child, especially photographs depicting their child after the onset of the illness. Disconnectedness from the affected child took a variety of forms in the narratives, mostly involving diminished communication (cases 1, 2, 3, 4, 6), increased distrust (cases 1, 2, 3, 4, 6), and actual physical distancing due to institutionalization or the inability to keep the child in the home (cases 2, 4, 5, 6).

One participant (case 6) alluded to feelings of disconnection in the sharing of her memory objects from her son's childhood. These included an abstract picture her son drew that he described as "his brain" and a handwritten story her son insisted was true in which he described how he could see through objects. These objects represented how the participant felt a sense of disconnection with her son, as he was thinking and behaving differently than he previously had. These thoughts and behaviors were estranging to the parent, underscoring the child's changing personality and disrupting their connection.

In most cases, participants described eventually rebuilding a connection with their child—albeit often in a new form. One participant described how over time she and her child were finally able to "get closer" and to a point where "he's comfortable discussing anything with me" (case 6). The renewal of connectedness sometimes resulted in the participant's sense that they were able to reconnect with their child on a deeper level (cases 3, 6).

Real/Ideal

The theme dyad of real/ideal referred to elements in the interviews that expressed participants' perceptions about how a child's disease altered their horizon of possibility. In its connection with the future and possibility, the real/ideal theme had some overlap with hope/despair. Whereas hope and despair were typical reactions of the participants to their perceptions of the options of the present or the possibilities that the future presented for them, the parents, the real/ideal theme specifically concerned participants' sense of their *child's* present and future. For instance, the most common expression of the real/ideal theme was articulated in descriptions of shattered expectations, usually in the sudden realization that an affected child would never follow the ideal life path the participant imagined for them—not ideals like winning the Nobel Prize or curing cancer, but the usual hopes and expectations a parent forms for a child, including going to college, getting married, and having children (cases 1, 3, 4, 5, 6). The dashing of these hopes was described in all but one case with sadness and even mourning. As one participant stated: “I still grieve over how much he will never have” (case 6).

Related to shattered expectations was the unsettling of the real in participants' descriptions of a loss of normalcy, the idea that after becoming ill with schizophrenia the child became a different person and nothing would never be the same (cases 2, 4, 5). Parents reported that the adult child had different behaviors, including acting like a small child again (case 4) or becoming isolative and aggressive. One result of this newly incongruent or non-normal real was that family members found they had to change their behaviors and roles within the family (case 3). One participant described how after her child’s diagnosis she found herself having to act in more of a nurse’s role than as a mother to her child (case 4). Another participant described the sobering sense of a new reality that came when she realized she would be the lifelong caretaker of her child (case 2). When ideals were undermined and the sense of real or normal disrupted, participants described surprise, shock, sadness, grief, and despair.

Several participants articulated processes of reframing the shaken ideals into a new reality for their child’s future (cases 1, 2). One participant described that she was able to reframe her expectations for her ill child by realizing that all her children “function differently,” that her son “wants to do his best” and is still able to contribute to the family, albeit to a different degree (case 1). Another participant talked about “letting go” of her idea of what family traditions or activities “should be” and learning to embrace “new standards” (case 2). One participant (case 1) described a kaleidoscope as her memory object, referring to how she had continually to readjust her vision of her child’s future. Through these processes of reframing, the participants were able to have new and realistic expectations for their children in light of their illness.

Despair/Hope

Another important theme for spiritual renegotiation was the dyad of despair/hope. Across the six cases, the theme of despair/hope included common threads as well as some distinct differences. Hope was featured in the interviews as a belief in the prospect of a future good, which might include less suffering for the child (cases 2, 5, 6), better-regulated symptoms (cases 1, 3, 6), or more understanding on the part of others (cases 2, 3). Participants who reported NAMI as an important source of connectedness also described the group as a source of hope about the future, since they were presented with examples of others who had been survived and even thrived when faced with similar experiences (cases 2, 3, 5, 6). Two participants described how their religious faith instilled in them a sense of hope (cases 2, 4). Also crucial as a source of hope were specific therapies, especially the initiation of long-acting injectable antipsychotic medications, which led in several cases to better adherence and control over a child’s symptoms (cases 1, 3, 6). Half the participants described humor as an important source of hope and discussed how keeping a sense of humor helped them cope with difficult situations and maintain a more positive outlook (cases 1, 2, 6).

There were several noteworthy sources of hope that participants did not share in common. One participant emphasized that having a secure job helped her to remain hopeful about the future (case 1). Family members, pets, and nature were described as specific sources of hope (case 6). One participant detailed how she maintained hope by purposefully remembering the importance of “living day to day” (case 3). Another participant focused on how a special moment with a nurse inspired her to maintain a positive outlook about the future (case 3). In yet another case, a participant spoke about how she remained hopeful by accepting and appreciating the evolving relationship with her daughter, even after the onset of the illness (case 2).

The flipside of hope is despair, a theme that also focuses on the future but in the sense of its foreclosure or the narrowing or closing down of options and possibilities. Despair was present across the cases. For several participants, despair took hold as they reached a last thread, a juncture in their journey in which they simply did not know what to do or where to turn next. Despair was often associated in the cases with experiences with an uncommunicative and uncaring healthcare system (cases 1, 3, 5). Another common occasion for despair was spiraling family conflict. Participants described despair as a nadir reached in the context of divorce (case 1), an abusive relationship (case 4), abandonment by non-immediate family (case 2), threats of violence from the affected child (case 3), and first hearing the diagnosis of schizophrenia (case 6). Two participants referred to the lack of an outside support system (case 5) and having to act as the sole provider for their family (case 4) as precipitating moments of despair. In four of the six cases, despair was directly related to dealing with a child’s illness. Despair included profound feelings of helplessness at the time of diagnosis (case 6) and the feelings of grief and anger that came later (case 5). Struggling with the stigma of having a child with schizophrenia was also expressed in terms of despair by a participant who found it exhausting to have to repeatedly defend her son against negative stereotypes held by family members and society in general (case 6). In case 2, treatment nonadherence and the rapid deterioration that followed was depicted by the participant in terms of despair, the participant recalling how she was “fed up” and wanted to scream at her child, “You’re killing me!” Despair was also described as a response to specific events, as when one participant described her son’s destruction of a house she had built for him (case 1). Two participants reported despair or hopelessness related to the future they imagined their child would face were they to die (cases 3, 6).

Values and Beliefs

The final two themes were values and beliefs. The most common of the values was related to the role of mother/parent/provider. Participants underscored the importance their role as a parent held for them in statements like one made in case 3, where the participant declared, “I lived my life for my kids,” and in case 6, where the participant described herself as “very involved with being a parent and being involved in their lives and wanting to share everything with them.” Two other values and beliefs that participants emphasized were specific religious beliefs (cases 2, 5) and a cluster of values involving notions of independence, self-reliance, and resilience (cases 1, 2). The value of education was another common thread, with three participants describing how they started, finished, or returned to school to attain more education while coping with some stage of their child’s illness (cases 1, 2, 4) and others underscoring the importance they placed on education in raising their children (cases 5, 6).

Finally, some distinctive differences in values and beliefs were noted in the cases that may have had bearing on participants’ renegotiation of spirituality. While two participants reported the importance to them of their religious beliefs in their child’s illness and diagnosis, a third described how, after her child became ill, religion was no longer important to her (case 6). One participant talked about her belief in the healing power of forgiveness (case 2). Another participant mentioned a spiritual experience in which she felt like a heavy burden had been lifted from her (case 4). Yet another described a revelatory spiritual experience that directed her to pursue work in the field of psychiatric-mental health nursing (case 2).

Advice for Parents

At the end of the final interview with each participant, I asked, “If you met a couple whose adult child had been just diagnosed with schizophrenia, what advice would you give them?” Two participants suggested getting as much help and information as possible, with one adding how crucial it was to get a case manager early on in the process (cases 1, 3). One participant said she would advise parents to know that it is okay to *not* have your child live with you and that parents should not worry about what other people think (case 1). Acknowledging the challenges of navigating the healthcare system, one participant said she would tell parents to know what to say to get their child admitted for an inpatient stay if necessary: that the child is a danger to themself and/or a danger to others (case 2). One participant advised that parents should prepare to advocate for their child by copies of all their healthcare records (case 5). It was recommended that parents get the child entered into the public mental health system early so they child has access to resources and the parents do not end up carrying an unmanageable financial burden (case 2). One participant advised that parents should consider filing for guardianship of their adult child so that they can obtain healthcare information and make informed choices for their child when the child is unable due to disability (case 4). Another participant stressed the importance of starting a child on a long-acting injectable medication to help keep symptoms under control and avoid issues around medication adherence (case 1). Half of the participants said they would encourage parents to be involved with NAMI in order to have a support system to help them through the process of adjustment (cases 1, 3, 6). Participants also suggested writing a will that, if possible, sets up means to support the child after the parent’s death (case 5).

In general, when asked to advise others, the participants in this study were eager to stress that schizophrenia can be a manageable disorder. Their advice—and the examples of their narratives—highlighted how important it is for parents to be present with their child, even in the midst of a crisis. As one participant indicated, parents should remember that having an adult child with schizophrenia means dealing with a world of uncertainties and constant change that demands corresponding flexibility of response from the parent (case 3). In coping with painful uncertainty, one participant advised parents to keep a sense of humor (case 5) and another emphasized the importance of keeping the child connected with other family and friends (case 6). Finally, one participant thought it important to remind parents that, yes, schizophrenia will turn a family’s world upside down, but “it’s not a death sentence” (case 4).

The Renegotiation of Spirituality

In this study, I asked, “How do parent caregivers of adult children with schizophrenia renegotiate their spirituality, defined as life meaning/purpose and connectedness, in the years following the onset of the illness?” Data from the interviews, observations, and memory objects indicated that caring for an adult child with schizophrenia profoundly affected how participants interacted with those around them, including their child, other family members, co-workers, friends, and institutions (e.g. school, church). These shifting interactional patterns, in turn, led to an evolving sense of participants' connectedness with others, in both positive and negative ways. Participants found meaning/purpose in existing and newly formed connections as well as their personal values and beliefs. Most notably, all participants stressed the high value they placed on their role as parent-provider for their family. While all participants experienced despair while caring for an adult child with schizophrenia, through the process of finding hope even in the midst of this despair, participants were able to find new life meaning/purpose. The renegotiation of spirituality was also evident in the ways in which participants handled disrupted norms and shattered expectations. Participants spoke of reexamining their understanding of normal and revising expectations for their child in light of the experience of living with severe mental illness. Through this process of reexamination and reframing, participants often found new, more realistic expectations for their children and were able to find new sources of meaning and new connections as they looked toward the future.

Examination of the patterns in individual cases and then in the cross-case comparison point to a model of spiritual renegotiation (Figure 8). While the model of spirituality from the theory of spirituality and health (Figure 9) provided preliminary codes for the study, it did not completely match with the findings of the IMPACT study. Therefore, a new model was constructed. This model of spiritual renegotiation illustrates how the shifts in the overlapping aspects of spirituality occur as individuals shift from conflict to peace, disconnectedness to connectedness, real to ideal, and despair to hope. This is an iterative and multifaceted process that is impacted by numerous factors, including values and beliefs, family, work, mental healthcare, support groups, and life events.

The IMPACT study involved six parent caregivers of adult children with schizophrenia. All of the participants gave an account of how the central elements of spirituality–life meaning/purpose and connection–came to be challenged and then renegotiated over the course of adjusting to their child’s diagnosis with schizophrenia.

As discussed in chapter 1, the onset of serious mental illness is a non-normative stressor for a family. The IMPACT study participants were all able to successfully navigate this crisis and come to a new state of equilibrium. The participants in the IMPACT study all exhibited a pattern of resilience in their accounts of dealing with life stressors; they described an ability to withstand stressors and rebound from them (Walsh, 2016). The major life events that were found across the cases were all directly connected with or representative of stressful life situations: family history of mental illness, domestic violence, divorce, frequent moving, child’s drug use, and child’s criminal justice involvement. Additionally, all participants had had significant experiences with major life stressors and/or trauma prior to their child’s being diagnosed with schizophrenia. We know that successfully navigating crises in the past can contribute to an improved sense of resilience when faced with new stressors (Walsh, 2016). Participants often described renegotiating their understandings of spirituality when caring for an adult child with schizophrenia in the context of a kind of learned resilience. Despite facing despair, participants were able to find hope and create new connections and new understandings of what was meaningful in their lives.

CHAPTER 5

DISCUSSION

In the analysis of the six IMPACT study cases, I identified four thematic dyads and two themes that repeated across cases and were related to the concept of spirituality: conflict/peace, disconnectedness/connectedness, real/ideal, despair/hope, and values and beliefs. The model of spiritual renegotiation (Figure 8) in the context of caring for an adult child with schizophrenia contributes a uniquely integrated account of how life meaning/purpose and connectedness changes when an adult child is diagnosed with schizophrenia.

Conflict/Peace

One of the main findings is the IMPACT study was the many conflictual interactions participants reported having with others, including hospital staff, family members, and with the child diagnosed with schizophrenia. Negative interactions with hospital staff included descriptions of poor communication, non-communication, and outright criticism of parents. Similar results were reported by Molefi and Swartz (2011) in a qualitative study that used semi-structured interviews with 10 family caregivers of individuals with schizophrenia to understand experiences of caring for a family member with schizophrenia. Molefi and Swartz's (2011) participants reported overwhelmingly poor relationships with mental health professionals, including ones similar to those described in this study. Other research documenting conflictual interactions with healthcare staff around caregiving and schizophrenia have shown that negative interactions can increase emotional distress (Mhaule & Ntswane-Lebang, 2009) and lead to physical problems such as sickness and fatigue (Gater et al., 2014).

Other research has reported similarly on how having an adult child with schizophrenia is associated with conflictual interactions within families. Shamsaei, Cheraghi, and Bashirain (2015) found that 41.8% of caregivers experienced moderate to severe objective and subjective burden as a result of disruptions in family relationships caused by altered family routines and restricted social and leisure activities (Shamsaei et al., 2015). Similar to my findings, researchers have also reported that siblings of individuals with schizophrenia often experience anger towards their ill sibling and tend to cope with isolation and avoidance (Stalberg et al., 2004).

Others have documented the stress to caregivers of increased negative interactions with the affected child. In the IMPACT study, participants reported conflictual and sometimes violent interactions with the child as they began to display symptoms of schizophrenia. For some IMPACT study participants, the threat of violence was sometimes so great they no longer felt safe at home with the child. Conflictual interactions between caregivers and the adult children to whom they provide care were reported by Hanzawa et al. (2013) whose qualitative study of 116 caregivers of people with schizophrenia indicated that violent behavior resulted in increased caregiver burden and harmful psychological impact. Interactions resulting in comfort for caregivers were also the subject of study by Landon et al. (2014) in which researchers interviewed parents of adult children with schizophrenia and found that over time parents reported improved communication with their children and increased feelings of empathy.

Disconnectedness/Connectedness

The participants in the current study frequently reported a sense of connectedness gained through involvement with support groups such as NAMI and Al-Anon. Studies have documented that connections made through support groups benefit caregivers in various ways. Chou, Liu, and Chu (2002), for example, measured the impact of support groups on the perceived level of burden and depression status using the Caregiver Burden Inventory (CBI) and Beck Depression Inventory (BDI), respectively, and found that perceived level of burden and depression both decreased after involvement in an 8-week support group (Chou et al., 2002). The emotional support gained from connection to a support group can be beneficial to those caring for a loved one with schizophrenia. All the IMPACT study participants who were involved in support groups described them as beneficial to them for the empathic connections and emotional support they received.

The IMPACT study participants experienced feelings of disconnectedness from the fracturing of relationships with others and especially with the child. This finding is congruent with results from a study by Mantovani et al. (2016) that was conducted to identify determinants of family burden among 31 caregivers of patients with schizophrenia. Symptoms of schizophrenia were correlated with increased objective burden, a variable defined in part as disconnectedness arising from disturbances in family routines and functioning (Mantovani et al., 2016). While IMPACT study participants reported similar examples of disconnectedness, all also described eventually building a new sense of connectedness with their child and other family members, some reporting even stronger relationships after the illness.

Real/Ideal

The theme of real/ideal referred to a pattern found in the interviews in which participants described a loss of normalcy and a shattering of expectations about a child’s future. Typically, the disruption of real and ideal prefaced the development of new norms and a reframing of future expectations. A similar pattern was observed in McAuliffe, O'Connor, and Meaghen's (2014) interview study conducted with six parents of adult children with schizophrenia. In that research, an "uncertain pathway" theme was identified in which, after dealing with the initial shock of the diagnosis, families went through a process of grieving and adaptation that resulted in a new vision for their child's future (McAuliffe et al., 2014). Similar to the IMPACT study, the McAuliffe et al. participants described having to change standards for their child and reframe expectations after the diagnosis of schizophrenia.

Despair/Hope

Participants experienced despair when they hit a low point and felt they did not know where to turn next. Often accompanied by a sense of being alone, without options, information, or the possibility of future improvement, despair was experienced by IMPACT participants as a momentary shutting down. Despair or some form of extreme distress in similar populations has elsewhere been described as an outcome of participants' dealing with a mental healthcare system perceived as uncommunicative and uncaring. Mizuno et al. (2013), for example, in a study exploring experiences of despair among family caregivers of patients with schizophrenia, showed that family members were distressed, confused, and uncertain about the future when healthcare teams withheld information and offered ambiguous patient treatment plans (Mizuno et al., 2013).

Regarding hope, IMPACT findings were similar to those reported by Redlich et al. (2010). In that study of 49 family members who participated in a "Keshet" program to enhance family communication, family members who completed the intervention showed increased hope concerning the future of the ill child (Redlich et al., 2010). By tying improved family communication to the experience of hope, Redlich et al.'s findings underscored, as did those of the IMPACT study, the central role of connectedness as a core component of spirituality. Hope among patients with schizophrenia has also been studied in regard to quality of life. A cross-sectional study by Vrbova et al. (2017) found that in patients with schizophrenia, high levels of hope are correlated to increased quality of life (Vrbova et al., 2017).

Values and Beliefs

A major value discussed by the participants included the role of mother/parent/provider. Milliken (2001) explored this topic in her qualitative interview study with 29 parent caregivers of adult children with schizophrenia. Milliken’s results showed that parents go through stages in which they iteratively redefine their parental role over the course of their child’s illness (Milliken, 2001). Two stages particularly relevant to the IMPACT study were the “becoming marginalized” stage, in which the parent experiences alarm when the child becomes ill, begins to take responsibility for the child, and encounters barriers and the “disenfranchisement” stage, in which the parent assumes responsibility for the child, but their role is not acknowledged by the adult child and/or the legal and healthcare systems (Milliken, 2001). Both stages were evident in the cases analyzed in the IMPACT study. The struggle of disenfranchisement was especially prominent, with all 6 of the participants expressing frustration about being expected to care for a child while not being given adequate information and support to do so. What was unique in the IMPACT study was the finding that this experience of disenfranchisement is related to the failure of the mental healthcare system to support families. All participants reported that the shortcomings of the healthcare system contributed to spiritual distress in the forms of conflict, disconnection, and despair.

Self-reliance and independence were the other values that surfaced numerous times in the interviews. This finding is similar to a study by Knight et al. (2018) that examined supported decision-making (SDM)–the ability to make informed healthcare decisions–among 29 people with mental illness. Through their interviews with participants, Knight et al. (2018) identified four distinct types of SDM, one being “Inward Experts.” “Inward Experts” have a strong sense of independence and self-reliance, as they value their inner strength and feel empowered to make decisions (Knight et al., 2018). Likewise, IMPACT study participants who reported self-reliance and independence had a strong sense of agency, feeling a sense of control in their life to make decisions for themselves to work towards their goals.

Several participants mentioned the importance of their personal religious beliefs. Religious coping and psychological wellbeing among caregivers of family members with schizophrenia was studied by Rammohan, Rao, and Subbakrishna (2002). In their examination of the strength of religious belief, perceived burden, religious and other coping strategies, and psychological wellbeing with 60 caregivers, they found that strength of religious belief was related to increased wellbeing (Rammohan et al., 2002). While similar findings emerged in the IMPACT study, where several participants described the role of their religious beliefs in helping them cope with their child’s illness, I also identified divergence in the role of religion, including one participant’s distancing from her religious beliefs after discovering that religion failed to offer a positive and meaningful support for her when her child became ill.

The most important finding of the IMPACT study was not the prominence of any one dyad, value, or belief but the way in which each participant’s story of renegotiation witnessed an iterative and complex shifting back and forth on each component in a constellation of spiritual concerns. As an integrated system, the four dyads along with the values and beliefs mapped a common course of grappling for these parents, a system in which barriers of disconnection, despair, loss of ideal/normal, and conflict with others were faced down and then met with again, and again. Values and beliefs could be tools of resilience or further sources of hope. Parents showed in all cases the capacity for rebounding and reframing, so that despite being faced with repeated challenges that come when caring for someone with a severe mental illness, their resilience allowed them to successfully navigate the challenges and find new sources of connectedness and meaning. There is no precedent in the literature for this kind of integrated view of spiritual renegotiation. This finding represents a signal contribution to our knowledge and an opportunity to inform future research so that psychiatric nurses can better assess and integrate spiritual needs into patient and family care.

Limitations

The greatest limitation of this study was the homogeneity of the sample. Unexpected challenges of recruitment extended that process from an expected three to nine months and resulted in a sample that was drawn mainly from nursing messaging boards and subsequent snowball referrals. A longer time frame and additional recruitment might have resulted in a more heterogeneous sample with more variation (Sandelowski, 1995). The sample did achieve some diversity in participant age (57–73 years) and in the length of time with which individuals had cared for their children (3–33 years), as well as some diversity in education level (high school diploma–doctoral degree); however, I was unable to recruit any men at all. While I was able to meet the goal of having six cases, those cases lacked diversity, with all six being middle-aged, white, and women, and four of them currently or formerly employed as registered nurses—specifically in psychiatric nursing. Having a sample of primarily psychiatric nurses who were very familiar with the mental healthcare system may have contributed to the prominence of one of the distinctive findings from the study–the extent to which the cases spotlighted the shortcomings of the mental healthcare system in supporting families.

Another limitation that arose from the exigencies of recruitment lay in how the interviews were conducted. I originally planned a purposefully selected convenience sample of participants from NAMI chapters in a major metropolitan region of Ohio near where I live and work. The interviews were then to be conducted face-to-face in participants' homes, which would have allowed for collection of additional data through observation of participants in interaction with their environment. When recruitment was expanded to social media, I knew that participants could come from distant points geographically. So, I shifted interviewing to all-videoconferencing before recruiting via social media. Undoubtedly, the videoconferencing afforded more opportunity for observation than telephone calls would have done since it enabled me to see the participants in their home setting, but, as a case study, having only the interviews and memory objects on which to draw was somewhat constraining.

A third unexpected limitation arose in connection to what it was possible to do with the memory objects. Per the consent, these participant-chosen objects included "photographs or other objects that represent feelings and ideas you would like to share during interview sessions." In total, 11 of the memory objects were photographs that included the affected child. While the participants' sharing of these photographs with me produced rich conversation in the interviews, a question arose about displaying the photographed images in the results. To protect participants' confidentiality and privacy, all had been assured of anonymity in reports issuing from the dissertation, so the display of unaltered photographs depicting family members was deemed unallowable. Blurring faces in the photographs remained a possibility, but I eventually determined against that remedy. As Pauwels (2008) has written, "The 'irreducible nature' of the camera image" means that, when faces or other identifying aspects of photo are "made 'illegible' to protect anonymity" (p. 244), much of the value of the photo as data is obviated. Though reference to the photos was made in the results, the images were not displayed in the dissertation, an absence that detracted from the overall construction and analysis of the cases. More detailed instruction about choosing memory objects—or, if possible, different terms of consent—would have led to a richer range of data sources for analysis.

Another possible limitation in the IMPACT study was the use of a single researcher to conduct all interviews and most of the data analysis. While in a naturalistic study, having a single person conduct all interviews can enhance consistency, a single analyst can mean that the interpretations are narrow and/or important themes in the data missed (Patton, 2015). To address this issue, my dissertation advisor reviewed case data and discussed analysis with me on a regular basis over the year of the study. The use of a semi-structured interview guide also helped ensure that topics important to the research focus were not missed and that all participants were asked the same set of main questions. Although answers could and did vary, they came from the same set of core questions, which facilitated case comparisons and enhanced my ability to answer the research question.

Implications and Recommendations

A prominent finding in the IMPACT study was the loss of connection that can happen when a child is diagnosed with schizophrenia. The connectedness within the family, as a whole, can suffer as well as the connection between the child with schizophrenia and their primary caregiver. These results indicate a need to prepare families for a loss of connection that can happen when a child is diagnosed. To answer that need, assessment and educational interventions are needed to prepare nurses to identify issues of spirituality and identify appropriate supportive interventions.

Nurses must assess spirituality as part of holistic patient assessment, starting at the first inpatient admission. Nursing has several spiritual assessment tools to assess patients' spirituality and to integrate spiritual needs and resources into the patient's plan of care (Cadge & Bandini, 2015). Two spiritual assessment tools that would be appropriate for use in a psychiatric-mental health setting are the FICA assessment and the 7x7 Model. FICA questions what gives life meaning and purpose (**F**aith), the role that spirituality plays in the patient's life (**I**mportance), involvement in a faith community (**C**ommunity), and how the nurse can address the patient's spiritual needs (**A**ddress) (McLaughlin, 2004). The FICA assessment has been tested in clinical settings and found to be a feasible tool for assessing spirituality (Borneman et al., 2010). The 7x7 holistic-approach model focuses on seven dimensions of assessment: the medical dimension, psychological dimension, psychosocial dimension, family systems dimension, ethnic and cultural dimension, societal issues dimension, and spiritual dimension (Fitchett, 1993; Robinson, 2012). In addition, the spiritual dimension is further characterized into seven distinct characteristics, namely: beliefs and meaning, vocation and consequences, experience and emotion, courage and growth, ritual and practice, community, authority and guidance (Fitchett, 1993). The FICA assessment and 7x7 model are two interventions nurses can use to assess spiritual needs so they can be incorporated into care. Psychiatric nurses need to be educated on using these tools at the time of diagnosis so they can identify when patients and families are experiencing a loss of connection and in turn identify appropriate resources to address this issue.

The findings from the IMPACT study also highlight the crucial importance of involving the family in patient care. All the participants had negative experiences interacting with healthcare staff. Often the parents did not receive much information about their child, yet they were the main caregivers and expected to take the child home after discharge and resume their caregiving role. As there are numerous challenges to family involvement and communication in light of patient confidentiality laws, nurses need to explore ways to involve the family in care, from admission to discharge. In many cases, the families know the patient best and will continue to be there and care for them; they must be involved in their care. It behooves nurses to advocate for both their patients and their families and strive to include families in patient care and treatment planning when possible. More research is warranted to support the design of interventions that nurses who assess patients and families can then use to involve them in patient care and teach them coping strategies.

The IMPACT study elucidated the challenge many families face when caring for someone with schizophrenia in fighting against the stigma of mental illness. Nurses are called to be advocates for their patients. Therefore, in recognizing societal stigma as a problem in our society, nurses need to find ways to counteract the stigma of mental illness. When providing care to patients and families dealing with a new diagnosis of schizophrenia, psychiatric nurses need to discuss the issue of societal stigma and offer support resources such as educational material and support group information. Psychiatric nurses can also provide education within the community to eliminate myths and spread the truth about individuals struggling with serious mental illnesses.

Suggestions for Future Research

Regarding future research, I would like to investigate how to better incorporate spirituality into patient and family care. This could initially be developing a survey that focuses on thematic dyads, values, and beliefs to assess spiritual needs. Using the results from that survey, I could then develop an intervention that nurses can use with patients and families. Participants could be assessed both before and after the intervention to see how it impacts their spirituality.

Conclusion

The onset of schizophrenia is a crisis for a family that causes disruptions to spirituality throughout the process of dealing with the crisis, finding equilibrium, and functioning at a new state of normal. Families can renegotiate their spiritual understandings through internal resilience, which allows them to find hope in the midst of despair, enabling them to find new sources of connectedness and new ways to find meaning/purpose in life. The findings from the IMPACT study informed the creation of a model of spiritual renegotiation (Figure 8) that illustrates the iterative and multifaceted nature of the process of renegotiation and the multiple factors that influence one’s spiritual understandings. Spirituality is an essential part of health, and psychiatric-mental health nurses need to recognize the importance spirituality can play in the life of patients and families in order to better incorporate this into care and treatment planning.

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Table 1

Studies of Spirituality in Psychiatric Nursing (1998-2019)

Year	Author	Study Design	Findings
1998	Fry	Concept analysis	Psychiatric nursing needs a framework to recognize issues of spirituality
2002	Thompson	Literature review	Psychiatric nurses need to assess spiritual needs as part of comprehensive patient assessment but may lack confidence to do so.
2003	Hammond	Literature review	Spirituality needs to be integrated into the plan of care for patients with a dual diagnosis of mental illness and substance abuse.
2004	McLaughlin	Literature review	Utilizing spiritual resources can be used to improve the quality of treatment in mental health nursing.
2005	Koslander & Arvidsson	Qualitative	Nurses approach spirituality by being good carers. Nurses approach issues of spirituality in different ways. Nurses admit a lack of knowledge regarding patients' spiritual needs.
2009	Koenig	Literature review	In mental health nursing, religious and spiritual involvement is related to better coping and less anxiety, depression, suicide, and substance abuse.
2010	Huguelet, Mohr, Gilleron, Brandt, & Borras	Qualitative	Spiritual visions of illness in patients with psychosis are neither negative nor positive. It depends on how the patient integrates these into their experiences, and it is not associated with clinical or social outcomes.
2010	Menezes & Moreira-Almeida	Literature review	Spiritual experiences in psychiatric patients needs to be differentiated from psychotic disorders.
2012	Koenig	Literature review	As published research has shown that spirituality benefits mental health, it needs to be integrated into patient care.
2013	McCarthy-Jones, Waegeli, and Watkins	Literature review	Spirituality needs to be assessed in psychiatric patients and incorporated into care, when appropriate.

Table 2

Attribute Themes of Spirituality in Psychiatric Nursing

Theme	Count	Exemplary Quotations
Connectedness	12	Spirituality is “related to the establishment of transcendental connections in three ways: to the sacred, to the inner self, and to the common world of life” (Neto, Rodrigues, da Silva, Turato, & Campos, 2018, p. 2326). Spirituality “works through a transcendental sense of connectedness that bridges the sacred and common world” (Neto, Rodrigues, da Silva, Turato, & Campos, 2018, p. 2326).
Consolation	3	Spirituality provides “comfort during distress, feelings that one is not alone and hope amid seeming hopelessness” (Thompson, 2002, p. 37).
Coping	6	“Spiritual beliefs are where most gain their reserve personal strength in times of crisis” (McLaughlin, 2004, p. 115). Spirituality “may offer an alternative explanation for people not satisfied with medical explanations, which may be more meaningful and aid coping” (McCarthy-Jones, Waegeli, & Watkins, 2013, p. 284).
Denial	2	Spirituality can have negative effects, such as “treatment interruption or avoidance, cases of isolation or alienation” (Neto, Rodrigues, da Silva, Turato, & Campos, 2018, p. 2326).
Ethics	4	Spirituality “expresses the ethical and metaphysical precedents between good and evil in conducting to life” (Neto, Rodrigues, Turato, & Campos, 2018, p. 282).

Expression of Deeper Self	4	“Spirituality is described as an expression of the needs of the soul, which are revealed in various individual inner experiences and a belief in someone or something” (Koslander & Arvidsson, 2005, p. 559).
Harmony/Reconciliation	3	“The person split up in the many positions needs a point of equilibrium that satisfies the multiple forces satisfactorily, this is the place of the beyond, of the greater force, the beyond itself” (Neto, Rodrigues, Turato, & Campos, 2018, p. 282).
Meaning and Purpose	12	“The language of spirituality provides a way of talking about meaning and purpose, and about the effects this life-long search has on people” (Nolan & Crawford, 1997, p. 291). Spirituality is “a personal quest for understanding of the ultimate questions of life, about meaning” (Menezes & Moreira-Almeida, p. 174).
Refuge	3	“Spirituality becomes an expression of different forms of thinking and behavior; it provides refuge” (Dziwota, Zmuda, Dubiel, Dziwota, Markiewica, Makara-Studzinska, & Olajossy, 2016, p. 190).
Relationality	8	“Every day relating makes an impact on the spiritual identity of the person and, indeed, the spiritual identity of the nurse” (Fry, 1998, p. 29).
Transcendence	7	“Spirituality is the essence behind each religion and can therefore transcend yet unite world religion” (Hammond, 2003, p. 34). “Spirituality is distinguished from all other things…by its connection to that which is sacred, the *transcendent*” (Koenig, 2012, p.3).

Note. The count is the number of articles in which the theme was found.

Table 3

Memory Objects

Case	Memory Objects	Description	Related Themes
1	Kaleidoscope	Participant described how the onset of her son's illness resulted in numerous changes in her life, like the turning of a kaleidoscope.	Real/ideal Despair/Hope
	Baby stroller	Participant described how she would use a baby stroller to take her son to visit his father at the bar	Conflict/Peace Disconnectedness/Connectedness
	Birthday cards	Participant described how her son would make homemade birthday cards to send to family members.	Disconnectedness/Connectedness
2	Photograph	Photograph of her daughter after becoming ill	Disconnectedness/Connectedness Real/Ideal
	Stuffed kangaroo dolls	Two dolls part of a collection; the participant and her daughter exchanged these for years as gifts to one another	Disconnectedness/Connectedness
	Grief bowl	Handmade bowl given out to family members at daughter's memorial service	Despair/Hope
	Book	*Da Jesus Book*–a Bible written in Pidgin, a native Hawaiian dialect	Disconnectedness/Connectedness Beliefs
3	Pop tabs	Soda can tabs that the participant's son would collect	Disconnectedness/Connectedness
	Baby blanket	Personalized baby blanket the participant gave to her son	Disconnectedness/Connectedness

	Cigar wrappers	The participant’s son collected these in his bedroom	Disconnectedness/Connectedness
4	Photograph	Photograph of three children in a butterfly garden	Conflict/Peace
	Photograph	Photograph of three daughters when symptoms began to appear	Disconnectedness/Connectedness Real/Ideal
	Photograph	Photograph of daughter on the outside deck of her apartment, after she became ill	Disconnectedness/Connectedness Real/Ideal
	Book	*A Bag Full of Nothing* – a favorite children’s book of her daughter’s	Disconnectedness/Connectedness
5	Photograph	Son’s high school graduation picture	Conflict/Peace
	Photograph	Photograph of her son after he became ill	Disconnectedness/Connectedness Real/Ideal
	Photograph	Photograph of three children in Ecuadorian costumes	Disconnectedness/Connectedness
	Photograph	Photograph of her three sons	Disconnectedness/Connectedness
	Photograph	Photograph of her son and his father	Disconnectedness/Connectedness
	Photograph	Photograph of all her children with their grandparents	Disconnectedness/Connectedness
6	Drawing	Drawing her son made in 8th grade	Beliefs
	Photograph	Photograph of her son and his brother in their Halloween costumes	Disconnectedness/Connectedness
	Story	Participant read a story her son wrote in 7th grade	Beliefs

Table 4

Themes Identified in Each Case

	Themes			***Exemplary quotes***
	Interview 1 Before diagnosis	Interview 2 Time of	Interview 3 After diagnosis	
Case 1: Sharon	Conflict/Peace* **Disconnect/Connect** Real/Ideal Despair/Hope Values & Beliefs	Conflict/Peace **Disconnect/Connect** Real/Ideal Despair/Hope Values & Beliefs*	Conflict/Peace **Disconnect/Connect*** Real/Ideal Despair/hope Values & Beliefs	“He kept retreating more,” “he kept getting ostracized [by] family members,” “nobody wants to accept him when he’s sick”
Case 2: Ruth	**Disconnect/Connect*** Conflict/Peace Real/Ideal Despair/Hope Values & Beliefs	**Disconnect/Connect*** Despair/Hope Values & Beliefs	Conflict/Peace **Disconnect/Connect** Real/Ideal Despair/Hope* Values & Beliefs	“My regular supports […] completely vanished,” “I knew she was totally attached to me […] no matter if her behavior was beyond bizarre,” “she was becoming a different person,” “when you are going through very hard times, people will emerge”
Case 3: Maggie	Conflict/Peace Disconnect/Connect Despair/Hope*	Conflict/Peace Disconnect/Connect **Values & Beliefs***	Conflict/Peace Disconnect/Connect Despair/Hope* Real/Ideal **Values & Beliefs**	“I lived my life for my kids,” “I’m his Mom, I never let him down” “I have faith, but I do have doubts. I have the faith of a mustard seed,” “My purpose at the time was being a mother”

Case 4: Julie	Conflict/Peace Disconnect/Connect Real/Ideal Despair/Hope **Values & Beliefs***	Conflict/Peace Disconnect/Connect Despair/Hope **Values & Beliefs***	Conflict/Peace Disconnect/Connect Real/Ideal Despair/Hope* **Values & Beliefs**	"The biggest thing in our life was emphasizing a good education," "My purpose as a parent is to aid my children and help them to have a happy life,"
Case 5: Geraldine	Conflict/Peace* Disconnect/Connect Real/Ideal Despair/Hope **Values & Beliefs**	Disconnect/Connect **Values & Beliefs***	Disconnect/Connect* Real/Ideal Despair/Hope **Values & Beliefs**	"I was ready for the worst, but […] it's been manageable," "I felt like I was getting a terminal diagnosis,"
Case 6: Donna	Conflict/Peace* Disconnect/Connect Real/Ideal **Despair/Hope**	Disconnect/Connect **Despair/Hope** Values & Beliefs*	Conflict/Peace Disconnect/Connect Real/Ideal **Despair/Hope*** Values & Beliefs	"I have to defend him,"

Note. *indicates most prominent theme in each interview. **Boldface font** indicates most prominent theme in each case, across all three interviews

Table 5

Participant Demographics

Case #	**Age**	**Years Since Diagnosis**	**Educational Level**	**Race/Ethnicity**
1	61	22	Bachelor’s Degree	Caucasian
2	73	31	Doctoral Degree	Caucasian
3	57	3	High School	Caucasian
4	59	8	Bachelor’s Degree	Caucasian
5	71	33	Bachelor’s Degree	Caucasian
6	63	15	Bachelor’s Degree	Caucasian

Table 6

Life Events

	FAMILY HISTORY OF MENTAL ILLNESS	DOMESTIC VIOLENCE	DIVORCE	FREQUENT MOVING	CHILD'S DRUG USE	CHILD'S CRIMINAL JUSTICE INVOLVEMENT
CASE 1	X		X	X	X	X
CASE 2	X		X	X	X	X
CASE 3	X	X	X	X	X	X
CASE 4	X	X	X	X	X	X
CASE 5	X		X			X
CASE 6	X	X	X	X	X	
Total	**6/6**	**3/6**	**6/6**	**5/6**	**5/6**	**5/6**

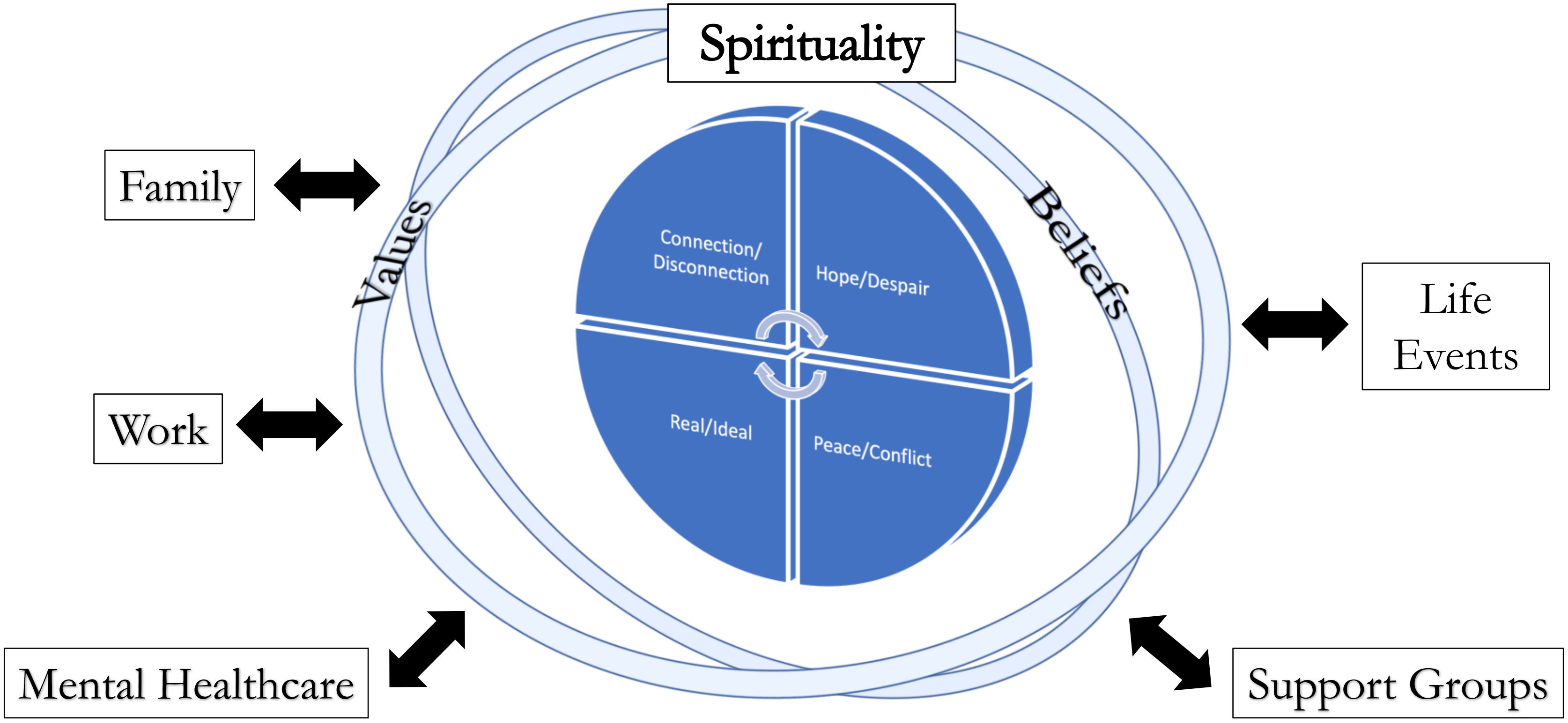

Figure 8

Model of Spiritual Renegotiation

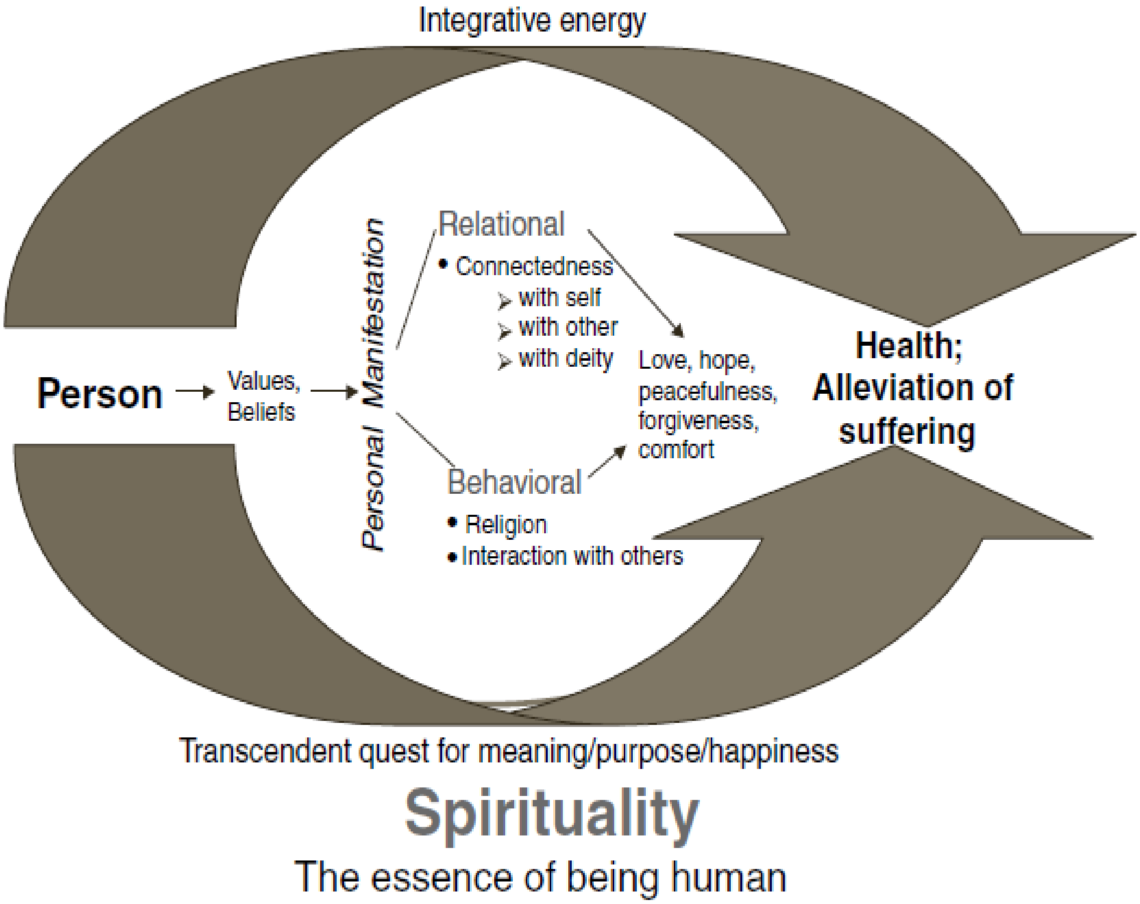

Figure 9

The Theory of Spirituality and Health Model

Note. The theory of spirituality and health. From "Putting a puzzle together: Making spirituality meaningful for nursing using and evolving theoretical framework," by D. Miner-Williams, 2006, *Journal of Clinical Nursing*, 15, p. 817. Copyright 2006 by John Wiley and Sons. Reprinted with permission.

Appendix A

Recruitment Flyer

Volunteers Needed for Research Study

Are you the parent of an adult child with schizophrenia?

Participants are needed to:

- Complete three 60-90-minute interviews from your own home using video-conferencing on your phone or computer
- Discuss how your understanding of spirituality (life meaning/purpose and relationships) changed after your child became ill

---

The identity of all participants will remain confidential.

The *goal of the study* is to learn from your stories
to help psychiatric nurses better support families
caring for a loved one with schizophrenia.

If you are interested, please contact:

Michelle Clark
mmzv32@mail.umkc.edu
216-202-7070 (call or text)

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Appendix B

Internet Recruitment Flyer

Volunteers Needed for Research Study

Are you the parent of an adult child with schizophrenia?

Participants are needed to:

- Complete three 60-90-minute interviews in your own home using video-conferencing on your phone or computer
- Discuss how your understanding of spirituality (life meaning/purpose and relationships) changed after your child became ill

---

The identity of all participants will remain confidential.

The *goal of the study* is to learn from your stories to help psychiatric nurses better care for families caring for a loved one with schizophrenia.

If you are interested, please contact:

Michelle Clark
mmzv32@mail.umkc.edu
216-202-7070 (call or text)

Appendix C

Recruitment Sources

Case #	**Recruitment Source**
1	American Psychiatric Nurses Association (APNA) Member Bridge
2	American Psychiatric Nurses Association (APNA) Member Bridge
3	Ohio Nurses Association (ONA) Connect
4	American Psychiatric Nurses Association (APNA) Member Bridge
5	Snowball sampling
6	Snowball sampling

Appendix D

Demographic Sheet

Case #:

Years since diagnosis:

Age:

Educational Level:

Appendix E

Initial Telephone Call Script

Hello, this is Michelle Clark. I am a PhD nursing student conducting a research study. You heard about my study and said that you were interested in learning more. I wanted to talk to you more about the study today and see if you meet the requirements and would be interested in participating. Is this an okay time to talk? I will be conducting a research study that involves interviewing parents of adult children with schizophrenia. This study involves a series of three interviews that will be conducted in your home using free video-conferencing software on your phone or computer. Each interview will probably last around 60-90 minutes. The interviews focus on life before, during, and after the onset of schizophrenia. I am interested in learning more about how your spirituality changed during this time. By spirituality, I mean your understandings of meaning and purpose in life and your important connections. If you participate in the study, I will send you the interview guides ahead of time, as some people like the opportunity to reflect on what we are going to talk about ahead of the interview time. At this point, do you have any questions? Are you interested in participating in the study?

[If no:]

Although you are not interested in participating in the study, I appreciate you taking the time to talk to me today. Have a good day.

[If yes:]

Thank you for your interest in participating in the study. I just have a few questions to make sure that you meet the requirements for participation.

Has your child been diagnosed with schizophrenia? (If yes, in what year were they diagnosed?)

Do you consent to be interviewed from your home using video-conferencing software on your phone or computer? The interviews will be audio recorded only, and no identifying information will be used in the study.

[If they meet all 3 requirements:]

You meet the requirements for participation. There is a research consent documents that will need to be read before the first interview. I will send you that via email or text. I will also send you the interview questions via email or text, so you can look at those ahead of time, if you wish. I have a couple questions I would also like to ask you before our first interview.

What is your age? Thank you.

And what is the highest level of education you have completed? Thank you.

How did you hear about the study? Thank you.

Can we set up a date for the first interview at this time? Thank you so much for your time, and I look forward to our first interview. You have my contact information if you need to reschedule.

[If they do not meet all 3 requirements:]

Thank you for answering those questions for me. Unfortunately, you do not meet the requirements for participation in the study. I appreciate you taking the time to talk to me today. Have a good day.

Appendix F

Interview Guides

Interview Guide #1

Introduction to the Interview:

Thank you so much for agreeing to participate in this interview. Today, I will be asking you about the period of time when your child became ill with schizophrenia. I did send you these questions ahead of time, so you could think about them if you wanted to. But please know that if it is the first time you are hearing them, that is fine. Feel free to ask me questions during this process if something is not clear to you. As a reminder, I will be audio recording our interview session (audio only, not video), and I will be taking some notes during this process. Is it okay that I am recording? _ [wait for assent_] _ Is it okay if I take photographs of your memory objects? _ [wait for assent_] _ Do you have any questions before we begin?

Interview Questions:

- Think about the time when your child became ill. Tell me about your child during that time. (How old were they? Were they working and/or at school? Were they still living at home?)
- Tell me about when you first noticed a change in your child's behavior. (What did you notice? How were things different than before?)
- If I was living at your house during that time, what would I have seen your child doing?
- How did it feel to see your child behaving differently? Do you remember what you told yourself to make sense of the behavior? What did you say about the behaviors to others who you were close to?
- Tell me the story of the first time you reached out for help. What was most helpful? What was not particularly helpful?
- Tell me about your interactions with the medical staff that was caring for your child.
- What were you told about what was going on with your child?

- Call to mind the scene when you were told of your child's diagnosis. What happened in that scene? What was said? What would someone looking on see, hear, and notice?
- Fast forward two years, how would you describe your feelings and thoughts about providing care for your child once things had settled in a bit? How did they differ or stay the same as the initial thoughts and feelings?
- What were you feeling when somebody labeled the illness?
- List for me where you found support when you were going through this. People often find support from family members, friends, neighbors, and co-workers.
- Describe a time when you received some support from a source that surprised you – that you would not have expected.
- What do you believe was your greatest strength during this time?
- If any, what activities or relationships during this time helped you see a purpose for what was happening in your life?
- Tell me about the memory objects you've chosen to share that remind you most of this time in your life with your child.

Interview Guide #2

Introduction to the Interview:

Thank you again for your participation. In our first interview session, we talked about the period of time when your child became ill with schizophrenia. In our second interview today, we are going to focus on the time before your child became ill. I am specifically interested in their childhood and school-aged years. As before, you had the questions ahead of time if you wanted to look at them before today. I will again be audio recording the session and taking some notes. Is it okay that I am recording? _[wait for assent_]_ Is it okay if I take photographs of your memory objects? _[wait for assent_]_ Do you have any questions today before we begin?

- Describe where your child grew up—what did it look like, sound like, feel like? (Have you always lived in this area?)
- Tell me about your family back then. (Is there anyone else in the family with a serious mental illness?)
- Tell me about your child when they were younger.
- How did you feel about being a parent when your child was preschool age?
- When your child was young – grade school age – how would you have described your purpose in life?
- When your child was growing up, before they became ill with schizophrenia, what five things do you think you would have listed as being most important in your life? (Ask to elaborate on each, one-by-one.)
- What were the most important relationships that you had when your child was grade school age?
- Tell me about what memory objects you chose to share that reminds you of your child during that time.

Interview Guide #3

Introduction to the Interview:

Thank you very much for your participation today. This will be our third and final interview session. The first two interviews focused on when your child became ill with schizophrenia and life during their childhood and school-aged years. Today's interview will focus on life since your child became ill with schizophrenia, from the onset of illness to now. I also have a few questions that as you to think about future situations. While you had the questions beforehand, it is fine if you did not review them before our session. I am audio recordings this session and will be taking notes. Is it okay that I am recording? _[wait for assent_]_ Is it okay if I take photographs of your memory objects? _[wait for assent_]_ Do you have any questions before we begin?

- What kind of things have changed in your family as a result of your child's illness?
- Tell me about how you care for your child now.
- How did your relationship – your feelings of connection – with your child change?
- Tell me about what has changed in terms of your sense of your purpose as a parent.
- What do you believe is your greatest strength now?
- What do you find most meaningful in your life now?
- Tell me about how your experiences, to where you are today, created any new or different sense of what is meaningful.
- How were you able to rework through things and find a new sense of meaning and connectedness in your life? (What was lost? What was gained?)
- What are the "little gems" that you found along your journey? (Bright spots that helped you along the way?)
- If you found out you had two weeks left to live, what do you feel was unfinished or unfulfilled in your life?
- If you met a couple whose adult child had just been diagnosed with schizophrenia, what advice would you give them?
- Tell me about what you chose to share that reminds you of your child now.

Appendix G

Observation Form

Observation Notes[1]

Case # **Interview #** **Date:**

TOPIC	**NOTES**
Physical Setting	
Social Environment	
Interactions	
Language and Meanings	
Nonverbal Communication	

Observation topics found in: Patton, M.Q. (2015). *Qualitative research and evaluation methods* (4th ed.). Los Angeles, CA: Sage Publications.

Appendix H

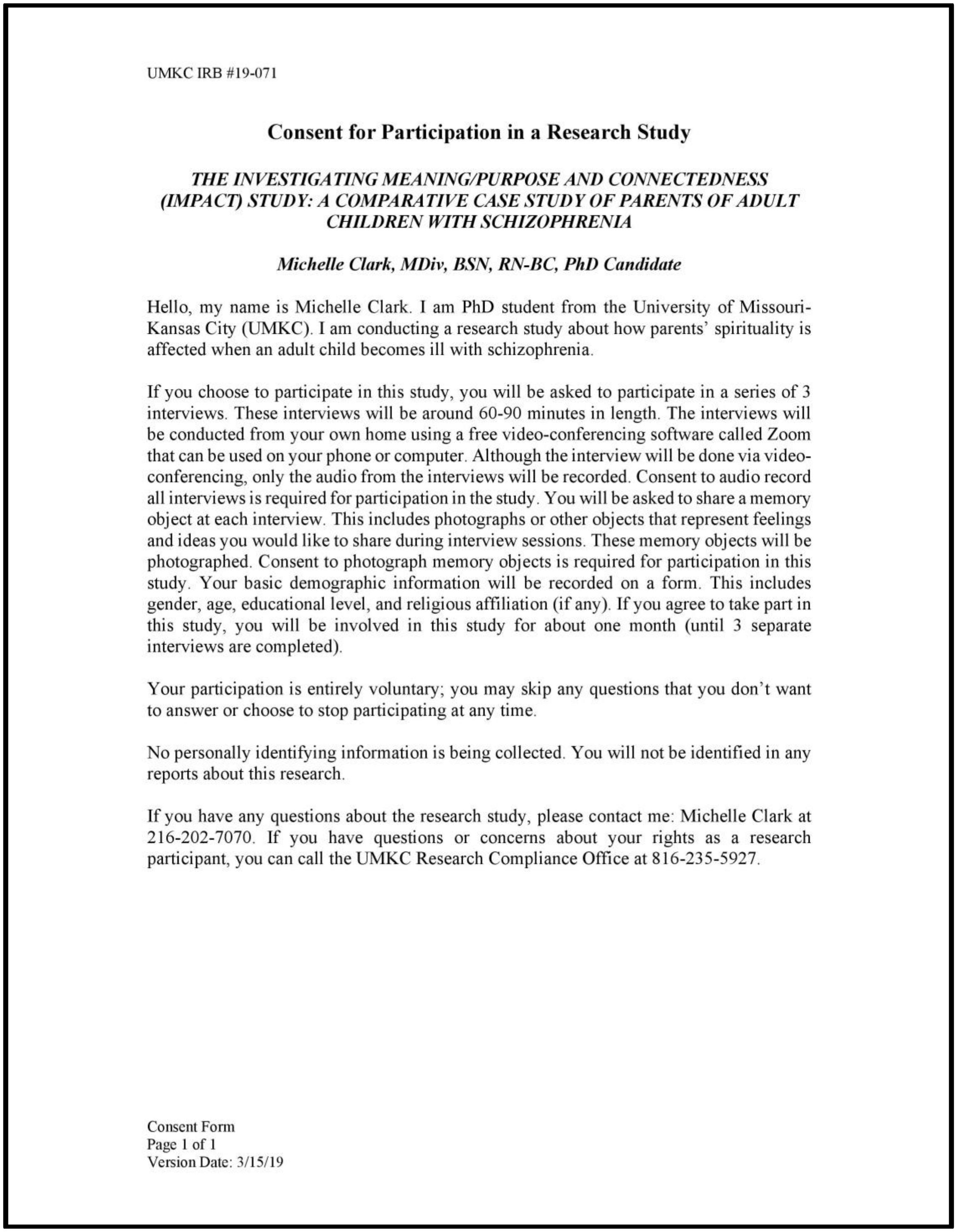
Preliminary Code List

Initial Codes:

- Connectedness
- Interactions with others
- Values and beliefs
- Hope

Appendix I

IMPACT Study Consent Form



UMKC IRB #19-071

Consent for Participation in a Research Study

THE INVESTIGATING MEANING/PURPOSE AND CONNECTEDNESS (IMPACT) STUDY: A COMPARATIVE CASE STUDY OF PARENTS OF ADULT CHILDREN WITH SCHIZOPHRENIA

Michelle Clark, MDiv, BSN, RN-BC, PhD Candidate

Hello, my name is Michelle Clark. I am PhD student from the University of Missouri-Kansas City (UMKC). I am conducting a research study about how parents' spirituality is affected when an adult child becomes ill with schizophrenia.

If you choose to participate in this study, you will be asked to participate in a series of 3 interviews. These interviews will be around 60-90 minutes in length. The interviews will be conducted from your own home using a free video-conferencing software called Zoom that can be used on your phone or computer. Although the interview will be done via video-conferencing, only the audio from the interviews will be recorded. Consent to audio record all interviews is required for participation in the study. You will be asked to share a memory object at each interview. This includes photographs or other objects that represent feelings and ideas you would like to share during interview sessions. These memory objects will be photographed. Consent to photograph memory objects is required for participation in this study. Your basic demographic information will be recorded on a form. This includes gender, age, educational level, and religious affiliation (if any). If you agree to take part in this study, you will be involved in this study for about one month (until 3 separate interviews are completed).

Your participation is entirely voluntary; you may skip any questions that you don't want to answer or choose to stop participating at any time.

No personally identifying information is being collected. You will not be identified in any reports about this research.

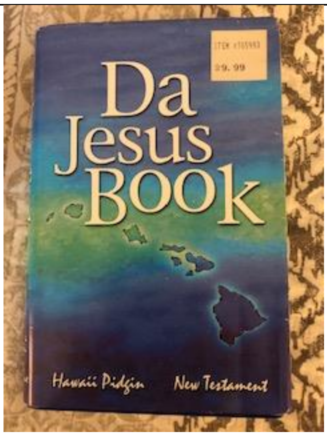
If you have any questions about the research study, please contact me: Michelle Clark at 216-202-7070. If you have questions or concerns about your rights as a research participant, you can call the UMKC Research Compliance Office at 816-235-5927.

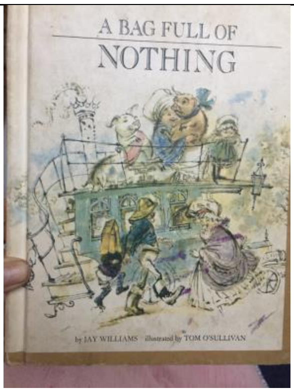
Consent Form
Page 1 of 1
Version Date: 3/15/19

Appendix J

Images of Memory Objects

Case	**Images(s)**
2	  

	 [1 image not included]
3	  [redacted]

4	 [3 images not included]
5	[6 images not included]
6	 [1 image not included] [Handwritten story by child read aloud]: *On Friday last week something very weird happened to me. All of a sudden, my eyesight was greatly magnified, and I could see through walls and read papers from across the room. At first, I thought I was having acute eyesight. At first, I thought having acute eyesight would be great, because I could cheat and look at test answers in social studies. I used my height and eye sight to see through the teacher's desk and copy the test answers. When I handed in my test, I looked through the wall to see what they were doing in math and science and got my homework done early. When the bell rang for social studies, I looked out the window and almost went blind because the sunlight was*

	like a flash of a camera. On my way to P E, I could hardly see, and I ran into everything in P E. I had such a headache from the sun I decided not to play any games in P E. I was glad to see my acute eyesight wearing off along with my headache. After that, I joined in for the last 20 minutes of class. I'm glad that day is over, and I hope it never happens again. That was the best and most hideous day of my life. It was great, because I aced my test. And it was the worst day, because I had the most painful headache of my life. - By Derek.

VITA

Michelle Madeline Clark was born on June 1, 1981 in Bethesda, Maryland. She grew up in Franklin, Indiana was educated in local public schools and graduated from Franklin Community High School as class valedictorian in 1999. She received a Hoosier Scholarship to Earlham College in Richmond, Indiana, from which she graduated with departmental honors in 2003. Her degree was a Bachelor of Arts in Religion.

After her undergraduate studies, Ms. Clark began a master's degree in religion at Earlham School of Religion. She was awarded the Master of Divinity degree in Spiritual Care & Counseling in 2006. In 2006, Ms. Clark began a residency program in Clinical Pastoral Education (CPE) at Kettering Medical Center in Dayton, Ohio. After this, she worked as a chaplain and bereavement coordinator for hospice as well as a hospital chaplain.

Ms. Clark began a Bachelor of Science degree in Nursing at Wright State University in 2011. She graduated in summa cum laude with departmental honors in 2013. In 2014, she worked as a psychiatric nurse on an inpatient pediatric and adult unit in Bismarck, North Dakota. During this year, she also began work towards her PhD in nursing at the University of Missouri-Kansas City. In 2015, she began a position on acute adult inpatient psychiatry for the Cleveland Clinic in Cleveland, Ohio. Ms. Clark earned her board certification in psychiatric-mental health nursing in 2017. Ms. Clark completed a graduate certificate in college teaching and career preparation in 2018. In addition to her work for the Cleveland Clinic, Ms. Clark is also on the clinical faculty at Case Western Reserve University teaching psychiatric-mental health nursing. Upon completion of her PhD, Ms. Clark plans to pursue a full-time faculty position.