

LIVED EXPERIENCES OF CARING FOR A FAMILY
MEMBER WITH SCHIZOPHRENIA

A DISSERTATION

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BY

ANLEE EVANS, MSN

DENTON, TEXAS

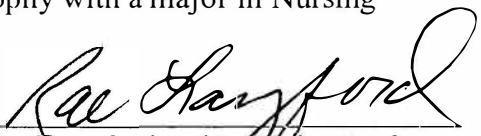
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To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Anlee Evans entitled "Lived Experiences of Caring for a Family Member With Schizophrenia". I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Nursing Science.


Rae Langford, EdD, Major Professor

We have read this dissertation and recommend its acceptance:





Associate Dean, College of Nursing

Accepted:


Dean of the Graduate School

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DEDICATION

This research project is dedicated the members of the National Alliance on Mental Health (NAMI), West Houston and Gulf Coast chapters. I would like to thank all of the members for welcoming me into their homes first of all to listen to their stories, and secondly for leading me through this research effort. From this research study I gained a greater understanding of their lived experience of caring for a family member diagnosed with schizophrenia. The researcher hopes that mental health professionals will use this new body of knowledge to improve interventions that will empower this population by recognizing the need for caregivers to have easy access to professional providers, allowed active participation in their family's treatment options when designated as the primary caregiver, and to listen without haste to their collective stories of caregiving. Prior to this study I could only make assumptions about the lives of caregivers, however, now I understand that the story of caring for a patient diagnosed with schizophrenia does not end with discharge from a hospital, its non-ending. As a clinician, I am more receptive to their communication needs and look forward to championing interventions that will sustain them in their caregiving role; it was a pleasure and an honor listen to their true stories.

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ABSTRACT

ANLEE EVANS

LIVED EXPERIENCES OF CARING FOR A FAMILY MEMBER WITH SCHIZOPHRENIA

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The purpose of this hermeneutic phenomenological research study was to describe, and construct, through understanding, how family caregivers have survived and sustained while caring for their family member diagnosed with schizophrenia. The study was based on seventeen audio-taped interviews with purposively selected caregivers of family members with schizophrenia. The philosophical underpinnings of Ricoeur guided the researcher from transcribed texts of interviews to the interpretation of the actual lived and human experience of caring for a family member diagnosed with schizophrenia. Insight was needed into those factors that foster certain caregiver's ability to defy the odds in surviving and sustaining while committing the patient in times of crisis, quality of resources, medication management, and violent and bizarre behavior. Transcripts were analyzed for common themes, differences, and patterns using a methodology inspired by the theoretical context of Ricoeur. The use of this method provided the researcher with congruence between the guiding framework for the study and the method used to analyze the data. The analysis resulted in four dichotomous themes: Beginning/Settling In;

Getting Through the Day; /Disruption; Isolation/Inclusion; Frustration/Satisfaction and two overarching themes, Surviving and Sustainability.

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CHAPTER I

INTRODUCTION

An estimated 26.2 percent of Americans ages 18 and older suffer from a diagnosable mental disorder in a given year (Kessler, Chui, Demler, & Walters, 2005). This means that approximately 57.7 million people in the United States are suffering from a mental illness (U.S. Census Bureau, 2004). The three major criteria used to rate the seriousness of mental illnesses are diagnosis, duration, and disability (Bachrach, 1988). Individuals diagnosed with schizophrenia require a greater number of periodic hospitalizations than individuals with any other mental illness diagnosis. Schizophrenia, while not the most common mental illness, is a serious chronic, and disabling disease. Andreason (1991) described this disease as the most costly for psychiatry to treat. It is estimated that 40% to 60% of patients with schizophrenia are likely to suffer from life-long impairment (Crown et al., 2001).

The disease is costly for both the family providing on-going informal care and society at large. An estimated 50% to 80% of persons with related psychotic disorders live with or have regular contact with family caregivers (McDonell, Sort, Berry, & Dyck, 2003). In the U.S. the overall cost of schizophrenia in 2002 was estimated to be \$62.7 billion, with \$22.7 billion of the cost seen in direct health care, \$7.0 billion in outpatient

costs, \$5.0 billion spent on the distribution of drugs, \$2.8 billion for inpatient care, and \$8.0 billion for the long-term care of these individuals (Wu et al., 2005).

Schizophrenia is diagnosed in about 1.1% of the population in the United States translating into about 2.2 million Americans (National Institutes of Mental Health <http://www.nimh.nih.gov>). With roughly 2.2 million people in the United States diagnosed with schizophrenia at any given time, or 7.2 individual per 1000, a city with a population over 3 million people will see 21,000 individuals diagnosed with this disease. Under and unemployment is also noted in this population and translates into poverty regardless of status or family origin. An already taxed healthcare system is further exhausted when the care of these individuals is placed upon publicly funded healthcare systems, primarily Medicaid, Medicare, and the department of Veteran Affairs (VA) (Lehman, Carpenter, Goldman, & Steinwachs, 1995).

The era of deinstitutionalization heralded a new care paradigm for a generation of consumers who were mentally ill with cognitive and functional impairments (Bachrach, 1978; Lefley & Hatfield, 1999). Beginning in the mid 1950's to the early 1980's residential treatment declined significantly in county and state facilities (Greenberg, Greenly, McKee, Brown, & Griffin-Francell, 1993). Residential admission rates dropped from over 550,000 to 120,000 or less (NIMH, 1985). Prior to deinstitutionalization, lengths of stays were measured in decades, and caregivers were not responsible for the care of their families for extended periods of time (Kiesler & Sibulkin, 1987). Hospitalizations are now measured in weeks with short length of stays and missing links

to continuity of care after discharge. This long-term trend ushered in the decline of inpatient treatment and a decrease in delivery of treatment modalities in public mental health facilities; public hospitals were closed and patients were transferred to community-based mental health services. This process led to patients diagnosed with schizophrenia receiving care in a wider variety of health care settings, modalities, and geographic areas. The major shift in the nation's method of treating its constituents, who were emotionally disturbed, from inpatient care to a community-centered system, thrust the family into a critical caregiving role (Thompson & Doll, 1982; Grob 1991, 1992, 1997; Klerman, Olson, Leon, & Weissman, 1992).

The deinstitutionalization of patients diagnosed with schizophrenia formerly receiving in-patient care created unforeseen challenges and care demands for family members (Saunders, J., 1999). As a result in this cultural and structural shift in the delivery of care, many families became the first line of defense for their family member with schizophrenia. Family members were ill equipped to handle the incurable nature of this diagnosis in an immediate family member and with two thirds of this population returning home, the impact of deinstitutionalization was immediately felt. Without training and adequate support families were thrust into the role of caregivers of people with mental health problems (Cook, 1988; Sanders, 1999; Fakhoury & Priebe, 2007)

Families and other caregivers play an important role in the lives of people diagnosed with schizophrenia (Dixon, 1999). Care recipients with a severe mental illness have typically been diagnosed for years, are unable to provide for their individual

socioeconomic needs, usually function below the intellectual age expected for their chronological age, and most likely to receive caregiving (Saunders, 2003). Over 60% of those with a first episode of a major mental illness return to live with relatives, and this decreases only by 10-20% when those with subsequent admissions are subtracted (Kessler, Chui, Demler, & Walters, 2005).

A paradigmatic clinical syndrome involving bizarre behavior as well as emotional, mental, and social dysfunction, the episodic nature of schizophrenia makes caregiving erratic and unpredictable (Carpenter & Buchanan, 1994). These new populations of informal caregivers are faced with episodes of unpredictable violent behavior in conjunction with hallucinations, delusions, preoccupations, and jumbled thoughts which impede self care, diminished levels of social interaction, and reduced employment opportunities (Schene, van Wijngaarden, & Koeter, 1998).

Care demands on the informal family caregiver can include activities of daily living (ADLs) of keeping the recipient safe; dealing with socially unacceptable or aggressive behavior, prompting the recipient to undertake personal hygiene, ensuring medication is taken on time. Care demands of instrumental ADLs often include administering or providing finances, ensuring the environment is appropriate, liaising with health and other professionals, educating family and friends, providing companionship and care, accommodation and advocacy, and being flexible about the level of care provided with no advance notice of change (Goodhead & Janet, 2007; Arksey & Hirst, 2005; Collings & Semnuik 1998). There is no quick fix for this disease,

and the social and psychological costs experienced by individual and family members are immense. Caregivers to family members with schizophrenia enter into what may be a lifelong and continuous commitment eliminated only by their death.

Deinstitutionalization also illustrated the evolution in the structure, practice, experiences, and purposes of mental health care in the United States (Warner, 1986; Cook, 1988; Grob, 1997; Talbott, 2004). Revealed in this movement were shifts from hospital care to community based systems, rank discrimination against long-term care and chronic illnesses such as schizophrenia, by governmental and private third party reimbursers, housing agencies, and labor laws. Revealed in full view of the caregiver was the inadequacy of mental health delivery systems or more aptly termed, the non-system of care (Talbott, 2004). Caregivers seldom receive adequate assistance from mental health agencies and/or professionals. Services are fragmented with different levels of state, local, and federal agencies all vying for the same contracts, and none singularly or collectively providing continuity of services.

Adding to this failure was the nonexistence of adequate community facilities for the chronically ill, and no immediate provisions for supplying services originally available in the state hospital (Talbott, 2004). Two new syndromes also evolved during this process, “falling between the cracks” (lack of follow-up) and the “revolving door” (continued admissions). After deinstitutionalization families were faced with the lack of availability of community based care, few possibilities for continuity of provided services, and the inheritance of the role of primary caregiver. This additional and

unexpected role came with difficulties and was associated with considerable personal costs. Based on the existing ineffective community-based model of care, and regardless of gender, age or sex, the informal caregiver assumes the majority of outpatient care. In providing this care, one of the most challenging issues is learning to cope with the social isolation, withdrawal, and lack of motivation that is characteristic of the patient diagnosed with schizophrenia.

This challenging diagnosis coupled with the shortcomings and ongoing decline in availability of care of the community- based system has produced far-reaching and often devastating consequences for both the individual with schizophrenia and their family members. The disease process in its everyday form is sometimes disruptive, stressful, and presents itself as a catastrophic event. The current trend of ineffective community support, short length of hospital stays, and inadequate respite opportunities, provides undisputable evidence for the need to develop interventions that are tailor made to sustain the informal caregiving family. The problem is how to best support those family caregivers who provide this care, so that the level of wellness of both the care recipients and their caregivers maybe maintained over a longer period.

In summary, deinstitutionalization did not effectively provide the promised impetus to move care provisions from hospitals to community based care. The needed interconnectedness between the mental health community, caregivers to family diagnosed with schizophrenia, and present interventions of care are presently non- existent. Family members are expected to assume responsibilities for care in which they have no formal

training and often interventions that support long term sustainability of the role are missing. By exploring the lived experience of caring for a family member with schizophrenia, relapse may be reduced, caregiving sustainability fostered, and repeated hospitalizations replaced with longer periods of symptom stabilization.

Problem of Study

The purpose of this hermeneutic phenomenological research study is to describe, and construct, through understanding, how family caregivers of family members diagnosed with schizophrenia stayed the course, or sustained while caring for their family members with schizophrenia. People with schizophrenia as a rule do not die from this disease but their families must confront the ongoing symbolic and slow demise of the person they once knew (Eakes, 1995). Past research studies have illuminated the perceived burden and coping skills associated with caring for a schizophrenic family member but provide little detail about the actual lived experiences of this population (Manderscheid, R. W. & Berry, J.T, 2004; Langa K, & Chernew et al., 2001; Langa, & Valenstein et al., 2004).

To date, the conceptualization of the experience of caring for a family member with schizophrenia has been either f distressful or satisfactory based on qualities attributed to various factors in the caregiver's external world (Joyce et al., 2002, p. 189). This conceptualization does not provide an adequate interpretive understanding of the caregiver's story of the particular ways and the particular circumstances of life while

caring for a family member with schizophrenia. It does not provide an understanding of the concept of caregiver sustainability.

The researcher sought to fill a gap in nursing science by investigating the meaning of the actual experiences of providing 24-hour care for a family member diagnosed with schizophrenia, to understand the concept of sustainable caregiving and how the caregiver stayed the course. The problem is not how we can measure caregiver sustainability; the more appropriate discourse is how mental health professionals will measure up to sustainability of successful caregiving.

The research question for this study is as follows:

“What is the lived experience of caring for a family member with schizophrenia?”

Through family caregivers’ descriptions of their lived experiences as caregivers of their family members who are diagnosed with schizophrenia the researcher hopes to understand how families have remained consistent through the years as caregivers. That understanding will aid the researcher in developing interventions that strengthen key processes for caregiver’s sustainability of providing care of over time.

Rationale for Study

The experience of caring for a schizophrenic patient has typically been studied in terms of measuring family caregivers’ coping strategies and the relationship to perceived burden or the negative aspects of caring related to the disease process (Mannion, 1996; & Stuckey, Neuendorfer, & Smyth, 1996). The aging baby boomer population, and public policies that limit accessible and affordable formal care services, has ushered in an

increase in informal caregivers, largely women, who bear the overwhelming responsibility for home and long-term care services.

Families faced with the responsibility of caregiving to members with persistent mental illnesses become involved by choice or necessity (Horwitz, Reinhard & Howell-White, 1996; Smith, Greenberg, & Selzer, 2007). These choices and/or necessities are coupled with many variables that affect the individual experience of caring for a family member with schizophrenia. Short lengths of stay, changing treatment modalities, and the advent of out-patient treatment, all present a strong call for research on how caregivers manage and cope with the difficulties encountered in their caretaking experience.

In the scope of nursing research and practice, this type of research has implications for understanding the long term outcomes of caregiving, such as the effects on the physical, mental health, and the inherent sustainability of the role of caregiver. Sustainable caregiving may be defined as the capacity of caregivers to stay the course of meeting the present needs of care recipients without compromising the ability of those same caregivers to meet their own present and future needs. The determination of these sustaining (or non-sustaining) factors could provide clear guidance on the requisites for meeting formal and informal caregiving needs, and may clarify what factors are precursors to developing resilience in the long term role of caregivers to people with schizophrenia. There is a need to understand the internal manifestations of sustainability of the caregiver role as they relate to the non-material and subjective lived experiences that are often side-lined because they are messy, interpretive, and time-

consuming; the world of hermeneutics. This phenomenological study sought to provide an understanding of caregiver sustainability not as a “thing” to quantify, but to illuminate the importance of this concept as it relates to ecological integrity, quality of life, and transformation or transcendence (<http://www.metafuture.org/articlesbycolleagues/AlanFricker/Measuring up to Sustainability>).

Unlike towering medical institutions, the human life span is relatively short and finite (Goodland, 2002). Human sustainability needs constant and continuous maintenance by investments throughout one’s lifetime (Goodland, 2002). Stronger interventions in support of caregiver sustainability will result in more resourcefulness when dealing with crisis, and unforeseen disease exacerbations, weathering persistent stressors, and meeting future challenges - the chaos of caregiving (Walsh, 2003). Health promotions and planning interventions for the informal caregiver should consider intermediate processes and outcomes, as well as long term outcomes. The exploration of lived experiences of caring for a family member with schizophrenia will ultimately lead to solutions that support the development and design of health information and promotion, identify needs for the sustainability of their role, and contribute significant information to the state of nursing science. Evidence-based nursing practices based on caregiver sustainability, may form the basis for providing support for the informal caregiver and become the impetus for an increase in research studies.

Philosophical Orientation

The philosophy and theory of Ricoeur will serve as a guide in the conduct this

study. His theory draws on the tradition of western philosophy, while combining phenomenology with hermeneutics (Edwall, Hellstrom, Ohrn, & Danielson, 2008).

Ricoeur's work acknowledges the interrelationship between epistemology and ontology, and highlights the pleural, changing, and incomplete nature of interpretation (Geanellos, 2000).

The primary theoretical construct of this theory focuses on the textual interpretation of hermeneutics leading to a theory of interpretation that embraces language, reflection, understanding, and the self (Geanellos, 2000). In textual interpretation the researcher moves from "what the text actually says, to understanding what it talks about" (Ricoeur, 1976, p. 88). An underlying theoretical premise asserts that the interpretation of research interviews, through transcribed language to text, is forged between the language and the lived experience (Ricoeur, 1974). This forged relationship does not subjectify the text but allows the researcher to comprehend that the meaning of the text transcends that of the research participant (Ricoeur, 1974). The lived experience will always remain in the private domain of the participant, but the meaning, through the hermeneutic interpretation of the researcher can be shared publicly (Ricoeur, 1976).

In the development of his theory, (Ricoeur, 1974), chose to objectify the text. Authorial intent was removed along with the idea that meaning resides only with the research participant (Geanellos, 2000). Objectification allows the researcher to move beyond the premise that only one correct truth or meaning exists. This textual plurality or pre-understanding provides a mechanism for the researcher to "interpret the same text

faithfully yet differently” while acknowledging a multiplicity of meanings in the text (Geanellos, 2000, p. 113).

Ricoeur’s conceptualization of interpretation is grounded in the link between experience, understanding, and self-understanding (Geanellos, 2000). Through the actualization of being and the relative state of being with others, the hermeneutic circle, implicitly or explicitly provides a channel for self understanding through understanding others through their lived experiences (Ricoeur, 1974, p. 17).

Four major tenets of Ricoeur’s theoretical construct of interpretation will be utilized for this study; distanciation, appropriation, explanation, and understanding. Distanciation, which is the objectification of the text, allows the researcher to distance themselves from the text or discourse in several ways. The first is the transcription of the spoken word into a literal textual form (Donnelly & Wiechula, 2005). In the second phase the research participant is overshadowed with the written word, and makes the text open for unlimited reading and interpretation (Geanellos, 2000). The literal translation of the written word frees the text from nonverbal aspects of the narrative while highlighting other elements of the conversation within the post-interview notes (Donnelly & Wiechula, 2005).

Appropriation identifies linguistic relationships for use in the construction of an interpretation (Donnelly & Wiechula, 2005). The conceptual framework infers that the researcher appropriates the meaning of the narratives which are no longer alien but familiar (Geanellos, 2000). Through this conceptualization, Ricoeur, 1981b, p. 192), saw

interpretive research as a vehicle to reveal to the world a dispossession of the text, and to remove the researcher's narcissistic ego, thus providing an opportunity for interpretation and explanation of the text to the world. In laymen's terms, the reader becomes an intricate part of the text and embraces a new understanding of the lived experience.

In the tenets of explanation and understanding, Ricoeur (1981), perceives no ontological difference in these categories, he instead notes a dialectic movement between the two. Explanation and understanding are seen as continuous prerequisites in the achievement of productive interpretations (Frid, Ohlen, & Bergbom, 2000). Explanation is what the text says and involves selecting the main ideas of the text (Geanellos, 2000). The logical implication is the presentation of a metaphoric process in which the meaning of the textual narrative moves from literal to figurative. This tenet is directed toward an analysis of the internal parts of the text. Ricoeur (1981) defines understanding as a naïve attempt to superficially understand textual meanings. "This naïve form of understanding may be rejected, or confirmed and expanded as understanding proceeds and deepens" (Geanellos, 2000, p.115).

Naïve understanding moves to a more in depth grasp of the lived experience and may result in multiple meanings of the text. The hermeneutic arc is "anchored in the lived experience" (Ricoeur, 1981, p .64) and explanation provides a metaphorical path to understanding. The theoretical constructs of explanation and understanding elucidates the multiple stages the interpreter follows in the path to understanding what is expressed and unexpressed within the text (Geanellos, 2000).

The researcher used Ricoeur's theory of interpretation as a theoretical foundation to clarify the essential meanings of the lived experience of caring for a family member diagnosed with schizophrenia and to provide both an understanding, and explanation of these experiences. In keeping with his theoretical interpretation, the process of discourse proved to be as important as the analysis. The analysis of the data was seen as acting or knowing or parts of the participant's journey, rather than the beginning or the end.

Summary

A gap exists in nursing research describing the actual lived experience of caring for a family member with schizophrenia. Short lengths of stay, changing treatment modalities, and the advent of out-patient treatment, all indicate a strong need for research on how caregivers manage, survive, and sustain through the difficulties encountered in their caretaking experience.

In the present study, the methodology and theoretical tenants of Ricoeur's interpretive theory provided effective guidance in steering the study through a clear and concise method of both explaining, and understanding the isolation, frustration, and day to day stressors associated with this phenomenon. The researcher began by interpreting the spoken word of the study participant while superficially (naively) understanding the lived experience of the whole text that described the lived experiences of the caregiver. The interpretation in the study moved to a full hermeneutic circle when a deeper understanding of parts of the text in relation to the whole and the whole of the texts in relation to the parts" (Geanellos, 2000, p. 112) was reached.

New findings should facilitate greater opportunities in the implementation of well-grounded prevention and intervention efforts. In considering health promotions for informal caregivers, interventions should consider intermediate processes as well as long term outcomes. Interventions based on understanding the lived experience may strengthen key processes for facilitating sustaining factors that enable informal caregivers to become more resourceful in dealing with crisis, weathering persistent stresses, and meeting future obligations and challenges (Walsh, 2003).

CHAPTER II

REVIEW OF LITERATURE

This chapter provides a review, analysis, and synthesis of available literature guiding the context for the purpose of this study. The following topics are reviewed: studies that are descriptive of the informal caregiver of the family member diagnosed with schizophrenia, documentary information about the phenomenon of caregiver burden, coping strategies, and caregiver perceptions (lived experiences) of the factors that result in these adaptive behaviors. A summary and gaps in the nursing literature will also be addressed.

Conduct of the Literature Review

Healthcare databases were selected for review of current indexed literature on the lived experience of caring for a family member diagnosed with schizophrenia. A broad search of Pub Med, CINAHL, ERIC, PsyInfo, MEDLINE, and Academic Search Premier was extended to include peer-reviewed literature with no date limits applied. The search strategy included the use of the key terms of burden, caregivers, coping, sustainability, lived experience, mental health, parents, fathers, siblings, schizophrenia, hermeneutic, and phenomenological. Search results were limited to human subjects, and to English documents.

Schizophrenia, the Caregiver, and Demands for Care

Few researchers have specifically explored the actual lived experience of caring for a schizophrenic family member. Studies and researchers have primarily focused on the negative aspects of caregiving described as caregiver burden (Brody, Litvin, Hoffman, & Kleban, 1992; Carpenter et al., 1992; Chafetz & Barnes, 1989; Cook, Hoffschmidt, Cohler, & Pickett, 1992; Glanville & Dixon, 2005; Justras & Veilleux, 1991; Maurin & Boyd, 1990; Norbeck, Chafetz, Skodol-Wilson, & Weiss, 1991; Parks & Pilisuk, 1990; Saunders, 2003; Thompson, E. & Doll, 1982; Thompson, R. & Weisberg, 1990). There is also a considerable amount of literature concerned with coping with severe mental illness, problem-solving, and coping strategies that families of a person with severe mental illness employ (Gubman & Tessler, 1987; Greenberg, Selzer, & Judge; Finley, 1998; Finley, 2000; Martens & Addington, 2001; Nehra, Chakrabarti, Kulhara, & Sharma, 2005).

As families have assumed a greater role in caring for patients diagnosed with schizophrenia, Oldridge and Hughes, (1992) and Cook, Hoffschmidt, Cohler, and Pickett, (1992) examined caregiver burden and health. Researchers have also attempted to understand the concept of caregiver burden and types of care (Bowers, 1988; Lim Luna, Cromwell, Phillips, Russell, & Torres de Ardon, 1996; Maurin & Boyd, 1990; Nolan Keady, & Grant, 1996). Systematic research studies have documented the reality of living with a family member diagnosed with a severe mental illness, through clinician assumptions, and through reports from families themselves.

Siblings of schizophrenia patients are, from the patient's perspective important support providers, but most studies on family burden have focused on the parental role (Stalberg, Ekerwald, & Hultman, 2004). This qualitative study used audiotaped semi-structured interviews of 16 siblings, which provided a detailed analysis of the psychological aspects of having a sibling with schizophrenia. The reliability of the inductive categorization of data was high. A unifying theme appeared to be an emotional sibling bond characterized by feelings of love, sorrow, anger, envy, guilt, and shame. The major categories linked to coping with the situation were avoidance, isolation, normalization, caregiving, and grieving. A third major theme consisted of a fear of possible schizophrenia heredity. The siblings described concerns about the impact of a family history of psychiatric illness, a fear of becoming mentally ill, and reflections about "bad genes." The study was supportive of earlier findings of coping patterns but was further supplemented by a model that included an awareness of genetic vulnerability as an important component in the subjective burden of the sibling (Stalberg et al., 2004).

In a preliminary exploratory and qualitative study, Wintersteen and Rasmussen, (1997) used an ethnographic method to explore the reactions of fathers' faced with the mental illness of an adult child. Twenty-five sets of parents were interviewed using parallel structured questions focusing on the father's involvement with their adult schizophrenic child (Wintersteen & Rasmussen, 1997). Results of the study found that a group of 25 fathers coping with the mental illness of an adult child exhibited emotional stress that was largely unrecognized and unacknowledged by mental health professionals.

In addition, fathers tended to utilize more isolating strategies for coping with their adult child's mental illness.

Using Neuman's theory, Yamashita, (1998), used a purposive sample of 12 Canadian and 14 Japanese to examine families' reactions to their relative's mental illness. Within Neuman's theory of health as an expanding consciousness, the study focused on the caregivers' transformation processes, noted as unitary process of pattern appraisal and deliberate mutual patterning based on a unitary transformative paradigm. The study demonstrated that regardless of society's view, caregiving was not necessarily a burden.

Doornbos (1997), through a nonprobability sampling strategy used mailed questionnaires to study the problems and coping methods of caregivers of young adults with mental illness. The results found that caregivers struggled with burden, grief, and client symptomatology that subsequently led to a negative impact on their family as a unit. Facilitative attitudes, reliance on their faith, use of support groups, and increasing their knowledge of mental illness were expressed as coping mechanisms.

In meeting the demands of care, caregivers frequently complain of that lack of information about the family member's illness, the evolving changes in the disease process, and treatment outcomes. Norbeck, Chafetz, Wilson, and Weiss (1990), noted in their research that family caregivers of individuals with severe mental illness believed that support in locating care recipient resources, specific information about the disease process, and methods for managing their family members unpredictable behaviors improved their ability to cope and handle the demands of care.

Schizophrenia, the Caregiver, and Strategies for Sustainability

The review of literature supports the premise that coping skills are a necessary precursor in the maintenance of coping strategies in the informal caregiver of the schizophrenic patient (McCubbin & McCubbin 1993; Lefley, 1990). There exists a need to evaluate caregiver coping strategies and the maintenance of normalcy in their lives while caring for the schizophrenia patient. Numerous studies have focused on adaptive qualities, coping skills, and strengths of families. Birchwood and Cochrane (1990), who examined coping strategies used by relatives of individuals with schizophrenia, found a number of significant relationships among relatives' specific coping strategies and the behaviors of the patients. Parent coping strategies were related to the level of expressed emotion exhibited, which in turn affected their relatives' behavior.

Schizophrenia, cyclical in nature with undetermined periods of exacerbation, completely changes the life of the individual diagnosed and impacts the family member providing care. During the periods of increased positive symptoms, family caregivers may have a difficult time coping with the increase in delusional and psychotic behavior. Periods of remission do not necessarily offer a respite for caregivers; negative symptoms can lead to feelings of helplessness, hopelessness, and challenge coping abilities.

In a cross sectional study Fortune, Smith, and Garvey, (2005), following Leventhal's self-regulation model, examined the relationship between psychosis perceptions, coping strategies, appraisals, and distress in the relatives of patients with

schizophrenia. Participants were 42 relatives of patients with schizophrenia who completed the Hospital Anxiety and Depression Scale (HADS), a brief coping strategies measure (COPE), the Revised Illness Perception Questionnaire (IPQR), and a measure of primary and secondary appraisals (Family Questionnaire). High distress scores were found among of caregivers who viewed their relative's psychosis as chronic, who had a stronger illness identity (experience of symptoms), who held a stronger belief in the severity of its consequences, and who reported weaker beliefs in treatment control but stronger beliefs that their relative could exert control over their condition had higher distress scores.. Coping through seeking emotional support, the use of religion/spirituality, active coping, acceptance, and positive reframing was associated with less distress. Higher distress scores in the study were associated with self-blame.

Navaie-Waliser, Spriggs, and Feldman (2002), examined gender differences among informal caregivers in caregiving activities. They considered intensity, challenges, and coping strategies and assessed the differential effects of caregiving on their physical and emotional well-being. A cross-sectional was study conducted between May and September 1998, using telephone interviews, with a randomly selected, nationally representative sample of 1002 informal caregivers. Caregivers' socio-demographic and physical and emotional health characteristics; caregiving type and intensity; formal care support; difficulty with care provision; unmet needs; coping strategies; and the care recipients' health and relationship with caregiver were examined between the genders using descriptive and multivariate analyses. Compared with men caregivers, women

caregivers were significantly more likely to be 65 years of age or older, black, married, better educated, unemployed, and primary caregivers; provide more intensive and complex care; have difficulty with care provision and balancing caregiving with other family and employment responsibilities; suffer from poorer emotional health secondary to caregiving; and cope with caregiving responsibilities by forgoing respite participation and engaging in increased religious activities. The study concluded that informal caregivers, particularly women, are under considerable stress to provide a large volume of care with little support from formal caregivers.

Hall and Docherty (2000), examined relationships between levels of expressed emotion and coping strategies used by 44 parents of individuals with schizophrenia. Coping strategies identified were assertive action, social joining, seeking social support, cautious action, instinctive action, antisocial action, aggressive action, avoidance coping, and indirect action. The study found that coping was not generally directly related to levels of expressed emotion; however, an interaction between parent coping style and patient behavior was found to predict the level of expressed emotion. The consequences of family efforts to cope may be either positive or negative, and the behaviors used may produce additional burdens on the already overwhelmed family.

Solomon and Draine, (1995), sought to describe factors associated with adaptive coping by family members with a psychiatrically disabled relative. A total of 225 family members of persons with serious mental illness were interviewed. Hierarchical regression analysis, using five variables that may have contributed to adaptive coping, was

conducted. The five factors were: demographic characteristics of the family member, severity of the relative's illness, the family member's subjective burden and grief, social support, and personal coping resources (self-efficacy and mastery). Notable in the research was that more extensive adaptive coping was associated with increased social support as measured by the density of the social network, the extent of affirming social support, and participation in a support group for families. Better coping was also associated with a greater sense of self-efficacy in dealing with the relative's mental illness. While many studies associate severity of the relative's illness with adaptive coping this association was not found in this research endeavor.

Several studies have focused on adaptive qualities, coping skills, and strengths of families. Birchwood and Cochrane (1990), who examined coping strategies used by relatives of individuals with schizophrenia, found a number of significant relationships among relatives' specific coping strategies and behaviors of the patients. Parent coping strategies were related to their level of expressed emotion exhibited, which in turn affected their relatives' behavior. Norbeck, Chafetz, Wilson, & Weiss (1991) found that family caregivers of individuals with severe mental illness believed that help in locating resources and the availability of backup care facilitated or improved their ability to cope.

Using a correlational study, Saunders (1999) explored the coping behaviors of 58 families providing care for a family member with schizophrenia. The researcher used the variables family coping behaviors, family psychological distress, family social support, patient behavioral problems, and family functioning. The caregivers were college

educated, with a mean age of 59 with an average of 17 years of providing care.

The study results found that the most effective nursing interventions are those that address family functioning in informal caregivers that directly impact psychological distress and patient behavioral problems (Saunders, 1999). The preceding research studies discussed coping, adaptation, useful coping strategies, and the need for addressing family functioning in caregivers. What they did not provide was an explanation of how they stayed the course and survived and/or sustained in this role. However, literature has explored ways in which some do well in the face of adversity through the use of resilience as a concept.

Research studies have attempted to describe how caregivers in varying situations adapt to a changing environment (Darwin, 1898; Cicchetti & Cohen, 1995), and the character of hardiness and invulnerability (Anthony, 1974; Kobasa, 1979; Rhodewalt & Zone, 1989; Maddi & Khoshaba, 1994; Florian, Mikulincer, & Taubman, 1995; Ramanaiah, Sharpe, & Byravan, 1999). Resilience has been conceptualized as a dynamic process involving an interaction between internal and external risks and protective processes that act to modify the effects of an adverse life event (Rutter, 1999). Resilience does not imply invulnerability to stress, but rather an ability to recover from negative events (Garmezy, 1991). Fonagy, Steele, Steele, Higgitt, and Target (1994), described resilience as “normal development under difficult conditions” (p. 233).

Measures of sustainability at present tend to be a blend of human, social, environmental and economic indicators (Goodland, 2002). Health care scientists still

have great difficulty in deriving indicators, because of intangible quality of life issues. Sustainability of caregiving is more than just the interconnectedness of the economy, society and the environment. Important though these are, they are largely only the external manifestations of sustainability.

A minute amount of literature, quantitative or qualitative, to date has documented measures, and or interventions that actually define the necessary components of sustainability for caregivers faced with caring for a family member diagnosed with schizophrenia. Researchers have not fully confirmed through the vehicle of lived experience, how caregivers have sustained and sustained, rather than cope, or merely survive, years of chaotic care responsibilities. The voice of the lived experience is absent in many studies and interventions, and assumptions have been based on what researchers' suppose are sustaining factors for this population.

Bainbridge, Cregan, and Kulik (2006), using data derived from a large government data base conducted by the Australian Bureau of Statistics (ABS) (1998), discussed the role of work in the lives of caregivers. The sample consisted of 742 participants using, who were primary caregivers of individuals with a mental disability. Based on ABS surveys data, the study noted that caregivers providing care for a person with a mental disability experienced fewer stress outcomes when involved in work outside of the home.

Using quantitative data from a subset of a larger study involving a cross section of

560 respondents having a relative diagnosed with schizophrenia, Chen and Greenberg (2004) examined caregiving gains as a result for caring for their relatives with schizophrenic spectrum disorders. Prevalent caregiving gains were reported as formal support from mental health professionals through collaborative information sharing, support group participation, and contributions from their diagnosed relative. All of the preceding was noted as significant and positive gains for family members. Gaugler, Davey, Pearlin, and Zarit (2000), used longitudinal data taken from the Caregiver Stress and Coping Study (Aneshensel, 1995) and a sample size of 137 dementia caregivers to identify individual caregiver differences. The study emphasized the long term impact of caring for a family member with dementia and why the task of caregiving is difficult for some and not others.

Several qualitative studies have touched on these sustaining factors and the need for interventions aimed at the caregiver population. Saunders and Byrne (2002), using written comments from 26 family members caring for family diagnosed with schizophrenia, discussed the need for social support and a more collaborative role with health professionals. Wong and Lok, (2002) interviewed 12 family members through in-depth interviews about family communication patterns. The participants noted that parental commitment, knowledge of mental illness, and the ability to recognize positive attributes in caregiving were associated with positive communication patterns.

Milliken, (2001), using a qualitative grounded theory method, interviewed 29 parent caregivers of adults with schizophrenia, and documented the need for recognition

of parental rights. Rungreangkulkig and Chesela, (2001) used a phenomenological approach with in-depth interviews to culturally explore the beliefs of 12 mothers from Thailand providing care for their adult children with schizophrenia. The mothers practiced Thumjai, which is defined in English as acceptance and obligation (Rungreangkulkig & Chesela, 2001), to respond to their children's symptoms.

Other studies have also identified but have not literally defined caregiver sustainability. Czuchta and McCay, (2001) using a descriptive method and questionnaires with a sample of 20 parents of individuals with schizophrenia, identified the need of enfranchisement as their child developed into adulthood, and the recognition of parental rights in assuming responsibility for the care of their child. Hines-Martin, (1998) used an ethnographic study with a purposive sample size of 16 African American participants to discuss the environmental context of caring severely mentally ill adults.

To place caring in a cultural context, Leininger's model was used as the theoretical construct. The author utilized interviews, participant observation, historical records, and artifacts to investigate the African American caregiving experience and context of care. Religion, support groups, and the police were described as useful community assets in carrying out the caregiving role (Hines-Martin, 1998). The study also highlighted the importance of health care professionals' possessing the necessary skills useful in the identification of needs; resources, strengths, barriers to, and facilitators of care (Hines-Martin, 1998).

A descriptive method was utilized by Karanci, (1995) using semi-structured

questions to interview 65 family members. The participants identified professional helpfulness as interest and support for their relative. Yamashita, (1996) used in-depth interviews to describe caregiving. Fourteen family members reported a closer relationship by supporting each other in caregiving and mothers who worked full-time quit their jobs or reduced their status to part-time.

Schizophrenia, the Caregiver, and the Lived Experience

Research employing interpretive methodologies related to caring for a family member diagnosed with schizophrenia is few in numbers (Milliken & Northcutt, 2003). Initially, numerous studies placed the blame on the family for the member's pathology and the entire family unit was viewed as dysfunctional (Lidz, Cornelison, Fleck, & Terry, 1957). The lived experience of the caregiver requires precise interventions in the achievement of coping strategies that are necessary in the transformation of adaptation to resilience (Carpenter, Goulet, Lalonde, & Renaud, 1992). Previous research studies have attempted to measure family caregivers' coping strategies and the relationship to burden or the negative aspects (Mannion, 1996; Stuckey, Neuendorfer, & Smyth, 1996). Two categories of stressors are applied to the process of coping with mental illness Normative stressors involve transitions throughout the life cycle as family relationships change and family members grow and develop. Catastrophic stressors strike at family members suddenly and overwhelm their ability to cope (McCubbin & Figley, 1983).

Chang and Horrocks, (2006), using the hermeneutic phenomenological approach to guide their research and the philosophical underpinning of Heidegger, explored the

lived experiences of Chinese family caregivers in Malaysia providing care for relatives with severe and persistent mental illness. Using qualitative study methodologies, they collected data through in-depth interviews with 19 Chinese caregivers. The researchers noted that inadequate coping skills of the caregiver were related to increased in-patient hospitalization of the schizophrenic patient, often leading to caregiver burden. They discovered the emergent themes of managing, enduring, and the surviving the day-day experiences (Chang & Horrocks, 2006).

Brady (2004) used a qualitative method, through individual interviews with 14 family members and 6 members diagnosed with schizophrenia, to construct a family portrait based on identified themes. Commonalities of family experiences were noted such as loss, uncertainty, sacrifice, misunderstanding, and enduring and escalating difficulties by recreating social roles.

Bland and Darlington, (2002) explored the importance and meaning of hope for family members of people with mental illness. The authors used 18 focused in-depth interviews with 16 family members who were treated for a severe mental illness.

In summary, the literature review was indicative of the difficulty experienced by some informal caregivers', who were unable to incorporate positive coping behaviors in the midst of serious life challenges, and those who were resilient in the face of adversity. While many informal caregivers are resilient in adapting positive coping mechanisms, many are emotionally and physically drained by the day to day responsibility of caring for a chronically mentally ill family member.

Howard (1998) used a naturalistic inquiry approach to investigate the experience of fathers of adult children with schizophrenia, exploring the extent to which they engaged in caregiving. Cross-sectional data were gathered from 12 fathers over a 2-year period. An interview guide developed by the author and an instrument designed for theme refinement guided in-depth explorations of caregiving experiences, theme extrapolation, and theme refinement. Data were collected via taped interviews and analysis used the constant-comparative method. Three themes explained the extent to which these fathers engaged in caregiving: involvement in care, unresolved issues, and severity of the event. Findings indicated that the caregiving event was prolonged and on-going.

Ryan (1993), through a qualitative descriptive study attempted to gain a greater understanding of the experience of living with schizophrenic adult children. Ethnographic interviews were used to understand the world view of five mothers with adult schizophrenic children living in their homes. Emerging from the study as the overall theme was a lifetime of mothering consisting of two elements, disruption and loss (Ryan, 1993). The mother's relation with the child and her own life were experienced through disruption. Two dimensions of loss evolved from a lifetime of mothering; loss of the child's ability to lead a normal life, and the subsequent loss of freedom by the mother, due to the numerous peaks and valleys associated with the chronicity of schizophrenia.

Tuck, duMont, Evans, and Shupe, (1997), documented the experience of caring for an adult child diagnosed with schizophrenia. This qualitative study used phenomenological methodology to interview nine primary caregivers to discover the

structure of the lived experience. Eight themes emerged from the interpreted narratives: The Temporal Life World; Struggling to reframe events as normal, seeking help, transformation of the loved child, living with changing levels of home, endless caring, gathering meaning, and preserving the self. The results of the study revealed that the diagnosis of schizophrenia in a child is experienced by the caregiver as a destructive force that interrupts changes the usual family life trajectory (Tuck et al., 1997).

Summary

The preceding literature review is indicative of the large amount of literature available on caregiver burden, coping strategies, and the outcomes of their use. It also demonstrates the paucity of nursing literature focusing specifically on the disease process of schizophrenia and its relationship to the actual lived experience of the caregiver. Absent from this review was a systematic situational exploration into the individual lives of caregivers providing care for their family member.

The section on schizophrenia and sustainability indicates that a large amount of literature is focused on the stressors and subsequent coping responses. One study did provide documentation on investigating the families' perception of their everyday life of caring for a family member diagnosed with schizophrenia. However, absent was an exploration of caregiver's ability to stay the course while surviving, or sustaining the caregiver role.

This review highlights the need for exploration into the subjective experience of living with a family member diagnosed with schizophrenia over a period of time. Studies

have focused on the management of the disease process, rather than the similarities and differences that describe the unique features of caring for a family member diagnosed with schizophrenia on a full-time basis. This study gave impetus to the need for the textual interpretation of the caregivers' story and their lived experiences. While the qualitative and quantitative studies discussed the extrinsic factors of caregiving, the present study explored both intrinsic and extrinsic factors.

CHAPTER III

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

The research design utilized for this hermeneutic phenomenological study was based on narrative interviews, using an interpretive method created by the philosopher Ricoeur. This method uses the dialectic movement of the whole, and parts of the text in arriving at the truth between understanding and explaining (Ricoeur, 1976). This method provided the connection between the guiding framework for the study and the process of data analysis.

Setting

Interviews were conducted in the homes of NAMI (National Alliance on Mental Illness) Gulf Coast members who are informal caregivers to family members diagnosed with schizophrenia. NAMI is the nation's largest grassroots mental health organization specifically dedicated to improving the lives of persons living with serious mental illness and their families. Participants resided in a large urban city or in surrounding small towns in Texas.

Participants

The purposive sample consisted of participants who were informal caregivers providing care to family members diagnosed with schizophrenia. To meet Inclusion criteria, participants were 21 years and older, English-speaking, and the primary caretakers of a family member diagnosed with schizophrenia after in-patient

hospitalization. Participants were recruited using flyers (Appendix A), postings in the NAMI newsletter, and announcements in NAMI meetings. During NAMI meetings any study related questions from perspective participants were addressed. All participants were afforded the opportunity to voluntarily participate in the study, and a time and place was agreed upon for the interview. Recruitment continued until data saturation was reached. Participants from the pilot study ($n = 3$) were included in the final sample size ($n = 14$) for final data analysis.

Protection of Human Subjects

Prior to the collection of any research data, the researcher obtained approval from the Institutional Review Board at Texas Woman's University. Before the first interview, participants provided informed consent to participate in the study and consent to be voice recorded (Appendices B and C). Each participant was also provided with an overview the study's purpose and proposed outcome via a study script (Appendix D).

File folders were numbered in sequential order of participant's interview, and contained the necessary consents, and completed demographic information tools and transcripts of the interview.

Data Collection

A semi-structured interview guide was designed, and used by the researcher to elicit discussion from the participants about the actual lived experience of providing care to family members diagnosed with schizophrenia. The interviewer/researcher (psychiatric clinician) facilitated the interview process. Two grand tour questions (Tell me what is like to care for your family member diagnosed with schizophrenia and what this

experience means to you? and How have you dealt with crisis in caring for your family member diagnosed with schizophrenia?) were used in the study (Appendix E). A demographic data form was used to capture age, sex, race, marital status, living arrangements, work status, and educational level of the research participant (Appendix F) and their family member diagnosed with schizophrenia (Appendix G). Additionally, the participant was asked to provide demographic information related to the year their family member was diagnosed with schizophrenia.

Face to face interviews occurred in the participant's home, to provide a natural setting for the interview. Interviews were recorded using digital recorders and field notes were completed after each interview. Audiotapes, digital recorders, transcription notes, and analysis of data were retained in a locked file in the private home office of the principal investigator for the duration of research period. Code numbers replaced all identifiable participant information on transcribed data.

Data Analysis

Results of the demographic information were statistically analyzed using frequencies, measures of central tendency and measures of spread to determine sample characteristics of the caregiver and the family member with schizophrenia. The phenomenological-hermeneutic method explicated by Ricoeur was used to interpret and analyze the narrative text of the interviews.

The analytic process revolved around the concept of understanding and explanation leading to a subjective description of the participant's lived experience. In interpreting the messages behind the text, the narratives were scrutinized for the

contextual features of their experiences, non-verbal reflections, and for an opening into the closed world of the informal caretaker. Lindseth and Norberg's (2004), three step method inspired by Ricoeur was employed.

In the interpretation of the message, a naïve reading occurred in step one and voice recordings were listened to several times and the transcribed texts read multiple times to grasp the whole lived experience of the caregiver. After reading and re-reading the texts for clarity, concept maps were constructed for each text in preparation of the second step of structural analysis. This part of the analysis enabled the researcher to closely examine the texts for explanations, and formulate preliminary meaning units associated with the phenomena. These meaning units were reduced to sub-themes which evolved and changed several times during the analysis process. Prior to the last analysis follow up calls were made to all participants to validate the initial data. Variants in individual availability and locations across the Gulf Coast area made it unfeasible for face to face follow up. The last step involved the actual interpretation of the text as a whole, and is the understanding phase of the analysis. A hermeneutic circle was formed after a comprehensive understanding of the texts was reached through saturation. The findings included the critical pre-understanding of the researcher as a psychiatric clinician, and the final themes, which will be presented in the results (Edwall, Hellstrom, Ohrn, & Danielson, 2008).

Anatomy of Theme Building

The process of theme building began with the researcher reading, interpreting and reviewing the text as visualized in figure one.

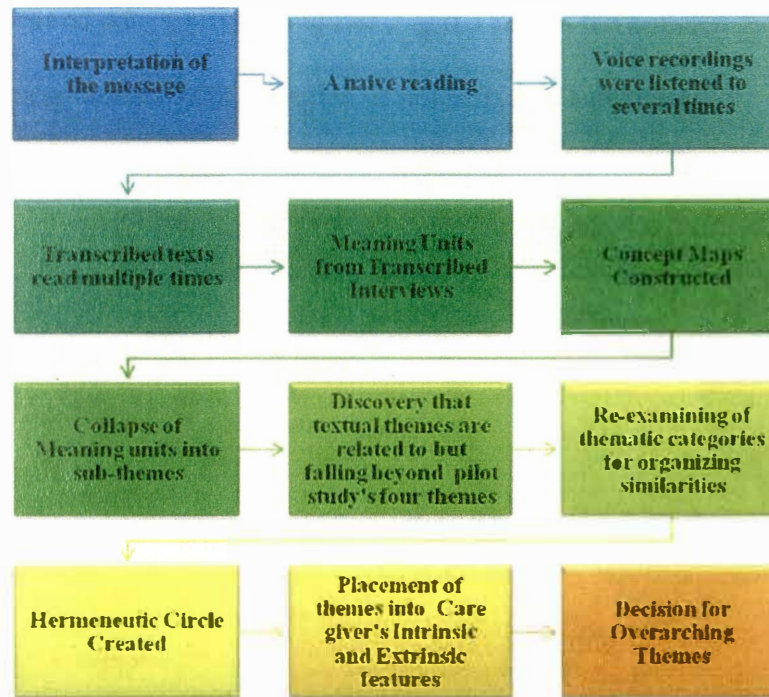


Figure 1. Process of Developing Themes From Text

Meaning units were teased from the caregiver transcripts and concept maps were formulated to envision the relationships in the text. The meaning units were then collapsed into subthemes which were examined for organizing similarities. The study also found that themes tended to either emanate from within the care giver (intrinsic) or from without the care giver (extrinsic). These were labeled as intrinsic and extrinsic features. The subthemes were then placed into the two features. Decisions were then made and two overarching dichotomous themes were identified and labeled surviving and sustaining.

Daley (1996) ascribes to using concept maps in qualitative research as a vehicle to reduce text based data to a manageable form without losing the embedded meaning.

Additionally, as Daley suggests, concept maps help the researcher with transparency in

the process of data analysis. Figures 2 and 3 reveal the concept maps for the two overarching themes with a display of patterns and subthemes.

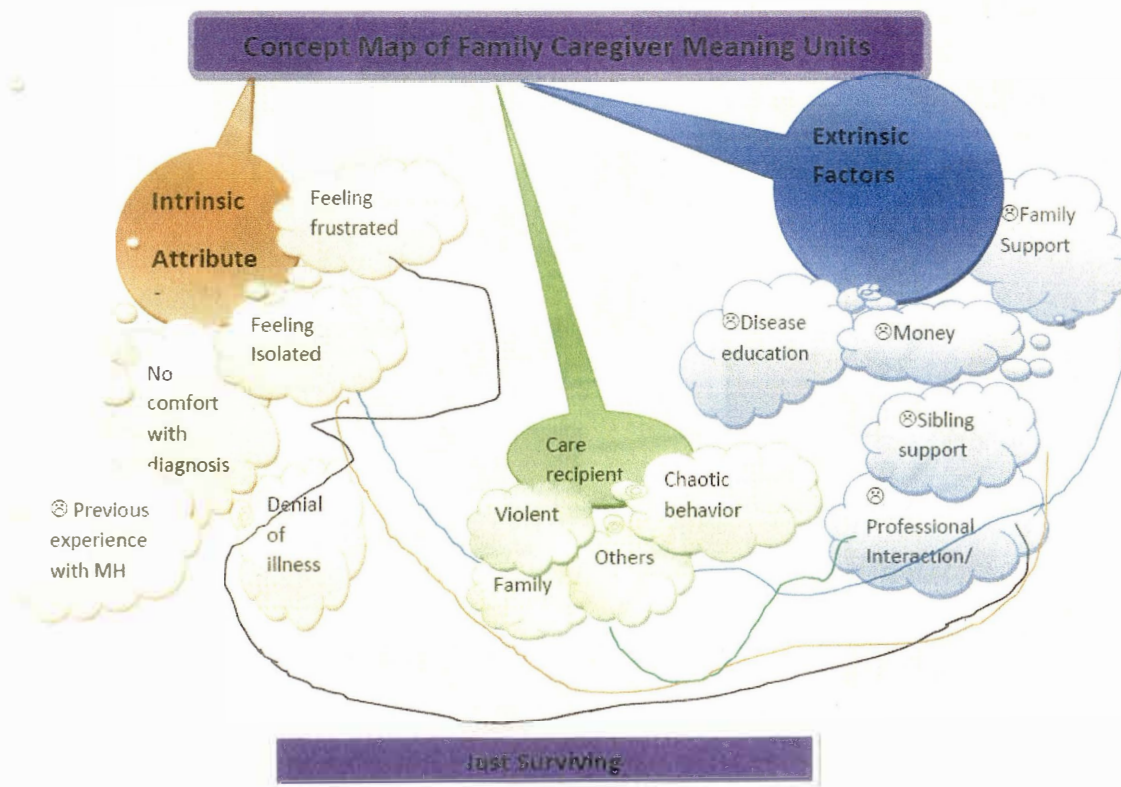


Figure 2. Example of Concept Map of Meaning Units

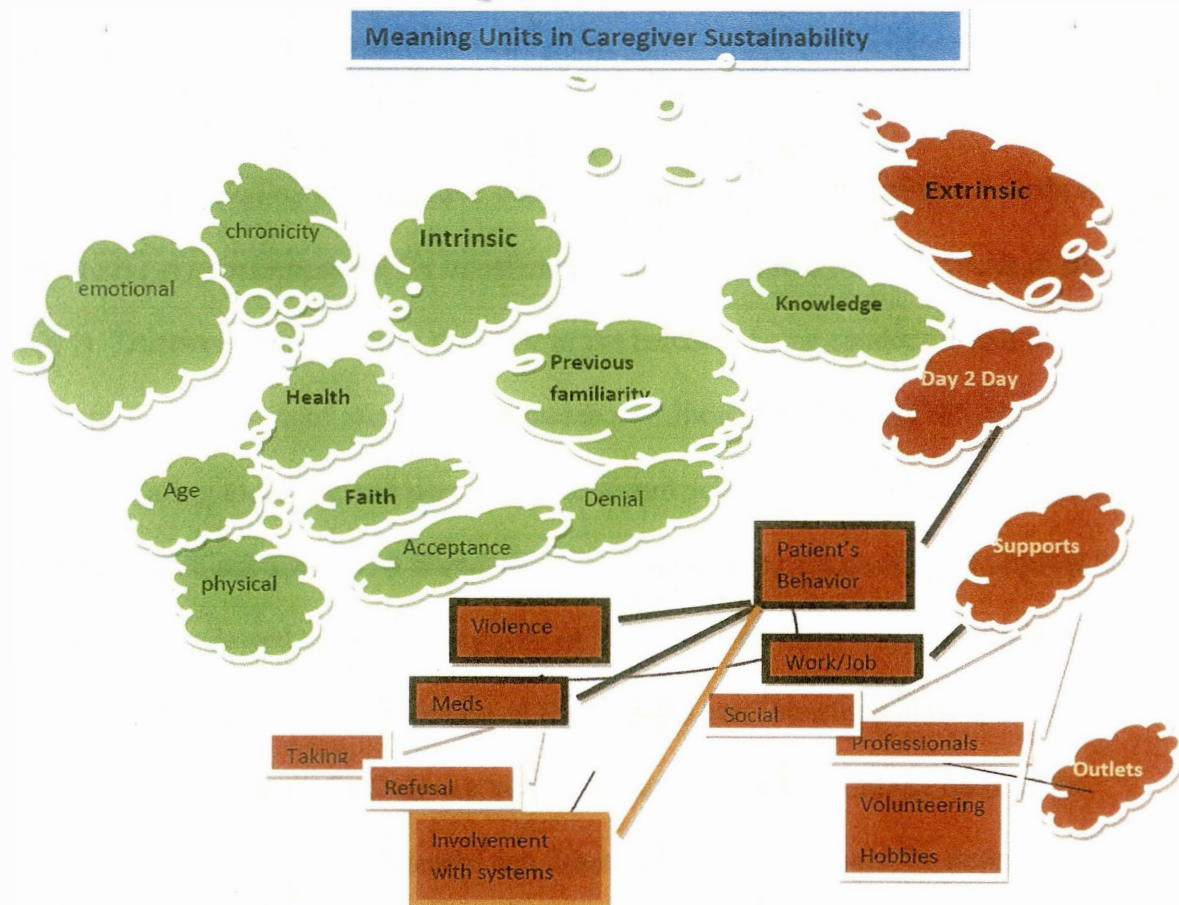


Figure 3. Concept Map of Meaning Units Discerned from Family Caregivers' Text

The researcher discerned that the subthemes fell into distinct groups; these groups looked at the same phenomena from different viewpoints. The study noted that some subthemes were more positive and sustaining while others were neutral or more negative with marks of surviving. Therefore, the same theme could have four dichotomous views, thus yielding four dichotomous themes. The overarching themes take into consideration the dual nature of the themes. The researcher noted that some parts of each theme pointed

to building or maintaining resources of the caregiver, other parts of the themes did not provide sustaining resources for the caregiver.

Scientific Rigor

Generalization of qualitative findings is not a goal of qualitative research; instead qualitative researchers strive for transferability of the research findings (Polit & Beck, 2004). Trustworthiness ensures the rigor of the research being conducted and is a necessary component of qualitative approaches. Lincoln and Guba (1985) discussed four factors relating to testing and rigor in conventional scientific research and “naturalistic” inquiry, which are useful as a framework for understanding the qualitative approach. Credibility is viewed as the primary goal of qualitative research and refers to how truthful particular findings and interpretation of the findings are. Transferability refers to how applicable the research findings are to another setting or group and the onus of the researcher is to provide sufficiently rich description to allow readers to determine applicability. Dependability refers to the stability of the data and whether the findings are consistent and reproducible. Confirmability or objectivity refers to how neutral the findings are in terms of whether they are reflective of the subjects and the inquiry, and not a product of the researcher's biases and prejudices.

In support of trustworthiness and to ensure that the findings were grounded in data, an audit trail consisting of field notes, original transcription prior to data reduction and analysis, and structuring of categories leading to final themes were maintained throughout the course of the study. To ensure accuracy in the data collected, the interviews were validated and reviewed by the investigator immediately after collection.

Credibility was supported by the use of prolonged engagement and problem engagement (Lincoln & Guba, 1985). The researcher delineated a sample size, determined by data saturation, to allow an adequate time span for collecting of data, critical analysis leading to understanding and explanation, and reporting of final data. The use of problem engagement (Lincoln & Guba, 1985), through initial phone contacts and subsequent interviews enabled the researcher to build both trust and rapport during the data collection period. Following the chosen methodology and framework helped ensure that the researcher focused not only on the scrutiny of content themes, but also exhibited a sense of real concern about the welfare of the participants (Lopez & Willis, 2004). The resulting outcome information is rich in descriptions useful to the further study of this phenomenon, and supports confirmability, and transferability.

Pilot Study

A qualitative phenomenological pilot study was conducted between January and May of 2008 to test the methodology, confirm the need for further research, and establish creditability for this study. Three primary caregivers to family members with schizophrenia were interviewed. In this limited undertaking an analysis of the narrative data resulted in five salient themes: the beginning, getting through the day, frustration with the system, isolation, and surviving informal caregiving.

The findings of the pilot study supported the need for a larger study to continue the expansion of knowledge related to the personal and collective experiences of caring for a family member with schizophrenia. A modification was made to descriptive language. Participants found the phrase “schizophrenic family member” demeaning to

their family members, stating that the phrase focused on the disease process rather than the individual. The phrase was removed from all dissertation study documents, and replaced by a “family member diagnosed with schizophrenia”. The methodology and theoretical framework were determined to be effective in guiding the study. To increase the transferability of the study results, the number of participants was expanded from 3 to 20 or until saturation was achieved.

CHAPTER IV

ANALYSIS OF DATA

The purpose of this hermeneutic phenomenological research study was to describe and construct the experiences of providing twenty-four hour care for a family member with schizophrenia. Semi-structured interviews were conducted, audio-taped, and transcribed from a purposive sample of primary caregivers who provide care for family members diagnosed with schizophrenia. Analytic documentation, conceived through naïve interpretation and structural analysis of the participants' spoken word and guided by the philosophical orientation of Ricoeur, provided answers to the research question: "What is the lived experience of caring for a family member with schizophrenia?" This chapter describes the participant sample and presents the findings of the study including an exhaustive description of the phenomenon studied.

Description of the Sample

The total sample of seventeen participants consisted of individuals 21 years and older who are the primary caretakers of a family member diagnosed with schizophrenia. All were members of the National Alliance for the Mentally Ill (NAMI) Gulf Coast Chapter. Spouses in three married couples were individually interviewed (6 participants) for this study. The overwhelming majority of the sample were married, Caucasian and female. Ages ranged from 52 - 81 ($M = 63.5$, $SD = 11.5$). Educational status ranged from some high school education to a PhD degree. Most provided full time care for the family

member with schizophrenia. Frequencies for the descriptive variables for the caregivers are detailed in Table 1.

Table 1

Frequencies for Participant Demographics

Variable	Frequency	Percentage
Gender		
Male	3	17.6
Female	14	82.4
Ethnicity		
Black	2	11.8
White	14	82.4
Multiracial	1	5.9
Marital Status		
Married	13	76.5
Divorced	3	17.6
Widowed	1	5.9
Education		
<12 yrs.	1	5.9
1-2yr. College	8	47.1
BS	5	29.4
High school	1	5.9
MS	1	5.9
PhD	1	5.9
Full Time Care		
Yes	13	76.5
No	4	23.5

The fourteen individuals receiving care ranged in age from 21- 60 ($M = 37.8$, $SD = 11.6$) and were predominantly unmarried, Caucasian, and male (Table 2). Their educational levels ranged from some high school to a masters degree. The living

arrangements for family members diagnosed with schizophrenia were varied and subject to change from month to month. The unpredictability of behaviors associated with the disease process was sometimes a determinant of where the care recipient would live. During the time span of this research study, four family members primary residence was at their parent's home, four lived alone, with three in an apartment, one in a trailer. All were subsidized by the caregiver. The remaining family members included one male who

Table 2

Frequencies for Demographics of Family Members With Schizophrenia

Variable	Frequency	Percentage
Gender		
Male	11	78.6
Female	3	21.4
Ethnicity		
Black	2	14.3
White	11	78.6
Other	1	7.1
Marital Status		
Married	13	92.9
Divorced	1	7.1
Living Arrangements		
Home with family member	4	28.6
Home alone	4	28.6
Home cohabitating	1	7.1
Other	5	35.7
Employment		
Part time	6	42.9
Disabled	5	35.7
Unemployed	3	21.4

was incarcerated and awaiting trial for murder, one living with a girlfriend, and five who were homeless or living in a personal care facility. Six family members were employed in part-time jobs ranging from grocery bagging to working in a gift shop for a minimum of 4 hours a day. Five family members were legally noted as disabled and three who were employed in the past, considered themselves unemployed (See Table 2 for frequencies).

Findings

The qualitative findings of the lived experience of caring for a family member diagnosed with schizophrenia are summarized with a description of patterns, themes, and subthemes. Ricoeur's (1976), philosophical assumption that the lived experience will always remain in the private domain of the participant, but the meaning, through the hermeneutic interpretation of the researcher, can be shared publicly is supported in this study. He further notes that the constructive phase of the interpretation relies heavily on clues in the transcribed text (1974). The interpretive meanings are a direct result of the participant's spoken word. A three step method formulated by Lindseth and Norberg (2004), and based on the theoretical constructs of Ricoeur allowed the researcher to freely interpret the text, grasp and understand the meaning, and coherently present the results of the data in this study.

Two patterns- intrinsic and extrinsic emerged from the analysis process. These two patterns intersected with overarching themes of surviving and sustaining that formed a continuum representing degrees of coping with mental illness. Four dichotomous sub-themes: Beginnings/Settling In; Getting Through the Day/ Disruption;

Isolation/Inclusion; Frustration/Satisfaction fit within the context of the patterns and overarching themes. Each of these components will be examined in detail in this chapter.

Intrinsic and Extrinsic Patterns

Two patterns emerging from the text analysis were labeled intrinsic and extrinsic. These two patterns were important in terms of their intersection not only with the overarching themes of surviving and sustaining the caregiving role over time as well as with the dichotomous themes. An intrinsic feature is a self-asset of the family caregiver while an extrinsic feature is a varying property that is outside of the family caregiver and depends on a relationship with others. For example, the belief that finding and reading as much as possible about schizophrenia will help was an intrinsic self-asset feature of a caregiver, while readily available information about schizophrenia, is an extrinsic feature of the caregiver's lived experience. Intrinsic aspects included spirituality, outside activities, felt support, knowledge of disease process, and past experience with the mental health system. Some extrinsic factors encompassed stigma, reaction of others, and acceptance.

The analysis process revealed dichotomous rather than singular themes. The four dichotomous themes are represented by the caregiver's ability to cycle back and forth through the over-arching themes, surviving and sustainability. In explaining the dichotomy of sustainable caregiving, the caregiver experiences at any given time on a continuum, opposing factors (four dichotomous themes) that form a relationship between the two overarching themes.

Overarching Themes

One overarching theme, sustainability, represents the caregiver role as sustained by effectively managing the day to day responsibilities of their own lives while dealing with the chaotic existence of schizophrenia, without depleting their own human, social, economic, and environmental resources. Sustainable caregiving represents the capacity of caregivers to stay the course of meeting the present needs of care recipients without compromising the ability of those same caregivers to meet their own present and future needs. Sustainability is about the quality and other intangible non-physical aspects of life, with focus placed on maintaining the standard of caregiving while simultaneously improving their quality of life. Family caregivers validated that even at the expense of their past standard of living; quality of life can be achieved.

For caregivers in the study, surviving is staying alive to take care of their family member diagnosed with schizophrenia, and having the will to go on during unpredictable exacerbations. Surviving is the realization that a crisis could occur and not knowing how to handle it. In the context of surviving and sustaining in this study, surviving is enduring the day to day disruptions in their lives, and suffering through initial denial of the diagnosis.

Dichotomous Themes

Within the continuum of sustainability versus surviving, of four salient dichotomous themes emerged, these include: Beginning/Settling In; Getting Through the Day; /Disruption; Isolation/Inclusion; Frustration/Satisfaction.

Theme 1: The Beginning/Settling In

Caregiver participants, who were all caring for family members with schizophrenia, assumed the role of primary caregiver by virtue of parental relationship. All of the caregivers had relationships with their family members prior to the development, diagnosis and awareness of the disease process. Initial experiences of living with a family member diagnosed with schizophrenia and their first encounters with the mental health system were difficult. Many family members were misdiagnosed as conduct disorders, learning disabilities, or routine adolescent angst. While misdiagnosis was occurring, caregivers were dealing with episodic and unpredictable behavior that is prevalent with schizophrenia. The majority of study participants had no previous experience with mental health system and lacked education about the disease process.

Participants shared their initial experiences with schizophrenia and the mental health care system. One mother shared her initial experience with the mental healthcare system when her son begins to exhibit signs of schizophrenia.

I spent three minutes with this social worker at _____ Hospital. We were struggling with him just to be average. I saw school counselors and psychiatrists and they said as little as possible. This needy child was not diagnosed and all we could do was blame everything on learning disabilities and childhood depression. It was small, medium, and large crises which grew worse for this early teen. He soon had a girlfriend diagnosed with schizophrenia, we were two elderly people, so we had two patients to care for since they were together day and night. He became more and more out of control; he would not come out of the room. He

would like to sleep with us at night and was lost. As a teenager he began to hear voices and kept them a secret. I had no knowledge of this disease and only minimum contact with the mental health system.

Another participant describes her experiences with initial diagnosis on a Sunday afternoon in an emergency department. While initial care was given – very little support was offered in the way of long term management.

When the first break came I called a little emergency room in Alvin, I said I have this child who does not know who I am, and they said don't stop here Mama we can't help you, go to Houston, don't stop here you will be wasting your time. So on a cold Friday afternoon in January, they sent us home with a very psychotic young man for the week-end, it was a horrible. I had this psychotic young man and no clue as to what had happened to him. Sunday afternoon they called and asked us to come in, I know it couldn't be good. We went in and the Doctor said the drug screens were fine; your son has a mental illness. I said what's that, tell me more, and he said we'll treat this like a broken leg except it's a broken brain. They gave me some medicine and said sometimes it works, and sometimes it doesn't. The visit ended with good-bye; that was my education and the start of absolute hell nightmare.

Even mental health agencies lacked the capacity to effectively assist family caregivers. A single mother who was new to Texas and Houston voiced her frustration about the lack of help provided during a call to a mental health agency...

Just like any parent, I had my hopes and dreams. I knew he had learning disabilities, but not schizophrenia! Living with someone who has rages and doesn't remember the rages is hard. I remember calling for help after arriving from Chicago, and the lady said in Texas no one wants to acknowledge that their child has a mental illness; they would rather call it bad behavior. I did whatever, I could, cleaned house, paid for medicines whatever it took; babysitting, working a full-time job but there's something wrong with the system in Texas.

Many participants initially thought of schizophrenia as a "one time thing", and in one way or another attempted to deny the illness, but eventually "settled in" with the unpredictability of the disease. However, the desire for normalcy still remained. One shared her tearful thoughts of wanting her child to be normal...

It could be worse. It could have been another disease. I thought she would be normal, go to prom but she was not. I no longer know what normal is. "What about a cure? In the beginning I could not say the word mental illness.

Another parent whose child is now 41 years old and has been diagnosed with schizophrenia for 25 years verbalizes...

In the beginning when he was first diagnosed we were like this was going to be a onetime thing and that he was going to be in the 25% or 10% or whatever it is to where he would have his normal episode and everything was going to be ok. I took him to Dr. _____; I know he was going to be the one that cured him! I knew if I found the right doctor and right place he was going to be cured! It took

the first relapse for me to realize that this was not going to happen, and that's a real devastating thing to happen after that first major relapse.

In keeping with the dichotomy of this theme many began to "settle in" and live with the idea of their family member having a disease with no foreseeable cure. Settling in consisted of dealing with crisis situations without over-reacting, accepting the long term implications of caring for a family member diagnosed with schizophrenia, and the finality of the disease process. Several caregivers shared...

I don't get excited when there is a crisis anymore; I just do what I can do. We learned that we can't control him. All we can do is call the authorities and get the help we need.

Another participant shared her thoughts on the reality of settling in...

I now look at schizophrenia as coming in and going out. As long as she is on the recovering side and working its ok, but when she hits a bump, it does not mean I won't have another time to face the same thing. I said that's fine, but I always need to know if this comes again, what shall I do?

I know that I would not be able to do anything better since there still is not any legal ways of taking of it but I have to at least keep track that she's ok. She's been at it long enough (schizophrenia) now, I think that maybe we will go for a while but I'm not really positive, I always ready if we have to face it again.

Three participants' through their narratives captured the essence of settling in. "I accepted what was, and then I began to take these lemons that had been thrown my direction".

The second participant noted...

I've learned patience that I have to be tolerant of a lot of things, you have to be complete, and you have to be understanding and forgiving. Although it's not always easy, I've learned to live with his illness.

The last participant summed up the lived experience of settling in...

This will never go away. I know we will live with this, so we will just try to do everything we can. She doesn't realize this, I don't think any child realizes what their parents do and there are so few of us who have legal guardians involved.

Theme 2: Getting Through the Day/ Disruption

Once family members were diagnosed – caregivers were in the position of living from day to day – providing care. Caregivers were completely involved and totally responsible for the day to day care of their family member, whether they lived in or out of their homes. They were generally responsible for personal hygiene, medication compliance, and shelter. Getting through the day caregivers endured poor hygiene, physical assault, and unexpected bizarre behaviors. One mother noted...

Disasters and illness are my life. He fights with his father and I am in the middle all the time. It's one crisis after another. I hear him talking to the voices, I know he's suffering, please forgive me for saying this; sometimes I think maybe his death would be better than suffering.

Everyday trouble was often times the norm rather than the exception. Even the smallest details of day to day life became a process of follow up. Getting through the day for this parent meant...

Living with him from then on [following diagnosis] was expecting trouble every day. The hardest thing was to fight with no medication which was impossible, so we became his watcher, often twenty-four-seven. I became the number one watcher, and my husband number two caregiver. He does not want to do the smallest things in the house. Flushing the toilet is a good example, my son did not want to flush the toilet. He does not want to take a bath, does not want to work. Yes he can get small part time job, but he probably won't. Will I wash his clothes, flush the toilet for him, and pay his way for the rest of my life?

Violence towards caregivers is not a positive symptom of schizophrenia but occurs in conjunction with hallucinations, delusions, preoccupations & jumbled thoughts. Caregivers are often on the receiving end of physically aggressive behavior, live with the uncertainty of when the next attack will occur, and are fearful in their own homes. Violence was an everyday occurrence in this participant's home...

You can't get him out of the house or room. For a while he did not come out of the room for a year. I have to work and I'm afraid of what I might come home to every day. He was angry every day, and I was pushed around and shoved around all the time. I went to work black and blue every day.

Violence was intense. One mother, while sobbing uncontrollably stated...

He punched me in the face and he punched his sister in the face. I don't know who he is anymore. We didn't think it was mental illness. We thought he was on something, because he punched me really bad, it took months to get me out of the

house and in the mean time he was out smoking marijuana with the boys. He turned our house into a war zone.

Relationships were affected by daily caregiving. One participant talked about living with her son and the possibility of losing her marriage because of his illness and resulting inability to maintain activities of daily living...

He lives in his room, we clean it up every week but it returns to the same pigsty week after week. Asking him to take a bath becomes a battle.

We provide all his daily necessities: food, clothing, even cigarettes and he doesn't like the generic brands. My husband has no patience; he's tired of living with the stench and the filth. I try to run interference in keeping the room clean, he's my child, and I love him. It's like going into the twilight zone. My entire house is pristine until you reach his bedroom; the smell erodes the entire house and it's as if a cloud of dirt lingers on the ceiling. My husband and I have been married for thirty five years, but I will not put my child in a personal care home. He'll [husband] probably leave me soon.

Getting through the day was not without constant and permanent disruptions to their lives. Caregivers were faced with depression, suicidal ideations, police encounters, denial of illness by spouses in the marriage, and divorce after one spouse, usually the husband, could not, or simply refused to deal with the rigors of caring for their family member diagnosed with schizophrenia on a daily basis. Many found themselves not living the retirement life they envisioned before their family member's diagnosis. The meaning structure of this theme is clearly evident in their collectively shared experiences.

Despair resulted in depression precipitated by caring for family members diagnosed with schizophrenia. In lives already devastated by a catastrophic disease, depression was an added disruption in caregiver lives:

I'm still dealing with my depression; I have been placed on different medications. Six months after it happened, I was ready to put _____ in a car, close the garage, start the car and just both of us would die, he would just sleep and not know what was going on. I worried I would die and he would not, or he would die and I would not. There are problems but I get through the day because of him. My son keeps me going because no one can step up and say don't worry _____. I would take care of him if anything happens.

One mother shared her feelings of depression and the constant disruption in her life brought on by the symptoms of schizophrenia...

I suffer from depression myself. I would never leave the house, I didn't get to sleep. I would sit in the sun room and think about nothing but what was going in _____ room. He was walking in the house; I listened while he was talking to the voices, listening to him scream at the voices in the bathroom and wandering what will happen next.

Caregiver depression intensified an already difficult situation. One mother shared her escalating feelings of depression and how her family member's diagnosis of schizophrenia affected the entire family...

I was getting more and more depressed about the whole thing, the way my life went down the tubes. My entire family and our lives were paced in jeopardy because of this illness.

All married participants spoke about relationships with their spouse and how their relationships were tested during their many years of caring for a family member diagnosed with schizophrenia. Two husbands survived and sustained through the many years of exacerbations, medication non-compliance, and the day to day complexities associated with their role of caregiving. “So we don’t always agree on how to handle his situations or how to help him with situations. We have had our ups and downs, but we always had each other”.

Relationships sometimes played a key role in the ability to provide care by having a team approach to care provision. One husband spoke about the importance of having each other while caring for their son... “My wife and I have worked as a team which has helped a lot. We talked about this earlier on and said we needed to stick together and be a united front with him”.

Alternatively, caregiving was sometimes a key reason for ending a relationship. The end of marriage for two participants’ came when they were faced with the decision of remaining with their spouses or relinquishing their caregiver roles...

His dad wouldn’t accept the illness, so finally after thirty-two years I had to divorce him. It was a mutual decision, he wanted out and I could not see anything getting better. He wanted to leave when _____ got sick before, he blamed me for

causing the illness. My husband would never let go of that! He would not accept the illness, he never really accepted _____

Rather than abandon her son, one mother made the decision that her caregiving role superseded her role as a wife... "It took away my husband, he did not have an interest, and he did not want to talk about it. There was a gap because my son was going to be number one".

Police became a familiar occurrence in getting through the day - disrupting the peace and sanctity of caregiver's homes. In getting through their day, this disruption was usually unplanned, violent, and did not always end with an empathetic ear from the police officer. Fathers in the study appeared to have the least patience in dealing with these instances. They loved their children but placed more emphasis on this disruption in getting through the day than their female partners. Men were also more likely to engage in physical altercations with their family members than their female counterparts. A male, one of three interviewed separately from their wives stated...

When she is not on her medicine the least thing will set her off. I told the _____ Police that I was going to put a sign in front of my house saying patrol car parking only because it was ridiculous it was on the average every day, sometimes two or three times a day, because of something she did not like that I did or she did not like something _____ did. One policeman came here and he was an older fellow, he had a sister or mother that was Bipolar. He looked me in the eyes and said kick her out of the house. I said I can't do that, I said if I do, she would walk out in my front flowerbed, and pick up some of those rocks, and start

knocking out all of the windows in the house. I started looking at him and said that's easy for you to say, it's my daughter not yours, it's true; it's easy to give that advice.

Rules for engaging with a child's violent behavior were learned. This father noted...

I guess I'm a little harder than my wife when it comes to dealing with his behavior. We went through times when he was a teenager, and we thought it was rebellion. I lost my cool once and I hit him and after that he attacked me. So he went to school and they had to turn in what had gone on in to the authorities. It was more or less I found out he could attack me all he wants, but I can't touch him.

While loving their children equally, the mothers' in the study appeared more tolerant of the often unpredictable and disruptive behavior. Mother's were concerned about the outcomes of calling police...

He's my child, I'm his mother, I will not call the Police, and I've seen what happens on TV. Yes, he scares me, threatens me and once, he hit me. I know he's sick, I know what kind of person he was before the illness.

This mother realized...

My daughter has rages, and the mental health police had to come and get her. Thank goodness they were not the police. I did not know what police officers do to the mentally ill. I read everything I could, I know they shoot them in the street; they have no idea of what mental illness is in Houston. I have accepted this quietly, I live day by day.

Theme 3: Isolation/Inclusion

Caregivers experienced isolation generated by their constant involvement in providing care, the individual life changing experience of caregiving, and their perceived feelings of powerlessness in dealing with the unpredictability of schizophrenia. These factors were coupled with the sense of other people pulling away from them because of the stigma associated with mental illness. All of the participants described their feelings of isolation from the mental health system, friends, family, places of employment, and the everyday activities of living a productive life. Two participants' shared their feelings of isolation after encounters with the mental health system...

When he was first diagnosed the doctor did not have much time, he shared about 10 to 15 minutes with us but then I was still alone. I had nobody; it was nobody in Alvin, nobody in Houston. Nobody had answers, nobody really cared to listen.

The second woman remarked...

He was discharged from _____ Hospital after two days. We were alone and were blocked from receiving any information about his care. He was self-medicating with opiates, and we had already experienced his violent and erratic behavior before he left home. Nobody called to say he was being discharged, we were forced back into the cage of our lives; alone, vulnerable, and no support from those we thought would help.

Participants' also shared their thoughts about losing friends, family, and the lack of understanding about their family member's illness in their workplace...

Nothing but isolation and loneliness for us, we began to spend day after day looking over him, supervising him, sitting with him following up on him, in other words intensive care. We isolated ourselves; we dropped out of church activities and what little friends we had were gone. This took over our lives from then on. The difficulty of living with schizophrenia providing care for a family member, and the attached stigma associated with the disease, isolated many participants' from their immediate family and past social circles. In talking about her feelings of isolation, a mother shared...

It made me feel alone, I felt like people were pulling away from me because they did not understand. My daughter says her brother is dead to her. When you have a daughter who says I don't care, he's not my problem, he's your son and you handle it, you feel very much alone. I shared with my neighbor across the street, who was good friend of mine for years about _____ problems that has since moved. She said, oh dear, he is like the boy next door to you, he will come out the house with a gun and shoot us all down dead. I have two kids and I don't want them shot.

Feelings of isolation did not end at home as one father noted when he spoke about his treatment at work after co-workers learned of his son's diagnosis...

There was very little understanding at work. They knew about _____ illness but no one spoke of it. I sat in my little cubicle feeling I was a small pea in the middle of a big football field. I often worried if they felt as if schizophrenia was

something to catch. My supervisors had very little understanding and did not want to learn.

Another father failed to advance in his chosen career because of his son's illness...

I was up for a promotion in my department and I didn't get it. The supervisor told me, how can you supervise if you can't control your own son? From then on at work, I was marooned on an island with no one to save me.

Participants spoke of the isolation they felt from friends, family, and work. They felt isolated from their past, and what they thought would be their future. Finding others like themselves, caregivers to family members diagnosed with schizophrenia found feelings of inclusion even if it was not within the social circles they were once in, or the past closeness of their nuclear family. Two caregivers spoke of their feelings of inclusion that ran perpendicular to their feelings of isolation. "Sometimes I feel alone in this but I felt a part of something with NAMI; I learned from other parents, they understood what I was going through".

Isolation from others also involved isolation from other children who did not have mental illness. As one participant explains – inclusion did not necessarily mean her immediate family...

My other children did not want to come to our house for the holidays, they were afraid of my son; they saw people with mental illness in the movies. They did not know how to support me, and I did not know how to tell them I needed what I needed. I'm trying to educate them slowly, they still want to come home, we meet them out. We are still without outside company most of the time but seeing my

children makes me think of all the good times we had together before _____
was diagnosed.

Some participants have made peace with their feelings of isolation and embraced inclusion with a new social circle...

I have made my peace with the loss of friends and family. I daydream about the past times but I know they are gone. We'll never have the same circle of friends, we're alone, and we're not. I meet with this consumer group, they are diagnosed with schizophrenia like _____, we meet sometimes for lunch on Saturdays, and I talk to the parents too. They began to trust me and talk to me a little bit about what they are going through. The families talk about being alone, we are and we aren't.

Theme 4: Frustration/Satisfaction

Caregivers experienced not only an on-going frustration with the mental health system but also spoke in very vivid and descriptive term the frustration of caregiving without adequate support systems. This frustration was generated by the lack of understanding about their role as the primary caregiver, lack of both information and resources for caregiver, and the overall ineffectiveness of mental healthcare in the state of Texas. Fragmentation of care often meant starting over with each new provider – often times cutting the caregiver out of the loop when decisions were being made. An example of the feelings of extreme frustration is exemplified by one woman's remark....

When we took _____ to _____, there we would have to go through the same story even though it was the same hospital. The doctors would not

communicate with us. The doctor wanted to send him to Austin without us knowing about it that was before the privacy laws came out. The doctor was making a report to the court and thought it was the first time he got sick. The doctor had all of the incorrect information, I had to interrupt and say I'm _____ mother, he's been sick since he was fourteen, and he has been refusing the medicine because of side effects. I have no voice, and yet I responsible for him, I know all of the history because I've lived it. If he's really sick, I am always afraid and frustrated if he decides that they can't talk to me.

Frustration was also experienced due to lack of support from health care professionals as exemplified by the following narrative by a mother ...

You do not get it for a long time, and you put your thoughts and experiences together and you are so uninformed. At times I felt like I had this person diagnosed with let's say cancer and I am home treating this patient. If my son had epilepsy, doctors would be all over my son. There would be lots of sympathy, support, and information, there is no comparison. You get little support and little or no understanding of medications, treatments, boundaries and everything you can think of. It was constant stress worry, and not knowing what to expect this week or the next week. I never got to see one social worker at a fine hospital in Houston, he never returned my call. No one shows an interest in having effective caregivers. Yes, what we get is caring is not my job, my job is to give medications.

The incidents leading to feelings of frustration may have varied, but the feelings of frustration rang true, even for this participant...

One of the worst parts was not being able to help him and knowing you wanted help but just did not know how. He finally went to jail for assaulting me. Even when he was at _____ I did not feel that they gave me anything valuable or tangible to help me. I'm frustrated that I can't afford to put him on my health insurance plan, so I have him on a gold card which does not allow me to have flexible appointments. I'm pretty sure he's going to relapse on his medication, so I don't know if I'm going to be prepared, things are good for now. Most of all it's just frustration, the lack of resources that's not there.

For one participant questions about the care of her son led to her own annoyance and the following response...

One time I was told by a doctor, if you don't like our services you can take your son home. _____ was sick and psychotic, and the hospital rules were that you had to go to the quiet room and they would bring big strong people from all over the hospital, they hated doing it too. They would hold him down and take his clothes off, I knew they had to do their jobs, but to hold him down like that in front of me was cruel. I think my greatest frustration is that there is no support for the caregiver. They just held him down with no explanation before or after.

One mother discussed her frustration with the lack of educational resources to support caregivers in understanding how to handle their family member during crisis situations...

We lived on the water and we had a big porch, it was very peaceful but when these dogs came out barking, he would say they are praising the Lord. There are very few resources, we need education on how to deescalate situations. Before NAMI, I would say shut up and eat, but after I learned about schizophrenia, I would say let's take our plates and go inside.

Another parent mother verbalized...

When you have people challenging what they are seeing and they see him for a few minutes or for a short period of time when he's in treatment, it's very frustrating. It's been a challenge all these years.

Participants were also completely frustrated with the delivery of mental health care in Texas. They were disgusted with the short length of stays, the non-existence of continuity of care, and funding for other catastrophic illnesses but not schizophrenia. One participant shared her experience about hospital length of stays...

We drove out of town after he was admitted to the hospital, and after we returned in three days, he was waiting on our front porch. He told us he was given medications (for three days) and prescriptions for two weeks on the day of discharge and told to call his clinic. My son was psychotic when we admitted him to the hospital and no better when we found him on the porch. "He was still in the crisis mode, so it was back to the EC at _____

A father shared his thoughts about the lack of continuity of care...

Do you want to spend this money on hospital bills or do you want some kind of system that will help these people live independently? There is no other system

out there, not in Texas. No, there is no continuity of care; they would rather spend money putting them in the hospital for three to four days.

A male participant offered the following about funding for mental health...

Have you ever heard of a telethon for schizophrenia or any other mental illness? I look at TV, see all the stars begging for this disease or another and I wonder why not us? There's this big mountain, and family members are digging with spoons.

Along with their feelings of frustration caregivers were able to express some things that provided periods of satisfaction in their caregiving role. Satisfaction was experienced through the intrinsic factors of spirituality, outside activities, felt support, and increased knowledge of the disease process. Two participants spoke of their contentment in the midst of their on-going frustrations:

I swear to God I would have been in the psych ward myself if it had not been for NAMI. I would have not been any help to _____ if it had not been for those NAMI families, if I had no one else, I had them. Once I learned about the hallucinations and delusions, God, it made our lives so much easier. You only know what you know and what you don't know, you don't know how to react; I reacted to everything!

Another participant noted...

When I was educated, and I was able to educate those family members and friends, it made everything so much better. There are two families that we occasionally go out to eat with, and they would bring my child into the

conversation. They don't have a family member with the illness but they volunteer for NAMI all of the time.

Satisfaction for this participant meant just getting out of the house...

Getting out the house has made me happy, even on the dark days. Well, I don't know if this is silly or not, but my job has helped me survive _____. I've been on my job for 35 years and I have received tremendous support. I don't go around talking about this all the time but I'm so devoted to that job; I have a wonderful job and fabulous people to work with. My job gives me a life beyond caring for _____ and it's a source of great satisfaction for me.

For participants' satisfaction also was experienced through spirituality. One participant shared...

My belief in God has helped me survive my only child's diagnosis of schizophrenia, the ups and downs of the disease, and now (tearful), his being in jail charged with murder. I can't talk about it because it hasn't gone to trial yet.

Though all of their frustrations, an abiding faith in God served as a source of satisfaction and sustenance for most of the participants. One mother, whose son is in jail awaiting his trial for murder, tearfully shared the following...

I use to enjoy walking but not anymore, I have a male friend, but he's a simple man and doesn't understand any of this. My faith in God brings me joy in the face of all of this adversity.

The Sustainability Model of Caring for Family Members Diagnosed with Schizophrenia

Through interpreted narratives the researcher was able to formulate a model that succinctly describes the cyclic movement of the lived experience on a continuum of surviving and sustaining. Figure 4 illustrates the Sustainability Model of Caring for Family Members Diagnosed with Schizophrenia.

Themes are presented as segments of a circle representing caregiver's lived experience. The arrows centered in the segmented circle indicate a cyclic relationship between the themes. The descriptors intrinsic assets and extrinsic attributes which affect the caregiver represent ever present factors that influence the caregiver's positioning along the sustainability continuum. The caregiver sustainability is visualized as a continuum that moves the caregiver from mere surviving to the more salutagenic sustaining. Salutagenic sustaining is based on the work of Antonovsky, (1996), and acts as a precursor for health promotion that directs research and actions to encompass all caregivers wherever they are on the continuum. The caregiver survives the disruption, frustration, and isolation of their role but also on the same continuum experiences positive outcomes through intrinsic and extrinsic factors such as spirituality, and social networking through NAMI. In this concept, unsustainability is not seen as the obverse of sustainability as this would indicate death or abandonment of the role; instead survival is the continued existence of the perceived or very real possibility of not being able to meet the caregiver's future needs.

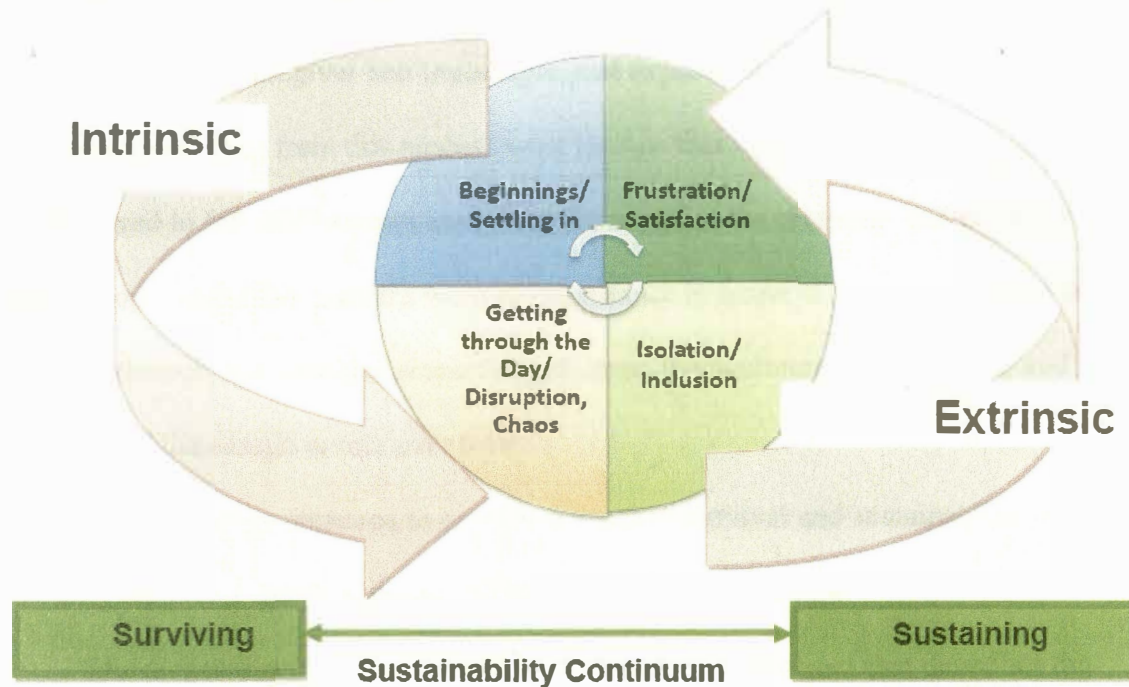


Figure 4. Sustainability Model of Caregiving to Family Members Diagnosed with Schizophrenia[®]

The study's findings presume there's a point at which caregivers' can both survive and sustain on a continuum in their role. They operate on a continuum that fluidly moves between intrinsic and extrinsic factors allows some measure of stability.

Summary

The purpose of this hermeneutic phenomenological research study was to describe and construct, through understanding, how family caregivers of family members diagnosed with schizophrenia, survived and sustained while caring for their family members diagnosed with schizophrenia. Analysis revealed two overarching dichotomous themes and four dichotomous subthemes.

The use of concept maps facilitated the exploration of meaning units as part of the analysis process of caregiver text transcripts, and exposed an aggregate of themes and subthemes. Emerging from this process were themes that were dichotomous in nature, but also appeared to fall into two patterns, those from within the caregiver and those factors from without. These two patterns were of importance in terms of their intersection not only with themes, but with the overarching themes; the continuum of surviving and sustaining of the caregiver role over time.

These intrinsic factors appeared to provide a sense of survival and sustainability in providing care for a family member diagnosed with schizophrenia.

The dichotomy of themes in this study provided a construct that describes the lived experience of these caregivers as a dynamic rather than a stable course of caregiving. During this cycle many of the participants were capable of sustaining and/or surviving through intrinsic and extrinsic patterns of denial, chaos, frustration with the lack of mental health resources, denial of their family's illness, support (personal and professional), and socioeconomic issues. One family member aptly defined the experience for all of the participants as a "constant roller coaster".

CHAPTER V

SUMMARY OF THE STUDY

This hermeneutic phenomenological study used participant narratives to describe and construct themes demonstrating, through understanding, how family caregivers have survived and sustained while caring for their family member diagnosed with schizophrenia. The philosophical underpinnings of Paul Ricoeur (1974), guided the researcher from transcribed texts of unstructured interviews to the interpretation of the actual lived and human experience of caring for a family member diagnosed with schizophrenia. The primary theoretical construct of this theory focuses on the textual interpretation of hermeneutics leading to a theory of interpretation that embraces language, reflection, understanding, and self (Geanellos, 2000). Data were analyzed using a three step phenomenological approach inspired by Ricoeur and formulated by Lindseth and Norberg, (2004).

This chapter provides a summary of the present study and a discussion of findings as they relate to caregiver research literature. From the research findings of this study, proposed practice interventions, limitations of study and recommendations for future research will be provided.

Summary

The purposive sample of seventeen participants consisted of individuals 21 years and older who are the primary caretakers of a family member diagnosed with schizophrenia.

All were members of the National Alliance for the Mentally Ill (NAMI) Gulf Coast Chapter. Spouses in three married couples were individually interviewed (6 participants) for this study. The overwhelming majority of the sample were married, Caucasian, and female. Educational status ranged from some high school education to a PhD degree.

Most provided full time care for the family member with schizophrenia.

Four dichotomous themes: Beginning/Settling In describes the caregiver's first encounters with the mental health system, their initial denial of the illness and settling in with the incurable nature of schizophrenia; Getting Through the Day/Disruption described the experience of living and or providing care to a family member diagnosed with schizophrenia on a day to day basis and the resulting disruptive forces brought into their lives by the illness; Isolation/Inclusion provides an understanding of the caregiver's isolation from the mental health system, friends, and their place of employment, and their search for inclusion in new social circles; and Frustration /Satisfaction was interpreted as the participants' perceived difficulty with the lack of understanding in their role as a primary caregiver and their ability to find satisfaction in intrinsic factors such as outside support.

Two overarching themes also emerged from the study's findings. The first, surviving represents the caregiver's attempt to successfully navigate through their caregiving role but failing to achieve stability and only survives through the disruption, frustration and isolation associated with caring for their family member diagnosed with schizophrenia. The second, sustainability represents the capacity of caregivers to stay the course of meeting the present needs of care recipients without compromising the ability

of those same caregivers to meet their own present and future needs. These dichotomous and overarching themes provided answers to the research question (What is the lived experience of caring for a family member diagnosed with schizophrenia) and provide an understanding of the actual lived experience of caring for a family member with schizophrenia.

Discussion of the Findings

It is a reasonable assumption that providing care for a severely mentally ill family member has been shaped by modern culture, however, the practical ways in which this care is delivered has not been well examined (Chesla, 1988, p. 167). A thorough literature review, quantitative or qualitative, to date has documented measures, and or interventions that actually define the necessary components of caregiver sustainability for those faced with caring for a family member diagnosed with schizophrenia. Researchers have not fully confirmed through the vehicle of lived experience, how caregivers have survived and sustained, rather than merely coped through years of chaotic care responsibilities.

The use of interpretive investigational methods demonstrates the complexity and variability of caring relations and caring practices for the chronically mentally ill (Chesla, 1988, p. 167). The voice of the lived experience is absent in many studies and interventions, and assumptions have been based on what researchers' suppose are sustaining factors for this population. In discussing the literature, it should be noted that only the findings from a few studies were consistent with the present findings (Chen & Greenberg, 2004; Karp & Tanarugsachock, 2000; Hines-Martin, 1998; Tuck, duMont,

Evans, & Shupe, (1997). The following documents the present study's findings as they relate to previous research.

Theme 1: The Beginning/Settling In

In this study, the dichotomous theme of Beginning/Settling In discussed the participants' initial contact with the mental health system and their initial denials of the illness. All of the participants in the study assumed the caregiving role by parentage and most had little or no experience in caring for an individual diagnosed with schizophrenia. The interpreted and analyzed narratives described settling in as facing the inevitable diagnosis of schizophrenia, the unpredictability of the symptoms associated with the disease process, and coming to terms with dealing with a disease with no foreseeable cure.

As noted earlier, Tuck, duMont, Evans, and Shupe, (1997), documented the experience of caring for an adult child diagnosed with schizophrenia. Using phenomenological methods the researcher interviewed nine primary caregivers to discover the structure of the lived experience. The results of the study revealed caregivers experience that the diagnosis of schizophrenia in a child as a destructive force that interrupts and changes the usual family life trajectory. Several themes were somewhat congruent with the analyzed findings in the present study. The first is the "temporal life world" (Tuck et.al, 1997), which draws a line of demarcation between before and after the diagnosis. In the present study this time span is described in the dichotomous themes of beginning, the period when the unpredictable behavior and manifestations of the disease process is given a name and the prognosis and settling in with the ensuing crisis

mode the family co-existed with on a daily basis. The Tuck study differed from the present study in that it described the participants' experience as a beginning, middle, no end, and static in its existence. Absent was the concept posited in this study of caregiving moving back and forth through a continuum of the overarching themes of surviving and sustaining.

Theme 2: Getting Through the Day/ Disruption

Caregivers in this study described their experiences of living and or providing care to a family member diagnosed with schizophrenia on a day to day basis. Their lived experiences included living with someone who completely ignored all of the activities of daily living, was non-compliant with and had exacerbations of their disease symptoms. Getting through the day also meant constant and permanent disruptions to their lives often leading to periods of permanent depression, violence inflicted by their family member, and marriages ending in divorce. Tuck et.al, (1997), also discussed the theme of "endless caring". This theme was described as the caregiver's continuous need to watch, protect, seek help, and sacrifice their personal needs. This theme in its interpretive form, exhibits the anxiety experienced by the caregiver in realizing that the family member is no longer capable of managing the activities of daily living. Findings from previous studies also included disruption in the lives of caregivers.

Other researchers found a relationship between negative family environments and care recipient relapse (Hooley, 2002; Weisman, Nuechterlein, Goldstein, & Snyder, 2000; King & Dixon, 1995; Stirling et al., 1993). Brady (2004) explored the painful memories of having been accused of causing schizophrenia in their children. Notable in

this study were the mothers' fears related to their own mortality and the fate of their sons after their death. The mothers worried about their sons' fates after their own deaths. Marital discord, divorce, and feeling trapped in an unhappy marriage were related to having adult offspring with schizophrenia (Brady, 2004).

Theme: 3 Isolation/Inclusion

Findings generated from the present study include that caregivers experiencing isolation from the mental health system, friends, and their place of employment. In keeping with the dichotomy of themes, their feelings of isolation ran along a continuum of feelings of inclusion. Although the inclusiveness of their nuclear family and past circles had disappeared, participants found feelings of inclusion from others experiencing the on-going drama of caring for a family member diagnosed with a severe mental illness and from their association with a support group. Previous research has also singularly discussed the caregivers' feelings of isolation and inclusion (Tuck, duMont, & Shupe, 1997; Brady, 2004; Chen & Greenberg, 2004).

Caregivers, including parents, spouses, and siblings, are often unable to deal with their own individual or family developmental needs because their lives revolve around the family with schizophrenia and the sequelae of the disease process. It has been documented in the literature that there is embarrassment experienced by parents and siblings because of the positive symptoms and unpredictable behaviors associated with the disease. These feelings of embarrassment lead to the avoidance of bringing visitors into the home and isolative behaviors (Brady, 2004; Espina, Ortego, Ochoa do Alda, & Gonzalez, 2003; Friedrich, Lively, & Buckwalter, 1999; Greenberg, Kim, & Greenley,

1997). Wintersteen and Rasmussen, (1997) explored the reactions of fathers' faced with the mental illness of an adult child. Results of the study found that fathers coping with the mental illness of an adult child exhibited emotional stress that was largely unrecognized and unacknowledged by mental health professionals. In addition, fathers tended to utilize more isolating strategies for coping with their adult child's mental illness.

Feelings of inclusion were discussed by Chen and Greenberg (2004), by examining caregiving gains as a result for caring for their relatives with schizophrenic spectrum disorders. Researchers documented prevalent caregiving gains as formal support from mental health professionals through collaborative information sharing, support group participation, and contributions from their diagnosed relative. Researchers in this and other studies documented the importance of inclusion. However, in other studies, themes were viewed as either / or rather than as dichotomies. Caregivers in the present study experienced isolation and inclusion on a continuous cycle with most surviving during the periods of isolation and sustaining through those periods of inclusion. This verbalized inclusion was to limited social circles that usually included family members experiencing the same rigors of caring for a family member with schizophrenia or a specific support group such as NAMI.

Theme 4: Frustration/Satisfaction

The dichotomous theme of frustration/satisfaction was interpreted as the participants' perceived difficulty with the lack of understanding in their role as a primary caregiver, lack of both information and resources for the caregiver and the overall ineffectiveness of the delivery of mental healthcare in the state of Texas. The findings

noted that while the participants experienced frustrations in their lives, they were able to find satisfaction in the intrinsic factors of spirituality, felt and outside support from a support group, and increased knowledge of the disease process of schizophrenia.

In meeting the demands of care, caregivers frequently complain about their frustration related to the lack of information about the family member's illness, the evolving changes in the disease process, and treatment outcomes. Karp and Tanarugsachock (2000) found that caregivers go through predictable phases throughout the illness of a chronic mental illness. The study found that caregivers' experienced early frustration when the family member is initially diagnosed which evolved into sadness and grief. Tuck, et al., (1997) described in the theme "seeking help" as the caregivers' desperate attempt to find someone who could provide an explanation and remedy for the disturbing behaviors of their child. In this study, parents described their frustration at the "inability of so-called experts to accurately diagnose the problem" (Tuck, et al., 1997, p. 121).

Doornbos (1997) found that caregivers struggled with burden, grief, and client symptomatology that subsequently led to a negative impact on their family as a unit. Facilitative attitudes, reliance on their faith, use of support groups, and increasing their knowledge of mental illness were expressed as coping mechanisms and facilitated the appearance of factors of satisfaction in their lives.

This research study resulted in an increased understanding and provided a larger view of the personal and collective experiences of caring for a family member with schizophrenia. Presently, most nursing research and interventions are designed, and

focused toward the care recipient rather than the caregiver. A new model of sustainability in caregiving provides a road map for understanding the continuum of surviving and sustaining through the roller coaster of cyclical exacerbations experienced by both the caregiver and family member. Interventions should be developed that decrease the frustration, disruption, isolation, and chaos that envelope the caregiver to family members diagnosed with schizophrenia.

Sustainability of caregiving is more than just the interconnectedness of the economy, society and the environment. Important though these are, they are largely only the external manifestations of sustainability. As a concept, ecological sustainability has captured imaginations of environmental and economic entities, however as a tangible and identifiable healthcare goal, it eludes us. Emphasis on the physical, the objective, and the rational sees only the external manifestations of caregiver sustainability. The internal manifestations of sustainability of the caregiver role are non-material, subjective, and experiential, and are often put to one side, since they are messy, interpretive, and time-consuming, the world of hermeneutics.

Sustainability however is more than a ‘thing’ to be measured, since it is about ecological integrity, quality of life, and transformation or transcendence. Health care scientists still have great difficulty in deriving indicators, because of intangible quality of life issues. Sustainable caregiving may be defined as the capacity of caregivers to stay the course of meeting the present needs of care recipients without compromising the ability of those same caregivers to meet their own present and future needs.

Finally, what can meaningfully be described as sustainable caregiving will depend on the ability to change the present mode of delivering care to the caregiver and their family. Caregivers should be afforded the privilege of sharing with the professional community, their individual stories related to the illness of their family members. Participants' in the present study were surprised that someone was interested in listening to their experiences for longer than ten minutes and were eager to share their thoughts, feelings and despair that had become their life. Rather than ask how we can measure caregiver sustainability, it may be more appropriate to ask how we as health care professionals measure up in being responsive to the real life experiences of caregivers.

Conclusions

Based on the findings of this study, the following conclusions were derived:

1. Caregiving is not static, it occurs on a continuum with periods of just getting through the day of unpredictable behavior and violence, feelings of depression; frustration with the present delivery of mental care; and settling in to the inevitability of the diagnosis and the fact that it is not going away; and finding satisfaction within the context of their role as caregiver.
2. Life stability is achieved by the caregiver within the context of intrinsic and extrinsic factors balancing on a continuum between survival and sustainability.
3. Inclusion in the care plan of their family member, clear and concise information and educational support based on individual experiences helps

provide a balance between the family member diagnosed with schizophrenia and the caregivers' perspective.

4. There is no specific timetable for cycling through the model of sustainability. Each caregiver moves through the model of sustainability - surviving or sustaining - according to their individual intrinsic and extrinsic attributes.

Implications

The implications of this study, based on the findings and conclusions drawn, include:

1. Collaboration of mental health care professionals and informal caregivers is essential in providing optimum care to individuals with schizophrenia.
2. The Caregiver Sustainability Model provides a strong platform for assessing the level of caregiver functionality on a continuum of factors. The use of the model should enable clinicians to implement individualized, and caregiver specific interventions rather than the “cookie cutter, all –in- one, or “one size fits all” intervention presently geared toward caregivers.
3. Health care policies and laws need to be revised to provide informal caregivers easier access to specific information regarding the treatment of a family member diagnosed with schizophrenia.

Recommendations for Further Study

Recommendations for further research include:

1. Additional phenomenological studies that will explore the implementation of sustainable prevention and intervention measures in populations other than those presented in this research effort.
2. Replication of this study using other ethnicities, age groups, and differing socioeconomic groups as participants could further broaden the understanding of the lived experience of caring for a family member diagnosed with schizophrenia.
3. Testing of the sustainability model in varied settings with varied populations.

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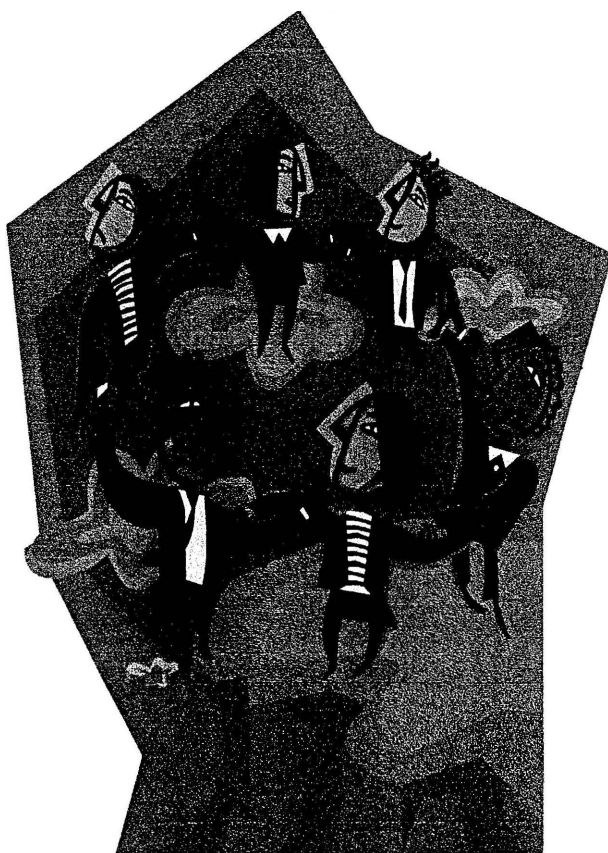
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APPENDIX A
Recruitment Flyer



**FOR MORE INFORMATION e-mail Anlee Evans at apsynurse@gmail.com
or contact at: 281-491-6421**

**TO HEAR ABOUT YOUR EXPERIENCES AS CARETAKERS OF FAMILY
MEMBERS WITH SCHIZOPHRENIA. RESEARCHER IS INTERESTED STUDY
PARTICIPANTS NEEDED FOR RESEARCH STUDY IN SPEAKING WITH ADULT
CARETAKERS 21 YEARS OR OLDER WITH THE PRIMARY RESPONSIBILITY OF
CARING FOR A FAMILY MEMBER WITH SCHIZOPHRENIA IN OR OUT THE HOME.**

APPENDIX B

Consent to Participate in Research

TEXAS WOMAN'S UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

Lived experiences of caring for a family member with schizophrenia

Investigator: Anlee Evans.....281/491/6421

Advisor: Rae Langford, Ed.D.....713/794-2393

Explanation and Purpose of the Research

You are being asked to participate in a research study for Anlee Evans's pilot study at Texas Woman's University. The purpose of this research is to understand the experience of taking care of a schizophrenic family member, and stayed the course while providing care for a family member with schizophrenia.

Research Procedures

For this study, the investigator will conduct face to face interviews with informal caregivers who are the primary caretakers for their family members with schizophrenia. This interview will be done in the privacy of your home or an alternate location agreed upon by you and the investigator. The PI will advise all study participants that they can break during or end the interview at any time. The PI will have a referral list of available resources on hand during each interview. If they feel the need to discuss their physical or emotional discomfort with a professional, the investigator will provide him/her with a referral list of names and phone numbers that they may use. You will be audiotaped during the face to face interview. The purpose of the audiotaping is to provide a transcription (of the information discussed in the interview and to assure the accuracy of the reporting of that information. Your maximum total time commitment in the study is estimated to be no more than two hours.

Potential Risks

Potential risks related to your participation in the study include interview or emotional fatigue during your interview. To avoid interview or emotional fatigue, you may take a break (or breaks) during the interview as needed. If you experience with self-disclosure secondary to grand tour questions, you may stop answering questions at any time. The PI will have a referral list of available resources on hand during each interview. If they feel the need to discuss their physical or emotional discomfort with a professional, the investigator will provide him/her with a referral list of names and phone numbers.

Another possible risk to you as a result of your participation in this study is release of confidential information. Audiotapes, digital recorders, transcription notes, and analysis of data will be retained in a locked file in the private home office or in locked file

cabinet in the office of the transcriptionist if used and accessible only to the principal investigator for the duration of research period. The tapes, digital media and transcription media will be erased and the hard copies of the transcriptions will be shredded within 5 years of completing the study. Face to face interviews will occur in the participant's home with his or her approval in the provision of providing natural setting for the interview. Code numbers will replace all identifiable participant information on transcribed data. All data will be kept in a locked filing cabinet, retrieved at the end of data entry, and destroyed by both the PI and transcriptionist, if one is used. Loss of your time could also be a possible risk. Prior to the interview the PI will establish a mutually agreed upon meeting time with you, be on time for scheduled interviews, and allow rescheduling if requested.

Lived experiences of caring for a family member with schizophrenia
Confidentiality will be protected to the extent that is allowed by law. The interview will take place in a private location agreed upon by you and the researcher. A code name, rather than your real name, will be used on the audiotape and transcription. Only the investigator, her advisor, and the transcriber will have access to the tapes. It is anticipated that the results of this study will be published in the investigator's thesis as well as in other research publications. However, no names or other identifying information will be included in any publication.

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participant Initials

Participation and Benefits

Your involvement in this research study is completely voluntary, and you may discontinue your participation in the study at any time without penalty. The only direct benefit of this study to you is that at the completion of the study a summary of the results will be mailed to you upon request.*

Questions Regarding the Study

If you have any questions about the research study you may ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at 713-794-2840 or via e-mail at IRB@twu.edu. You will be given a copy of this signed and dated consent form to keep.

Signature of Participant

Date

The above consent form was read, discussed, and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge of its contents.

Signature of Investigator

Date

* If you would like to receive a summary of the results of this study, please provide an address to which this summary should be sent.

APPENDIX C

Consent to Record Voice

TEXAS WOMAN'S UNIVERSITY

CONSENT TO RECORD VOICE

Lived Experiences of Caring for a Family Member with Schizophrenia

You consent for the recording of your voice by Anlee Evans, who is acting on this date under the authority of Texas Woman's University. It is understood that the material recorded today may be made available for educational, informational and/or research purposes, and you consent to such use.

Signature of Participant

Date

The above consent form was read, discussed, and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge of its contents.

Signature of Investigator

Date

APPENDIX D

Study Information Script

Texas Woman's University

Research Study Information Script

The Lived Experience of Caring for a Family Member with Schizophrenia

Lead Researcher: Anlee Evans MSN RN CNS

Doctoral Nursing Student at College of Nursing

Texas Woman's University – Houston Campus

Contact information: 281-491-6421

apsynurse@hotmail.com

- Hello, my name is Anlee Evans, I am a registered nurse and doctoral student at Texas Woman's University. I am conducting a research study to understand the experience of having the primary responsibility of caring for a schizophrenic family member living in or out of your home. Your responses during the interview will be audiotaped using a digital voice recorder and your words will be transcribed, which means your spoken word will be transferred to paper either by the interviewer or a paid transcriptionist, a professional who specializes in transferring your words to paper. Would you like to participate in this study?
- (If yes) Thank you, I will need your primary telephone number and an alternate phone number to reach you. The phone numbers will be destroyed at the end of your scheduled interviews. During this first meeting I will provide you with further information about the study and request that you sign two (2) consent forms. One form is consent to participate in the research study and the other is the consent to record your voice during the interview. After the written consents are obtained, you will be requested to complete two (2) questionnaires on both yourself and family member. It will take approximately 20 minutes of your time to complete demographic data which is information about you and your family member with schizophrenia. This information will include questions about age, gender, race, marital status, work status, education, and how many years your family member has been diagnosed with schizophrenia. After both consents are signed, we will begin our first interview next week. I will call you next week to schedule our first interview and at this time we can

discuss a time that is convenient for both you and I. The maximum commitment of your time will be no more than 2 hours Participation in this study is voluntary and there is no cost related to your participation. At any time during the study you may refuse or discontinue your involvement without penalty

APPENDIX E

Interview Questions

Semi-structured Interview Questions

Grand Tour Questions

- 1. Tell me what is like to care for your schizophrenic family member and what this experience means to you?**
- 2. How have you dealt with crisis in caring for your family member diagnosed with schizophrenia?**

APPENDIX F

Study Participant Demographic Information

APPENDIX G

Family Member Diagnosed with Schizophrenia Demographic Information Form

(Family Member diagnosed with Schizophrenia)

Age (Write in age of family member diagnosed with schizophrenia age) _____

Year diagnosed with schizophrenia _____

Sex

☐ Male = (1) ☐ Female = (2)

Race

☐ White = (1) ☐ Black = (2) ☐ Hispanic = (3) ☐ Asian = (4)

☐ American Indian = (5) ☐ Pacific Islander = (6) ☐ other = (7)

Marital Status

☐ Married = (1) ☐ Divorced = (2) ☐ Widowed = (3) ☐ Single = (4)

Living Arrangements

☐ Home Alone = (1)
☐ Home, Cohabiting = (2)
☐ Home with family member = (3)
☐ Other = (4)

Work Status

☐ Full-time = (1)
☐ Part-time = (2)
☐ Homemaker = (3)
☐ Unemployed = (4)
☐ Retired = (5)
☐ Disabled = (6)

Education Level

☐ < 10 years (= 1)
☐ 10 – 11 years (= 2)
☐ High School Diploma or GED (= 3)
☐ 2 years College (= 4)
☐ Bachelors Degree (= 5)
☐ Masters Degree (= 6)
☐ PhD / MD / JD (= 7)