A QUALITATIVE ANALYSIS OF CAREGIVING EXPERIENCES OF RURAL MOTHERS WITH AN ADULT CHILD WITH PSYCHIATRIC DISABILITY

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A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

Rehabilitation Counselor Education

2012

ABSTRACT

A QUALITATIVE ANALYSIS OF CAREGIVING EXPERIENCES OF RURAL MOTHERS WITH AN ADULT CHILD WITH PSYCHIATRIC DISABILITY

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A qualitative research study was conducted using in-depth phenomenology to answer the research question of interest in the proposed study, how do rural mothers who have an adult child with a psychiatric disability describe their caregiving experiences? Examining the experiences and factors contributing to choices, risks, effective coping and problem solving, and adaptation of mothers who are care providers to adult children with psychiatric disabilities is a salient rehabilitation issue. The potentially significant needs adult children may have throughout the life span can place a considerable burden on families, as they are the main support, and especially mothers, as about two thirds of family care comes from women (Gutierrez-Maldonado, Caqueo-Urizar, & Kavanagh, 2005). Women caregivers are at high risk for developing depressive disorders and experiencing a lower quality of life (Gutierrez-Maldonado et al., 2005; Zauszniewski, Bekhet, & Suresky, 2009). Along with community cultural factors such as values and expectations, and physical barriers such as lacking resources, mothers may become over stressed, depressed, and anxious, and they may experience loss of income, relationships and isolation. Such results can lead to their own medical and mental health concerns, make them unable to provide adequate care, and thus exacerbate the child's illness. A new model focusing on the influence of community and societal expectations was also introduced in this study. Information gathered from women caregivers was useful for better understanding the caregiving experiences of rural mothers who have an adult child with a psychiatric disability.

Interviews were conducted with eight women who were mothers of adult children with a psychiatric disability. While women often explained their caregiving experiences in negative terms, they also grew in beneficial ways. Through their caregiving, women became more educated, assertive, advocates, developed enriched relationships with others, and developed purpose in their caregiving experiences. The support women received from support groups or religious affiliations may have bolstered their ability to provide care, develop meaning, and serve as motivation to continue providing care.

Recommendations for rehabilitation and mental health professionals included the recognition and inclusion of family in the treatment process. Practitioners should assist the family to establish goals that focus on positive outcomes that make the family feel empowered, develop meaning in the caregiving experience, and to successfully adapt. Recommendations for researchers included the need for recognition of family experiences, benefits of support group involvement, women's perceptions of community and societal expectations, and how these perceptions influence caregivers and decisions they make. Additionally, there is limited research on what defines rural culture and its influence on choices women caregivers make. Future research should focus on the influence that culture has on the meaning and decision making process in caregiving. Research is also needed to examine caregiver support and benefits such as advocacy, empowerment and resiliency.

DEDICATION

This dissertation is dedicated to my parents for making me who I am, and to my sister, thank you for your inspiration.

ACKNOWLEDGEMENTS

I would like to express my deepest gratitude to my program advisor and dissertation chair, Dr. John Kosciulek, for your guidance and encouragement throughout my journey. I would like to thank all members of my dissertation committee, Dr. Barbara Ames, Dr. Elizabeth Heilman, and Dr. Michael Leahy. I am forever grateful to the support you have provided throughout this process. Special thanks to the women of NAMI and the other special women who let me into their lives for a short while. Without you, this project would not be possible. Finally, all my love to my husband, Jonathan. Thank you so much for taking this long and amazing adventure with me.

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CHAPTER 1
INTRODUCTION

About one in seventeen people live with a psychiatric disability (National Alliance on Mental Illness: NAMI, 2006), making it the second leading cause of disability for people ages 15 to 44 in the U.S. (*Scaling up care*, 2008). Most serious mental illnesses develop during the late teens and early twenties. Thus it is important to understand the needs of the family, especially mothers, as they are the first line of defense and the main source of support for an individual with a serious mental illness (Zauszniewski, Bekhet, & Suresky, 2009). Yet there is very little research on the experiences of mothers caring for adult children with psychiatric disabilities, especially those living in rural communities. Additionally, there is great disparity in the location of services throughout the U.S., and rural areas are dramatically underserved.

The purpose of this study is to explore the experiences of rural mothers of adult children with psychiatric disabilities through in-depth phenomenology. While a number of studies have explored these issues using concepts such as burden, coping and resiliency, few studies have researched family experiences more holistically. The theoretical framework selected for this research is based on the family stress theories. Given the complex interactions among multiple systems (caregivers, child with a serious mental illness, community, and cultural and societal resources and beliefs), this theoretical framework offers direction in addressing the experiences of mothers in caring for an adult child in a rural community.

While psychiatric disabilities represent only a small portion of the total general disability population, worldwide psychiatric disabilities are both costly and complex (*Scaling up care*, 2008; *What is psychiatric disability*, 2010). Serious mental illness can result in significant impairment in daily functioning by disrupting thinking, feelings, mood, relationships, and ability to cope. Such impairments can interfere significantly with the ability to participate in high school, postsecondary education, employment opportunities, and self-care. Individuals with serious mental illness face the highest under and unemployment as well as high out of labor force rates (OLF), and they have an inability to maintain employment, earn low pay (often near minimum wage), and live in poverty (Cook, 2006).

Statement and Significance of the Problem

Psychiatric disabilities affect five to seven percent of adults and five to nine percent of children in the U.S., resulting in high financial cost to the U.S. economy (*Achieving the promise*, 2002; NAMI, 2006). Each year, the U.S. experiences indirect economic costs at almost $80 billion. The majority of costs ($63 billion) is lost productivity as the result of illness, $12 billion due to in mortality (premature death), and about $4 billion in loss of productivity for incarceration and time and expense of caregivers (*Achieving the promise*, 2002). Social Security Administration (SSA) expenditures for people with psychiatric disabilities are substantial. Over the last 20 years, the number of Supplemental Security Income (SSI) beneficiaries with psychiatric disabilities has increased at a rate higher than total program growth. The WHO (2008) reported that from 1988 to 2001 alone, the number of SSI recipients with psychiatric disabilities more than tripled from 411,800 to 1.5 million (*Scaling up care,* 2008). Unfortunately, once individuals with psychiatric disabilities enter Social Security, few leave the system, remaining on the rolls longer than any other disability group.

The Independent Living (IL) movement and other grass roots advocacy groups spear headed deinstitutionalization in the 1960’s and ‘70’s, and the establishment of community care, with the Federal Government assuring that it would establish over 2000 community mental health centers around the U.S. to provide comprehensive services (*Achieving the promise,* 2002). Unfortunately, there was little accountability for community mental health agencies, resulting in significant gaps and fragmentation between service providers, and many agencies only took the most mild cases, known as *creaming* (*Achieving the promise,* 2002; Rosenheck, 2000). Beginning in the 1980's, community mental health agencies finally began to focus on providing care to those with severe mental illness. Today, however, many agencies now accept only the most severe cases after a number of hospitalizations, leaving significant gaps in service (Rosenheck, 2000) and forcing people to seek alternative means of service and reliance on the family to provide care with little support from professional services.

People with psychiatric disabilities face high under and unemployment, with unemployment rates ranging from 60-90%, the highest of any disability group (*Scaling up care*, 2008). Mental illness has a significant hindrance on education, at both the high school and post-secondary educational levels, with one half of all lifetime cases of mental illness beginning by age 14, and three fourths beginning by age 24 (NAMI, 2006). Teens and young adults with mental health conditions often have a difficult time with concentration, emotional regulation, short-term memory, socialization, and even hygiene. Such deficits hinder career exploration opportunities, lower self-esteem and identity, and lead to high dropout rates in high school and college, significantly limiting access to adequate employment, adequate shelter, proper nutrition, health care and services (only about 50% of young adults receive adequate mental health treatment), and lead to homelessness and isolation (Baron, & Salzer, 2002; Beveridge, Craddock, Liesener, Stapleton, Hershenson, 2002; NAMI, 2006). Furthermore, according to the U.S. Department of Education (1999), over 50% of teens and young adults with emotional impairments and mental health conditions drop out of high school, the highest dropout rate of any disability group.

With the rise of the independent living movement, along with the closing of psychiatric institutions and limited resources, care for people with psychiatric disabilities has increasingly fallen to families, affecting the whole family unit and causing substantial stress. Today, one to two thirds of people with psychiatric disabilities live with family members (Zauszniewsk et al., 2009), and half of those living with family receive the majority of their socialization from those family members (Kuipers, Bebbington, Dunn, Fowler, Freeman, et al., 2006). About two thirds of family care comes from women, who are at high risk for developing depressive disorders and experiencing a lower quality of life (QOL), compared to women who do not provide such care, or even to men who do care for a family member with mental illness (Gutierrez-Maldonado, Caqueo-Urizar, & Kavanagh, 2005; Zauszniewski, et al., 2009).

Families report high levels of stress in care provision. Families are often poorly equipped with resources and coping techniques necessary to handle stress associated with care, resulting in significant feelings of anxiety, frustration, anger, grief, and shame. Such feelings can create a downward spiral, further hampering the ability to provide proper care (Szmukler, Kuipers, Joyce, Harris, Leese et al., 2003). Additionally, individuals with psychiatric disabilities who live in high stress environments and lack support run significant risk of not adhering to medications, therapy, and services, and they experience significantly higher relapse rates (O’Connell, 2006).

The majority of mental health services are located in urban areas, with small and rural communities left to face significant short falls in service provision, lack of professionals, and needs being inadequately met or not met at all (Thomas, Ellis, Konrad, Holzer, & Morrisey, 2009). This leaves rural families to face significant challenges in providing care to loved ones with psychiatric disabilities, and in receiving care for themselves (Barbopoulos & Clark, 2003; Thomas et al., 2009). Families living in rural areas face unique difficulties in general compared to urban families, including limited accessibility and availability of physical, mental health, social services, and adequate health insurance. They must also deal with transportation issues and lack educational and employment opportunities (Barbopoulos & Clark, 2003; Evans & English, 2002; Hyjer Dyk, 2004; Lee, Anderson, Horowitz, & August, 2009). Limited available services can result in poverty, unemployment, high stress, poor physical and mental health, unhealthy physical and psychological living conditions, and potential for violence and crime (Evans & English, 2002). Distinct cultural values of rural areas also create barriers to service (Evans, Boxhill, & Pinkava, 2008). Rural people often are conservative, have a strong sense of self-reliance, are distrustful of outsiders, and have strong religious faith, a strong work ethic, and emphasis on the family (Barbopoulos & Clark, 2003). Such cultural values, along with physical barriers to services, can result in unwillingness to utilize community and health services, increasing the stigma and isolation of people who do use particular services and further exacerbating stress, poor health, poverty, and potential for abuse, neglect and violence (Evans et al., 2008).

Furthermore, as McCubbin and Patterson (1983) discussed, families rarely experience a single stressor, but instead experience multiple stressors. It is not so much the primary event (the family member's illness) that is most stressful, but the accumulation of stressors with which the family must deal (lacking service options, transportation difficulties, health insurance, income) (McCubbin & McCubbin, 1989a,b; McCubbin & Patterson, 1983). In rural communities, prior strains with which a family already lives are intensified when a new stressful event is added, such as a family member’s illness. Due to lacking resources and opportunities, rural families may face more stressful situations than their urban counterparts, significantly impeding an individual’s ability to care adequately for one’s self, and a parent’s ability to care for a child. A vicious cycle is thus created. Caregivers who experience such difficulties are less likely to be involved in family activities, provide less support, communicate less, and become depressed, increasing the risk for hostility and coercive, disengaged care practices (Lee et al., 2009).

Purpose of the Study

The purpose of this study was to explore the experiences of rural mothers of adult children with psychiatric disabilities through in-depth phenomenology. It was anticipated that this study would obtain data useful for better understanding the caregiving experiences of rural mothers who have an adult child with a psychiatric disability.

The experiences and factors contributing to choices, risks, effective coping and problem solving, and adaptation of mothers who are care providers to adult children with psychiatric disabilities is a salient rehabilitation issue. The potentially significant needs adult children may have throughout the life span can place a considerable burden on mothers. Along with community cultural factors such as values and expectations, and physical barriers such as lacking resources, mothers may become over stressed, depressed, and anxious, and they may experience loss of income, relationships and isolation. Such results can lead to their own medical and mental health concerns, make them unable to provide adequate care, and thus exacerbate the child’s illness. This study is to document experiences useful for better understanding the caregiving experiences of rural mothers who have an adult child with a psychiatric disability.

Research Question

The research question of interest in the proposed study is:

How do rural mothers who have an adult child with a psychiatric disability describe their caregiving experiences?

Definition of Terms

For this study it is assumed that participants will know what key terms mean to them. However, it is important to understand the traditional meanings of these terms, to help recognize when the terms themselves are used, and also when words, actions, and beliefs around these terms are used by participants. For example, a participant may repeatedly refer to a church she belongs to or an organization in which she is actively involved. This could be coded as her community without the participant directly saying that this is the community with which she most identifies. The following are key terms for this study and their definitions.

Caregiving

While it is important for women in this study to define the concept of caregiving for themselves, it is also necessary to understand a general definition of caregiving in order to recognize signs, particular actions, words, and feelings associated with caregiving and what caregiving means to mothers if they do not actively define it. In general, *caregiving* includes provision of services including meals, shopping and errands, housekeeping, transportation, and assistance with personal care including bathing and dressing (National Institutes of Health [NIH], 2006).

The quality of care also is important to understand. Shaffer, Dooley and Williamson (2007) defined quality of care, ranging from extremely high quality care to extremely low quality care. Extreme high quality care includes providing niceties beyond basic needs, and respecting a loved one’s values, wishes, and goals. Extreme low-quality care includes not meeting an individual’s needs, and not respecting values, wishes, and goals, which may lead to abuse or neglect.

For women caregivers, though, it is often more than just providing basic necessities to a loved one that defines caregiving. As in many cultures, women are expected to be the family care taker, and to value interpersonal relationships. Women are raised to believe that caregiving is just what they are “supposed” to do (Kim, Carver, Deci, & Kasser, 2008). Therefore, within the caregiving process, the quality of the relationship with the person receiving care is highly valued and influences the quality of care a person receives (Kim et al., 2008). Bunting (2001), in her study on the caregiving experiences of women with loved ones with AIDS, found that women in the meaning making process of caregiving focused on roles within the relationship. Women defined caregiving as “sustaining the relationship”. Women caregivers often felt the relationship with the loved one was constantly changing and had to be renegotiated. Due to this constant change in relationships, women felt that the demands in sustaining and maintaining a caregiving relationship with a loved one with a chronic illness were higher than in a non-caregiving relationship. Women provided loved ones with physical, psychological, and spiritual health and comfort. Caregiving also included maintaining meaningful relationships between the individual with the chronic illness and the other important people in his or her life, and managing conflicts and stress among self, the individual, and others. Balancing independence and distance also was important to caregivers. Women had to learn how to balance their own independence and learn how to keep appropriate distance to take care of themselves, as well as allow the loved one to make choices for his or her self.

Coping

Family stress theories rely on an understanding of the coping framework developed by Folkman and Lazarus (1988). According to Folkman and Lazarus (1988), *coping* “consists of cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 310). People use two types of coping: *problem-focused* or *emotion-focused*. Problem-focused coping has been found to be more effective in situations that can be changed, whereas emotion-focused coping is more effective for chronic and perceived unchangeable events (Webb, Pfeiffer, Mueser, Gladis, Mensch, DeGirolamo, Levinson, & 1998). To evaluate whether or not a situation is changeable, people use *cognitive appraisal* in three steps: (1) what of value is threatened by the stressor (primary appraisal), (2) whether the problem situation can be changed (secondary appraisal), and (3) whether the stressful event continues to be stressful after some environmental changes or coping efforts (reappraisal) (Webb et al., 1998).

Moos and Holahan (2007) further defined coping through *coping skills.* First, people either cope with situations by approaching them and making an effort to understand and fix the problem, or by avoiding the problem. Next, people respond using two methods: cognitive or behavioral response efforts. Combining these methods, people use four domains of coping: cognitive approach coping (e.g. search for meaning, logical analysis), behavioral approach coping (e.g. seeking guidance and support), cognitive avoidance coping (e.g. denial and avoidance), behavioral avoidance coping (e.g. seeking alternative rewards, emotional discharge)

(Moos & Holahan, 2007). Research has found that high levels of cognitive and behavioral approach coping are related to better adjustment and adaptation, and as psychiatric disability can be a life-long, chronic event with little recourse, seeking emotional support is found to be related to successful adjustment to a loved one's disability (Webb et al., 1998).

Community

Community is a term that has been debated for decades, and experts have been unable to develop a satisfactory definition (Cohen, 1985). At its most basic, Cohen (1985) defines community as a group of people who "have something in common with each other, which distinguishes them in a significant way from the members of other putative groups" (p. 12). He further defines community as "that entity to which one belongs, greater than kinship. . . It is the arena in which people acquire their most fundamental and most substantial experience of social life outside the confines of the home. In it they learn the meaning of kinship . . . they learn friendship. . . Community, therefore is where one learns and continues to practice how to be social" (p. 15). Community can include one's immediate home, the street in which person lives, a neighborhood block, a town, a faith-based group, or a group or organization in which a person is actively involved.

Crisis

Crisis is a period of tension brought about by stressors that are beyond a family's capabilities and that create significant imbalance and disorganization in a family (Kosciulek, 2004; Patterson, 2002). A crisis is viewed as a cross roads for a family, demanding major change in their structure and interaction patterns. As a crisis is often beyond a family's current coping and problem solving capabilities, learning and outside resources are important to be able to improve functioning and restore balance. Families who do not restore coherence may be trapped in a cycle of tension and chaos, completely impairing the family.

Culture

Culture is the integrated pattern of human knowledge, customary beliefs, and pattern of behaviors that a group of people share. Through these indicators a group can pass down knowledge to succeeding generations. Culture also includes social and gender roles, religious ideals, shared attitudes, values, goals, and practices that characterize a group (Merriam-Webster, 2011). Culture contains many communities. While communities themselves can appear highly different from one another, when looking at them from a larger stance, many similarities, shared beliefs, practices, and attitudes can be found. For instance, within rural culture there are many different communities. There is the farming community, which can be different across states, and highly different from non-farming rural communities. However, these communities share similar characteristics, such as trust, religious beliefs and poverty.

Family Resilience

While the purpose of this study is to learn about the experiences of mothers, it is important to recognize the family as a unit. If one close family member is not able to cope effectively with another family member's illness, then strain can be placed on the whole family and keep the mother and the family itself from adapting and becoming resilient.

Family resilience is defined as "characteristics, dimensions, and properties of families which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations" (McCubbin & McCubbin, 1989a). Resilience is the complex combination of problem-solving and coping strategies a family uses to prosper during stressful times. Families demonstrate their resiliency through positive, effective strategies such as seeking personal emotional or mental health support, making the most of community resources, and educating themselves in the child's condition and treatment regimen. Resilient families are able to be flexible and to acquire coping strategies to various situations in unique ways (Malia, 2006).

Society

Society is an enduring, large cooperating broad group whose members have developed organized patterns of behaviors, attitudes, and beliefs. People within a society have common traditions, institutions, collective activities and interests (Merriam-Webster, 2011). Society is the broadest category to contain people, made up of many different cultures. Across cultures similarities can be seen that make up a society and make it distinct from other societies.

Psychiatric Disability

The Center for Psychiatric Rehabilitation (*What is*, 2010) defines *psychiatric disability* as "when mental illness significantly interferes with the performance of major life activities, such as learning, working and communicating, among others." Psychiatric disabilities include bipolar disorder, schizophrenia, schizoaffective disorder, severe forms of major depression and anxiety, personality disorders, and PTSD (NAMI, 2006).

Rural

There are difficulties defining urban and rural areas (Gunderson, 2006; Isserman, 2005). Researchers and policy makers use two different federal systems to define urban and rural. The U.S. Census Bureau separates the nation into either urban or rural, defining urban as having a population density of at least 1000 people per square mile at the center and surrounding blocks, with an overall density of at least 500 people per square mile and a densely settled area with at least 50,000 people. Rural is defined by a population outside of urban areas with fewer than 2500 people (see Isserman (2005) for more complete details on how the U.S. Census Bureau separates territory). The Office of Management and Budget defines the nation by metropolitan, micropolitan, and noncore areas (Isserman, 2005). While the U.S. Census Bureau seeks to separate urban from rural, the OMB seeks to integrate the two. Urbanized areas with 50,000 or more residents meet the criteria for metropolitan; urban clusters of 10,000 to 49,000 are labeled micropolitan, and everything else is noncore or rural. The concern with current urban vs. rural definitions, according to Isserman (2005), is that counties and regions can include both urban and rural areas. Therefore, there can be many people who actually live in rural areas who are counted as living in urban areas, and urban people counted as living in rural areas. For example, the area surrounding the Grand Canyon is considered urban (Isserman, 2005). Researchers and policy makers may forget the distinction between urban and rural and misuse the defining criteria, thus running the significant risk of misallocating policies, funding, and services for those in serious need. For the purpose of this study, the U.S. Census Bureau definition will be used.

Stress

According to Malia (2006) *stress* is a complex process of an individual or family trying to keep emotional and physical balance of one’s self and the family unit. Stress includes the taxing demand itself that is causing stress, as well as the appraisal of the event as being stressful, or the recognition of the event and seeing it as being stressing. It is important to recognize that an event cannot be stressful unless the individual views it as such. Stressors, or the demands that can be stressful, are either internal or external (Malia, 2006). Internal stressors can be emotions such as worry, anxiety, or depression, and attitudes. External stressors could be physical resources, negative attitudes and behaviors of others, changes in a child’s mental/medical health, and ineffective coping and problem-solving strategies caregivers may use.

CHAPTER 2
LITERATURE REVIEW

The purpose of the proposed study is to understand the experiences of rural mothers in providing care to adult children with psychiatric disabilities. The research question is as follows: How do rural mothers with an adult child with a psychiatric disability describe their experiences? To address this purpose and research question, a literature review was conducted in the following primary domains: (a) what *psychiatric disability* is, (b) the effect of psychiatric disability on a family, (c) family coping and adjustment to psychiatric disability, (d) rural characteristics, (e) influence of culture, community, and society on mothers.

First, this literature review describes the psychosocial characteristics and barriers of psychiatric disability. Individuals with psychiatric disabilities demonstrate various functional changes in cognitive, emotional, and behavioral domains, depending on the severity of the illness (*Scaling up care*, 2008). Psychiatric disabilities interfere with the ability to learn and to function in family, employment, and within society. People with psychiatric disabilities face persistent disruptions in loss of gainful employment and loss of family income, in self-care and need for caregiving, in cost of treatment and medications, and in need and cost of social services. The literature review will demonstrate how the difficulties of behavior, emotions, and cognition can affect and disrupt an individual's social interactions, relationships, roles, and quality of life.

Second, the literature review informs the current investigation and provides a context for it by examining the effect psychiatric disability has on the family. Up to two-thirds of people with psychiatric disabilities live with family members (Zauszniewski et al., 2009), and most people living with that family receive the majority of their socialization from family members (Kuipers et al., 2006), creating a significant potential for stress on the family. Past research indicates that families experience a myriad of difficulties caring for a loved one with a serious mental illness, including stress, isolation, loss of income, and stigma in providing care (Szmukler et al., 2003).

Third, the literature review describes how families cope and adjust to providing care to a loved one with a psychiatric disability. Previous research indicates that families may often use negative coping and problem solving strategies (O'Connnell, 2006; Valiakalayil, Paulson, & Tibbo, 2004; Walton-Moss, Gerson, & Rose, 2005). Negative coping and problem solving skills lead to poor adjustment and adaptation for the family, and can significantly impair the individual’s ability to cope and recover, leading to a worsening of symptoms and a poorer outlook. A topic often ignored in the family research literature is a focus on resiliency, effective coping techniques and problem solving skills families use to provide care. The literature review will describe positive coping and problem solving techniques families use that lead to proper adjustment and bonadaptation.

The literature review then describes the characteristics of rural communities. Rural areas have their own culture, different from urbanized communities, and experience unique challenges and barriers (Harowski, Turner, LeVine, Schank, & Leichter, 2006). Recent literature suggests rural communities have distinct values that can affect the use of mental health services, including a strong sense of self-reliance, conservatism, distrust of outsiders, work ethic, and emphasis on the family. Physical barriers include accessibility and availability of services, ability to maintain privacy and confidentiality, and availability of income, health insurance, and poverty. Such characteristics and barriers can significantly hinder the use of mental health services and can increase likelihood of individual and family dysfunction.

Finally, it is vital to explore the experiences of women, because the majority of the time they are the primary caregivers to adult children with psychiatric disabilities (Gutierrez-Maldonado et al., 2005; Malacrida, 2009). The literature will inform the research regarding the influence of community, culture and society on mothers and the choices and risks they make in caring for a loved one with a psychiatric disability. The limited available research indicates women are expected to be the ideal, nurturing mother, always act selflessly, and be involved and available to their children (Malacrida, 2009).

What is Psychiatric Disability?

Definition

According to the Diagnostic and Statistical Manual-IV-TR (DSM; American Psychiatric Association, 2000), *mental illness* is defined as "a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual . . . and is associated with present stress. . . or disability. . . or with a significant increased risk of suffering" (p. xxxi). The Surgeon General (1990) further defined mental illness as "the term that refers collectively to all diagnosable mental disorders. Mental disorders are health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning" (*Mental health: A report*, p. 5). Mental illness can result in significant impairment in daily functioning by disrupting thinking, feelings, mood, relationships, and ability to cope. The most common forms of mental illness include anxiety, such as obsessive compulsive disorder (OCD) and post-traumatic stress disorder (PTSD), mood disorders including bipolar and major depression, and schizophrenia (Iyer, Rothmann, Vogler, Spaulding, 2005). The most *severe* or *serious mental illnesses* are known within rehabilitation as *psychiatric disabilities*. The Center for Psychiatric Rehabilitation (2010) defines psychiatric disability as "when mental illness significantly interferes with the performance of major life activities, such as learning, working and communicating, among others." Psychiatric disabilities include bipolar disorder I, schizophrenia, schizoaffective disorder, severe forms of major depression and anxiety, personality disorders, and PTSD (NAMI, 2006).

Prevalence of Psychiatric Disabilities

Mental illness can occur at any age and affects people from all walks of life and across race, religion, and income. Additionally, the same illness affects each person in a unique way, making these illnesses difficult to treat and requiring multiple interventions (Iyer et al., 2005). Some people experience mental illness over many years with severe symptoms, while others experience milder symptoms over a shorter duration. Symptoms can fluctuate in an unpredictable manner, despite treatment and medication consistency. Psychiatric disability can significantly affect emotions and cognition, hindering memory, concentration, and communication. Such hindrances can become significant barriers to education, relationships, independent living, and health care. While second only to cardiovascular disease worldwide, psychiatric disabilities are the leading cause of disability for people ages 15 to 44 in the U.S. (*Scaling up care*, 2008), and they make up a substantial portion of economic burden in post-modern countries such as the U.S. (Iyer et al., 2005).

Additional problems also exist in that people with psychiatric disabilities are at significant risk for other disorders (Iyer et al., 2005; NAMI, 2006; *Scaling up care*, 2008). Approximately 80% of people with psychiatric disabilities also present with coexisting problems including anxiety and depression or medical health conditions. Furthermore, over 30% have substance abuse issues, creating their own unique problems and significant treatment difficulties

(Iyer et al., 2005). People with psychiatric disabilities often have inadequate access to health care and insurance, creating a significant barrier to effective treatment and quality of life. Due to these factors, people with psychiatric disabilities live a shorter life span by about 25 years compared to the general population, largely due to what could be preventable measures (*Scaling up care*, 2008).

According to the National Alliance on Mental Illness (NAMI, 2006) one in four people (57.7 million people) has a mental health condition in any given year. About one in seventeen people live with a psychiatric disability such as schizophrenia, major depression, or bipolar disorder; about 2.5 million people in the U.S. have schizophrenia; 5.7 million have bipolar disorder; about 15 million have major depression; and 40 million have anxiety disorder including generalized anxiety disorder, panic disorder, OCD, PTSD, and phobias. While anxiety disorders are the most common form of mental illness in the U.S., major depression, according to the World Health Report (WHO), is the leading cause of disability in the U.S. and Canada, and by 2020 is expected to be the leading cause of disability worldwide *(Scaling up care*, 2008). Furthermore, mental illness has a significant correlation with substance abuse disorders, with over 5 million people in the U.S. having dual diagnosis (NAMI, 2006).

Teens and young adults diagnosed with mental health conditions often have a difficult time with concentration, emotional regulation, short-term memory, socialization, and even hygiene. Such deficits hinder career exploration opportunities for young adults, lower self-esteem and identity, and lead to high dropout rates in high school, at over 50% (the highest of any disability group), significantly limiting access to adequate employment (Baron, & Salzer, 2002; Beveridge et al., 2002; NAMI, 2006). Furthermore, within the juvenile justice system, at least 70% of youth experience at least one mental health condition, and at least 20% experience significant impairment (NAMI, 2006). Perhaps the most serious issue with teens and young adults experiencing mental illness is that only about 50% receive adequate mental health treatment (NAMI, 2006).

Fragmentation of the Mental Health System

The Independent Living (IL) movement led the charge towards deinstitutionalization in the 1960's and 1970's, in favor of establishing community care (*Achieving the promise*, 2002). Local community mental health programs, however, were often not able to move quickly enough or to gather enough funding to establish adequate services as people reentered the community. Furthermore, the federal and state governments did not hold local agencies accountable, creating huge gaps and fragmentation among service providers. To make matters worse, many agencies only took the mildest cases, known as creaming (*Achieving the promise*, 2002; Rosenheck, 2000). Where people needed the most assistance in housing, income support, employment, and structured activities, very little was done. The little community or national focus there was on caring for the mentally ill was on medication and stabilization of symptoms (Rosenheck, 2000).

Beginning in the 1980's, community mental health agencies did become more focused on providing care to those with severe mental illness, an approach which is still pursued today throughout the country. However, the pendulum may have now swung too far the other way, with many agencies now only accepting the most severe cases after a number of hospitalizations. Further, psychiatric admissions are now most often frequent yet brief stays, with individuals rapidly returning to the community. Such tactics unfortunately create a revolving door for people seeking services, not allowing families enough time to locate appropriate community services, and turning families into what Cook (1988) described as "de facto therapists."

Finally, with nationwide budget cuts, limited funds, and reduced services, there is little service provision available for those with milder symptoms, still leaving significant gaps in service, and leaving the majority of the burden on the shoulders of family members who often are ill-equipped (Rosenheck, 2000). Such current approaches in mental health care have unfortunately shifted a significant amount of care to other service realms, and many people have slipped through the cracks. According to Harcourt (2006), 16% of the jail and state prison population in the U.S. have mental illness. Furthermore, it appears that people with psychiatric disabilities who are imprisoned or who reside in nursing homes and other institutions such as group homes are reaching the same numbers as the height of institionalization of the mid 1950's (Harcourt, 2006). Additionally, while it is difficult to measure accurately, it is estimated that at least one quarter to one-third of the homeless in the U.S. have serious mental illness (*Access to disability*, 2004). Out of this population, about two-thirds have a co-occurring substance abuse problem (*Access to disability*, 2004).

Employment and Education

People with psychiatric disabilities face high under and unemployment, with unemployment rates ranging from 60-90%, the highest of any disability group (*Access to disability*, 2004; *Scaling up care*, 2008). The effect of mental illness on employment is most clearly seen in schizophrenia, with a host of potentially debilitating symptoms such as hallucinations, delusions, thought disorders, bizarre/disorganized behavior, paranoia, hostility, and lack of motivation (Baron, & Salzer, 2002). Employment rates for those with psychiatric disability range from 10-40% (*Access to disability*, 2004; *Scaling up care*, 2008). Those employed most often make a minimum wage (38% compared to 20% of people without disabilities), with no benefit coverage, and they often work only part-time (36% compared to those without disabilities at 16%) (*Scaling up care*, 2008).

Psychiatric disability has a significant effect on education, at both the high school and post-secondary educational levels. Teens and young adults with emotional impairments and mental health conditions in high school face the highest dropout rates of any disability group, at over 50% according to the US Department of Education (1999). However, the NHIS-D study found this percentage to be perhaps on the positive side. They found special education students with severe emotional disturbances to have only about a 40% graduation rate (*Scaling up care*, 2008). Through improved medical and societal treatment, and legislation such as the Individuals with Disabilities Educational Act (IDEA), more people with mental illness are able to attend college. However, despite assistance through campus disability and counseling centers, students face significantly high drop-out rates, reaching over 80% (Salzer, Wick, & Rogers, 2008). Those who do finish college are still not guaranteed adequate employment, with over 40% of people with psychiatric disabilities who have a college degree unemployed, compared to only about 13% of those without mental health conditions (*Scaling up care*, 2008). In the Employment Intervention Demonstration Program (EIDP) study, 70% of those with mental illness and a college degree earned less than $10 an hour at their highest level job, and over 50% worked only part-time (*Scaling up care*, 2008).

People with psychiatric disabilities face significant issues with proper medical and mental health treatment, access to adequate employment, and low educational attainment, and they are most likely to be on the Social Security disability roles (*Scaling up care*, 2008). This in turn means this population struggles with poverty, inadequate housing, nutrition, and substance abuse. People with psychiatric disabilities often have low self-efficacy, learned helplessness, and little community support, and they are often isolated from family and friends and face stigma (Wilton, 2004).

Prevalence of Poverty

People with disabilities are more likely to live in or near poverty (She & Livemore, 2009; Soffer, McDonald, & Blanck, 2010; Wilton, 2004). Over 55% of people with disabilities are "asset poor", meaning they are unable to meet their most basic needs, own their own home, or have adequate health insurance and finances to pay for necessary assistive technology (Soffer et al., 2010). She and Livemore (2009) found that poverty rates for people with disabilities were two to five times higher than the general population and represented 47% of those in poverty. Parish, Rose, and Andrews (2009) found that women with disabilities experienced food insecurity, housing instability, inadequate health care, and loss of phone service at rates higher than those among nondisabled women. They concluded that although hardship declines as income rises for all women, those with disabilities show worse outcomes at every income level and experience substantial levels of hardship well into the middle and upper income ranges.

Due to the high price of adequate health insurance, service provision, medication, and the loss of income caregivers can incur, parents can experience financial hardship and poverty. Parish, Rose, and Swaine (2010) studied the financial well-being of parents providing care to children and adult children with developmental disabilities. Researchers analyzed SIPP (U.S. Census Bureau) data to describe income poverty, asset poverty, income, net worth, and liquid assets of 753 parents. Results indicate that income and asset poverty was greatest for youngest and oldest parents. Liquid assets were relatively flat across cohorts, while net worth declined sharply for elderly parents, and income was highest among parents ages 45-54.

A cyclical relationship between mental health and poverty exists. People living in poverty who experience hunger, debt, low levels of education, and limited employment opportunities are more likely to experience mental disorders. For example, people living at the lowest ends of the social economic status are eight times more likely to be at risk for schizophrenia (*Breaking the vicious cycle*, 2007). The lack of employment and financial resources pushes people further into poverty and increases their inability to access adequate services and beneficial treatment, further decreasing their mental health. Level of education has a significant effect on use of mental health services, with only 21% of people with some type of mental health condition and no high school diploma receiving any type of mental health services. This is in comparison with 42% of those with college degrees (*Access to disability*, 2004).

The Effect of Psychiatric Disability on the Family

Just 50 years ago, almost 600,000 people with disabilities, including psychiatric disabilities, lived in hospitals and institutions (Harcourt, 2006). With the deinstitutionalization grass roots movements of the 1960's and 1970's, primary care shifted to family and the community, as did the heavy expenses of medication and treatment, and the significant time and energy it can take to provide daily care (Ochoa, Vilaplana, Haro, Villalta-Gil, Martinez, & Cruz Negredo, et al., 2008; Stern, Doolan, Staples, Szmuckler, & Eisler, 1999). However, community and state resources and services were poorly developed, highly limited, and expensive. Along with poor employment outcomes of people with psychiatric disabilities, such barriers intertwined to reduce the capability of a family to provide proper care and receive the support that they need (Ochoa et al., 2008).

Current mental, medical, and legal systems still hinder parents' ability to provide effective care, and thus decrease well-being. In her qualitative study on the caregiving experiences of parents for adult children with schizophrenia, Milliken (2001) found that stigma and barriers set up within the mental health and medical systems result in parents often feeling they are unable to adequately care for their child or make appropriate decisions with or for a child. Furthermore, adult children with psychiatric disabilities often have the right to refuse treatment. Yet, parents are expected to be the primary caregivers. Parents report feeling disenfranchised, isolated, alone, and ignored in the treatment process. They are not provided adequate information on the prognosis of the child or treatment methods, or how to care for themselves. Parents, especially mothers, report high levels of stress, loneliness, grief, financial strain, helplessness, fear, depression, anxiety, chronic pain, and increases in physical illness (Milliken, 2001). With little resources and support, families incur heavy emotional burden, experience hopelessness, anger, fear, vulnerability, guilt, loss and grief, uncertainty, stigma, dissatisfaction with professional services, piling up of demands, and confusion (Stern et al., 1999).

Burden or Perceived Stress

Many of the support services that were to be developed in the 1980's after deinstitutionalization did not occur. Furthermore, due to hospital policies and insurance practices psychiatric hospital stays have shortened significantly from long term stays to short term. Today, it is often the case that once an individual is stabilized the patient is allowed to leave the hospital, often with very little follow-up care. Such gap in services increases the amount of stress, or *burden*, and overwhelms families (Walton-Moss et al., 2005). The term "burden" has been traditionally used for the level of stress or disruption a family perceives when caring for a loved one with a mental or physical health condition (Zauszniewski et al., 2009). However, a change in terminology recently has been argued, due to *burden's* negative connotations. Today, *burden* and *perceived stress* are now used interchangeably in many studies. Burden has been well studied and has been associated with decreases in quality of life, health, and functioning of caregivers (Gutierrez-Maldonado et al., 2005). High levels of perceived stress also are associated with increases in dissatisfaction with life events, perceived losses, stigma, financial problems, and other family issues. Webb and colleagues (1998), in their examination of perceived burden and well-being of relative caregivers, found caregivers who reported higher levels of burden had lower levels of well-being. Gutierrez-Maldonado and colleagues, in their study of perceived burden, found similar results. Burden was closely associated with poor functioning, and diminishes health and well-being of caregivers. Family members reported having little time for themselves, resulting in decreases in their own social networks and personal leisure time (Gutierrez-Maldonado et al., 2005).

Perceived Expressed Emotion

Another area of study is the emotional impact of care, measured through Expressed Emotion (EE). Families typically express high or low emotions. High EE is marked by negative behaviors including criticism, hostility and over-involvement (Kuipers & Bebbington, 2004; Ochoa et al., 2008). Previous research indicates high-EE caregivers perceive the caring situation as more stressful than low-EE care providers. They experience more subjective burden, perceive more social problems in the loved one and try to avoid the perceived stressful situation they are facing (Kuipers & Bebbington, 2004).

A relationship between EE and burden, or perceived stress, has been found. Corring and Cook (2007) observed in their focus group study that families of a loved one with a psychiatric disability who had high levels of EE perceived their caring situation as more stressful. Kuipers and Bebbington (2004) examined EE and burden in families of people with psychiatric disabilities experiencing their first hospitalization. High-EE caregivers were found to appraise their situation as more stressful than low-EE caregivers. High-EE caregivers also displayed less adaptive coping styles such as higher levels of avoidant coping, experienced higher subjective burden and perceived lower patient functioning.

Zauszniewski and colleagues (2009) examined the relationship between burden, depression, and resourcefulness between African American and Caucasian women who were primary caregivers of a family member with a psychiatric disability. Caucasian women reported significantly higher levels of burden and stigma than African American women. No differences between levels of depression, resourcefulness, and quality of life were found between the two groups of participants. Lopez and colleagues (2004) compared Caucasian and Mexican American families with a loved one with schizophrenia. For Mexican American families, the warmer the family was toward a family member, the less likely that individual was to relapse. There was no relation between level of criticism and relapse. However, criticism was related to relapse for Caucasian family members with schizophrenia. Lopez et al. suggested that for Mexican Americans, family ties are most valued, and individuals with psychiatric disabilities may experience significant stress if they do not have close family ties, increasing chances of relapse. For Caucasian families, independence is valued, so verbal criticism may cause significant stress and trigger relapse.

High-EE also affects the functioning of individuals with psychiatric disabilities (Lopez, Nelson, Snyder, & Mintz, 1999). People with psychiatric disabilities living in high-EE environments have poorer outcomes, such as higher chances of relapse and more hospitalizations, than people living in low-EE environments (Kuipers, 1993). McCreadie (1992) reported that people with schizophrenia who lived in high-EE environments were more likely to experience relapse than people in low-EE environments. McCreadie also found it difficult to engage families to participate in interventions to help cope with a family member with a psychiatric disability, however, when high-EE families did participate in learning intervention strategies, there was a decrease in relapse of the family member. McCreadie found in this study that the majority of parents (70%) showed high levels of EE, as did almost half (44%) of other family members, and almost one quarter of spouses (22%), demonstrating the importance of understanding the family experience.

Few studies have investigated perceived caregiver EE by individuals with psychiatric disabilities. Thompson and colleagues (1995) found perceived caregiver criticism by psychiatric patients to be a predictor for future relapse compared to individuals who do not perceive high amounts of caregiver criticism. Onwumere, Kuipers, Bebbington, Dunn, Freeman, Watson, Garety (2009) found similar results. They examined caregiver EE and individual perceptions and functioning level. Patients, even poorly functioning individuals, were able to accurately perceive caregiver support and criticism.

Family Coping and Adjustment to Psychiatric Disability

The whole family is affected by a family member with a disability, and perhaps more so than the individual with the condition (Kosciulek, 2004). As the family today is the main care provider, it is vital to understand how the family copes, and to assist families in proper coping techniques.

Assessing coping styles is vital in understanding how people handle stress. Previous research indicates that caregivers who use action or problem-focused coping strategies experience less burden or better adjustment. Caregivers using emotion-focused coping strategies (process of managing one's emotions) may be experiencing situations felt to be chronic and unchangeable (Webb et al., 1998). Webb and colleagues (1998) investigated caregiver perceived burden, well-being, coping style, secondary appraisal (perceived changeability and acceptability of the problem), and level of social support. Caregivers who used problem-solving coping skills were more likely to believe they could change symptoms and reported less perceived burden. Emotion-focused caregivers who felt they must accept symptoms and had no control reported higher levels of perceived burden. Champlin (2009) found problem-focused coping skills include taking action and being an advocate for a loved one, assisting in the search for appropriate services, calling the police when necessary, and having the ability to put life on hold for a while to care for the ill family member.

Doornbos (1996), in her review of family coping with serious mental illness, found families experienced low levels of cohesiveness and satisfaction with family functioning, marital strain, financial stress, and high amount of transition. Effective coping strategies families use include hope, seeking education and management strategies, locating appropriate resources, and turning to others for support. Doornbos found that despite the amount of stress and dissatisfaction a family may feel, families actually experienced a significant degree of adaptation, low conflict, more flexibility, and greater likelihood of using a variety of coping strategies compared to families without an ill family member.

Stressful family relationships can affect the mental health of an individual with a psychiatric disability and can lead to higher rates of relapse (McCreadie, 1992; Mueser, 1996; Mueser, Glynn, Cather, Zarate, Fox, Felman, et al., 2009). Family stress and blaming the individual for his/her behavior can result in loss of family support, employment and housing instability, and homelessness. Family interventions have been found to be successful (Mueser et al., 2009). Successful intervention strategies include education about symptomology, prognosis, proper medication and side-effects, role of stress in relapse, and emotional support. Other family interventions include families learning how to avoid blaming one's self, other family members, or the ill person, encouragement of family development, paying special attention to siblings and spouses, learning how to have hope in the future, taking a long term perspective, and participating in long-term therapy or staying active in support groups (Mueser, 1996; Mueser et al., 2009).

Defining Resilience and Issues in Resiliency Research

Resilience is the ability of an individual or family to "bounce back" from a stressful event or a series of stressful events. Previous research indicates that people with positive social assets or supports who can use them are often able to deal successfully with current and future negative events (Gilgun, 1999). Resiliency is a combination of complex relationships among positive characteristics and environmental factors. Learned optimism, problem solving abilities, autonomy, social support, family hardiness, confidence, social competence, determination, sense of purpose, cooperation with others, forgiveness, and openness to each other have been found to be signs of resiliency (Abelev, 2009; Gilgun, 1999; McCubbin & McCubbin, 1989a,b). Environmental factors that contribute to resiliency include support from families, communities, and schools (Abelev, 1999). These characteristics combine to allow people to resist, be flexible, succeed, and adjust positively. Such behaviors lead to adaptation to adverse circumstances and crises (McCubbin & McCubbin, 1989a,b; Othner, Jones-Sanpei, & Williamson, 2004). Understanding how families successfully deal with stressful situations is important so that practitioners, researchers, and policy makers can develop effective programs and strategies to increase positive responses to adversity that rural families may face.

Investigators often focus on how factors negatively affect families during crisis events, with little regard for how families manage stress in a positive manner and increase resiliency (Maupin, Brophy-Herb, Schiffman, & Bocknek, 2010). While resiliency research has begun to make headway, it is plagued by confusion in defining resilience and in determining who is resilient (Patterson, 2002). According to Patterson (2002), practitioners and researchers use different definitions of resilience and different ways to measure it. Practitioners, for example, look at the strengths of families to determine resilience, while researchers focus on positive outcomes. Resilience as an outcome itself has created confusion. Gilgun (1999) asked the questions “what makes a good outcome?” and “who decides whether a person is functioning well or not?” Confusion also stems from how much risk a family faces in being exposed to a stressful event.

Family Resiliency Factors

There is a growing body of literature on family resiliency factors. It is especially important to understand the positive family factors that determine a family’s ability to do well in highly stressful and often chronic situations (Rothwell & Han, 2010). Adequate support systems (informational support, emotional support, instrumental support, companionship), possession of an inner locus of control, belief in a higher power, and the use of downward comparison coping strategy are indicators of family resiliency (Juby & Rycraft, 2004). Orthner and colleagues (2004) found relationship factors such as communication, problem solving, and social support to predict positive outcomes for low-income families.

McCubbin, Balling, Possin, Frierdich, and Bryne (2004) conducted in-depth interviews with parents of children treated for cancer within the past three years to understand what resiliency factors helped the family cope. Resiliency factors included internal family rapid mobilization and reorganization, social support from a health care team, family, community, and the workplace, and changes in appraisal to make the situation more comprehensible, manageable, and meaningful. Orbuch, Parry, Chesler, Fritz, and Repetto (2005), in their investigation regarding quality of life of childhood cancer survivors, found that children who reported better relationships with parents reported having a higher quality of life.

Rural Characteristics

Rural communities experience very different stressors than their urban counterparts due to barriers such as limited employment opportunities, access to resources, and geographical isolation (Gunderson, 2006; Hyjer Dyk, 2004). Additionally, actual and perceived lack of control and of the long, on-going, chronic experience of events and stressors contribute to stress (Barbopoulos & Clark, 2003). Stressors include high rates of unemployment or under-employment, financial stress, low wage jobs, limited educational opportunities, limited access to adequate child care, inadequate access to medical and social services, limited transportation, higher rates of accidents, unpredictability of weather, and inadequate and unsafe living conditions (Barbopoulos & Clark, 2003; Hyjer Dyk, 2004). Such barriers and stressors can lead to the potential for poor decision making, family chaos, higher rates of violence and crime, poorer physical health, higher rates of mental health problems, and issues with substance abuse (Gunderson, 2006; Hyjer Dyk, 2004; Kastras, et al., 2004).

Previous studies have shown that rural households have unique characteristics and contend with different challenges and stressors than urban households (Kastras, Zuiker, & Bauer, 2004). Low-income rural households rely more on family with whom to exchange resources, such as child care and transportation, than their higher income counterparts. Low-income, rural families also are more likely to have two working adults, have lower levels of education, and fewer employment options, and be working more than one job (Kastras et al., 2004).

Poverty in Rural Areas

It is estimated that 20-25% of the U.S. population (over 60 million people) resides in rural areas, covering 80% of the U.S. landmass (Miller, 2009). Rural communities face higher levels of poverty than their urban counterparts, with non-urban income 71% of urban income. While rural poverty rates have declines since the 1960's (*Rural poverty & well-being*, 2012), they have still been high compared to their urban counterpart. During the 1980's rural versus urban poverty rates differed by almost 5%. Then in the 1990's rural poverty rates began to decline dramatically, decreasing from 17% in 1993 to 13% by 2000, leaving only a 2.6% poverty gap between rural and urban areas. However, the U.S. has recently experienced a great economic recession. In 2009, 14.3% of the U.S. was in poverty, or 42.9 million people total (Bishaw & Macartney, 2010). By 2010, poverty in rural areas reached its highest rate since the early 1990's, and increased to 16.5% (*Rural poverty & well-being*, 2012).

Rural Minorities in Poverty

The poorest rural counties are overwhelmingly composed of minority populations (Lichter & Johnson, 2007). Rural minority populations historically have experienced high rates of poverty, discrimination, oppression, and concentrated mainly in geographically remote, significantly depressed areas of the U.S. Over 18% of nonmetropolitan areas are comprised of minority groups, with Latinos and Asians the fastest growing populations (Probst, Samuels, Jespersen, Willert, Swann, & McDuffie, 2002). African Americans still represent one of the highest minority groups in poverty, however. As of 2007, almost half (47%) of all persistent poverty counties were predominantly Black (Lichter & Johnson, 2007). Residents face lower rates of high school and college education, high rates of unemployment and poverty, and little access to adequate medical and social services. Similarly, rural Native Americans have long experienced poverty and its effects. With 9% (40 counties) of high poverty counties predominantly Native American, those living on reservations, especially in the Great Plains, face staggeringly high rates of poverty (Lichter & Johnson, 2007).

Rural communities throughout the U.S. are experiencing dramatic growth in foreign-born residents and in illegal immigration (Jones, Kandel, & Parker, 2007). As of 2008, the foreign born make up 12.5% of the total population, with significant numbers, especially Latinos (17% in metro areas and 7% in nonmetro), settling in rural communities and taking jobs in farming, ranching, construction, and manufacturing (Miller, 2009). Unfortunately, almost 20% of persistent poor rural counties in the U.S. have a Latino majority population. As with persistently poor rural Black and Native American counties, the rural Latinos have less education, work low paying jobs, and have less access to adequate health care and social services.

Women, Community, Culture, and Society

Despite growing interest in caregiving of people with psychiatric disabilities, little attention has been paid specifically to the prolonged parenting of mothers of adult children with psychiatric disabilities, or coping styles and choices mothers make, and the role community, culture, and society plays in the decision making process (Mailick, Greenberg, Krauss, 1995). Additionally, while contemporary societal expectations for women still demand intensive mothering (McQuillan, Greil, Shreffler, & Tichenor, 2008), and women still assume the major responsibility of caring for children (Millikan, 2001), empirical research regarding cultural and societal expectations is lacking. Furthermore theories specifically addressing the importance of motherhood in women's lives and societal expectations also are lacking (McQuillan et al., 2008).

Women are more likely than men to develop a strong sense of empathy towards another person's needs and feelings, and more likely to be a nurturer and caregiver (Gilligan, 1993). Personality formation usually is established within the very early years of development, with the primary caretaker being predominantly female. Young girls identify with this ongoing relationship, as mothers tend also to identify with their daughters more so than their sons. Such experiences between mother and daughter fuse together the role of carer and nurturer within one's identity (Gilligan, 1993). Chodorow argued that girls emerge from this stage of life with a sense of empathy that is intrinsically tied to their sense of self (as cited in Gilligan, 1993). Such experience and identity development may be due to genetics, the nurturing and developmental experience, or societal expectations alone, or some combination of these factors. Whatever the case, the nurturer and child care provider roles are highly valued and expected. Women's role as caregiver is viewed as a moral imperative (Milliken, 2001). Self-sacrifice is the moral ideal, and caring for oneself is self-indulgence (Milliken, 2001).

Society's expectation of women as the primary caregiver can have significant negative effects. Over the last half century, more mothers have entered or re-entered the workforce, and the number of female-headed and grandmother headed households continues to rise (Crosnoe & Cavanagh, 2010; Snyder, McLaughlin, & Findeis, 2006). Female headed households experience poverty rates as high as 28% (Edin & Kissane, 2010). The majority of African American, Hispanic, and Native American born children live in single parent households, mostly with mothers living in significant poverty (Snyder et al., 2006). Women living in rural communities also are more likely than their higher income urban counterparts or even men living in rural communities to work nonstandard shifts, work lower wage jobs, and be less educated (Crosnoe & Cavanagh, 2010).

London, Scott, Edin, and Hunter (2004) conducted a longitudinal ethnographic study of the transition of women from welfare to work and the consequences women and their children faced afterwards. Multiple costs and benefits of work for women and their children were identified. Benefits of employment included increased income, increased self-esteem, feelings of independence, social integration, and the ability to model work and self-sufficiency for their children. However, London and colleagues found that despite the increase in positive factors such as income and self-sufficiency, women experienced increases in negative mental health factors due to working more without increased income, overload of responsibilities, increased exhaustion and levels of stress, and less time and energy to be with, supervise, and to support their children.

In an 18-month longitudinal study on stressors mothers experience when working and the spillover stressors the family experiences, Goodman and Crouter (2009) found a connection between negative work environment, stress, depression, and perceived negative family spillover effects. The less flexibility and the more pressure there was in a work environment, the more likely women were to have depressive symptoms and feel stress. Furthermore, for women who worked full-time, the more pressure they felt at work, the more likely they were to perceive an inability to care for personal and family needs. This negative family spillover can cause women to feel more stress and depressive symptoms, which in turn, affect a mother's work performance and associated stress and levels of depression, potentially creating an endless cycle.

Evans and colleagues (2008) conducted a quantitative survey with 223 mothers and one of their children from low and middle class incomes. Low-income female-headed households experienced elevated levels of stress, were less responsive to children, had few social resources and networks for social support, and were less involved in community organizations than middle class female-headed households. Evans and colleagues also found that female headed households living in nonmetropolitan or rural communities face such stressors to a higher extent their urban counterparts due to geographical isolation, distance from adequate services, lack of community services, difficulties with transportation, and physical and emotional isolation. The authors concluded that such experiences of single mothers can be felt by children. Low income youth living in female headed households were more likely to have mothers who were less involved and are less responsive to their needs, and the children themselves experienced high levels of chronic stress and had smaller social networks.

Although caregiving is often shared by parents or other family members, the majority of responsibility for care of a child with a psychiatric disability falls to the mother or other female household members (Milliken, 2001). The difficulty of providing care to someone with a psychiatric disability, with the addition of societal expectations of intensive motherhood and caregiving, creates a pile up of demands and significant burden and stress. Women experience chronic worry, anxiety, and blame for poor parenting and not seeking assistance from professionals earlier for diagnosis and treatment (Millikan, 2001). Mothers also experience feelings of loss and grief "associated with the recurrent realization that their child will not experience a normal life. . . .and about their child's future when they are no longer able to provide care and supervision" (Mailick et al., 1995, p. 64). Furthermore, women may find themselves not only caring for their adult child but expected to also care for other family members (Mailick et al., 1995). Such sandwiching between adult child and aging parents or spouse only adds to the pile up of demands and stress women incur. Such demands put women care providers at high risk for developing depressive disorders and experiencing a lower quality of life (QOL), compared to women who do not provide such care, or even men who care for a family member with mental illness (Gutierrez-Maldonado et al., 2005; Milliken, 2001; Zauszniewski et al., 2009).

In her 1988 article on the effect of deinstitutionalization on mothers, Cook noted the limited number of empirical studies regarding gender influence on reactions to mental illness. Unfortunately, little has changed in the literature since that time. The majority of research does not distinguish potential differences between male and female caregivers. Cook (1988) compared the experiences of mothers and fathers as their children came back into the home and community during deinstitutionalization. Mothers, more than fathers, dealt with anxiety due to recurring symptoms and decompensation. Mothers were more likely to report depression, fear, sadness, and loss of hope. Mothers also were much more highly involved in their children's lives, and their self-worth was defined by their ability to care for the ill child. Mailick and colleagues (1995) examined aging mothers who care for adult children with developmental and psychiatric disabilities. They reported that women's declining self health was stressful and increased the risk of depression. Milliken (2001) found that mothers reported high levels of stress, loneliness, grief, financial strain, helplessness, fear, depression, anxiety, chronic pain, and increases in physical illness.

A growing body of caregiver literature is beginning to focus on the influence of culture on caregivers (Corring & Cook, 2007; Lopez et al., 2004). It is important to understand cultural and societal expectations of motherhood and pressures of women in the U.S. to have and provide for children. As McQuillan and colleagues (2008, p. 478) stated, "Culture and identity approaches to motherhood emphasize the motherhood mandate and pronatalist normative pressures on women in the U.S." Zauszniewski and colleagues (2009) reported significantly higher levels of burden due to family disruption and perceived higher levels of stigma among Caucasian women as compared to African American women.

Such experiences raise serious questions regarding the acceptability of society's expectations of women and mothers. While it may be viewed as the norm and be accepted within society to place primary responsibility of caregiving on women, it does not necessarily make it correct. Furthermore, the expectations of women and their experiences raise questions regarding the implications such values have on accessibility to proper employment, resources, and other community supports, and in policy. By continuing to encourage such values, society may only further hamper mothers in their ability to provide effective care while maintaining their own physical and mental health.

Theoretical Framework

Family Stress Theory: The Dominant Paradigm

Family stress theories focus on positive aspects of family coping, explaining the complexity of the roles and relationships between various family characteristics such as family strengths and capabilities and how these characteristics buffer the impact of stressful events. This theory and its models focus on two phases: adjustment and adaptation to stressful familial events. Hill's (1949) ABC-X Model of Family Stress is the foundation of family stress research (Hobfoll & Spielberger, 1992**;** Malia, 2006). Each letter of this model stands for a particular step or factor in the family's ability to adjust and adapt to stressors (McCubbin & McCubbin, 1989b). Factor A stands for the initial crisis, while the interacting factor B is the resources the family has to meet the situation. Factor C is the meaning the family gives to the situation, and factor X is the outcome. McCubbin and Paterson (1983) added to Hill's model, developing the Double ABC-X Model of Family Stress and Adaptation (Hobfoll & Spielberger, 1992; Kosciulek, 2004; Malia, 2006), with emphasis on the follow-up responses families make after the main stressor. The researchers stated that families most often have to deal with multiple stressors while dealing with a family crisis, a pile up in demands (McCubbin & McCubbin, 1989b). It is not necessarily the crisis itself that is most stressful. It is the multiple demands that build up and the time it takes to resolve them that are most stressful to families (Hobfoll & Spielberger, 1992).

More recently, McCubbin and McCubbin expanded on the Double ABC-X Model, and developed the Typology Model of Family Adjustment and Adaptation (1989b) in which families are sorted into types based on their placement (low/high) on dimensions of: a.) family hardiness and family coherence, b.) family flexibility and family bonding, c.) family time and routines, and d.) valuing family time and routines. This model again includes the two phases of adjustment and adaptation, with two separate models for each phase (McCubbin & McCubbin, 1989b). The Adjustment Phase Model includes: A Factor – the stressor; V Factor - the vulnerability of family, consisting of pile-up demands, normal demands, and family resources; T Factor – the family's typology or the basic characteristics of how the family appraises, operates, and behaves; B Factor – the family's resources, capabilities, and strengths; PSC Factor – the family's ability to manage the stressful event including problem-solving capabilities and coping techniques; and C Factor – the family's perception and meaning of the event, pile-up demands. This factor can include family and cultural values, and previous similar experiences. The X Factor is the level of family adjustment.

The Family Adaptation Phase explains the family's capability to transition from adjustment to adaptation of an event. This model is more complicated and includes much more in resources available to the family and the family's use of them. This model also taps into the influence that a family's community can have on coping with a stressful situation. The Adaptation Phase of the Typology Model includes: AA Factor – pile-up demands; BB Factor – family strengths, resources, and capabilities; BBB Factor, community based resources; CC Factor – family perceptions of the stressors; CCC Factor – the family's set of beliefs about themselves in relationship to one another, and about their family's relationship to the community they belong to, and other family schemas; PSC Factor – process of acquiring and allocating resources to deal with the main stressor and pile-up demands; and the XX Factor – the outcome of the family's efforts to reach adaptation.

The Family Resiliency Perspective

Resilience is complex combination of positive factors and relationships providing an individual or family with the ability to "bounce back" from a stressful event or a series of stressful events (Abelev, 2009; Gilgun, 1999; McCubbin & McCubbin, 1989). Positive factors can include characteristics and environmental factors such as learned optimism, problem solving abilities, autonomy, social support, family hardiness, confidence, social competence, determination, sense of purpose, parental education, family cohesiveness, cooperation with others, forgiveness, and openness to each other (Abelev, 2009; Gilgun, 1999; McCubbin & McCubbin, 1989; Patterson, 2002). Previous research indicates that people with positive social assets or supports and who use them are often able to successfully deal with current and future negative events (Gilgun, 1999).

Despite progress in understanding the long term effects of a crisis situation on a family's well-being, current family stress and coping theories still focus across the life span (Patterson, 2002). The Family Adjustment and Adaptation Response Model (FAAR) (Patterson, 2002) was developed out of the need to focus specifically on how families adjust and adapt over time to achieve precrisis adjustment and postcrisis adaptation. The FAAR Model places emphasis on family capabilities and demands, whereas the Double ABC-X Model and the Typology Model of Family Adjustment and Adaptation emphasize family appraisal and meaning making. The FAAR Model contains four central constructs: family demands (normal and nonnormal stressors; unresolved stressors; daily minor strains), family capabilities (tangible resources the family has; coping behaviors the family does), family meanings (family definitions of demands and capabilities; identity as a family; and world view), and family adjustment or adaptation. During adaptation, the family begins to restore balance by acquiring new resources and coping strategies, reducing demands, and/or changing the way their situation is viewed (Patterson, 2002). For a family to reach bonadaptation it must restore balance between capabilities and demands between family members and the family unit, and between a family unit and the community.

The Resiliency Model of Family Stress, Adjustment, and Adaptation (Kosciulek, McCubbin, & McCubbin, 1993; Kosciulek, 2004; McCubbin & McCubbin, 1989a, 1993) is the more recent model focusing specifically on family adaptation to disability. This model seeks to underline the importance of family adaptation and not just adjustment as in the earlier models. The adjustment phase is only one piece of a family's ability to cope appropriately with a family stressor. To be able to truly cope, the family will have to make changes and transition, or adapt.

The coping techniques a family uses to respond to stressors are important determinants in the family's ability to successfully maneuver through them, leading to positive adaptation (Kosciulek et al., 1993; Kosciulek, 2004). The final outcome of adaptation includes: *bonadaptation* (positive health of family members, promotion of family development, and maintenance of the family unit); and *maladaptation* (deterioration of health, of the family unit, imbalance of individual family roles or role of the family to the community). This model includes several factors. The main family crisis event, which is influenced by and itself influences other stressors, pile-up demands. The next factor within the Resiliency Model is Family Typology, the basic characteristics of the family, which includes family strengths, resources, and capabilities; personal resources; family system resources; community resources and supports; family situational appraisal, family schema and meaning; and problem-solving and coping capabilities (Kosciulek, 2004). This factor in turn determines the family's ability to adapt and whether family will bonadapt or maladapt to a stressor.

Towards a New Model

While family stress and coping theories provide the foundation for how families can effectively cope and eventually adapt to a stressful event, and do take the family's surroundings into consideration, they do not place the family's cultural background, environmental setting, and societal views and expectations at the fore front. Boss (2001), a pioneer in family stress research, called for understanding the influence of community and cultural contexts of the family's environment. Rural populations, for example, have unique characteristics, and face unique challenges and barriers not experienced by urban populations. These challenges can significantly affect the way care is provided and how a family copes with caregiving (Barbopoulos & Clark, 2003). However, the importance of community, culture, and societal contexts are often ignored, buried within family meaning.

Additionally, despite indications that parental roles between mothers and fathers are changing, and efforts to change stereotyped motherhood ideals, women are still expected to act as primary care giver, providing nurturance and support to children, and be responsible for household management (Malacrida, 2009). Women face unnatural expectations of motherhood. The ideal mother is always present to provide care to her children, act selflessly, be responsible for physical care, education, and moral development, and "be all things, at all times" to children (Malacrida, 2009). Mothers are placed on a pedestal, and when they do not live up to societal expectations, they are blamed and considered failures (Malacrida, 2009), placing them at risk for depression, anxiety, and other mental health conditions (Gutierrez-Maldonado et al., 2005).

Furthermore, Western Society still highly stigmatizes mental illness (Corrigan, Watson, Miller, 2006). People with mental illness often are blamed for and considered responsible for their illness, and are seen as highly dangerous (Corrigan et al., 2006; Hasson-Ohayon, Levy, Kravetz, Vollanski-Narkis, & Roe, 2011). Families also experience, as well as participate in, stigmatizing attitudes towards loved ones with mental illness (Corrigan et al., 2006; Hasson-Ohayon et al., 2011). Up to one-half of people in the U.S. with a family member with serious mental illness view the illness as a source of shame and keep knowledge of the illness secret from others. Corrigan and colleagues (2006), in their examination of family stigma, found a relationship between shame and blaming of the family for the individual's psychiatric disorder. Struening and colleagues (2001) report similar results in their shame of a family member's illness and perceptions of blame. About half of mothers surveyed were concerned about being blamed for their children's mental illness. Previous research indicates that blame is attributed to bad parenting skills (Corrigan et al., 2006). Corrigan and colleagues in their family stigma investigation report that family members experience significant stigma. Families are blamed for the onset of the relative's disorder, held responsible for relapse, and viewed as an incompetent family member. Actual blame or even perceptions of blame can lead to feelings of shame and contamination (Corrigan et al.). Such societal influences affect the perception of and actual choices families make and perceived power of the family over the illness and care.

Conceptual Framework: The Sociocultural Model of Maternal Caregiving

With the added knowledge of rural community characteristics, societal expectations of the role of the mother, and stigma of mental illness, it is now apparent that stress and coping theories lack major components. For this study I propose the Sociocultural Model of Maternal Caregiving (see **Figure 1**). This model includes: (1) The influence of rural community demographics and culture on family meaning making, appraisal, and coping and problem solving skills, and (2) Societal hegemonic views and myth of the role of the mother influence. Further, I argue that the family’s appraisal, or perceptions of stressors, must be separated into two factors: a) *situational appraisal* and how the family perceives the stressfulness of the family member’s illness. This can influence the family’s perceived choices or b) *choice appraisal*. Does the family perceive choices? Does the family perceive itself to have power? This can be influenced by the actual availability and accessibility of resources and supports in the community. Choice appraisal can influence the family’s ability to develop and use effective coping and problem solving techniques, and also influence whether the family succumbs to the event or is strengthened.

Boss (1992) criticized family stress theory research for its focus on resources. She argued that no matter what resources are available, not all families will use them. Further, people without resources do not always work harder to obtain them. Boss argued that the attainment and use of resources is about perception of power and choice, especially for disenfranchised families. Families and individuals with mental illness, and rural families often have few available resources, and perhaps more importantly, face significant levels of stigma from society, creating a sense of powerlessness, even for those families with ample resources. This sense of powerlessness can in turn exacerbate the perception of lack of choice and creates hopelessness. The perception of a lack of choice can create a sense of loss of control of a loved one’s illness, creating a belief that no matter what assistance is offered, none of it matters. This creates an inability for families and individuals to make their own decisions regarding their future. As Boss (1992) argues “families will not develop resources or act on them without a sense that their actions will make a difference. . .” (p.114).

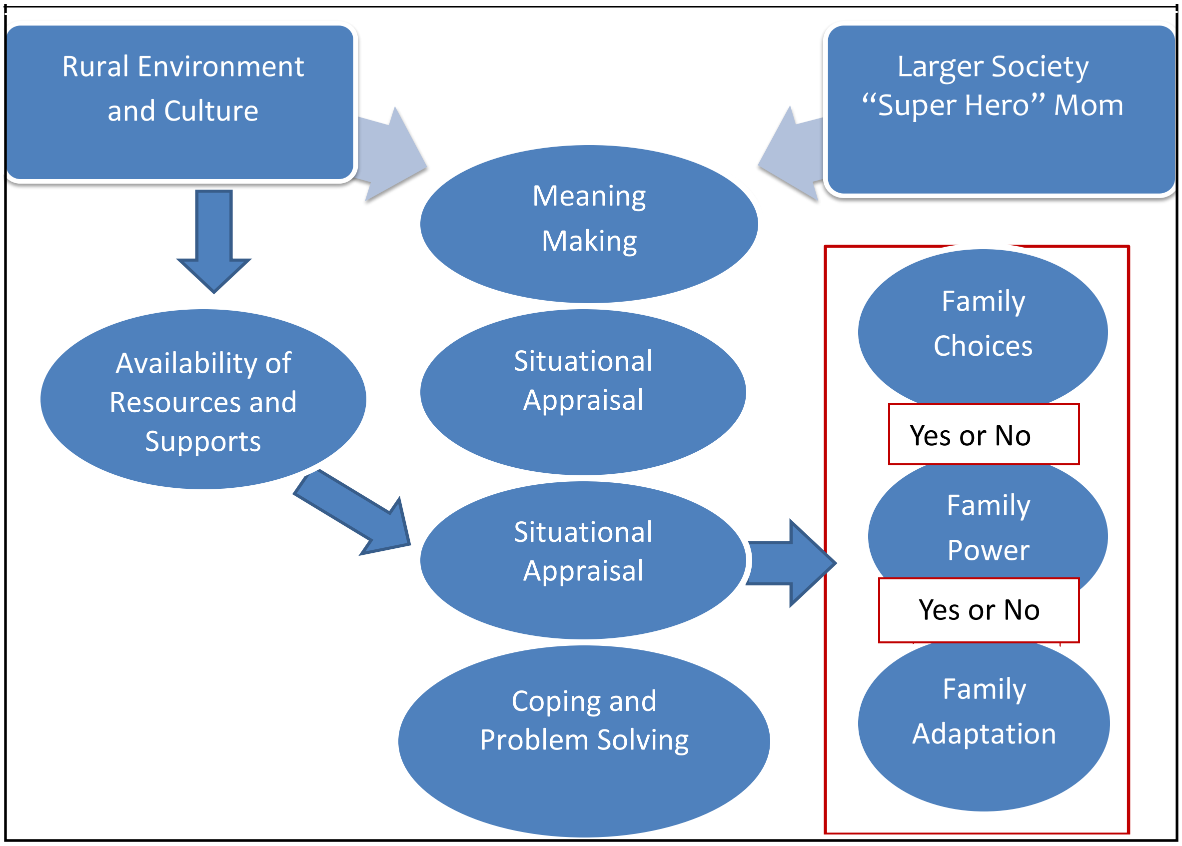

Figure 1: The Sociocultural Model of Maternal Caregiving. *For interpretation of the references to color in this and all other figures, the reader is referred to the electronic version of this dissertation.*

Conclusion

This literature review has identified the need to examine the caregiving experiences of rural mothers with children with psychiatric disabilities. The need to relate these experiences to the coping, problem solving, and meaning making process for mothers, and to the community, cultural, and societal expectations placed on women also has been identified. It is worthwhile to provide and enhance knowledge about coping and expectations of mothers and caregiving. The literature on family stress and coping theories, psychiatric disabilities, family care provision and coping with psychiatric disability, poverty and rural culture, and women's caregiving experiences helped to inform the literature review. Knowledge from this preliminary study on the caregiving process of mothers will help to inform rehabilitation research and contribute to research, clinical, educational, and policy application efforts that seek to enhance the caregiving experiences of rural mothers.

CHAPTER 3
METHODOLOGY

Participants

Participant Selection

The population of interest in this study was mothers who were primary caregivers of adult children with psychiatric disabilities. For the purpose of this study was to understand the caregiving experiences of mothers, it was anticipated that eight adult women were needed to meet the requirements for data completeness and saturation. Moustakas (1994) explained that phenomenological research involves studying a small number of participants through extensive and prolonged engagement to develop patterns and relationships of meaning. Dukes recommended 3 to 10 individuals, whereas Polkinghorne recommended 5 to 25 individuals (as cited in Creswell, 2007, p. 61, 126). Given the depth of the interviews, a large amount of data may be collected without need for a larger sample if the participants talk at length about their experiences.

The inclusion criteria for this study were: (1) currently or previously (within the last five years) the primary care giver for an adult child (18 years and older) with a psychiatric disability; (2) have a child with one of the following disabilities: schizophrenia, personality disorder, bipolar type I or II, clinical major depression that includes at least one hospitalization in the past five years, schizoaffective disorder, or severe anxiety that significantly hinders daily activity (including PTSD, agoraphobia, social anxiety disorder); (3) assist adult children with at least three of the following types of assistance: housekeeping, transportation, meal preparation, laundry, personal care, and finances; (4) be in a rural community; (5) be able to speak English; and (6) be female.

The sample was recruited from a non-urban National Alliance on Mental Illness (NAMI) support group in a Midwestern state. Creswell (2007) recommended that participants come from a single site. For a phenomenological study, participants must have all experienced a similar phenomenon. Creswell (2007) stated “the more diverse the characteristics of the individuals, the more difficult it will be for the researcher to find common experiences, themes, and the overall essence of the experience for all participants” (p. 122). Therefore it was important to locate women who lived within the same area and who were associated with the same organization. There was then a higher likelihood to find a shared experience of a phenomenon across participants.

A focus group was first conducted with the NAMI group, then individual interviews were conducted. NAMI provides peer-to-peer support, education, and advocacy for families who are caregivers to loved ones with mental illness (NAMI: National Alliance on Mental Illness, 2012). All participants were asked to complete the *Demographic Information Sheet* (Appendix D) and provide demographic information including age, ethnicity, marital status, number of children, current work status, highest grade level completed, supports used, leisure activities, child’s diagnosis, age when child was diagnosed, child’s current age, gender of child, child’s living situation, assistance mother provides to child, amount time mother spends assisting child, child’s current work status, highest grade level of child, and services child receives.

Demographic Characteristics

The focus group sample consisted of six participants who qualified as primary caregivers for their adult children with psychiatric disability. Two women who participated in the focus group declined to participate in the individual interviews. Three women who did not participate in the focus group took part in individual interviews. One woman belonged to NAMI, and the other two did not. Of these two women, one was identified through a mutual friend, and one was an acquaintance of mine. Ages of the participants ranged from 38 to 76 years. All women who participated in the focus group and individual interviews reported themselves as Caucasian. Most women were married, with one woman separated from her husband and in the process of a divorce, and another woman was a widow. Age of children ranged from 17.5 to 42 years. All mothers except for one were the biological parents of the children. Length of time spent caring for child ranged from 2 to 30 years. Diagnoses of all children included post-traumatic stress disorder, panic attacks, major clinical depression, bipolar I and II, schizophrenia, borderline personality disorder, and narcissistic personality disorder. Most children lived independently. One child owned his home and small farm, one child lived with the mother, and the others lived independently or with friends.

Summaries of Mothers in the Individual Interviews

Mother 1. Mother 1 was in her 60's. She was college educated and was a retired teacher. Mother 1 and her husband had attended other types of support groups and other NAMI groups in surrounding counties before they established theirs. However, they were disappointed in how the groups were run. They felt that people talked too much about their frustrations with little action to resolve problems. Mother 1 wanted to belong to a group that was highly supportive and sought answers. She and her husband established their county NAMI support group, and she was the first president. After seven years as president, she recently stepped down. She was still highly active in NAMI and assisted the current county president. At the time of her interview, she actively worked with the recently developed mental health court in her county. She facilitated support groups for young adults with psychiatric disability for the court house. She reported that her primary support was her husband and the friends she has made through NAMI. Her son was diagnosed bipolar disorder and PTSD about 15 years ago. He was divorced with two teenage children who lived out of state. He owned his own small farm, yet Mother 1 and her husband provided much support to him, as he frequently experienced severe manic and depressive episodes and psychosis that required hospitalization. Mother 1 described her relationship with her son as often difficult, and relied on her husband for support and as the buffer between her and her son. They had two other children who lived out of state.

Mother 2. Mother 2 was in her late 50’s. She was college educated and a retired teacher. She was the current NAMI president for her county. She was married, but received little support or understanding from her husband regarding their son’s illness and his care. Mother 2 became involved in NAMI soon after her son was diagnosed with schizophrenia about 10 years ago. Her son had begun experiencing problems in his early teens and was diagnosed when he was 18. The son currently lived independently with a roommate. Just before her son’s diagnosis, Mother 2 had read an article written by Mother 1 published in the local newspaper. She had saved the article with the thought that one day she would need to speak with Mother 1. It was only a couple weeks later when Mother 2 contacted her. Mother 2 reported that before her son’s illness, she was not assertive. During the early years of her son’s illness, she struggled with how to care for him as well as herself. Due to her stress, she experienced physical illness as well as depression and anxiety. Through NAMI, she became assertive, highly educated about psychiatric disability and available local and state wide resources, and the importance to ask for help and take time out for herself. She had two other children who lived out of state. She assisted her son with transportation to appointments, filled out paperwork, reminded him to take his medications, and hospitalization when necessary.

Mother 3. Mother 3 was in her early 40's. She was college educated. During the interview, she stressed how it was important to her to be able to work part-time so she could take care of her children, especially when her daughter became when in high school. The daughter was diagnosed with bipolar disorder during her senior year of high school. Mother 3 was married and reported her husband to be her primary support and very supportive of his daughter. They were both active in NAMI. Mother 3 has had to assist her daughter with locating appropriate services attending medical appointments. At the time of this interview, the daughter was doing very well. She was completed high school and college, and was a peer support for other students with mental illness at her university. She currently lives out of state and lives independently. Mother 3 reported that she currently assisted her daughter with emotional support, as her daughter tended to take on too much and become stressed, and put herself at risk for relapse.

Mother 4. Mother 4 was in her middle 40's. She was college educated. She was leader in her church and her husband was a pastor. Mother 4 and her husband belonged to local and state wide advocacy groups for people with disabilities. She described her husband as her primary support in the care of their daughter who was diagnosed with bipolar disorder. At the time of this interview, the daughter lived independently with her boyfriend of about two years. The boyfriend was reported to be very supportive, however, Mother 4 still frequently checked in with her daughter to make sure she was alright. Mother 4 reported that in the past, she and her husband had to frequently assist their daughter with transportation, making sure she was following medical treatment, taking her medications, was eating properly, and had a safe place to stay.

Mother 5. Mother 5 was in her early 50’s. She had college education, worked part-time, and was married. She reported that her primary emotional support came from her NAMI group. She reported that over the years, her husband has become more understanding and supportive of their daughter’s illness. However, he still often did not understand their daughter’s illness, and why she could not pull herself together. Their daughter has had lifelong emotional and interpersonal difficulties. She was finally diagnosed with Asperger’s when in her early 20’s along with major clinical depression. A personality disorder has not been ruled out. Mother 5 assisted her daughter with transportation to medical appointments and to a club house program she belonged to, and with hospitalization.

Mother 6. Mother 6 was in her late 40’s. She had college education and worked full-time. At the time of this interview, she was going through a divorce. She still reported her husband as her primary support in the care of their son who was diagnosed with bipolar disorder. She was the vice-president of her local NAMI group. The son had lived independently until recently and moved back in with his mother. He was diagnosed with bipolar disorder over 10 years ago when he was in his late teens. In the early years of his illness, the son was able to go long periods of time without medication and do well. He worked full-time, made good money, and was in a long-term relationship. However, in the last 3 or 4 years, he has experienced more frequent episodes of mania. Mother 6 has struggled to get her son to take medication, especially as his work and personal life have deteriorated due to his mental illness. She assisted him with housing, meal preparation, medical care and medication, and hospitalization when necessary.

Mother 7. Mother 7 was in her middle 70's. She was twice married. Her first marriage ended due to her then husband's unstable mental health. She was currently married at the time of this interview for over 20 years. She reported her husband and her NAMI group to be her primary supports. She struggled with the care of her daughter, who was in her early 40's, throughout her entire life. The daughter had severe behavioral problems since she was very young, and was diagnosed with two different personality disorders and bipolar disorder. Mother 7 sought help from all over the state, and finally received assistance from a director of a state run residential program. Mother 7 felt she had no other choice but have her daughter placed within the residential facility. The daughter lived in 3 different facilities until she was about 18. The daughter was able to attend college and work full-time. She married twice and had four of her own children. Mother 7 reported that she did not recognize her daughter's illness again until the daughter was in her early to mid-30's before her second divorce. Mother 7 had assisted her daughter with transportation to therapeutic appointments, housing, frequent hospitalizations, and had permission to speak with her daughter's therapists and case workers. Mother 7 reported that due to the stress of caring for her daughter, she previously made herself so physically ill that she was hospitalized and almost died. She finally sought help for herself and was actively working with a therapist over the few years. At the time of this interview, Mother 7 believed that she finally reached the point where she could no longer help her daughter due to the daughter's self-destructive behavior.

Mother 8. Mother 8 was in her late 30's. She was college educated, married, and had adopted nine children, all with either physical, cognitive or psychiatric disabilities. During her interview, she focused on her two daughters who both have bipolar disorder and borderline personality disorder. She reported that her husband was her primary support. About 10 years ago, they began as foster parents and over the years began to adopt the children that came into their care. Mother 8 assisted her daughters with transportation to medical and therapeutic appointments, housing, had adopted her younger daughter's own daughter and was currently raising her as her own. At the time of this interview, Mother 8 was struggling with both daughters' severe emotional and behavioral problems. The older daughter was refusing to take her medications and was manic. She lived independently with friends, yet was struggling emotionally and financially. The younger daughter was in legal trouble and had run away to live with her biological mother. Mother 8 felt she was at a loss with this younger daughter and could no longer care for her.

Researcher Biases and Assumptions

Rural Upbringing

Growing up in a rural community in the Midwest provided me with an enriched experience of culture values and expectations. I grew up in a region that has been heavily affected by economic recession for decades, with little industry except for logging and some iron mining. Copper mining was once prevalent, however, beginning the 1950's rapidly declined, leaving once highly prosperous communities in near ghost town conditions. Our primary industry today is tourism due to our natural resources, logging and farming. We can be fiercely protective of our natural resources including our abundant forests and the Great Lakes which surround us. Additionally, due to our economically depressed state, our remoteness, and long hard winters, we can see ourselves as survivalists. We see ourselves as rough and tough, stubborn, and able to take on almost anything. We value these viewpoints as they are beneficial to have. However, they also can be limitations. My family, similar to other Scandinavian families in my community, is private, with the expectation that we do not tell others of our woes and personal issues. We expect in ourselves and others to be able to survive any situation with little assistance, and can view the asking of help as weakness. We can also be distrustful of outsiders. We can feel a common bondage to people from other areas of my region at first meeting, however, it can take a long time to build trust with those from outside of this area. This connection we have for one another, though, despite still valuing our privacy even from each other, creates a value in us to watch out for our neighbors. We are often quick to come to one another's assistance and make sure others do not go without. Due to our depressed economic state, little employment opportunities, long cold, dark winters, and culture, we also appear to have a potentially high rate of mental health issues and alcohol abuse and addiction. Growing up, there was not a family I did not know of whose lives were not affected by mental illness and/or addiction. I have witnessed the effects of the inability to ask for help, addiction and poor mental health can have on a person and family, and the repeated cycle of addiction generationally in families. These experiences and values have shaped my development and worldview and have influenced me as an adult.

Caregiver Experiences

One of the most influential people in my life has been my sister. Living with one of the most potentially debilitating mental illnesses, my sister was diagnosed with Borderline Personality Disorder when she was 18. Borderline Personality Disorder (BPD) is a chronic, lifelong condition that when I look back, could be easily recognized in her behaviors at a very young age. Growing up, I witnessed my sister struggle with controlling her emotions and behaviors. I also witnessed my parents, especially my mother, struggle with parenting her. Throughout my sister's life, my parents have not been educated about BPD. They have not been educated in how to work effectively with my sister, understand her thinking patterns, behaviors, and inability to control her emotions. They have not been educated about BPD's etiology, its genetic as well as development through poor nurturing. Finally, my parents were not taught appropriate coping techniques as BPD is exhausting to work with. My parents were rarely included in my sister's years of therapy and treatment, especially once she was finally diagnosed with BPD, as they should have. This is something I never fully understood, even now. There stands between them, my parents and my sister, an often tumultuous relationship, pulled thin and tattered at the seams. How could my sister, living in our parents' home, or independently, become fully well if my parents were never included in treatment when they were and often still are the main support providers? How could my parents understand my sister's illness, effectively support her, develop effective coping techniques, and do well in their care of her, allowing my sister a better likelihood of becoming well when they are not included in the treatment process? My sister has done fairly well for herself. She has educated herself about her illness, stuck with therapy through much of her life, work full-time, and support herself. However, due to the nature of BPD, my sister will most likely struggle with her condition all of her life and need lifelong therapeutic support. My parents will probably continue to support her in a variety of ways, perhaps never fully understanding her illness and how to properly deal with her.

Professional Experiences

I have worked with individuals with psychiatric disabilities and families in a variety of settings such as mental health agencies, residential group homes, vocational rehabilitation, and social services. I also have a master's degree in rehabilitation counseling, having been trained in counseling techniques unique to individuals with disabilities. I have had the opportunity to assist individuals in developing effective coping skills, with relapse prevention, job development, and develop stronger connections with their families. I have also had the opportunity to work with families, provide education about a child's illness, and assist with the provision of appropriate resources. I have heard stories of frustration, anger, grief, loss, helplessness, as well as stories of hope, excitement and success, and gained a deeper and more enriched understanding of both parent and child's perspective of psychiatric disability and the caregiving experience. My involvement with individuals and families has been extensive and meaningful.

As I am a product of my culture and my experiences, I had to be careful about preconceptions as I moved forward. I understood that I could not erase biases and assumptions I had, I could become aware of those presumptions and set them aside through bracketing and epoché to view the phenomenon of caregiving as if for the first time (Moustakas, 1994).

Procedures

Data Collection Methods

The study research methods were approved by the Michigan State University Social, Behavioral, and Education Institutional Review Board (SIRB). I emailed all people listed as NAMI county representatives located on the Michigan NAMI website. Two representatives from different non-urban counties responded in interest. I was able to schedule speaking engagements for two meetings with one of the groups. I provided a brief PowerPoint presentation with details of the objective and importance of the study. I answered questions pertaining to the study, provided contact information, answered questions and discussed concerns. Copies of the *Informed Consent Form* (Appendix E) and a copy of the *Study Announcement* and *Flyer* (Appendix C) were provided to individuals. Once IRB approval was granted, I contacted the president of the local county NAMI group who put an announcement in the monthly NAMI bulletin to indicate the date, time and location of the focus group.

Focus groups can be advantageous for several reasons (Creswell, 2007). They are beneficial when interviewees are likely to be cooperative with one another, similar in their experiences, when there are time constraints, and when individuals may be hesitant to speak alone. Furthermore, the focus group allowed for me to (1) develop rapport with participants, (2) pilot test and refine my interview guide, (3) reframe questions, (4) assess my potential bias, (5) ensure women met study inclusion criteria, and (6) collect demographic information.

During the focus group, six women were in attendance. The focus group lasted approximately 90 minutes. I explained the *Informed Consent* procedures with participants, by verbally describing the purpose of the study, assumed risks, benefits, participant rights, and confidentiality. I clarified that discussion of caregiving experiences has the potential to evoke strong emotions and may be uncomfortable. I explained that our conversations were confidential within normal limits, and that any reference of intent to self-harm or abuse/neglect of the adult child in care must be by law reported. I also stated that I could arrange for referrals in the event that a participant needed counseling. Participant signature was requested to indicate voluntary agreement to participate in the study. A copy of the *Informed Consent* form was provided to each participant, and a signed copy was placed in the investigator's interview portfolio. This information was secured in my office along with other confidential data obtained during the study. The *Demographic Information Sheet* was then filled out by participants as shown in Appendix D. Participants had the opportunity to choose their own pseudonym so it would be easier for them to respond naturally during both the focus group and individual interview. All interviews were audio recorded. Following each interview, recordings were labeled with the pseudonym and date of the interview.

Once IRB approval was granted for the individual interview portion of the study, I followed up with potential participants by email and telephone to further discuss the study and schedule a time and place to meet. Interviews lasted approximately 90 minutes. All interviews were audio recorded. Interviews took place in a neutral location. Locations were determined based on proximity of setting to participant, how comfortable each participant felt with a location, noise and other distractions in the surrounding environment, and level of privacy and ability to keep confidentiality within the environment. During each interview, I again went over informed consent with participants. Women signed one copy of the *Informed Consent for Individual Interviews* form (Appendix B) and were provided another copy to keep. Demographic information was gathered from women who did not participate in the focus group.

To assist in the data collection phase a field log was actively used. Notes were made throughout the data gathering process to document participant behaviors, interactions between participants and me that were not part of the recorded interview, and non-verbal expressions during and after each interview. The field log also was used to provide a detailed account of my observation, to chronicle my own thinking, feelings, experiences, and perceptions throughout the research process, and for the transcription and analysis phase.

The audio recordings, printed documents, and field notes will be retained for a minimum of three years, in order to be used for future research. These data are stored in a secured and locked location in the office of the investigator. Any information entered into a computer has been secured through password identification, Norton Anti Virus and Windows firewall protection. Other people who will have access to documents was committee chair, Dr. Kosciulek and a first year doctoral student in the Rehabilitation Counselor Education program at Michigan State University. They have assisted with data analysis and summary. I transcribed all interviews using Dragon Naturally Speaking software.

Instrumentation

Interview Guide

An *Interview Guide*, which can be found in Appendix A and B, was developed with the assistance of a committee member who was an expert in qualitative research. The *Interview Guide* was organized around six primary concepts, including rural culture and societal expectations, meaning making of the caregiving experience, availability of resources, situational and choice appraisal, coping and problem solving strategies, and family power and adaptation. The *Interview Guide* consisted of a series of semi-structured, open-ended questions and structured to elicit information from mothers about their caregiving experiences. Interviews also consisted of sub-questions and personal disclosure designed to elicit in-depth narrative descriptions about women's caregiving experiences. Attention also was paid to non-verbal cues, including descriptions of facial expressions, posture, gestures, behaviors, and tones of voice, expressions, and behaviors with symbolic meaning, as well as my own feelings during the interviews. Based on the discussion in the focus group, changes were made to the interview guide with the help of an assisting first year doctoral student, to ensure the most appropriate questions were being asked to gather women's stories accurately. By having women tell their stories, they were able to state what was meaningful to them, and rich descriptions of these events could be developed.

The content and structure of the *Interview Guide* was developed from a variety of sources, including: (1) the empirical and conceptual psychiatric rehabilitation, caregiving, rural, family stress and coping, and feminism literature, (2) an emerging conceptual framework regarding stress, expectations, choices, and risks women make, (3) qualitative literature pertaining to phenomenological research, (4) the investigator's clinical experience with individuals with psychiatric disabilities and their families, (5) review and input from rehabilitation, family and qualitative experts.

Research Design

The purpose of this study was to explore the experiences of rural mothers of adult children with psychiatric disabilities through in-depth phenomenology.

The central question was "How do rural mothers who have a child with a psychiatric disability describe their caregiving experiences?" This question was answered with a phenomenological qualitative design that consisted of interviews, field notes and specified demographic information.

The underlying theme of phenomenology is people making meaning of their experiences, and the meaning is contained in their stories (Moustakas, 1994). The aim of the interview was to bring out the meaning by having women tell stories about their lives as caregivers to their adult children (Corbin & Strauss, 1990). This methodology was chosen because the question was based on the meaning of the phenomenon of caregiving set within the cultural and societal perspective of women (Laverty, 2003). According to Creswell (2009) phenomenological research "is a strategy of inquiry in which the researcher identifies the essence of human experiences about a phenomenon as described by participants" (p. 13). Creswell further describes phenomenological research as capturing “the meaning for several individuals of their lived experiences of a phenomenon . . . and describing what all participants have in common as they experience a phenomenon” (p. 57 – 8).

Previous family stress and coping research relies heavily on quantitative methods, with investigators using large scale surveys and standardized instruments (Gilgun, 1999). However, a qualitative design is the most appropriate approach for understanding the question because qualitative methodology was the foundation of stress and coping theories and continues to be recommended by the founders of current theories. For example, Boss (1987) advocated the use of qualitative methodology to grasp personal meanings and interpretations. Much stress and coping research uses surveys, questionnaires, and complex statistical analyses as the means for understanding processes. These methods, however, are not conducive to generating how mothers actively participate in providing care giving or how they perceive the world around them and undermine any goal of truly being able to capture human interpretations.

Data Analysis

Data were collected and analyzed from in-depth semi-structured interviews that focused on choice and the risk appraisal process, coping and problem solving strategies, meaning making of caregiving experiences, views of community, and cultural and societal expectations.

For the analysis of the study, both a phenomenological and an open-coding theory were used. Open coding is important for identifying similar themes within the data and to confirm or challenge the model prepared in this study (Corbin & Strauss, 1990).

Audio recordings were transcribed by me using Dragon Naturally Speaking. I listened to each recording and read transcriptions. I analyzed the transcripts using modified methods developed by Moustakas (1994). I began by describing my own experience of the phenomenon as a way to set aside my personal experiences. Focus could then be directed to the study participants. Next analysis continued by reviewing transcripts against the audio recordings for accuracy and making necessary corrections. I then analyzed each transcript line by line to obtain significant statements made by participants regarding their caregiving experiences. I used *horizonalization*, listing and developing preliminary groups of expressions. I then reduced and eliminated expressions that were not necessary and did not enhance the understanding of the phenomenon. I kept working until I had a list of nonrepetitive, nonoverlapping statements. I allowed for patterns, themes, and categories of analysis to emerge from the data rather than creating them prior to data collection. I objectively identified patterns in the data by placing significant statements into thematic codes or "meaning units". Referring to my field log I noted additional reminders about nonverbal communication and emotions elicited during the interviews. Key concepts expressed by participants in various different symbolic forms were coded. Each code was compared to other identified codes within and across interviews to investigate similarities, differences and general patterns. Next, I clustered codes and concepts into themes that represented summaries of the experiences of mothers. I also used *triangulation* methods to ensure validity. This was done by examining previous research similar to the phenomenon of my study, and comparing results to develop and justify the themes in my study. I also provided thick, rich descriptions of statements made by participants.

To ensure accuracy, Creswell (2007, 2009) and Moustakas (1994) recommended for qualitative researchers to engage participants more fully into the research process by having them read drafts of analyses to ensure reliability. However, as most of the women in this study were well acquainted with each other through NAMI, there was concern of how to protect confidentiality. Therefore, the decision was made not to share results with the women.

Much of the data analysis was completed by hand. I hand wrote and then typed field notes and memos. Interviews were recorded using a Live Scribe pen, then transcribed using Dragon Naturally Speaking. I also used a trial version of NVivo 10 software to assist in word searches, word queries, retrieval, and search for words between interviews. However, it proved to be more useful to conduct most research by hand than to use NVivo 10.

To recognize and limit researcher bias I met with and provided notes and analysis summaries to my dissertation chair and assisting first year doctoral student. Creswell (2007) recommended the use of peer review and debriefing to keep "the researcher honest, ask hard questions about methods, meanings, and interpretations" (p. 208). I met with the first year doctoral student on four occasions, prior to gathering data, after the focus group to assist in refining the interview guide, and twice after data had been gathered to review results. This individual had access to transcription summaries and my notes. I also included issues with bias as part of the research data. Creswell (2007, 2009) encouraged researchers to clarify bias from the beginning of the study to help prevent influence on results. I documented my reactions, thoughts, and personal experiences through memos, meetings with the assisting doctoral student, and additional readings. Finally, an outside person assisted in auditing the proof reading of manuscripts of each chapter, asking questions, and ensuring accuracy and clarity of the work.

CHAPTER 4
RESULTS

The purpose of this study was to explore the experiences of rural mothers of adult children with psychiatric disabilities through in-depth phenomenology. As there are few studies exploring the experiences of mothers as caregivers for adult children with psychiatric disabilities in the literature, a phenomenological study seeking to understand women's' experiences was best suited to exploring this question. The phenomenological approach illustrated by Moustakas (1994) was used for analysis. Transcriptions were read several times and significant phrases, statements and quotes directly related to how participants experienced the phenomenon of caregiving were extracted. I then developed meanings from the significant statements and phrases and clustered them into themes. Finally, I used the compiled themes to write a description of what participants experienced and how they experienced the phenomenon of caregiving. The collection of derived themes is included in this section.

A total of eight major themes describing the experience of caregiving emerged from the caregiver interviews. They included (1) emotionally caregiving is…. (2) coping techniques (3) faith/spirituality (4) advocacy (5) relationships (6) education (7) concern and (8) lessons learned. Each theme was the result of a meticulous reflecting process that examined the differences and similarities among the selected categories.

*Emotionally caregiving is…*includes descriptions of the varied emotions caregivers experience, and thoughts on the mental and physical cost of providing care. *Coping techniques* details the many positive and negative techniques women use in their caregiving experience. *Faith/Spirituality* refers to the importance of religious faith to caregivers. *Advocacy* summarizes caregivers' experiences of helping their own children, assisting others and advocating for the mentally ill in their communities. *Relationships* refer to the support received from family and friends and help strategies used by caregivers. *Education* includes the importance of education for oneself to better assist one's child, as well as education of others. *Concern* describes the worry caregivers have for their children as well as the continuation of helping their children, even despite negative consequences, and the co-dependency, helplessness and hopelessness with which women may struggle. Finally, *Lessons learned* summarizes reflections by caregivers about knowledge and understanding gained in their experiences, advice to new caregivers, and how they developed meaning in their caregiving experience.

Emotionally caregiving is…

In this theme, women focused on what caregiving has been like for them emotionally. Women described the feelings they have had in caring for their ill child, the stress they have incurred, and their thoughts about the mental and physical cost of providing care.

Mother 2 shared the story of what she was going through emotionally during the early years of her son's illness.

> *"I was just a bunch of nerves trying to keep my son on track and I was forgetting about myself . . . so I was referred to a specialist . . . I was diagnosed with anxiety and depression and I said to my therapist, 'I don't feel depressed' and he said 'Well, you are depressed for so long you don't know what it feels like'. . . I couldn't sleep at night. I was teaching school. I was getting four - five hours sleep at night. Things going through my head at night for my son's work, what paper needs to get done and who needs it. . . ."*

Today, Mother 2 said that she much more at peace with herself.

> *"I was seeing a therapist once or twice a week, then once every two weeks and now once a month…"*

Mother 1 shared that her feelings depend on how her son is doing.

> *"Well, I they've guess they've been really mixed, um, it gets really discouraging, particularly during times and he's not doing well. And when he is on his meds and doing well it's been an up-and-down ride."*

Mother 7 shared her current feelings of frustration with her daughter using a variety of terms and phrases. During my interview with her, she sat calmly and was matter-of-fact during much of the interview. I had a sense that she reached her end point with caring for her daughter, and that she felt defeated as she stated at one point during the interview.

> *"I feel a lot of pain", "grief", "that just breaks my heart", "it's just so painful and seems to keep on hurting and hurting, hurting me and everybody", "it just hurts so much and there's no relief until I die. I don't feel I will be free of it".*

Mother 8 shared similar current frustration she was feeling with her daughter, using a variety of terms and phrases. During my interview with her, her frustration could be felt through her animated body language, and I had a sense that she felt as if she was at the end of her rope. She would often use her hands and arms when she spoke, slap her hands on the table, and raise her voice. She stated how her daughter would:

> *"Suck the life right out of you", "would stress you out", "it was draining", "I don't know if I want another one", "it didn't matter if you gave her positive - it was never enough", and "would just suck everything out of you to the point you would - that – it – it would almost push you away emotionally, and you'd want to shut down."*

Mother 4 spoke of the worry she feels when her daughter is in a manic state or when she does not hear from her for a few days. She also spoke of the relief she feels when she finally does hear from her daughter, or when her daughter is hospitalized.

"When she finally gets in the hospital setting, there is relief because she is cared for in a *safe place. There is great relief from that."*

Mother 5 spoke candidly and with much emotion about her daughter's recent suicide attempt and how it made her feel.

"Awful. Kind of like a failure. . . I felt guilty but we got through that."

She later spoke of the incident again saying

"I felt so inadequate . . . and I couldn't protect her . . . I couldn't help her."

Coping

This theme is composed of descriptions of the types of coping techniques women use while caring for a child. Their shared reflections organize around two main categories (a) *positive* and (b) *negative* techniques. Each category includes several strategies used by women.

Positive Coping Techniques. Collected in this category are descriptions of positive behaviors women use to help them better provide care to an ill child. Positive behaviors women used include: talking to others, therapy for self, laughter, support groups, volunteering, advocacy, self-education, belonging to various community groups, taking time for self, acceptance of child, and exercise. Mother 1 discussed the importance of staying out of what she calls the "pit." She stated:

> *"A huge pit. And your loved one is at the bottom of the pit and you are at the edge of the abyss. And you are taught to pull somebody up. But if you fall down in the pit, you end up pushing. And it's easier to pull then to be down there pushing and pushing somebody out of there. It doesn't work. That's the pit I'm looking at and trying very hard to stay out of that pit."*

She went on to discuss how volunteering and working as an advocate for mental health and in her church helped her to stay out of this pit.

Mother 2 discussed the importance of working personally with a therapist after struggling for years with anxiety and depression and physical illness due to the stress she was incurring in her caregiving.

> *"So I'm doing everything I can to make myself better. . .and feeling a lot better physically as well as emotionally."*

This mother also stated how learning to let go of small things in caring for her son, learning to take one day at a time, and exercise help her to take better care of herself, as well as more effectively care for her son. She stated:

> *"You learn to take one day at a time and that's what I do. I've learned to take care of myself. And that's been a big major thing in my life to take care of myself. I walk every day and take care of myself. Because if I don't, then I get in that old habit "of poor me" and I'm not going to go there anymore. I don't want to be that way anymore, because if I'm that way, I can't take care of my son or anybody else."*

By learning to let go of the small events in her caregiving experience and taking one day at a time, she stated that she is now pretty happy with her life.

A common theme among all the mothers was volunteering as a positive coping technique. All mothers volunteer in some form. Mother 1, for example, was a volunteer at her church and belonged to multiple church groups. She also was the president of a NAMI group for six years. She also volunteered with a County Court House that operates a Mental Health Court, in which she ran a support group for young adults with mental illness that were in trouble with the law.

Four women shared how they were open with others about their children's illness and events that occur. For example, Mother 1 reflected about when her son was first diagnosed and that she and her husband did not know they were not supposed to say anything, and were open right from the beginning. They would have articles in the newspaper and began the NAMI chapter in their county. Mothers 2, 3, and 4 also discussed how they were open to others about their children's illness and their own personal experiences.

Negative Coping Techniques. Collected in this category are descriptions of behaviors women exhibit in caring for a child that could potentially have negative consequences for themselves or in other life aspects such as on their child or in their relationships with others. Negative behaviors include: avoidance, denial, anger, self-blame, and control.

Mother 1 spoke of avoidance techniques that she uses, and tries to ignore the 'downside' by staying busy. However, while she uses negative coping techniques, this mother also incorporated positive techniques as the action. She stays busy by volunteering. This mother also discussed the difficulty she sometimes has in dealing with the emotions of caring for her child:

> *". . .I can't concentrate sometimes on what I'm supposed to be doing. I get out the puzzles or whatever, to get my mind off of what's going on. Maybe I'm avoiding the emotions but, um, but it seems to be working. . .It's tough sharing emotions. I think I try to bury them. At least the negative ones . . ."*

A common theme among the women was a need for control over every aspect of their own lives as well as their children. As one mother explains that she has difficulty letting things go and states *"I try to control things."* This is confirmed by Mother 6 stating *"I'm a huge control freak. Not a good personality trait at all."*

Mother 5 stated:

> *“I guess I kind of like to control things. Because I want - I want things to go certain way. I have an idea of how things should work, and if it's not going to my specifications, sometimes I get anxious or angry that I can't control this.”*

Mother 4 stated:

> *“I've learned that sometimes my mothering can be too- too much. That I want to be active in every aspect of her life, but that's not healthy. So I've learned that I can definitely over mother (laughing). I’ve also recognized a lot of myself in her and she can very much like me and I try to put on her decisions that I would make.”*

This mother, as with the others, has recognized this need for control and has also recognized how disruptive the sense for the need of control can be:

> “*But those are my things -they're not hers. I've learned not to over share with her and not over ask. Yet be supportive of who she is. . . And being right about something isn't always the best thing.”*

Mother 2 shared the heavy amount of stress she was under due to caring for her son and becoming ill herself.

> *“I was focusing on my son and wasn't really taking care of myself. And that's when, after five years, I got sick. I lost 10 pounds in two weeks. I couldn't eat. My stomach was up-and-down. I went to the doctors. They did all kinds of tests and everything. . .”*

Spirituality/Faith

In this theme, women reflected on how their faith assisted them in their ability to provide care. Caregivers attributed their faith as an important factor to keep wanting to provide care during negative experiences, and in finding meaning. All mothers discussed the importance of faith in their lives, and four women spoke of being active in their churches.

Mother 4, who is a leader in her church stated:

> *"I feel a real connection to God and my faith experiences they have been real significant in this. I don't always know what's happening, but I know it's in God's hands. I know to trust God. And trusting her into God's hands. That's very meaningful."*

Another mother made a similar comment that *"anything's possible with God."*

Two statements are notable among the women when asked if they sought an answer to why their children developed a psychiatric disability, as reflected in a comment made by Mother 5: *"I know God doesn't give you anything that you can't handle",* and by Mother 6 saying *"Why him? Why not him?"*

Mother 3 said *"you can do a lot more than you think you can. It's like that saying that if you couldn't handle it, it wouldn't have been given to you."*

Mother 8 said *"God doesn't give us stuff we can't handle."*

Mother 4 said:

> *"It's more like why not her, God?. . .So there's a lot of things that come up that present themselves as challenges, and it's more like we're part of real life rather than, I don't know, if we should be excluded from difficulties or things. . .Why not her? Or any of us as part of life experiences."*

She then added:

> *"I feel a real connection to God and my faith experiences they have been real significant in this. I don't always know what's happening, but I know it's in God's hands. I know to trust God, and trusting her into God's hands."*

Mother 5 also shared similar views. *"I turn around and say why not her. . .I think that God loves her and God made her like that. . .Why not her?"*

There were also similar statements made regarding why they should be the mother to their children: *"I'm glad that God picked me to be her mom"* and *"So it's more like why not me?"*

As one mother summarized:

> *"I think God puts us all here for a reason and that's part of his plan and he's giving me the grace - the compassion to go after that, and to do it. You know, sometimes I asked why God, why did you do this to me but to the same answer comes to me why not me? Why not you?"*

While faith appears to be highly important to these women and beneficial in their caring experience, Mother 7 discussed the struggles she faces regarding Christ's calling to take care of those in need (in this situation, her child) and the need to take care of herself.

> *"Especially because of being a Christian. Reading the word every day and hearing every day how you got to help. . .that's what God wants us to do, I would do it. It's because of my faith. And a lot of the struggles that I've had. It's because of my faith. I do daily devotions. And if there's one theme that runs through that Bible it's help other people, help the needy."*

This comment exemplifies the struggle between what her faith tells her to do and what she thinks is best for herself, as she has given up hope that anything can be done for her daughter.

> *"I guess that's most challenging that I just can't cope with her anymore. So my choice is the let go of how I feel about my daughter . . . especially because of being a Christian . . .*

> *We're just scratching the surface here of the many times of the rescues and actually putting my life on the line two or three times to save hers, and to let all that go… Like I said, I know how to get things done, but I don't know how to get this done."*

However, this mother also reflected how she has grown due to her faith, even though she struggles with doing what she thinks is right:

> *"I believe that I have grown through this experience in ways that I would not have. And that's part of the reason why I say I would probably do it again, as painful as it's been. We only grow through our pain. . ."*

She went on to share how she would do it all over again and still care for her child because of her faith. Again, there appears to be an intense struggle she is experiencing between taking care of herself and taking care of her child no matter what, such as the verse: *"if a man takes your coat, give him your shirt, too." (Luke 6:29).*

Advocacy

All women shared that it was important to them to help others. This theme is divided into three categories that address: (a) help child (b) help others and (c) advocate for people with psychiatric disabilities.

Help child. In this category caregivers reflected upon the support they provided to children, support mothers provide include making sure their children are eating properly, taking their medication, providing a place to stay, helping look for appropriate housing, locating adequate services, and admitting children into the hospital when necessary. Mother 4 shared the amount of contact she has with her daughter to help support her.

> *"We have had an awful lot of contact by phone - almost daily phone calls while she's been going through difficulties, she would call us or we would call her, and often it would be early in the morning like Saturday's. And while she is real sick, it's even focusing on going into the kitchen, getting her pills out, and making sure she was eating and taking food with her pills. To help start her day, to help her through certain parts of her day. And there were times and that was more needed. Other times it is just the phone contact. . . When she's in the hospital, we would try make sure to go down every couple days to visit her and have that visual contact and also financially. We've supported her in many different ways over different periods of times making sure she has a place to live and adequate food and clothing and stuff like that . . ."*

One mother was the payee for her child, however, it became too much for her, causing many arguments between her and her daughter. The local CMH is now the daughter's payee. Another mother set up a special needs trust for her son. Two mothers helped their children to receive Social Security Disability Insurance (SSDI). Mother 6 shared how upset she was with a particular hospital to which her son was admitted, and she demanded that the son's attorney search for another placement for him. In the meantime, she would check her son out every day and bring him home with her, an hour drive one way.

Three mothers shared how over the years they built relationships with their children's physicians and therapists. Mother 7 shared that she was very involved in her daughter's treatment for most of the daughter's life and would have frequent contact with her daughter's therapists. Mother 2 was concerned that her son was not being honest with his therapist, so she began writing the therapist letters. Today, she will make a copy for her son and go over it with him and then mail a copy to the therapist. Mother 1 developed relationships with some of the nurses in the psychiatric unit of the local hospital where her son is usually admitted.

> *"There are times we didn't know what was going on. I sometimes found a nurse that would talk to me a little bit. I know they're not supposed to, but I had one woman call me one time saying 'I have this patient on the floor that needs a new pair of shoes.' And I said 'okay I'll take care of that.' She didn't say who it was. But we knew who it was . . ."*

Help others. This category included caregivers' discussions about how they help others who have loved ones with mental illness. All mothers report that their children's illness has actually provoked them to want to help others. As one mother shares: *"I think it's given me a real understanding of people. . ."*

Mother 2, the president of a local NAMI chapter, reflected upon her experience of helping others through NAMI.

> *"This is a good opportunity to do outreach. People come up to me and tell me a story and I'll say this is what you might want to do and I keep brochures in my purse to give. And sometimes, the very first time when people come to your support group, all they need is a hug. You can tell. . . I tell people that it's a lifelong journey."*

Despite Mother 7's strained relationship with her daughter, she reflected how she continued to attend the NAMI support group to help others. She reflected on how she has grown through her caregiving experience and wants to give back:

> *"You know, I've grown so much through these last few years with my faith. I sort of want to give."*

Advocate. In this category women shared how they advocate for people with psychiatric disabilities. Six mothers belonged to a NAMI support group. Mother 2 is current president of her local NAMI chapter, Mother1 served as president of her local NAMI chapter for six years, and Mother 6 is the current vice-president of her local NAMI chapter. These three women participate frequently in conferences and fund raisers. Mother 1 works throughout her county to advocate for people with psychiatric disabilities. She works with the local jails and County Court House to develop more awareness for the rights and needs of those with mental illness. Mother 2 frequently contacts her State and U.S. Representatives to increase awareness and increase funding for local and State programs. Mother 8 is in the human services field and works with youth living in residential care who have mental health and emotional concerns. Three husbands of participants also are advocates for people with psychiatric disabilities. Two husbands are active in NAMI, and the third husband worked for several years for a disability advocacy group.

Relationships

This theme included reflections of five different social circles women recognized were somehow affected by the care they gave to their children. These categories include: (a) with child, (b) with spouse, (c) with other family members, (d) with friends, (e) and within their community. Women provided multiple examples to illustrate the various ways, both positive and negative, the care of their children has changed their relationships with others.

With child. In this category, caregivers reflected on their relationship with their children. Women described a mix of relationships with their children. Five mothers described having close relationships with their children. One mother explained that while she supports her child, she does not have a close relationship with him compared to what her husband has, and that she relies on her husband for support when interacting with their son.

Two mothers shared current struggles they were having with their children at the time of their interviews. Mother 7 struggles with having a close and loving relationship with her daughter. She described their relationship:

> *"Because with her, you can't have - you can't have any kind of a phony or surface relationship: 'Hi how are you? Goodbye.' Because when she gets a crack in the door she'll be pushing and pushing. We have done so much for so long. And she just moved out for the last time in the middle of April, and I haven't even healed from that time that she was here."*

She went on to share the pain she feels regarding the difficult relationship she and her daughter have and the inability to have a loving relationship. *"I want my daughter. I would love to have a normal loving relationship with her, but I don't think it's possible."*

Mother 8 also shared the pain and frustration she was currently going through with her daughter and how her feelings toward her child made her feel.

> *"It was like get away from me. You know, I mean like really - right now with her. It's like I just don't want to talk to, I don't want to see you. I don't want to know nothing. If I don't hear from you ever again, it'll never be too soon. And I feel horrible thinking that, I really do. I feel like a really crappy person. But the up and downs, the roller coaster rides, just - and the intensity, there's never a break. You have your own emotional needs, and other kids who have their own emotional needs, and then you have this kid. Holy hell! You know what I mean? Where do you want me to delve from because I don't have any left. I have my husband, myself, these kids and then you have her."*

Co-dependency. It appeared that some mothers answered questions from the child's point of view (Mother 1, 3, 5, 7). During interviews, mothers would frequently have to be pulled back to talking about themselves, and not focus on their children. Mother 3, for example, tended to answer questions that were supposed to be about her, such as her personal feelings and experiences, from her daughter's perspective. Of the 13 questions asked during the interview, this mother answered five questions from her daughter's point of view. When asked about what surprised her about her caregiving experience, this mother replied how her child is *"so strong and in control of her illness."* When asked more specifically about what she had learned about herself in her caregiving experience, the mother did begin to answer from her perspective. However, she quickly began talking about her daughter and how sad she was that her daughter has lost her faith since her diagnosis.

With spouse. In this category caregivers discussed their relationships with their spouses. All women were married, and one was separated from her husband. All women reported that they had supportive husbands. When asking women who they turn to for support, 6 women said their husband. Mother 1 discussed at length of the supportive relationship with her husband.

> *"My husband, he's one of the few men I've met who really has really stood right with me the whole way and I've seen so many families where one of the other doesn't admit that there's something wrong with the child but my husband has been right there with me right from the start. . . And so when I see men coming to classes for support, I say 'that's really important for you guys to be here' . . . And what my husband and I finally realized that what we were doing is that if my husband or I were having a bad day then we make sure the other one is not having a bad day. So if my husband is having a tough day, I try and*

> *stay positive. So between the two of us, after 48.5 years together we've kind of got it figured out."*

Mother 3 reflected that in the beginning when their child was first diagnosed, her husband had difficulty accepting what was happening, but since has become an advocate for people with psychiatric disabilities. She stated:

> *"My husband was in deep denial for a long time and he just kept going on and doing his things. He thought everything would be fine . . . After he went through all of his stages of grief and finally accepted her illness and stopped blaming everybody else he became a super advocate. He's heavily involved in NAMI. He's run the walk for many years, and he was a regular at the meetings and did the family to family program*."

Mother 2, however, discussed the opposite with her husband, and the lack of support he has provided. This mother went on to describe the lack of support from her husband as being the most difficult part of her caregiving experience.

> *"For years I never got the support from my husband that I really needed . . . I was the one that took the bull by the horns and started the ball rolling and getting Medicaid and SSDI – becoming my son's representative payee. So I paid all of his bills. So I guess I get kind of angry sometimes because - because the support wasn't there. If I called SSDI and I knew I wasn't going to be home, and even though I would've explained it to my husband and wrote notes, yet he wasn't willing to - if I wasn't home - to take the phone call. He would say "I'll let my wife call you back." So I was the one that doing all the paperwork – all the grunt work."*

In asking whether or not she can rely on husband for support, she replied: *"Sometimes. Not all the time. We have disagreements."*

Mother 5 shared some of the complexities in her marital relationship. When she and her husband first began to notice their daughter's behavior changes, her husband was unsupportive and did not understand. Since he began attending NAMI, he became more supportive. This mother said that her husband is her main support, however, there are still difficulties with her ability to rely on him.

> *"I talk to my husband and most of the time I feel that he does support me. . . But sometimes I feel that he doesn't understand - he has no clue. So, I might as well go talk to the wall."*

With other family members. In this category women reflected on their relationships with other family members. All mothers reported having some support from family. When asked about relationships they had with other family members, or relationships between the ill child and other family members, mothers were likely to speak of relationships between their children. Five mothers spoke of strained relationships between the ill child and siblings. Only two mothers spoke of having support from other family members. Mother 1 reflected how supportive her family has been through the years. She also discussed how her other children need to step up to care more for their brother.

> *"Our daughter is becoming a better listener, so relying on her little bit more, but I'm getting old and someday my children will have to take care of our son. So it opens the door a little bit."*

Mother 1 went on to explain how her other son moved his family away from the area to be away from his ill brother, due to his violent tendencies.

Mother 2 shared how during the first seven years of her son's illness, she explained how her husband did not want his family to know of their son's illness. It was seven years after the son’s diagnosis when Mother 2 finally told her husband’s sister when she sent her a letter to support the upcoming NAMI Walk. She said that her sister-in-law has been supportive since then, and is now on the son’s emergency contact list. Mother 2 also explained that her youngest daughter is supportive, but the oldest daughter and son do not have much of a relationship. The mother believes the oldest daughter thinks her brother should be doing better and “he should pull up his bootstraps.” Mother 7 also spoke of relationships between her and her children, saying that she had little support from them regarding her daughter, as this daughter had burned her bridges with them. None of the other children wanted anything to do with their sister, creating a totally non-existent relationship between them.

Mother 3 reflected on how her son’s relationship with his sister who has bipolar has recently changed. When the daughter was first diagnosed, the son did not understand and was distant from his sister. As he became older, the two children become closer, and the son is very helpful in caring for his sister, describing one particular experience when she and her husband were out of state:

> *“I had to call him one time . . . and I said ‘your sister’s overdrawn her bank account. She's at school. She needs a couple hundred bucks just till we get home. Could you help me out?’ And he said ‘definitely, no problem.’ He was there within a couple hours to make sure such she had money and see if she needed anything else and took her out to lunch. So if I say ‘[Your sister] needs your help’ he's there.”*

With friends. This category included caregivers’ discussions of how caregiving has affected relationships with friends. All mothers reported having developed close and more meaningful relationships with others since their children became ill. This was interesting to me as the caregiving literature often reports of caregiver isolation (Kirk, 1999; Perlick et al., 2006; Wang & Barnard, 2004). Mother 1 reflected:

> *"We've made many new friends in our activities, such as NAMI, that have become good friends, in that way. So, if you're having a really bad day there's always someone I can call up, and they know what I'm talking about, and vice versa. So we have a really nice network now of friends it's been a big help . . .It's opened up a lot of new doors for us, rather than becoming isolated."*

Mother 7 shared similar thoughts:

> *"You know, if anything I think I have more friends now. And I'm closer to the ones that I do have… I've been through so much. I just seem to have a lot more empathy and compassion. I always did but I seem to have more so now."*

Not all mothers have experienced positive experiences with friends and co-workers. While Mother 6 did describe having two very close friends, she also described situations she encounters with co-workers when her son is ill.

> *"I feel like they judge me. You know what kind of mother are you? Or you're too over doting or you love too much. And I don't believe that you can do that. So yeah, I do believe that it does affect relationships. You know relationships at work. Well, you're spending so much time on the phone. Well my kid's in the hospital. Oh that again. That kind of judgment."*

Within the community. This category included caregivers' reflections of how caregiving has affected their relationship with their community. Mother 2 shared how as the current president of her local NAMI chapter, she often receives phone calls from people in her community and even from around the country. She shared two experiences just prior to this interview in which she helped two different families. One family Mother 2 helped when a woman noticed the NAMI t-shirt she was wearing and began asking questions. Mother 2 provided her with her contact information and brochures. The second family she assisted when a grieving father called her just after his young son was admitted to the local hospital. She spoke with the father for a half an hour on the telephone, then went to the hospital to visit the mother and provided her with some information. She explained:

> *"It makes me feel good that I can give back that I can help people because I knew what it was like asking for help. Not knowing what questions to ask or who to call or how much to tell a person and stuff like that."*

Education

This theme is shaped by caregiver recognition of the importance of education as well as its role in advocating for the rights of people with psychiatric disabilities. This theme is divided into two categories: (a) education of self and (b) education of others.

Education of Self. Mother 3 spoke frequently of educating herself about her daughter's illness to be able to better help her.

> *"I got a couple of books. I got a better picture, I became educated. I did research. To me reading is the only way you're going to learn. . . I just sat down and learned. I learned as much as I could, then I felt better able to deal with it. Then I could talk to the doctors and ask better questions because a lot of it was just so new to us."*

Mother 2 also shared how educating herself helped her to not only be better prepared to assist her son, but helped her to become a stronger person. For Mother 2, education and strength appeared to be intertwined, which in turn guided her to want to help others.

> *"And when I have a question, and it's not answered, I just go to someone else. I do the research on it or ask questions . . . And I think it's made me stronger in my in my quest for information on mental illness stuff, and in contacting representatives."*

This relationship between developing strength through self-education appeared to assist her to become a good advocate for her son as well as build their relationship.

For Mother 6, meaning in her caregiving experience came through education.

> *"I've jumped right into it. I'm just that way. I get on the Internet, I go to the library. I want to know. I've educated myself and that's been meaningful."*

Education of Others. The need to educate others about psychiatric disability appeared to be important to all women, as all women were involved in education of others about mental illness. Mothers saw the necessity in speaking out for mental health rights and to provide information to new caregivers, community members, and government representatives.

As Mother 3 stated:

> "*It feels like they need to educate people because I was one of those people. I didn't understand or know . . . I feel that people need to be educated. Sometimes it's not their fault that they don't know. So if you just explain things to them. And that's how my husband looks at it. People just need to be educated*."

Concern

Women shared the extent of concern they have for their children. Such feelings were reflected in a number of different and profound ways, dividing this theme into three categories. All caregivers described (a) worry they have for their children, (b) helplessness and (c) hopelessness they have in their experiences.

Worry. Every mother described the love she had for her child, and wanting to help and make everything all right. *"We are there to help her out and love her and let her know that it's going to be okay"* Mother 5 reflected. However, they express uneasiness about the well-being of their children. Mothers used phrases such as:

> *"It's a lot of work and a lot of worry and stuff like that", "It's difficult worrying about her and know is she going to be okay?", "there were worries about her safety and her well-being. You know those underlying kinds of concerns",* and *"do I always have to worry? But I guess that's my problem, I'm her mom."*

Mothers expressed long-term concern for children. Mother 2 stated *"What's going to happen when we're gone?"*

Mother 6 shared similar concerns:

> *"He has nothing. When he's working he makes an incredible amount of money. I worry mainly for his health. I think the role that I play is the worrier. He's got nothing. He's living with me he has no money. What's going to happen, when I'm not around to help him? Who is going to take care of him when he needs to go to the hospital? He's burned out a lot of friends and family because it can appear that he doesn't care."*

Mothers also shared the worry they always felt regarding reoccurrence of symptoms and probable hospitalization. For example, Mother 5 described how when her daughter is doing well, she is always looking for signs of her daughter's next episode: *"But there's always that, gosh, that next episode - when is the second episode going to happen?"*

Mother 6 shared similar thoughts when discussing the pain she feels every time her son is hospitalized: *"And I wait for it, 'cause I know it's going to happen again. . . Always. Every time he walks in the house when he's been out, I'm looking at his eyes."*

Hopeless. A sense of hopelessness was interpreted from interviews. Hopeless is defined according to the Merriam Webster Dictionary (2012) as "providing no hope, beyond hope or optimism, without hope, despairing, impossible to accomplish."

Mother 7 reflected on how she went from believing there was hope for her daughter to her current feelings:

> *"I never gave up believing in her and constantly reinforced that with her: 'I believe in you. You'll get through this.' And I've come all the way from that to today thinking that I have no hope…and I just kind of clarified in my mind last night, it's not that we don't have hope for her. As being a Christian I know God can do anything. I've given up hope that there's anything that we can do, and our roll now should be to be out of her life completely for this moment in time."*

She later commented: *"I'm a fixer, and I can't fix this."*

Helpless. Helplessness also was sensed during interviews, and women sometimes felt helpless to assist their children or to locate the most appropriate services. Helpless is defined according to the Merriam Webster Dictionary (2012) as "unable to help oneself, weak or dependent, deprived of strength or power, powerless, incapacitated, and unable to defend oneself or act without help."

Mother 5 shared the painful story of when her daughter slit her wrists and how lost she felt to do anything:

> *"I felt so inadequate . . . and I couldn't protect her . . . I couldn't help*."

She went on to say: *"I felt that I always could deal with things. We could talk but this time there was nothing."*

Mother 8 also expressed a profound sense of helplessness in her story of the situation she was currently having with her daughter.

> *"The thing is there's no way to force her into CMH services that we know of. So you're at a loss because you know she needs medications, she needs services and she's into drugs again. She just stayed the night at our house last week trying to tell me that she was pregnant. I don't think that's true. Again, what you do?"*

She also remarked about the lack of support from family and community members:

> *"Where are they at to help? You're on your own really . . . I guess the only part that ever has been an issue has been what you want me to do with these kids of mine that you say we're such wonderful parents for when it's very clear they have certain needs that we can't get met?"*

Lessons Learned

This theme is shaped by caregivers' discussions of the lessons they have learned. This theme is divided into three categories: (a) advice to others, (b) learned about self and (c) finding meaning. The categories addressed challenges with which caregivers struggle and have overcome; and the development of how they found meaning in their caregiving experience as well as in their children's illness.

Advice to Others. In this category women share stories about lessons learned from personal experiences, mistakes they made, what has worked for them, and suggestions for what to avoid. Mothers described how they took care of themselves by making sure they had time for themselves, engaged in leisure activities such as exercise, played games, volunteered, sought therapy for themselves, and support of others.

Mothers 1 and 2 shared that it was important for them not to become depressed and focus on the negative, that parents are unable to help a loved one if they themselves are depressed. To avoid feeling down, Mother 1 spent time volunteering and participating in leisure activities. For Mother 2, it was important to take care of one's self. Mothers 2 and 7 shared how therapy has been helpful for them. Both women were very focused on their children, putting themselves on the back burner for so long that they became physically ill. Their therapists were there for them as someone to talk to, to sort through emotions and thoughts, and to develop effective strategies to help themselves, and their children. For Mother 2, her therapist helped her identify what her triggers to provoke her anxiety and depression are, learn to take time out for herself, to take one day at a time, and to not control every situation. She also found that her involvement in NAMI, attending conferences and workshops has been helpful. She reflected on the importance of mothers not trying to take everything on:

> *"Can't do all things for all people all the time. And that's what I was trying to do and that's what gets me going. . ."*

When discussing how she currently was doing compared to five years ago when she fell ill due to the heavy amount of stress she was under, she replied:

> *"I'm more at peace with myself now"* and *"Some days are good and some days are bad, and when I have bad days I put on my shoes and go for a long walk or bike ride or something."*

Mother 6 also shared how much she can become so wrapped up in her son's well-being that *"I sometimes feel like - that my life really wasn't my own."* She stressed the importance of taking care of one's self:

> *"That you have to take care of yourself. It's paramount. You have to take care of yourself... If that child's in the hospital, they'll be okay for the extra 10 minutes, that you just go take an extra-long shower, or 'I have to go to bed now. Good night.' You just gotta trust that it'll all be there in the morning, if you stay up and extra hour or not. You have to take care of yourself. And so many people told me that in the beginning. And I said I'm fine, I'm fine, but it accumulates. Until all of a sudden, Oh, I am not fine."*

Mothers would sometimes struggle between taking care of their children and the need to take care of themselves. Mother 7 shared her heartbreaking story of her caregiving experience with her daughter. She reflected on everything she did for her daughter over the daughter's life time, only to have the daughter's psychological health continue to become worse, ruin relationships with others, harm the health of the mother's grandchildren and her own health. With the help of her therapist, this mother came to the realization that, for her own health, she had to end her relationship with her child.

> *"I want my daughter. I would love to have a normal loving relationship with her, but I don't think it's possible, my therapist doesn't think it's possible."*

She then commented:

> *"We've done so much and it doesn't help. For now it has to be this way."*

Mother 8 also was currently going through a difficult situation with her daughter. While she shared exacerbated emotions at one point regarding how she did not care if right now she ever saw her daughter again, she later shared how she could never give up on her in two very poignant statements about how to get through the tough times.

> *"I look for little pockets of these things that make my heart immensely happy in they're always little small things"* and *"they're those little things. Little things. And I make sure that I recognize them because if you don't it's awful gloomy."*

She also reflected on the importance of laughter and of not giving up.

> *"Laugh is much as you can find the good and the humor in everything that you can, be creative. If one thing doesn't work, try something else. Sometimes you are gonna mess up. Sometimes you are gonna fail. You just you got to keep going and you just find those little bits of happiness and don't give up. God, be better than me. . . And make it as bearable as you can by not stressing over what you don't have to."*

Learned about Self. Women shared reflections about what they learned about themselves through their caregiving experiences such as developing self-reliance. For example, Mother 8 reflected:

> *"I've learned that I'm stronger than I think I am"* and *"it's made me stronger . . . It's made me depend on myself."*

Mother 6 reflected:

"I've learned that – that inner strength. I felt that way, but I've never said it out loud. The inner strength I have is incredible. I've learned that about myself. It's amazing."

Women also felt that they are more comfortable with themselves, want to be involved with other people, have learned how to listen to others, to be more patient and understanding of other people, and that they are not perfect and are not supposed to be able to fix everything. As Mother 8 said in a very emotional moment for her:

> *"It's about being human and understanding that you're not supposed to be able to fix everything. You're not supposed to be responsible for everything and you're certainly not supposed to be perfect. And when I remind myself of that I can kind of settle down and I can live with that. I'm not as, um - I am not the phenomenal parent that I thought I could be because I knew of all the wrong things not to do. . . I know I'm gonna make a bunch more mistakes. And I'm not looking forward to that. But damn I love those kids."*

Meaning Making. In this category are women's descriptions about how they came to develop meaning in either their caregiving experience or in their children's illness. Five women shared how they developed meaning in their caregiving experience and their children's illness by helping others. For example, Mother 1 and 7 reflected on how they found purpose through their difficult relationships with their children by sharing their experiences and assisting others.

Mother 4 reflected:

> *"The reward of knowing that your involvement helps at a deeper level. And giving thanks and all things, even in difficult situations."*

Mother 5 found meaning in her daughter's illness through her daughter's ability to help others: *"Because maybe someday she's going to turn around and help somebody else."*

CHAPTER 5
DISCUSSION

The purpose of this study was to explore the experiences of rural mothers of adult children with psychiatric disabilities through in-depth phenomenology. The research question of interest was: How do rural mothers who have an adult child with a psychiatric disability describe their caregiving experiences? While some of the findings are consistent with current research, careful review reveals additional findings in this study that were contrary to previous research. Most interesting, when comparing current findings to previous research, was the positive experiences caregivers shared. I was struck by how much the women spoke of positive aspects of their caregiving experiences and how involved they are in their communities. While I assumed caregivers must experience some benefit from caregiving, I did not expect these women to talk so much about the benefits they received from caregiving such as relationships, community involvement, and spirituality.

Research and clinical interventions focus primarily on alleviating negative elements. I witnessed and partook in this same mentality in my own work experience, where primary focus was often on providing services to alleviate negative attributes in clients. Furthermore, in my personal experience, emphasis was on the individual with little focus on the wishes and needs of the family. Such personal experiences could have hindered my ability to recognize that caregivers matter and do experience positive benefits. Such perspective also could have hindered my ability to understand the caregiving experience in a holistic way, to ask questions in a way that encourages expression of, and to recognize the positive experiences women had even when discussing negative experiences.

Previous research traditionally has focused on the negative experiences and outcomes (Berg-Weger, McGartland Rubio & Tebb, 2001), thus creating a large gap in research and service provision. This leaves researchers and practitioners with little understanding of benefits or rewards caregivers may experience, and development of effective and creative prevention and intervention strategies that could be implemented (Heru, 2000; Kramer, 1997). By focusing on the positive and identifying strengths, practitioners could assist in elevating a client above a neutral point that could better serve the individual and her or his family with moving forward (Berg-Weger et al., 2001).

The little available research regarding positive perceptions and experiences of mothers and other care providers suggests that the more positively one perceives the caregiving experience to be, the higher caregiver well-being is (Berg-Weger et al., 2001). Positive perceptions also are influential in the decrease of caregiver burden and physical and emotional illness and with increasing the potential to improve quality of care (Hilgeman et al., 2007). In fact, according to Schulz and colleagues (1997), 40% of caregivers experienced no negative effects in caregiving. In an earlier study by Farran, Keane-Hagerty, Salloway, Kupferer, and Wilken (1991), 90% of 94 caregivers interviewed held positive beliefs in their caregiving experiences. The following sections will provide a comparison of the current study to previous findings, contributions to the field of counseling and caregiving, study limitations, and recommendations for future research.

Comparison to Previous Research Findings

Emotions. Some of the findings in this study support existing caregiving research regarding the emotional impact of caregiving on caregivers. In this study, women shared emotions they have felt as a result of their caregiving experience. Women spoke of feeling nervous, anxious, depressed, and discouraged, and experience of pain, grief, hurt, and guilt. The statement made by Mother 1regarding how her caregiving experience has been an emotional roller coaster ride epitomizes the feelings women felt in their caregiving experiences.

> *"It gets really discouraging, particularly during times and he's not doing well, and when he is on his meds and doing well it's been an up-and-down ride."*

Mother 1 also made a poignant statement about the emotional toll caregiving has had on her in her "huge pit" statement:

> *"A huge pit. And your loved one is at the bottom of the pit and you are at the edge of the abyss."*

While women often focused on the negative feelings they experienced, they did speak of positive feelings of relief, for example when Mother 4 spoke of how she feels when her daughter is finally hospitalized when in a manic state:

> *"When she finally gets in the hospital setting, there is relief because she is cared for in a safe place."*

Past literature regarding the negative emotional effect of caregiving has been well studied (Hilgeman, Allen, DeCoster, and Burgio, 2007). However, despite the importance of focusing on both the positive and negative emotions caregivers may experience, few researchers have investigated both aspects of caregiving, and even fewer have focused on the positive (Boerner, Schulz, & Horowitz, 2004). Hilgeman and colleagues (2007) found caregivers who appraised the caregiving experience as positive to have better emotional health. According to Cohen, Colantonio, and Vernich (2002) caregivers who focus on the positive feel more useful, important and competent when providing care to a loved one. While the women in this study often spoke of the negative emotions they felt and less often of the positive emotions, they did focus on positive experiences and actions, such as developing close relationships and helping others. An example is Mother 7's comment about developing empathy and closer relationships:

> *"You know, if anything I think I have more friends now. And I'm closer to the ones that I do have… I've been through so much. I just seem to have a lot more empathy and compassion. I always did but I seem to have more so now."*

Furthermore, caregiver burden literature (Kuipers & Bebbington, 2004) indicates that caregivers who experience higher amounts of stress and burden due to their caregiving are more likely to perceive their situation as unbearable. In the current study, all women spoke of stress and frustrations, and had at some point struggled with when to draw the line in helping Mother 7 currently was wrestling with this as she commented: *"We've done so much and it doesn't help."* However, most women reported that they would not give up, and in fact had found meaning in their caregiving experience which in turn may help them to want to keep providing care. An example of not giving up and finding meaning is found in a comment made by Mother 4:

> *"The reward of knowing that your involvement helps at a deeper level. And giving thanks in all things, even in difficult situations."*

It is reasonable to conclude that such actions stem from having positive feelings about their caregiving experiences.

Folkman and Moskowitz (1997) have suggested that positive emotions stem from the use of positive coping techniques. However, they also warn that while there is an abundance of research regarding both coping and emotion, it is still unclear how they are connected. While emotions and coping techniques may appear intrinsically tied, they may be very separate. Folkman and Moskowitz (2000) have called for researchers to focus on *how* caregivers experience positive emotions and not just on *what* emotions they experience. Further research is needed to more fully understand the role of emotions in the caregiving experience, coping process and adjustment/adaptation.

Coping Techniques. Folkman and Lazarus (1988) indicated that people use two types of coping strategies: cognitive and emotional. Folkman and Moskowitz (2000) later reported on their findings of caregiver appraisal that caregivers use three broad positive coping techniques. These include positive reappraisal (discovering opportunities for personal growth, seeing how one's own efforts can benefit others), problem focused coping (learning how to manage and solve stressful events), and creation of positive events (taking the time to create meaning from every day events).

In the current study, women used a variety of cognitive and behavioral techniques to cope with their caregiving experience that could be either effective or ineffective. For the current study, effective techniques were categorized as positive, and ineffective were negative techniques. Positive techniques the women used included: talk to others, therapy for self, laughter and humor, support groups, advocacy, self-education, belong to various community groups, take time for self, and exercise. These findings coincide with previous research (Folkman & Moskowitz, 2000; Wrosch, Amir, & Miller, 2011). Wrosch and colleagues, in their study of effective and ineffective coping strategies, reported effective coping strategies to include acceptance, positive reframing, active coping, and planning, and that these decrease burden and increase emotional well-being. In the current study, negative coping techniques included: avoidance, denial, anger, self-blame, and control. Previous research has found ineffective coping strategies including self-blame, venting, denial, avoidance, and resignation have been found to decrease emotional well-being (Wrosch et al., 2011).

Previous research on problem focused coping, or cognitive and behavioral approach techniques (Folkman & Lazarus, 1988; Moos & Halohan, 2007, Wrosch et al., 2011), indicates that such techniques are used more often when a situation is viewed as changeable, or when the individual has personal control. Kling, Mailick-Seltzer and Ryff (1997), however, argued that despite being faced with a situation that was unchangeable, mothers who had long-term experience with a stressful situation such as caring for a child with a disability, have higher rates of well-being than mothers who were newer to caring for a child with a disability, or had less experience, such as when the child resides in residential care. In the current study, all women interviewed have had long term caregiving experience, and appeared to have an understanding that their children would always have their psychiatric disability. Furthermore, while caregivers reported a decreased ability to cope with their situation overall compared to residential mothers, they reported higher levels of well-being and meaning in life.

The women in the current study reported use of problem focused coping techniques. This is observed in the following statement made by Mother 2:

> *"And when I have a question, and it's not answered, I just go to someone else. I do the research on it or ask questions."*

The use of problem solving techniques is also observed in a comment made by Mother 6:

> *"I've jumped right into it. I'm just that way. I get on the Internet, I go to the library. I want to know."*

These women took charge of their lives, began helping others, became mental health advocates and actively involved in their communities, and found purpose in their caregiving experiences. While women did use emotional and negative coping techniques, their use of positive and problem-solving coping techniques stood out. As Kling et al. found, the use of coping techniques caregivers use may depend on experience. Future research should focus on longitudinal studies of caregivers and ill children to see how coping techniques change over time. No such study could be found. Furthermore, Folkman and Moskowitz (2000) caution researchers not to assume that coping techniques that decrease negative emotions are necessarily the same techniques that increase positive emotions. Future research is needed to address what specific coping mechanisms caregivers use to increase positive emotions and decrease negative emotions.

The women in the current study appeared to have developed effective coping strategies that have helped them to have positive well-being, and have led to successful adjustment and adaptation in their caregiving roles. This is found in a statement made by Mother 8 about not giving up:

> *"Laugh is much as you can, find the good and the humor in everything that you can, be creative. If one thing doesn't work, try something else. Sometimes you are gonna mess up. Sometimes you are gonna fail. You just you got to keep going and you just find those little bits of happiness and don't give up. God, be better than me. . . And make it as bearable as you can by not stressing over what you don't have to."*

Thoits (as cited in Kling et al., 1997) found that effective coping increased positive well-being in participants, buffered people from negative experiences and allowed them to get through life's challenges with greater ease then people with less effective coping skills and lower well-being. In the current study, indicators of participant well-being were represented by self-reliance, advocacy, and empowerment.

Self-reliance. Previous research indicates that the longer people live with chronic health conditions, the more likely they are develop a sense of mastery and self-efficacy, and cope effectively with their illness (Kling et al., 1997). This may be due to the increased familiarity and long term knowledge of the health condition, available services, medications, or health care/service management.

The women in the current study shared frustrations they currently were experiencing, and discussed feelings of anxiety and depression, but in past tense terms during the child's initial diagnosis. All women in the current study were in their caregiving roles for a number of years, so it is reasonable to conclude that they would experience increased feelings of self-reliance, and decreased levels of anxiety and depression. At this point, their experiences are routine. They know what they must do when their children experience an episode such as mania or clinical depression, and must be hospitalized

Empowerment. The limited previous research regarding empowerment in the caregiving experience indicates that caregivers can feel empowered (Berg-Weger et al., 2001). In the current study, while the women did not speak directly of feeling empowered, there was indirect reference to feeling of empowerment. This was demonstrated through their involvement in helping other families, educating people and their communities, working with youth, willingness to speak openly about their children's illness, and to standing up for mental health rights. For example, Mother 1 began the local NAMI group and was the first president for the county. Today, she works with her county mental health court and runs a support group. Mother 2, the current president of the NAMI group, spoke of attending conferences and charity events, and working with families:

> *"It makes me feel good that I can give back that I can help people because I knew what it was like asking for help."*

Resilience. In the current study, women appeared to be resilient. Little literature on caregiver resiliency could be found. Indicators of resiliency include effective coping strategies, optimism, problem solving abilities, social support, sense of purpose, determination, and self-efficacy (Abelev, 2009; Gilgun, 1999, Lockenhoff, Costa, Duberstein, & Friedman, 2011; McCubbin & McCubbin, 1989a,b). The current findings support this. The women in this study appeared to have developed effective coping strategies, self-efficacy, and reported positive relationships. An example of resilience is Mother 2's comment about taking care of herself:

> *"You learn to take one day at a time and that's what I do. I've learned to take care of myself. . .Because if I don't, then I get in that old habit 'of poor me' and I'm not going to go there anymore. I don't want to be that way anymore, because if I'm that way, I can't take care of my son or anybody else."*

Mother 4's statement about her reliance on her faith is another example of resilience:

> *"It's more like why not her, God?. . .So there's a lot of things that come up that present themselves as challenges, and it's more like we're part of real life rather than, I don't know, if we should be excluded from difficulties or things. . .Why not her? Or any of us as part of life experiences."*

Mother 7 had experienced a very difficult time with her daughter, and was coming to the conclusion that she needed to stop caring for her daughter for her own health. While she often spoke negatively of her caregiving experience, she also spoke of how she had grown:

> *"I believe that I have grown through this experience in ways that I would not have. And that's part of the reason why I say I would probably do it again, as painful as it's been. We only grow through our pain. . ."*

These women knew how to access appropriate services for their children and who to speak with, such as Mother 1 who received phone calls from nurses when her son was hospitalized, and Mother 6 who had her son's lawyer locate another hospital for the son.

They also had meaningful relationships with others:

> *"We've made many new friends in our activities, such as NAMI, that have become good friends, in that way.. . .It's opened up a lot of new doors for us, rather than becoming isolated."*

Involvement in a support group may have played a role in the women's resilience. Chen and Greenberg (2004) found a positive correlation between caregiver support and resilience. An earlier study by Marsh and colleagues (1996) also found a positive relationship between support received by caregivers and resilience.

Support and Relationships. According to previous caregiver literature, it is the mother who takes on most caregiving responsibilities (Gutierrez-Maldonado et al. 2005; Zauszniewski et al., 2009). Previous research has indicated that family caregivers experience a loss of relationships with friends and family and experience isolation (Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006; Zauszniewski at al., 2009) due to time spent caring for the loved one. Previous research also has revealed that women care providers, more than their male counterparts, experience mental health issues such as depression and anxiety. Additionally, loss of social support is a detriment to caregiver physical, emotional, and mental health (Pakenham et al., 2006). The current study did not confirm these findings. Women talked about how they developed enriched relationships with others and had supportive and highly involved husbands. For example, in this study, all mothers, except Mother 2, reported their husbands to be a primary support for both them and their children, even Mother 6 who is separated from her husband. No studies could be located that specifically addressed implications of spousal support.

Support group involvement and effects. The women in the current study also spoke of their reliance on support groups, specifically NAMI, and positive relationships they have developed within this group. While women did speak of losing some friends and lack of understanding from others, they also spoke of developing more enriched relationships with others since their children became ill. This may, in part, be due to six of the mothers involvement in NAMI. For example, Mother 1 said:

> *"We've made many new friends in our activities, such as NAMI, that have become good friends."*

Little research exists regarding benefits of support group involvement (Chen & Greenberg, 2004) to compare to the current findings. Chen and Greenberg examined the type and amount of support caregivers received, and benefits (perceived personal growth and interpersonal relationships) caregivers received who had support. A positive correlation was found between the amount of support received and benefits. Caregivers felt that support helped them to cope better with their situations, to be more understanding of their loved one with mental illness, and more patient. Most interesting, participants reported becoming advocates for mental health services due to support received.

Munn-Giddings and McVicar (2006) found that people who belonged to support groups valued the relationships they developed with others in the group due to a high level of positive support they received from each other, a deep level of trust in fellow group members, and seeing the support group as a "safe place" to express one's self. They also found that caregivers who belonged to support groups experience increased self-confidence, assertiveness, empathy, improved ability to listen to others, and avoidance of judgment. The women in the current study spoke of how they have learned to be more patient with people, be better listeners, be more empathetic, and become more assertive and self-reliant. Mother 2's comment about outreach is an example:

> *"This is a good opportunity to do outreach. People come up to me and tell me a story and I'll say this is what you might want to do and I keep brochures in my purse to give. And sometimes, the very first time when people come to your support group, all they need is a hug. You can tell. . . I tell people that it's a lifelong journey."*

Aschbrenner, Greenberg, Allen and Mailick Seltzer (2010), in their study of subjective burden and personal gains of parents with adult children with psychiatric disabilities, found that parents who were active members of NAMI and other support groups reported more personal gains than parents who did not belong to such groups. Furthermore, the researchers found these parents who belonged to support groups also have lower levels of subjective burden compared to their counterparts. Further examination of the benefit of belonging to a support group are needed, little research could be found comparing caregivers involved in support groups versus those not involved regarding outcomes. While research traditionally indicates that caregivers experience burden, isolation and at risk for mental health conditions such as depression and anxiety, what would happen if they belonged to a support group? Support group involvement may be an informal intervention for practitioners to introduce to clients and their families to alleviate much of the stress and resulting outcomes they experience.

Advocacy. All women in the study were advocates for their children. They ensured their children received adequate services, helped search out appropriate services and providers, filled out necessary paperwork, and made necessary arrangements when their children were hospitalized. Many of the women also were advocates for all people with psychiatric disabilities, and those with mental health concerns. Finally, a common pattern found in the current study was women speaking about education. They spoke of the need for self-education to give them a better understanding of what their children were going through, as well as a way to cope with their experiences. This can been observed in comments made by Mothers 2, 3 and 6 who all stated that self-education helped them to be better advocates for their children. Mother 2 spoke of her work to educate other parents who were new to the caregiving experience. Mother 3 spoke of the need for education in one’s community and society. Women participated in conferences and awareness walks, and contacted legislators and congress members as ways to educate one’s community and society about mental health.

Little literature was found on caregivers as advocates. Instead, focus has been on the need for advocacy for caregivers. In an older study by Koren, DeChillo and Friesen (1992), they suggested, through anecdotal evidence, the initial years of caregiving is focused on the health and well-being of children. Later, parents may turn to helping other families. Eventually, parents may become engaged in advocacy and education at a more global level. In their study, Koren and colleagues found that parents who felt empowered were more likely to become advocates for various conditions. Neufeld, Harrison, Stewart, and Hughes (2008) found that, as advocates, women were better able to develop effective strategies to assist their loved one's mental health and treatment management, educated themselves and others, and were better equipped to seek out and fight for services and campaign for adequate services and mental health rights.

Aschbrenner and colleagues (2010) found that education and mutual support influenced parents to become advocates for their children and for mental health rights. They concluded that by participating in a support group and having the opportunity to share with others going through similar situations "may help parents become more aware of their own growth and development through their own personal journey in coping with their child's illness" (p. 609).

Stigma. Previous research indicates that people close to individuals with psychiatric disabilities experience stigma themselves (Mak and Cheung, 2008). Such attitudes can, in turn, negatively affect the level of care provided to a loved one (Zauszniewski at al., 2009). The current study did not support these findings. Women were asked directly about how they think their community and society views parents with children with psychiatric disabilities, and if they have felt judgment by others. While the women did acknowledge that stigma existed and spoke about the need for more awareness, they spoke little of personally experiencing negative attitudes from individuals, their community or society. Mother 8 did share that she sometimes felt judgment from others, but thought this just may be her perception. Mother 6 said that she experienced judgment from friends and co-workers regarding why she continued to help her son. Mother 2 and 5 said that in the beginning they felt judgment, but no longer paid attention to attitudes of others. Despite my attempts to have mothers focus on attitudes they may have experienced in their community and society, all mothers focused very little on this topic, and had very little to say. Community and societal attitudes and expectations did not appear to affect the care, or quality thereof, these women provided to their children. This may be due to different reasons. One, it would be reasonable to conclude that as these women are highly involved in their communities regarding disability awareness and are willing to fight for just treatment, may be able to look past the stigma and negative attitudes to do what they think is right. Second, as the women in this study had many years of experience caring for their children, what others think may simply not matter to them at this point in their lives. Third, the women in this study reported to have positive and supportive relationships with a spouse, friends, church, or support group. This support from others may provide them with the strength and confidence to ignore attitudes from others and societal expectations.

Religious faith and Spirituality. Previous research indicates caregivers may feel a connection and reliance on religious faith and spirituality (Berg-Weger et al., 2001). In fact, in one study, investigators reported that about 70% of caregivers attend regular church services and used prayer as a coping mechanism (Berg-Weger et al., 2001). In the current study, all women shared stories about their personal connection to faith and reliance on God, and exemplified the importance of religious faith in their lives. I was surprised by how often the women spoke of their reliance on God. Several women spoke of placing their destiny and trust in God's hands. When asked if they had sought answers for their children's illness, women would respond with "*God does not give you more than you can handle*" and "*why not my child*." One mother demonstrated her reliance on God by saying:

> "*You know, sometimes I asked why God, why did you do this to me but to the same answer comes to me why not me? Why not you?"*

The women also placed importance on spirituality in their caregiving. Religious faith and spirituality, while often associated together, can be separate entities (Carr, Hicks-Moore, & Montgomery, 2011). According to Carr and colleagues, spirituality is “the essence of a person; a quest for meaning and purpose in life; forgiveness; inner strength; and connectedness to self, others, nature, and/or a higher power” (p. 400). There is limited research on the role of spirituality and its importance in caregiving, coping and health. Early evidence suggests that spirituality can play an important role in the health of caregivers and loved ones, can increase the quality of care provided, and increase quality of life (Carr et al., 2011). The mothers demonstrated spiritual caregiving through the small things they did for their children, including making sure a child was taking his/her medications, getting to appointments, eating proper meals, and talking frequently with the child either in person or on the telephone. Carr and colleagues conducted a phenomenological qualitative study on the spirituality of Alzheimer’s patients and caregivers. When asked to describe how caregivers provide spiritual care to patients, participants referred to “little things,” or seemingly small and insignificant actions, such as learning someone’s likes/dislikes, taking a walk with a patient, having tea or coffee, or just sitting and talking to a patient for a while. Spirituality increased positive relations between patients and caregivers, provided meaning in caregiving and in finding out what is meaningful to patients, increased a sense of personhood, and “fostered connections” between people. Such findings were similar in the current study. The majority of the mothers who provided these “little things” to their children spoke of having close relationships with the children.

Meaning. People can find meaning through events that cause suffering. For example, spousal bereavement and traumatic events have been found to be catalysts for people to search for meaning (Kim, Schulz, & Carver, 2007; Reker & Woo, 2011). Frankl (1988) stated that people find purpose in life when they forget about the self and seek to serve others. He later argued (2006) that people find meaning through three different outlets: (a) doing good deeds, (b) encountering others in their uniqueness by loving them, and (c) choosing a positive attitude when faced with unavoidable suffering and being challenged to change oneself. Women in the current study appeared to have accomplished this. They spoke of finding meaning in their lives, accepting their children for who they are, working with families, educating others, and being advocates. Farran and colleagues (1991) explained two types of meaning people can develop: (a) developing meaning through day to day care (as Carr and colleagues explained to be the "little things"), and (b) a greater existential meaning. For the women in the current study, developing purpose appeared to intertwine with spirituality as demonstrated by their responses regarding God not giving people more than they can handle and why not their children. While I did ask women whether they sought meaning in their caregiving experiences, they were not asked to explain the difference between religious faith and spirituality, as this was not the purpose of this study. Future research should address ways caregivers provide spiritual care and investigate the relationship between faith, spirituality and meaning making.

Conclusion

The women in this study appeared to be resilient and have a sense of empowerment in their caregiving experiences. Despite facing many frustrations in caring for their children, they were involved in support groups and/or worked with youth with mental health conditions, and were advocates for people with mental illness and their families. They worked with other families, contacted State and U.S. Representatives, attended conferences and participated in fundraisers. Women also spoke of having developed meaningful relationships since their children became ill. They found meaning in their experiences and children's illness, and were religiously faithful and spiritual. While they may use negative coping strategies such as avoidance and denial, they also used many positive strategies, accepted their children, and refused to give up. They learned how to adjust and adapt to their situations in an effective manner. They also appeared to have been able to learn how to move past negative attitudes, and not let stigma, stereotypes and expectations affect the way they live their lives and provide care.

The results gathered in this qualitative study provide a richer understanding of the caregiving experience. Traditionally, focus of psychiatric disability research and service provision has been on the individual, ignoring the family. Additionally, caregiving research has largely focused on negative aspects such as the burden families experience, expressed emotion, isolation, and limitations. As this study demonstrates, families do have positive experiences, gains and emotions, and can do well when caring for a loved one. Families can effectively cope, adjust to their situations, and adapt successfully. A skewed perception has been maintained in both practice and research that mental health is about the alleviation of negative attributes, and that good mental health is the lack of negative emotions and disorder. Mental health is more than just the alleviation of negative emotions and mental health. Mental health is about well-being and striving to move forward. By placing primary emphasis on negative aspects of mental health, we lose sight of the positive gains and experiences that clients and families can have. We limit our ability to help people to reach for something more, and to truly help. Focus on negative aspects, such as limitations, also leave a significant gap in theory.

Revisiting the Sociocultural Model of Maternal Caregiving

This study appears to have confirmed some portions of the model introduced in this study. In the introduced model, it was hypothesized that Society and Community views and expectations would influence the meaning women developed regarding their experiences. This would affect women's situational appraisal of their caregiving experience and the choices they perceive themselves and their families to have. Situational and Choice appraisal would then affect the power women perceived themselves and their families to have, the resulting coping techniques and actions they developed and their adjustment/adaptation to their situation. Their appraisals and resulting choices also would be influenced by available services in the community. In other words, women who felt they had limited choices and appraised their situation as hopeless would be less likely to use available services, even if they were highly effective and easily accessible services. Furthermore, if the only services available were limited, ineffective, or difficult to access, women would be more likely to assess their situations and choices as limited and see themselves and family as having less power.

Meaning Making

In the current study, women developed purpose in their caregiving experience and their children's illness. They developed purpose through helping their children, helping and educating other individuals with psychiatric disability and families, and advocating for mental health rights. Such meaning appeared to have positively influenced their situational and choice appraisal.

Situational and Choice Appraisal

While there appeared to be an underlying understanding that their situations would not change, women still saw their situation and their children's illness in a positive light. Women accepted their children for who they were, wanted to help their children, and looked beyond their immediate family to want to help others. The women did discuss difficulties in locating appropriate services, and the time and energy spent finding adequate providers, yet they never gave up. They continued to search out options, and when there were not enough choices, they advocated for their development.

Coping and Problem Solving

The women used effective coping and problem solving techniques. Through experience and the help of others, they learned that they needed to take care of themselves. They participated in therapy for themselves and in leisure activities, belonged to a support group, educated themselves about psychiatric disability, sought emotional support from others, developed meaning in their experiences, helped others, and found the positive even in dark moments. These women realized that if they do not take time out for themselves, they would not be able to help their children and would succumb to their situations.

Availability of Resources and Supports

Through their ability to see their situations in a positive light and that they had choices, the women in this study were able to recognize that there were service options. The women spoke much of the lack of and frequency of inadequate services. This gap in services, however, did not stop this group of women from keep searching until they found the most appropriate services for their children. They did not give up, and even advocated for the development of effective resources, and helped other families to locate appropriate services for their own children.

Family Power and Adaptation

The ability to find meaning, development of positive situational appraisal, recognition of choices, and use of effective coping and problem solving techniques led these women to become empowered and adapt successfully to their situations. Despite their dealings with very stressful situations, and sometimes having to struggle with where to draw the line in stop helping their children for their own health, these women all appeared to do well. Through the use of this model and future replication of this study, effective interventions could be developed that could benefit caregivers and their loved ones.

Considerations to the Model

While much of this model appears to have been confirmed by this study, it is still unclear how these women developed their meaning and positive appraisals. The model hypothesis is that meaning making would come from Community and Societal views and expectations. However, the results of this study did not confirm this. The women in this study did acknowledge the need for more education and mental health awareness in their communities, and stigma is still a problem in society. However, when I directly asked them if they had experienced negative attitudes from others, or what they thought of societal expectations and felt the expectation to be a “super hero” mom, and how these influenced them and the decisions they made for their children, women would not focus on this. Despite my attempts to direct and redirect conversation to this topic, women said little and were difficult to engage in discussing their personal experiences. It felt as if they brushed the topic off. They did not see it as important, or had not thought about it before. Or, perhaps they had been able to move beyond what their community and society thought, and no longer thought this to be important. Future research should further examine the influence of one’s community and culture on meaning and decision making.

One possible factor for inclusion to this model would be support group involvement. Six out of eight of the women in this study belonged to NAMI and all women discussed the importance of having the support of others in their lives. The influence of support group involvement on the women in this study to become assertive, educated about psychiatric disability and importance take care of themselves, meaning development, relationship development, and become advocates is uncertain. Future research should focus on the benefits of support groups and conduct comparison studies between caregivers who belong to support groups and those who do not.

A second factor for inclusion to this model would be faith and spirituality. All of the women in this study shared the importance of their reliance in their faith to help them in their caregiving experiences. This was not a finding that I had expected. The potential influence of faith in a caregiver’s life must be further examined, as it may play an important role in how a caregiver develops meaning, appraises one’s situation, examines and uses possible choices, uses particular coping and problem solving techniques, and determine if a caregiver adapts or succumbs to one’s situation.

Study limitations

The aim of this study was to gain understanding of the thoughts, emotions and personal subjective experiences of mothers. Women’s subjective experiences and any inconsistencies in their stories noted by me were viewed as a part of the phenomenon and interpreted in the results. These were their stories through their eyes, how they see their experiences and thus treated with respect. Inconsistencies add authenticity and credibility to the study, instead of taking away from it (Moustakas, 1994).

There are several limitations to be noted when interpreting the results of this study. First, this study was limited to mothers from a single state with most participants from a single area of the state. Additionally, only one focus group was conducted with six women, and one individual interview conducted with eight women. Therefore, only a snap shot of these women's experiences over a life time were captured, and means that only a small part of the caregiving experience was captured. Also, all women were Caucasian, non-Hispanic, and most women were college educated. Therefore, interpretations made beyond these parameters should be made with caution. Furthermore, the women who participated in this study may be different than other mothers with unique attributes (e.g. resilience, assertiveness, active involvement in support groups, education).

Despite these limitations, this study has several important implications for practitioners, researchers and policy makers. I was able to access a unique population that has rarely been examined. The mothers in this study were caregivers to adult children with psychiatric disability who belonged to support groups, were religious, and highly educated. Additionally, these women appeared to have adjusted well to their caregiving situation. The examination of the coping techniques, adjustment process, meaning development, and other attributes of this group of women can help other families.

Study Findings and Contributions to the Field

Recommendations for Practitioners

Practitioners must acknowledge the role and importance of the family. In the current study, women spoke openly of constant barriers they experienced in accessing appropriate services for their children, and to be included in the treatment process. Children often did not want their parents to know what was happening when they were hospitalized, or to speak with treatment providers, leaving parents in the dark. Yet, parents were most likely to ensure appointments were made and kept, and treatment routines were followed. To be left out of the treatment process is an insult to parents and everything they do for their children. By acknowledging the importance of the family, practitioners can then include them in the treatment process, and assist the family to develop effective coping strategies and guide them to successful adjustment.

Practitioners must recognize that there are positive aspects to caregiving. Through practitioner recognition of positive benefits in caregiving and helping families to focus on the positive, families can feel strengthened and empowered, and experience growth. This would be especially beneficial for new caregivers and families experiencing difficult situations or focused on the negative.

Families who are included in the treatment process and focus on positive gains and their strengths are better able to provide care to their loved ones (Aschrenner, Greenber, Allen, & Mailick Seltzer, 2010; Kremar, 1997; Kuipers et al., 2010). Furthermore, high quality care can lead to increased self-efficacy, self-esteem and the potential for recovery for individuals with psychiatric disabilities (Aschbrenner et al., 2010; Kuipers et al., 2010). This creates reciprocity between family caregivers and their loved ones, allowing both family and individual to grow in a healthy manner and potentially recover. Families who perceive positive gains in their caregiving experience are better able to provide support and enhance the loved one’s ability to do well. Individuals with psychiatric disability who do well decrease the family’s subjective burden, increase the family’s ability to experience positive benefits, and allow for the family to provide more positive support and high quality care.

Practitioners also must help families to find meaning in their caregiving experiences and in their loved one’s mental illness. Finding purpose in providing care to a loved one can decrease emotional distress, enhance quality of care and help the individual with psychiatric disability recover (Chen & Greenberg, 2004). To help a family find purpose, practitioners could incorporate Frankl's logotherapy (1988) into their work with families. Additionally, families are more likely to find purpose in caregiving if provided information and education about psychiatric disability and treatment options, were included in the treatment process, felt validation of their feelings, and felt supported by providers (Chen &Greenberg, 2004).

Fleischman & Klupp (2004) reported that relatives of people with psychiatric disabilities perceived themselves to have a significantly low quality of life compared to the general population. Women in the current study shared the amount of stress they experienced, especially in the beginning years of the child's diagnosis. Initial response during the early years of the child's diagnosis was for some mothers to feel overwhelmed, lost, and stressed. Mothers spoke of revolving their lives around their children, to the point of making themselves ill. During the focus group conducted prior to individual interviews, two women spoke about physical health complications due to stress of caregiving, and one mother spoke of having depression due to her caregiving experience. The focus group mothers also spoke of having resentment toward their children in having to provide care, and difficulty in being able to live their own lives. However, mothers also spoke of close friendships, positive support from spouses, helping others and being advocates for mental health rights. Therefore, it may be concluded that women in the current study did not experience a lower quality of life, but in fact, perceived themselves to have coped well. This is especially so in evidence of women finding meaning in their experiences, willingness to care for one's child all over again if provided the chance, and not changing anything if they had it to do over again, except be more educated about mental illness and available services.

Stress and caregiver burden has been well studied (Gutierrez-Maldonado et al. 2005). The burden of caring for a person with a psychiatric disability is associated with a reduced quality of life and significant impacts on the health and functioning of caregiver (Gutierrez-Maldonado et al. 2005). However, in the current study, while women did indicate that they experienced stress, physical and/or emotional health problems, and other negative consequences, all women appeared to have a good quality of life, as indicated by their faith, meaning they developed, help they provided to others, and advocacy.

Recommendations for Future Research

As researchers move forward, there must be a stronger recognition of the experiences of families who provide care to a loved one with a psychiatric disability. The Sociocultural Model of Maternal Caregiving can be instrumental in facilitating positive change in family and psychiatric rehabilitation research. Results of this study indicate that caregivers develop meaning in their caregiving experiences, which can influence situational and choice appraisal, the power the caregiver feels she has, the supports she seeks out for her child and herself, and adjustment and adaptation to the situation. Further research must be conducted to test the reliability of this model. Replication of this qualitative study could be conducted using the same procedures and interview guide and would provide much depth to both the model and findings.

As there were many new findings in this study, future research should focus in-depth on one or two areas at a time. An interesting direction of this study would be an examination of faith/spirituality in caregiving, or the development of meaning making, and their influence in coping and adjustment and decision making in the caregiving experience. Furthermore, replication of this study in a quantitative or mixed methods manner would provide a more complete investigation the caregiver experience. Various quantitative measures could be implemented such as a stress indicator, depression inventory, quality of life scale, alcohol and drug indicator, and a hope inventory. The use of surveys would be beneficial to uncover information not provided during an interview, and unearth information that a researcher did not intend to explore. Larger sample sizes could be recruited from the involvement of more NAMI groups, community mental health agencies and psychiatric units of hospitals. Potential participants could easily be directed to an online survey that could be completed quickly and with confidentiality. Replication of this study and further exploration of emerged themes could inform and improve the developed model.

There are several valuable directions for future research based on the findings of this study. There is limited research regarding what defines rural culture and its influence on people’s values, beliefs and choices they make. Future directions for studies regarding the influence of culture may include caregiver perceptions of community and societal expectations, and how these perceptions influence the decisions caregivers make for themselves and for their children. Additionally, there is little examination of the caregiver appraisal process. Further understanding of how caregivers view their situation, such as positive or negative, and how they then feel about their situation would be highly valuable. Such understanding would allow both researchers and practitioners to develop effective interventions for families.

Research regarding the benefits of support group involvement is needed. Comparison research is also needed to examine coping techniques, adjustment and well-being of caregivers who belong to support group versus those who do not. Such results may have significant implications for practitioners and researchers alike. Caregiver support and resulting benefits could be significant contributors to overall health of the caregiver, help caregivers to provide better support to loved ones, and increase a loved one's likelihood for recovery. Additionally, research focused on caregiver support can help service providers to develop more effective and inexpensive interventions. They could be better able to help clients with psychiatric disabilities and their families if families are actively involved in support groups. Families who are active in such groups and benefit from them may be better able to serve their children and other loved ones, and help the family to better adjust and adapt to mental illness itself and the caregiving experience, as well as lead the individual towards recovery.

Researchers must also investigate how families cope with long term caregiving experiences, as there are few longitudinal studies examining the caregiving experience over time and how it changes. Current caregiver research focuses on small increments of time during what is often a lifelong experience. By examining what new caregivers do and how they appraise their situation compared to older and more experienced caregivers could greatly assist researchers and practitioners to understand the needs of caregivers and better assist new caregivers to effectively adjust to their situations.

Implications for Policy Makers

There are implications for policy makers to ensure that families dealing with psychiatric disability are adequately served, especially those living in rural communities as they most often go without proper services. Policy makers must understand that the main support for an individual with psychiatric disability is the family. While laws regarding confidentiality, such as The Health Insurance Portability and Accountability Act of 1996 (HIPAA), are necessary to protect patient rights, they also bar the family from fully understanding the child's illness, needs, and assisting in the treatment process. If an individual with psychiatric disability does not want family to know information regarding his or her case, then the practitioner cannot relay pertinent information that could help the family as whole and assist the family to better serve the loved one. Furthermore, due to current policies, the family as a whole is often not served. By not providing services to the family and including them in the treatment process leaves significant room for the family to succumb to the illness as well as create further potential for the individual to relapse. Policies must become family friendly, and provide the family more rights to obtain information when a loved one is ill, especially when hospitalized. Policies must be developed to include service provision to the family, and funding must be allocated for family services including family counseling, assistance with transportation, and caregiver relief services such as adult daycare and personal assistants.

APPENDICES

Appendix A
Questions for the Semi-Structured Focus Group Interview

1. Tell me what it's been like caring for your child?

2. What aspects of this are you best at?

3. What is the hardest for you?

4. What changes have you made as you went along?

    a. What have you learned?

5. What are you doing differently from when your child first became ill?

    a. What would you do differently?

6. If you were to design an ideal support program for others taking care of their children like you what would it include?

    a. What do you think of the kinds of services you have received?

7. What about your experience do you think people would find surprising?

8. What is hardest to share with others? To talk about?

9. What keeps you going?

10. How do you think society perceives of what mothers like you should do? Who you are?

    a. How do you feel about that?

Appendix B
Questions for Semi-Structured Individual Interview

1. Please describe your feelings regarding what it's been like caring for your child

   a. Please describe your feelings
   b. what is easy? (What aspects of this are you best at?)

   Have women pick from a few emotions and have them describe and <u>*define*</u> *what they mean by certain emotions.*
   Have women discuss emotions they discussed during the focus group, and if they still feel this way.

2. What is challenging about caring for your child? (What is the hardest for you?)
   Help people focus on what they spoke of last time and if they still feel this way.

3. Please describe your relationship (and how it's changed over time) with your child.

   a. What lead you to become a primary caregiver?
   b. How does your child's relationship look with his/her____compared to yours?
      i. Father
      ii. siblings

4. How has caring for your child affected your relationship with others? *(Possible probes listed)*

   a. Who do you turn to for support?

   Find out who women are turning to, what percent of the time (spouse 50% vs. friend 10%)

   a. your spouse
   b. children?
   c. grandchildren?
   d. Friends
   e. Neighbors
   f. Community
   g. work relationships
   h. Others??

5. What have you learned from being a primary caregiver?

   a. How prepared did you feel in caring for your child?

b. What are you doing differently from when your child first became ill?
    i. What have you learned?
    iii. What have you learned about yourself?

6. If you were to design an ideal support program for others taking care of their children like you what would it include?

    a. What do you think of the kinds of services your child has received?

7. What has surprised you about your experience?

    a. What about your experience do you think other people would find surprising?

8. What is hardest to share with others?

Have the person specify WHO it would be difficult to share with.

9. What keeps you going (What motivates you)?

10. What is meaningful about your caregiving experience?

    a. What reward do you gain from caregiving?
    b. Have you found meaning in your caregiving experience?
    c. How did you come to find meaning?
    d. Was there a specific event or moment that lead you to find meaning in caregiving?

Also probe for: "Have you sought out meaning in the development of your child's illness?"

"Have you asked and sought an answer as to why he/she has this illness??

11. What would you think would be useful for other mothers (new caregivers) to know?

12. How do you think your community perceives you?

    a. your child?
    b. How does that make you feel?

For this last question, need to discuss first about society's expectation that mothers should be perfect, sacrifice everything for their family, and never be angry or depressed. Then how a child's behaviors, and actions as an adult, are often viewed by society as a reflection on the mother's parenting.

13. Do you think people judge your parenting by your son/daughter's actions?

    a. How do you feel about that?

Ending Question

E1. If you knew what you know now, would/could you do it all over again?

    a. What would you do differently?

Appendix C
Study Announcement

Dear Caregiver:

I am conducting a qualitative study on the experiences of mothers who are caregivers to adult children with psychiatric disabilities. Caregiving can be a very stressful and intense responsibility, but caregivers may also find some benefits or rewards in their experiences. Most research conducted is about the burden of caregiving. However, few studies have been conducted about the positive aspects of caregiving. Furthermore, few studies have been conducted about the caregiving experiences of mothers specifically in rural communities. The purpose of this study is to explore the caregiving experiences of rural mothers.

If you are interested in learning more about this study and participating, please contact me. If you know of caregivers who would be willing to participate in my study, I would appreciate your giving them a copy of the attached flyers.

I am a doctoral candidate in the Rehabilitation Counselor Education program at Michigan State University (MSU) in East Lansing, and this project is my dissertation research. The faculty member supervising this research project is John Kosciulek, Ph.D. at MSU 438 Erickson Hall, East Lansing, MI 48823, phone 517-353-9443.

Thank you for your assistance, and please contact me if you have any questions at 517-388-1085.

Sincerely

Melissa Manninen Luse MEd., CRC
Doctoral Candidate, Rehabilitation Counselor Education

Figure 2 Recruitment Flyer

I want to hear your story

I am conducting a study to describe the experiences of mothers who are caregivers to adult children with serious mental illness. Caregiving can be stressful and overwhelming, yet caregivers often find rewards in their experiences that help motivate them to continue. The purpose of this study is to describe the experiences of caregiving. This is your chance to tell someone about it!

If you would be interested in participating in an interview about your caregiving experiences please call me. I want to hear from you!

Melissa Manninen Luse, MEd., CRC

Doctoral Candidate, Rehabilitation Counselor Education

Phone 517-388-1085

Email: lusemeli@msu.edu

Appendix D
Demographic Information

PARENT INFORMATION	
Name/Pseudonym	
Date of Interview	
Age	
Ethnicity	☐ African American ☐ Latino ☐ Caucasian ☐ Native American ☐ Asian and/or Pacific Islander ☐ Other
Marital Status	☐ Married ☐ Single ☐ Divorced ☐ Widowed
Children YES NO	Number of children: Ages:
Living Situation	☐ Own Type of home:____________________ ☐ Rent
Current Work Status	☐ Employed full-time ☐ Employed part-time ☐ Not employed ☐ Retired ☐ Student ☐ Volunteer
Highest Grade Level Completed	☐ Elementary School ☐ Middle School ☐ 9th-10th grade ☐ 11th – 12th grade ☐ Some college or trade ☐ Associates ☐ 4 yr. degree ☐ Some graduate school ☐ Graduate school
Supports used	☐ Talking to family ☐ Talk to friends ☐ Therapist ☐ Formal Mental Health support group (i.e. NAMI) ☐ Other support group: ________________________________

	☐ Other: ____
Leisure Activities	☐ Exercise ☐ Reading ☐ Gardening ☐ Sports ☐ Other: ______________________
CHILD INFORMATION	
Diagnosis of Child	☐ Anxiety: GAD_____ OCD_____PTSD_____ Panic Attacks_____ Agoraphobia_____ ☐ Major Clinical Depression ☐ Bipolar: I___ II____ ☐ Schizophrenia ☐ Schizoaffective Disorder ☐ Personality Disorder: Type _____________ ☐ Other:________________________________
Date or Age of Diagnosis	☐ 14 yrs or younger ☐ 15 – 18 ☐ 19-22 ☐ 22-25 ☐ 26-29 ☐ 30+
Current Age of Child	
Gender of Child	☐ Male ☐ Female
Living Situation of Child	☐ Independently in apartment/house ☐ SIL apartment ☐ With family: Relation to child_____________ ☐ With friend ☐ Other:________________________________
Assistance Child Requires	☐ Budgeting/Banking ☐ Utilities

	☐ Transportation ☐ Cleaning ☐ Cooking ☐ Hygiene ☐ Medication ☐ Medical/Mental Health Appointments ☐ Advocacy ☐ Other:______________________________
Amount of Time Spent Assisting Child	☐ Up to 30 minutes per day ☐ 30 min. to 1 hr. ☐ 1-2 hr. ☐ 2-4 hr. ☐ 4-6hr. ☐ 6-8hr. ☐ 8 hr. +
Length of Time Caring for Child	☐ Less than 1 yr. ☐ 1-2 yr. ☐ 2-4 yr. ☐ 4-6 yr. ☐ 6-8 yr. ☐ 8-10 yr. ☐ 10-15 yr. ☐ 15+ yrs.
Current Work Status of Child	☐ Employed full-time ☐ Employed part-time ☐ Not employed ☐ Retired ☐ Student ☐ Volunteer
Highest Grade Level Completed	☐ Elementary School ☐ Middle School ☐ 9th-10th grade ☐ 11th -12th grade ☐ Some college or trade ☐ Associates ☐ 4 yr. degree ☐ Some graduate school ☐ Graduate school
Services Received	☐ Medication ☐ Primary Physician ☐ Individual therapy

	☐ Group therapy ☐ Psychologist ☐ Psychiatrist evaluation ☐ Employment services ☐ SIL ☐ ACT ☐ Other: ______________________
Services Sought	☐ Medication ☐ Primary Physician ☐ Individual therapy ☐ Group therapy ☐ Psychologist ☐ Psychiatrist evaluation ☐ Employment services ☐ SIL ☐ ACT ☐ Other: ______________________
Services Available in Community	☐ Medication ☐ Primary Physician ☐ Individual therapy ☐ Group therapy ☐ Psychologist ☐ Psychiatrist evaluation ☐ Employment services ☐ SIL ☐ ACT ☐ Other: ____________________

Appendix E
Informed Consent for Focus Group

Participant Consent to Take Part in the Study:

A Qualitative Analysis of Caregiving Experiences of Rural Mothers with an Adult Child with Psychiatric Disability

Michigan State University

You are being asked to participate in a research study. Researchers are required to provide a consent form to inform you about the research study, to convey that participation is voluntary, to explain risks and benefits of participation, and to empower you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Study Title: A Qualitative Analysis of Caregiving Experiences of Rural Mothers with an Adult Child with Psychiatric Disability
Researcher and Title: Melissa Manninen Luse, MEd., CRC Doctoral Candidate
Department and Institution: Rehabilitation Counselor Education, Michigan State University
Address and Contact Information: 455 Erickson Hall, East Lansing, MI 48823 (517) 388-1085

PURPOSE: You are being asked to participate in a research study to explore experiences of mother caregivers of adult children with psychiatric disabilities. The family, particularly the mother, is usually highly engaged in caring for adults with serious mental illness. Unfortunately, the family is often ignored in the treatment process, leaving parents without appropriate education and their own services to better care for an adult child. Additionally, most resources for individuals with mental illness and families are located in urban areas, leaving smaller communities and rural areas without adequate services. We want to learn what your experiences have been like caring for an adult child with a psychiatric disability. We want to learn about what resources have been sought for the child; what resources and supports have you sought for yourself; what has been meaningful about the caregiving experience; and what might be done to improve the caregiving experience. You have been selected to participate because you are a mother with an adult child with a psychiatric disability and you live in a non-urban county. We feel that your experience can contribute much to our understanding and knowledge of the caregiving experience and service options.

PROCEDURE: The study will consist of one focus group with mother caregivers of adult children with psychiatric disabilities. You will take part in a discussion with other women with similar experiences. This discussion will be guided by myself. The group discussion will start with me making sure that you are comfortable. We can also answer questions about the research that you might have. This focus group will last approximately 90 minutes. You will be asked to respond to questions like “Tell me about your caregiving experience”, and “What aspects are you good at?” This focus group will be audio recorded, and will be heard by me and a professional transcriptionist when transcribed for analysis. The recording and transcript will be kept in a secure place to ensure your confidentiality. The recordings will be kept for at least three years after the project closes. You may be asked to review the transcript for accuracy, or will be contacted for a short follow up telephone interview for clarification of the information obtained. ***We***

will not ask you to share personal beliefs, practices or stories and you do not have to share any knowledge that you are not comfortable sharing.

RISKS: There are no anticipated health or social risks involved by participating in this study. You will be asked to share some very personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the discussion if you do not wish to do so, and that is fine. Participants do not have to give any reason for not responding to any question, or for refusing to take part in the interview. If, at any time, you feel that you are too uncomfortable with the process, you may withdraw from the study or simply decline to respond without any negative consequences.

BENEFITS: I hope that your participation may leave you feeling that the time was well spent on a worthy project. You may be provided a copy of the results of this study, if you choose.

CONFIDENTIALITY: Participant information will be kept confidential to the maximum extent allowable by law. If names are used in the reporting of this study, I will not identify you, child, or practice site, but use pseudonyms. Recordings and data will be labeled with the pseudonym and date of the interview. No one, other than the researcher, will be able to link the data to participants. Other people who will have access to summaries and analysis, but not raw data or actual names, include committee chair and primary investigator, Dr. Kosciulek, a first year doctoral student in the Rehabilitation Counselor Education program, and the Institutional Review Board (IRB). A transcriber will assist in transcribing the audio recordings. The results of this study may be published or presented at professional meetings, but the identities of all participants will remain anonymous.

FOCUS GROUP CONFIDENTIALITY: During the focus group you will be asked not to talk to people outside the group about what was said in the group. Each of you will be asked to keep what was said in the group confidential. You should know, however, that the researcher cannot stop or prevent participants who were in the group from sharing things that should be confidential

LENGTH OF TIME DATA WILL BE KEPT: Audio recordings, printed documents, and field notes will be retained for a minimum of three years, in order to be used for future research.

STORAGE REQUIREMENTS: Data will be stored in a secured and locked location in the office of the primary investigator at Michigan State University. Any information entered into a computer will be secured through password identification, Norton Anti Virus and Windows firewall protection.

LIMITS OF CONFIDENTIALITY: The investigator is obligated by professional ethics to report incidents of threat to self-harm or harm to others. The investigator is obligated by law to report suspected abuse or neglect of children.

PARTICIPATION IS VOLUNTARY: Your participation in this study is voluntary. You may choose not to participate or to stop participating in the study at any time without penalty or punishment. You may decline to answer any question your want to without negative consequences to you.

AUDIO RECORDING IS REQUIRED: Interviews will be audio recorded. Taping is required for this study, and participants cannot be in the study without being recorded.

QUESTIONS: If you have any questions, please feel free to contact me. My name is Melissa Manninen Luse and my telephone number is 517-388-1085. My email is lusemeli@msu.edu. I am a doctoral student at Michigan State University, and this study is my dissertation project in the Rehabilitation Counselor Education program. If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury (i.e. physical, psychological, social, financial, or otherwise), please contact me or the primary investigator and faculty member supervising this research project, John Kosciulek, Ph.D. at MSU 438 Erickson Hall, East Lansing, MI 48823, phone: 517-353-9443.

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180. Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 408 W. Circle Drive, Room 207 Olds Hall, MSU, East Lansing, MI 48824.

Your signature on this document indicates that you have decided to take part in this study and that you have read the information provided and explained to you.

I agree to participate in this research study.

Printed Name of Participant Date

Signature of Participant Date

Signature of Investigator Date

Appendix F

Informed Consent for Individual Interview

Participant Consent to Take Part in the Study:

A Qualitative Analysis of Caregiving Experiences of Rural Mothers with an Adult Child with Psychiatric Disability

Michigan State University

You are being asked to participate in a research study. Researchers are required to provide a consent form to inform you about the research study, to convey that participation is voluntary, to explain risks and benefits of participation, and to empower you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Study Title: A Qualitative Analysis of Caregiving Experiences of Rural Mothers with an Adult Child with Psychiatric Disability
Researcher and Title: Melissa Manninen Luse, MEd., CRC Doctoral Candidate
Department and Institution: Rehabilitation Counselor Education, Michigan State University
Address and Contact Information: 455 Erickson Hall, East Lansing, MI 48823 (517) 388-1085

PURPOSE: You are being asked to participate in a research study to explore experiences of mother caregivers of adult children with psychiatric disabilities. The family, particularly the mother, is usually highly engaged in caring for adults with serious mental illness. Unfortunately, the family is often ignored in the treatment process, leaving parents without appropriate education and their own services to better care for an adult child. Additionally, most resources for individuals with mental illness and families are located in urban areas, leaving smaller communities and rural areas without adequate services. We want to learn what your experiences have been like caring for an adult child with a psychiatric disability. We want to learn about what resources have been sought for the child; what resources and supports have you sought for yourself; what has been meaningful about the caregiving experience, and what might be done to improve the caregiving experience. You have been selected to participate because you are a mother with an adult child with a psychiatric disability. We feel that your experience can contribute much to our understanding and knowledge of the caregiving experience and service options.

PROCEDURE: The study will consist of face to face interviews with mother caregivers of adult children with psychiatric disabilities. You will participate in one interview which will last approximately 90 minutes. You will be asked to respond to questions like “Tell me about your caregiving experience”, and “What aspects are you good at?” The interview will be audio recorded, and these recordings will be heard by the investigator when transcribed for analysis. The recordings and transcripts will be kept in a secure place to ensure your confidentiality. You may be asked to review the transcript for accuracy, or will be contacted for a short follow up telephone interview for clarification of the information obtained.

RISKS: There are no anticipated health or social risks involved by participating in this study. You will be asked to share some very personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the discussion if you do not wish to do so, and that is also fine. Participants do not have to give any reason for not responding to any question, or for refusing to take part in the interview. If, at any time, you feel that you are too uncomfortable with the process, you may withdraw from the study or simply decline to respond without any negative consequences.

BENEFITS: You will not be provided any incentive to take part in the research. I hope that your participation may leave you feeling that the time was well spent on a worthy project. You may be provided a copy of the results of this study, if you choose.

CONFIDENTIALITY: Participant information will be kept confidential to the maximum extent allowable by law. If names are used in the reporting of this study, I will not identify you, child, or practice site, but use pseudonyms. Recordings and data will be labeled with the pseudonym and date of the interview. No one, other than me, will be able to link the data to participants. Other people who will have access to summaries and analysis, but not raw data or actual names, include committee chair and primary investigator, Dr. Kosciulek, a first year doctoral student in the Rehabilitation Counselor Education program, and the Institutional Review Board (IRB). A transcriber will assist in transcribing the audio recordings. We will lock up transcriptions and data in a cabinet in the primary investigator's office. The results of this study may be published or presented at professional meetings, but the identities of all participants will remain anonymous.

LENGTH OF TIME DATA WILL BE KEPT: Audio recordings, printed documents, and field notes will be retained for a minimum of three years, in order to be used for future research.

STORAGE REQUIREMENTS: Data will be stored in a secured and locked location in the office of the primary investigator at Michigan State University. Any information entered into a computer will be secured through password identification, Norton Anti Virus and Windows firewall protection.

LIMITS OF CONFIDENTIALITY: The investigator is obligated by professional ethics to report incidents of threat to self-harm or harm to others. The investigator is obligated by law to report suspected abuse or neglect of children.

PARTICIPATION IS VOLUNTARY: Your participation in this study is voluntary. You may choose not to participate or to stop participating in the study at any time without penalty or punishment. You may decline to answer any question your want to without negative consequences to you.

AUDIO RECORDING IS REQUIRED: Interviews will be audio recorded. Taping is required for this study, and participants cannot be in the study without being recorded.

QUESTIONS: If you have any questions, please feel free to contact me. My name is Melissa Manninen Luse and my telephone number is 517-388-1085. My email is lusemeli@msu.edu. I am a doctoral student at Michigan State University, and this study is my dissertation project in the Rehabilitation Counselor Education program. If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury (i.e. physical, psychological, social, financial, or otherwise), please contact me or the primary investigator and faculty member supervising this research project, John Kosciulek, Ph.D. at MSU 438 Erickson Hall, East Lansing, MI 48823, phone: 517-353-9443.

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180. Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 408 W. Circle Drive, Room 207 Olds Hall, MSU, East Lansing, MI 48824.

Your signature on this document indicates that you have decided to take part in this study and that you have read the information provided and explained to you.

I agree to participate in this research study.

Printed Name of Participant

Signature of Participant Date

Signature of Investigator Date

REFERENCES

REFERENCES

Abelev, M. (2009). Advancing out of poverty. *Journal of Adolescent Research, 24*(1), 114-141.

Access to disability data. (2004). Retrieved from the Infouse Project website: http://www.infouse.com/disabilitydata/mentalhealth/1_5.php

Achieving the promise: Transforming mental health care in America. (2002). Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration: The President's New Freedom Commission on Mental Health.

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders DSM IV-TR.* (4th ed., Text Revision). Washington DC: American Psychiatric Association.

Ascbrenner, K., Greenberg, J., Allen, S., & Mailick Seltzer, M. (2010). Subjective burden and personal gains among older parents of adults with serious mental illness. *Psychiatric Services, 61*(6), 605-12.

Barbopoulos, A., & Clark, J. (2003). Practising psychology in rural settings: Issues and guidelines. *Canadian Psychology*, *44*(4), 410-25.

Baron, R., & Salzer, M. (2002). Accounting for unemployment among people with mental illness. *Behavioral Sciences and the Law, 20,* 585-599.

Berg-Weger, M., McGartland Rubio, D., & Tebb, S. (2001). Strengths-based practice with family caregivers of the chronically ill: Qualitative insights. *Families in Society, 83*(3), 263-73.

Beveridge, S., Craddock, S., Liesener, J., Stapleton, M., & Hershenson, D. (2002). Income: A framework for conceptualizing the career development of persons with disabilities. *Rehabilitation Counseling Bulletin*, *45*(4), 195-211.

Bishaw, A., & Macartney, S. (2010). Poverty: 2008-2009. Retrieved from the U.S. Census Bureau website: http://www.census.gov/

Boerner, K., Schulz, R., & Horowitz, A. (2004). Postive aspects of caregiving and adaptation to bereavement. *Psychology and Aging*, *19*(4), 668-75.

Boss, P. (1987). Family stress. In M. B. Sussman & S.K. Steinmetz (Eds.), *Handbook of marriage and the family*, 695-723. New York, NY: Plenum Press.

Boss, P. (1992). Primacy of perception in family stress theory and measurement. *Journal of Family Psychology*, *6*(2), 113-119.

Breaking the vicious cycle. (2007). Retrieved from the World Health Organization website: http://www.who.int/mental_health/policy/development/1_Breakingviciouscycle_Infosheet.pdf

Bunting, S. (2001). Sustaining the relationship: Women's caregiving in the context of HIV disease. *Health Care for Women International, 22,* 131-148.

Carr, T., Hicks-Moore, S., & Montgomery, P. (2011). What's so big about the 'little things': A phenomenological inquiry into the meaning of spiritual care in dementia. *Dementia, 10*(3), 399-414.

Champlin, B. (2009). Being there for another with a serious mental illness. *Qualitative Health Research*, *19*(11), 1525-1535.

Chen, F.P., & Greenberg, J.S. (2004). Caregiving gains in family care for people with mental illness. *Community Mental Health, 40*, 423-435

Cohen, A. (1985). *The Symbolic Construction of Community.* Tavistock London: Publications Ltd.

Cohen , C., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry,* 17(2), 184-8.

Cook, J. (1988). Who "mothers" the chronically mentally ill? *Family Relations,* 37, 52-49.

Cook, J. (2006). Employment barriers for persons with psychiatric disabilities: Update of a report for the president's commission. *Psychiatric Services, 57*(10), 1391-1406.

Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology, 13*, 3-21.

Corrigan, P., Watson, A., & Miller, F. (2006). Blame, shame, and contamination: The impact of mental illness and drug dependence stigma of family members. *Journal of Family Psychology, 20*, 239-246.

Corring, D., & Cook, J. (2007). Use of qualitative methods to explore the quality-of-life construct from a consumer perspective. *Psychiatric Services*, *58*(2), 240-5.

Creswell, J. (2007). *Qualitative Inquiry & Research Design*. Thousand Oaks, CA: SAGE Publications.

Creswell, J. (2009). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches.* Thousand Oaks, CA: SAGE Publications.

Crosnoe, R., & Cavanagh, S. (2010). Families with children and adolescents: A review, critique, and future agenda. *Journal of Marriage and Family, 72*, 594-611.

Culture. (2012). In Merriam-Webster.com. Retrieved from http://www.merriam-webster.com/dictionary/culture

Doornbos, M. (1996). The strengths of families coping with serious mental illness. *Archives of Psychiatric Nursing*, *X*(4), 214-220.

Edin, K., & Kissane, R. (2010). Poverty and the American family: A decade in review. *Journal of Marriage and Family, 72,* 460-479.

Evans, G. (2004). The environment of childhood poverty. *American Psychologist, 59*, 77-92.

Evans, G., Boxhill, L., & Pinkava, M. (2008). Poverty and maternal responsiveness: The role of maternal stress and social resources. *International Journal of Behavioral Development, 32*(3), 232-7.

Evans, G., & English, K. (2002). The environment of poverty: Multiple stressor exposure, psychophysiological stress, and socioemotional adjustment. *Child Development, 79*(4), 1238-48.

Farran, C., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, C. (1991). Finding meaning: An alternative paradigm, for alzheimer's disease family caregivers. *The Gerontologist,* 483-9.

Fleischman, H., & Klupp, A. (2004). Quality of life in relatives of mentally ill people. *Psychiatrische Praxis, 31.*

Folkman, S., & Lazarus, R. (1988). The relationship between coping and emotion: Implications for theory and research. *Social Science and Medicine, 26*(3), 309-17.

Folkman, S., & Moskowitz, J. (2009). Stress, positive emotion, and coping. *Current Directions in Psychological Science, 9,* 115-120.

Frankl, V. (1988). *Man's Search for Meaning: An Introduction to Logotherapy.* NY, NY: Simon & Schuster.

Frankl, V. (2006). *Man's Search for Meaning.* Boston, MA: Beacon Press.

Gilgun, J. (1999). Mapping resilience as process among adults with childhood adversities. H. McCubbin, E.Thompson, A.Thompson, A., & J. Futrell (Eds.). In *The Dynamics of Resilient Families.* Sage Publications: Thousand Oaks, CA.

Goodman, W., & Crouter, A. (2009). Longitudinal associations between maternal work stress, negative work-family spillover, and depressive symptoms. *Family Relations, 58,* 245-58.

Gunderson, C. (2006). Are the effects of the macroeconomy and social policies on poverty different in nonmetro areas in the United States? *Rural Sociology*, *71*(4), 545-72.

Gutierrez-Maldonado, J., Caquo-Urizar, A., & Kavanagh, D. (2005). Burden of care and general health in families of patients with schizophrenia. *Social Psychiatry and Psychiatry Epidemiology, 40*, 899-904.

Harcourt, B. (2006). From the asylum to the prison. *Texas Law Review 84*(1751), 1752-1788.

Harowski, K., Turner, A.L., LeVine, E., Schank, J., & Leichter, J. (2006). From our community to yours: Rural best perspectives of psychology practice, training, and advocacy. *Professional Psychology: Research and Practice, 37*, 158-164.

Hasson-Ohayon, I., Levy, I., Kravetz, S., Vollanski-Narkis, A., & Roe, D. (2011). Insight into mental illness, self-stigma, and the family burden of parents of persons with a severe mental illness. *Comprehensive Psychiatry, 52*, 75-80.

Heru, A. M. (2000). Family functioning, burden and reward in the caregiving for chronic mental illness. *Families, Systems and Healt,.18* (1), 91-103.

Hilgeman, M. M., Allen, R. S., DeCoster, J., & Burgio, L.D. (2007). Positive aspects of caregiving as a moderator of treatment outcome over 12 months. *Psychology and Aging, 22*, 361–371.

Hobfoll, S., & Spielberger, C. (1992). Family Stress: Integrating theory and measurement. *Journal of Family Psychology*, *6*(2), 99-112.

Hyjer Dyk, P. (2004). Complexity of family life among the low-income and working poor: Introduction to the special issue. *Family Relations*, *53*, 122-126.

Helplessness. (2012). In Merriam-Webster.com. Retrieved from http://www.merriam-webster.com/dictionary/helplessness

Hopelessness. (2012). In Merriam-Webster.com. Retrieved from http://www.merriam-webster.com/dictionary/hopelessness

Isserman, A. (2005). The national interest: Defining rural and urban correctly in research and public policy. *International Regional Science Review, 28*, 465-499.

Iyer, S., Rothmann, T., Vogler, J., & Spaulding, W. (2005). Evaluating outcomes of rehabilitation for severe mental illness. *Rehabilitation Psychology, 50*(1), 43-55.

Jones, C., Kandel, W., & Parker, T. (2007). Population dynamics are changing the profile of rural areas. *Amber Waves, 5.* Retrieved from http://www.ers.usda.gov/AmberWaves/April07/PDF/Population.pdf

Juby, C., & Rycraft, J. (2004). Family preservation strategies for families in poverty. *Families in Society, 85*(4), 581-8.

Katras, M., Zuiker, V., & Bauer, J. (2004). Private safety net: Childcare resources from the perspective of rural low-income families. *Family Relations, 53*, 201-9.

Kim, Y., Carver, C., Deci, E., & Kasser, T. (2008). Adult attachment and psychological well-being in cancer caregivers: The meditational role of spouses' motives for caregiving. *Health Psychology, 27*, S144-S154.

Kirk, S. (1999). Caring for children with specialized health care needs in the community: The challenges for primary care. *Health and Social Care in the Community, 7,* 350-357.

Kling, K., Mailick Seltzer, M., & Ryff, C. (1997). Distinctive later-life challenges: Implications for coping and well-being. *Psychology and Aging, 12*(2), 288-95.

Koren, P., DeChillo, N., & Friesen, B. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology, 37,* 305-21.

Kosciulek, J., McCubbin, M., & McCubbin, H. (1993). A theoretical framework for family adaptation to head injury. *The Journal of Rehabilitation, 59.*

Kosciulek, J. (2004). Family Counseling. In *Counseling Theories and Techniques for Rehabilitation Health Professionals* (pp. 264-281). New York, NY: Springer Publishing Co.

Kramer, B. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist, 37*(2), 218-33.

Kuipers, L. (1993). Family burden in schizophrenia: Implications for services. *Social Psychiatry and Psychiatry Epidemiology, 28*, 207-10.

Kuipers, D., & Bebbington, P. (2004). Expressed emotion at first-episode psychosis: Investigating a carer appraisal model. *British Journal of Psychiatry, 184,* 321-326.

Kuipers, E., Bebbington, P., Dunn, G., Fowler, D., Freeman, D., Watson, P., Hardy, A., & Garety, P. (2006). Influence of career expressed emotion and affect on relapse in non-effective psychosis. *British Journal of Psychiatry, 188,* 173-179.

Kuipers, E., Onwumere, J., Bebbington, P. (2010). Cognitive model of caregiving in psychosis. *The British Journal of Psychiatry, 196,* 259-65.

Laverty, S. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods, 2*(3).

Lee, C., Anderson, J., Horowitz, J., & August, G. (2009). Family income and parenting: The role of parental depression and social support. *Family Relations, 58,* 417-430.

Leve, L., Fisher, P., & Chamberlain, P. (2009). Multidimensional treatment foster care as a preventive intervention to promote resiliency among youth in the child welfare system. *Journal of Personality, 77*(6).

Lichter, D., & Johnson, K. (2007). The changing spatial concentration of America's rural poor population. *Rural Sociology*, *72*(3), 331-58.

Löckenhoff , C., Duberstein, P., Friedman, B, Costa, P. (2011). Five-factor personality traits and subjective health among caregivers: The role of caregiver strain and self-efficacy. *Psychology and aging*. *26*(3),592-604.

London, A., Scott, E., Edin, K., & Hunter, V. (2004). Welfare reform, work-family tradeoffs, and child well-being. *Family Relations*, *53*(2), 148-159.

Lopez, S., Hipke, K., Polo, A., Jenkins, J., Karno, M., Vaughn, C., & Snyder, K. (2004). Ethnicity, expressed emotion, attributions, and course of schizophrenia: Family warmth matters. *Journal of Abnormal Psychology*, *113*(3), 428-439.

Lopez, S., Nelson, K., Snyder, K., & Mintz, J. (1999). Attributions and affective reactions of family members and course of schizophrenia. *Journal of Abnormal Psychology, 108,* 307-314.

Malacrida, C. (2009). Performing motherhood in a disablist world: Dilemmas of motherhood, femininity and disability. *International Journal of Qualitative Studies in Education*, *22,* 99-117.

Malia, J. (2006). Basic Concepts and Models of Family Stress. *Stress, Trauma and Crisis: An International Journal*, *9*(3-4), 21.

Mailick Seltzer, M., Greenberg, J., & Krauss, M. (1995). A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation. *Psychology and Aging, 10,* 64-75.

Mak, W., & Cheung, R. (2008). Psychological distress and subjective burden of caregivers of people with mental illness: The role of affiliate stigma and face concern. *Community Mental Health Journal.*

Maupin, A., Brophy-Herb, H., Schiffman, R., & Bockneck, E. (2010). Low-income parental profiles of coping, resource adequacy, and public assistance receipt: Links to parenting. *Family Relations, 59,* 180-94.

McCubbin, M., & McCubbin, H. (1989a). Families coping with illness: The Resiliency Model of Family Stress and Adaptation. In C. Danielson, B. Hamel-Bissel, & P. Winstead-Fry (Eds.). *Families, health, and illness: Perspectives on coping and intervention.* St. Louis: Mosby.

McCubbin, M., & McCubbin, H. (1989b). Theoritical orientations to family stress and coping. In Figley, C. (Ed.), *Treating Stress in Families* (pp. 3-43). Philadelphia, PA: Brunner/Mazel.

McCubbin, M., Balling, K., Possin, Frierdich, S., & Bryne, B. (2004). Family Resiliency in childhood cancer. *Family relations, 51*(2), 103-111.

McCubbin, H., & Patterson, J. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage and Family Review*, 6(7), 7-37.

McCreadie, R.G. (1992). The Nithsdale schizophrenia surveys. *Social Psychiatry and Psychiatry Epidemiology, 27*, 40-5.

Mcquillan, J., Greil, A., Shreffler, K., & Tichenor, V. (2008). The importance of motherhood among women in the contemporary United States. *Gender & Society, 22* (4), 477-496.

Mental Health: A Report of the Surgeon General. (1990). Retrieved from the Surgeon General’s web site: http://www.surgeongeneral.gov/library/mentalhealth/home.html

Miller, K. (2009). Demographic and economic profile: Nonmetropolitan America. Retrieved from The Rural Policy Research Institute (RUPRI) website: http://www.rupri.org

Milliken, P. (2001). Disenfranchised mothers: Caring for an adult child with schizophrenia. *Health Care for Women International, 22*, 149-166.

Moos, R., & Holahan, C. (2007). Adaptive tasks and methods of coping with illness and disability. In Erin Martz & Hanoch Livneh (Eds.), *Coping with Chronic Illness and Disability* (pp. 107-28). New York, NY: Springer Science + Business Media, LLC.

Moustakas, C. (1994). *Phenomenological Research Methods*. Thousand Oaks, CA: SAGE Publications.

Mueser, K. (1996). Helping families manage severe mental illness. *Psychiatric Rehabilitation Skills, 1*(2), 21-42.

Mueser, K., Glynn, S., Cather, C., Zarate, R., Fox, L., Felman, J., et al. (2009). Family intervention for co-occurring substance use and severe psychiatric disorders: Participant characteristics and correlates of initial engagement and more extended exposure in a randomized controlled trial. *Addictive Behaviors, 34*, 867-877.

Munn-Gidding, C., & McVicar, A. (2006). Self-help groups as mutual support: What do carers value? *Health and Social Care in the Community, 15*(1), 26-34.

The National Alliance on Mental Illness (NAMI). (2006). *Mental illness: Facts and numbers*. The National Alliance on Mental Illness.

Neufeld, A., Harrison, M., Stewart, M., & Hughes, K. (2008). Advocacy of women family caregivers in response to nonsupportive interactions with professionals. *Qualitative Health Research, 18*(3).

Ochoa, S., Vilaplana, M., Haro, J., Villalta-Gil, V., Martinez, F., Cruz Negredo, M., & et al. (2008). Do needs, symptoms or disability of outpatients with schizophrenia influence family burden? *Social Psychiatry and Psychiatry Epidemiology, 43*, 2008.

O'Connnell, K. L. (2006). Needs of families affected by mental illness. *Journal of Psychosocial Nursing & Mental Health Services, 44*(3).

Onwumere J, Kuipers E, Bebbington P, Dunn G. Freeman, D., Watson P, & Garety, P. (2009). Patient perceptions of caregiver criticism in psychosis: links with patient and caregiver functioning. *Journal of Nervous and Mental Disease, 197*(2), 85-91.

Orbuch, T., Parry, C., Chesler, M., Fritz, J., & Repetto, P. (2005). Quality of life: Resilience among childhood cancer survivors. *Family Relations, 54*(2), 171-183.

Orthner, D., Jones-Sanpei, H., & Williamson, S. (2004). The resilience and strengths of low-income families. *Family Relations*, *53*(2), 159-168.

Ou, S., & Reynolds, A. (2008). Predictors of educational attainment in the Chicago longitudinal study. *School Psychology Quarterly, 23*(2), 199-229.

Pakeham, K., Chiu, J., Bursnall, S., & Cannon, T. (2006). Relations between social support, appraisel and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology, 12*(1), 89-102.

Parish, S., Rose, R., & Andrews, M. (2009). Income poverty and material hardship among US women and disabilities. *Social Service Review, 83,* 33-52.

Parish, S., Rose, R., & Swaine, J. (2010). Financial well-being of US parents caring for co-resident children and adults with developmental disabilities: An age cohort analysis. *Journal of Intellectual & Developmental Disability, 35*(4), 235-43.

Patterson, J. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family*, *64*(2), 349-361.

Perlick, D., Rosenheck, R., Kaczynski, R., Swartz, M., Canive, J., & Lieberman, J. (2006). Components and correlates of family burden in schizophrenia. *Psychiatric Services, 57,* 1117-1125.

Probst, J., Samuels, M., Jespersen, K., Willert, K., Swann, S., & McDuffie, J. (2002). Minorities in rural America: An overview of population characteristics. Retrieved from: *rhr.sph.sc.edu/report/minoritiesInRuralAmerica.pdf*

Rosenheck, R. (2000). The delivery of mental health services in the 21st century: Bringing the community back in. *Community Mental Health Journal*, *36*(1), 107-26.

Rothwell, D., & Han, C.K. (2010). Exploring the relationship between assets and family stress among low-income families. *Family Relations, 59*(4), 396-407.

Rural poverty & well-being. (2012). Retrieved from the United States Department of Agriculture web site: http://www.ers.usda.gov

Salzer, M., Wick, L., & Rogers, J. (2008). Familiarity with and use of accommodations and supports among postsecondary students with mental illness. *Psychiatric Services, 59*(4), 370-77.

Scaling Up Care for Mental, Neurological and Substance Use Disorders. (2008). WHO Press: Geneva Switzerland: World Health Organization.

Schulz, R., Newsom, J. T., Fleissner, K., Decamp, A. R., & Nieboer, A. P. (1997). The effects of bereavement after family caregiving. *Aging and Mental Health, 1,* 269–282.

Shaffer D., Dooley W., & Williamson G. (2007). Endorsement of proactively aggressive caregiving strategies moderates the relation between caregiver mental health and potentially harmful caregiver behavior. *Psychology and Aging, 22,* 494–504.

She, P., & Livermore, G. (2009). Long-term poverty and disability among working-age adults. *Journal of Disability Policy Studies, 19*(4), 244-56.

society. 2011. In Merriam-Webster.com. Retrieved from http://www.merriam-webster.com/dictionary/society

Soffer, M., McDonald, K., & Blanck, P. (2010). Poverty among adults with disabilities: Barriers to promoting asset accumulation in individual development accounts. *American Journal of Community Psychology, 46,* 376-85.

Snyder, A., McLaughlin, D., & Findeis, J. (2006). Household composition and poverty among female-headed households with children: Differences by race and residence. *Rural Sociology, 71*(4), 597-624.

Stern, S., Doolan, M., Staples, E., Szmukler, G., & Eisler, I. (1999). Disruption and reconstruction: Narrative insights into the experiences of family members caring for a relative diagnosed with serious mental illness. *Family Process*, *38*(3).

Szmukler, G., Burgess, P., Herrman, H., Benson,, A., Colusa, S., & Bloch, S. (1996). Caring for relatives with serious mental illness: the development of the experience of caregiving inventory. *Social Psychiatry and Psychiatry Epidemiology*, *31*, 137-48.

Szmukler, G., Kuipers, E., Joyce, J., Harris, T., Leese, M., Maphosa, W., & Staples, E. (2003). An exploratory randomized controlled trial of a support program for carers of patients with a psychosis. *Social Psychiatry and Psychiatry Epidemiology, 38,* 411-418.

Thomas, K., Ellis, A., Konrad, T., Holzer, C., & Morrisey, J.(2009). County-level estimates of mental health professional shortage in the United States. *Psychiatric Services,* 60(10), 1323-28.

Thompson, M., Goldstein, M., Lebell, M., Mintz, L., Marder, S., & Mintz, J. (1995). Schizophrenic patients perceptions of their relatives' attitudes. *Psychiatry Research, 57,* 155-67.

U.S. Department of Education's 1999 performance report and 2001 annual plan. (1999). Retrieved from the US Department of Education web site: http://www2.ed.gov/pubs/AnnualPlan2001/index.html

Wadsworth, M., & DeCarlo Santiago, C. (2008). Risk and resiliency processes in ethnically diverse families in poverty. *Journal of Family Psychology*, *22*(3), 399-410.

Walton-Moss, B., Gerson, L., & Rose, L. (2005). Effects of mental illness on family quality of life. *Issues in Mental Health Nursing*, *26*, 627-642.

Wang & Barnard (2004). Technology-dependent children and their families: A review. *Journal of Advanced Nursing, 45,* 36-46.

What is Psychiatric Disability and Mental Illness? (2010). Retrieved from the Center of Psychiatric Rehabilitation web site: http://www.bu.edu/cpr/reasaccom/whatis-psych.html

Webb, C., Pfeiffer, M., Mueser, K.T., Gladis, M., Mensch, E., DeGirolamo, J., & Levinson, D.F. (1998). Burden and well-being of caregivers for the severely mentally-ill: the role of coping style and social support. *Schizophrenia Research*, *34*, 169-180.

Weber, B., Jensen, L., Miller, K., Mosley, J., & Fisher, M. (2005). A critical review of rural poverty literature: Is there truly a rural effect? *International Regional Science Review*, *28*, 381-414.

Wilton, R. (2004). Putting policy into practice? Poverty and people with serious mental illness. *Social Science & Medicine*, *58*, 25-39.

Wrosch, C., Amir, E., & Miller, G. (2011). Goal adjustment capacities, coping, and subjective well-being: The sample case of caregiving for a family member with mental illness. *Journal of Personality and Social Psychology*.

Valiakalayil, A., Paulson, L., & Tibbo, P. (2004). Burden in adolescent children of parents with schizophrenia: The Edmonton high risk project. *Social Psychiatry and Psychiatry Epidemiology*, *39*, 528-535.

Zauszniewski, J., Bekhet, A., & Suresky, M. (2009). Relationships among perceived burden, depressive cognitions, resourcefullness, and quality of life in female relatives of seriously mentally ill adults. *Issues in Mental Health Nursing*, *30*, 142-150.