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PARENTING TO POSTHUMOUS: A GROUNDED THEORY OF AGING AND
PARENTING AN ADULT WHO IS MENTALLY ILL

by

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Bachelor of Arts, Metropolitan State University, 1993
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A Dissertation

Submitted to the Graduate Faculty

of the

University of North Dakota

In partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

Grand Forks, North Dakota
May
2012

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This dissertation, submitted by Roxanne Wilson in partial fulfillment of the requirements for the Degree of Doctor of Philosophy from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

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This dissertation meets the standards of appearance, conforms to the style and format requirements of the Graduate School of the University of North Dakota and is hereby approved.

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Dean of the Graduate School

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Department: Nursing

Degree: Doctor of Philosophy

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              Roxanne Wilson

              May 9, 2012

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I am indebted to the parents who were participants in this research. They shared thoughts, feelings and stories hiding within their hearts. Their willingness to participate because it might help other parents is symbolic of what they have quietly done throughout their lives. This grounded theory is dedicated to aging parents who are keenly aware that parenting is an evolving and essential role during each stage of life.

ABSTRACT

The purpose of this study was to generate a grounded theory that explains the main concerns of aging parents of adult mentally ill children and how they cope with those concerns. The methodology used was Classic Grounded Theory. Findings included the development of a substantive grounded theory titled, *Parenting to Posthumous*. Strategies to address this basic social process include *complicated caring, shifting, examining, transitioning and messaging.* Nursing implications include increased understanding of the dimensions of parenting as a process within aging.

CHAPTER I

INTRODUCTION

The aging population is rapidly increasing in the United States. Those 65 or older will increase 36% over the next decade (Department of Health and Human Service, 2012). The American Geriatrics Society predicts that by 2030 approximately 80 million (20%) Americans will be 65 or older (AGS Foundation for Health in Aging, 2005). More than one in 17 adults lives with a serious mental illness such as schizophrenia, bipolar disorder, or major depression (National Alliance for the Mentally Ill, 2011). Schizophrenia, bipolar disorder, and major depressive disorder are major mental illnesses that cause issues with social functioning for protracted periods of time, frequently lasting a person's lifetime. Severe mental illness is distinguished by three criteria: diagnosis, duration, and disability. Of these three criteria, disability likely has the greatest impact upon the sufferer (National Alliance for the Mentally Ill, 2011).

"Functionally impaired adults having periodic needs for stabilization and/or hospitalization and ongoing needs for outpatient care and long term rehabilitation are often in need of care giving" (Lefley, 1996, p. 4). Major mental illness often strikes young adults and few persons with major mental illness marry or have children. Consequently, the role of long-term caregiver is almost inevitably filled by parents who become the safety net.

Aging can present unique challenges for this parent population. Jungbauer, Stelling, Dietrich, and Angermeyer (2004) reported, "older parents, in particular, were increasingly occupied with the question of who would take responsibility (for adult mentally ill children)…when their own illness or death intervened" (p. 611). Horn and Meer (1987) suggest parents' fears related to what their adult mentally ill child will do "when I am gone" is such a widely discussed aspect of family burden that it has acquired its own acronym, WIAG. Ashbrenner, Greenberg, Allen, and Seltzer (2010) suggest subjective and objective burdens occur for parents of adult mentally ill persons, but positive personal gains are rarely reported.

Statement of the Problem

The impact of mental illness affects not only the identified persons, but also other family members. Mental health professionals expect family members to cope effectively with their personal thoughts and feelings while participating in the care of their loved ones. If family members are unable to cope effectively they are labeled as pathological or dysfunctional (Torrey, 1995). Family members struggle to maintain relationships with mentally ill relatives as they deal with the changes and loss of the persons they once knew. Researchers have examined the constructs of burden and chronic sorrow as responses family members may have to mentally ill or chronically ill relatives; however, these constructs do not encompass the full range of emotional responses nor do they offer much hope for resolution or healing for family members (Lindgren, Burke, Hainsworth, & Eakes, 1992; Maurin & Boyd, 1990; Pejlert, 2001).

In the United States, attitudes toward caring for family members with mental illness have changed in recent decades. Many adults over 40 years old can recall the

shame experienced when a family member was diagnosed with a mental illness. Mental health professionals have demonstrated some progress in affirming the needs of family members with seriously mentally ill relatives and responding to family members' feelings and behaviors (Bernheim, 1990; Howard, 1998; Kisely, Smith, Lawrence, Cox, Campbell, & Maaten, 2007). The Richardson, Cobham, Murray, and McDermott (2011) qualitative review of the literature reported on 12 studies of grief experienced by parents having adult children diagnosed with mental illness with the most current study completed in 2005. Few research studies address how aging parents experience caring for mentally ill adult children in later years (Aschbrenner, Greenberg, Allen, & Seltzer, 2012; Ozgul, 2004). There was no literature found related to the developmental tasks of this aging parent population. Overall, little is known about this population from a parenting perspective. Further insight into how aging parents of mentally ill adult children perceive their roles and resolve their concerns can lead to specific understanding and interventions.

Purpose

The purpose of this study is to generate a grounded theory that identifies and explains the main issues and coping strategies of aging parents of mentally ill adult children.

Research Question

Classic Grounded Theory methodology is designed to develop formal or substantive theories that can contribute to the rich, contextual understanding of the subject, in this case aging parents' perspectives, experiences, and coping mechanisms. The specific objectives of this study are:

1. Explore individual experiences and perceptions of aging parents of mentally ill adult children to develop a conceptual understanding of their main concerns and how they resolve their concerns.

2. Build a grounded theory of parenting mentally ill adult children as part of this parent populations' aging process.

3. Identify characteristics of the conceptual process aging parents of mentally ill adult children use to support and sustain themselves.

Glaser (1998) asserted:

It is still very typical to think that the interest of the researcher can define a relevant problem…the researcher could not possibly dream what will be discovered as relevance. And once the problem is discovered and verified by constant comparisons no one will be able to tell the researcher anything different about what her study is a study of" (p. 118).

Significance of the Study

The experience of parenting as we age has received far less attention than attention devoted to the experience of children providing care for aging parents. The experience of aging parents caring for mentally ill adult children clearly deserves more focus. The intent of grounded theory is to "approach a subject inductively with as few preconceived ideas about the phenomenon as possible" (Glaser, 1998, p. 122). Thus, this research is exploratory in its quest to investigate experiences of aging parents and identify significant patterns or constructs of parenting mentally ill adult children during the later stages of life. The conceptualization of "data grounded in reality provides a powerful means for both understanding the world and for developing strategies to allow

some measure of intervention" (Glaser & Strauss, 1967, pp. 245-249). Grounded theory supports the explanatory potential this study may offer on the concerns, coping strategies, and motivations of aging parents of mentally ill adult children.

Definition of Terms

For the purpose of this study, terms are defined as follows:

1. Aging parents of mentally ill adult children are defined as fathers and/or mothers over 65 years of age with living mentally ill adult children.

2. Mentally ill adult children are defined as persons diagnosed with schizophrenia, bipolar disease, or major depression based on parental reporting.

3. Coping is defined as the wide range of responses used to address life experiences, including negative and positive responses.

Assumptions

This study is based on the following assumptions:

1. Aging parents of adult children with mental illness will have responses to questions about aging and parenting.

2. The effect of mental illness on individuals has an impact on their relationships with others, particularly parents who create meaning from this experience.

3. Study participants will provide open and honest answers.

Summary

This dissertation is comprised of five chapters as follows:

Chapter I introduces readers to the research problem, the purpose of the study, the significance of the study and the assumptions.

Chapter II offers an overview of the literature that the researcher is sensitized to and highlights the significant literature on family responses to mental illness and the developmental process of aging.

Chapter III provides an overview of Classic Grounded Theory, the methodology chosen for this study. The chapter describes origins of the methodology, the study design and conduct of the study, data sources and collection procedures, as well as ethical protections in data collection.

Chapter IV presents the substantive theoretical model from this study.

Chapter V offers conclusions from the study findings, compares and contrasts this model to the literature and empirical research, and addresses the contributions of the study to knowledge in relation to theory, practice, and research method. The chapter concludes with findings, limitations, and implications.

CHAPTER II

REVIEW OF LITERATURE

This literature review has been in process since 1995 and is drawn from searches of the following databases: Medline, CINAHL, Cochrane, Academic Search Premier, MasterFILE Premier, Psychology and Behavioral Sciences Collection, PsycINFO, and Nursing and Allied Health Collections Keywords used included aging, bereavement, grief, parenting, mental illness, family care, caregiver burden, chronic sorrow, stigma, schizophrenia, bipolar disorder, dementia, vulnerable, disabilities, aging parents, elderly caregivers, developmental tasks of aging, adult children with mental illness, and aging parents of adult children with mental illness. Additional literature review was conducted during data analysis and is reported as part of the findings in Chapter V.

Chapter II gives an overview of aging parenting and previous research on family responses to mental illness. The goal is to place this study within the framework of the literature to identify bias and known concepts. This research began with the researcher's Master's thesis, measuring the grief response of 72 family members of mentally ill adults. The concept of studying the grief response of aging parents was based on letters the researcher received from older parents participating in her original grief study. The letters expressed concerns about who would care for their adult children when they died. When the researcher was attending a Grounded Theory Seminar, Glaser (May 23, 2008, personal conversation) challenged her pre-determination of grief as the response

of aging parents. After reflecting on this, the researcher changed the question to leave room for parents to share their experiences related to aging and parenting mentally ill adult children without a preconceived grief focus.

The literature review examined special issues of concern to older persons parenting mentally ill adult children. The review found that informal or family-based care of mentally ill adults has increased due to a number of institutional and societal factors. This has placed an increased burden of care on informal caregivers, raising interest in the issue termed, "caregiver burden" and the impact this burden may have on informal or family caregivers of a mentally ill adult (Brodaty & Donkin, 2009; Eisner & Johnson, 2008; Gordon, 2009). The concept of stigma has also increasingly been studied as contributing to the caregiver burden of families and informal caregivers of adults with mental illness (Corrigan & Shapiro, 2010; Kroska & Harkness, 2011; Logonathan & Murthy, 2008). The grief response of families and parents of persons diagnosed with mental illness has been established (Richardson, Cobham, Murray, & McDermott, 2011). Evidence was found indicating that not only do mentally ill persons continue to be stigmatized by society, but that, by association, families taking care of mentally ill persons are also stigmatized, adding to the burden of care. After establishing the fact that caregiver burden and stigma are challenging to family caregivers, the review focused on the special case of elderly parents caring for adult mentally ill children (Magana & Ghosh, 2010). The review found that care in this relationship is greatly complicated by the fact that the caretaking is likely to have been long-term, the caregiver him- or herself is also beginning to experience health problems

and, if these problems advance, the caregiver develops concern about what will happen to the adult mentally ill child after they die.

Case studies are presented of the problems experienced by older adults taking care of adult mentally ill children, generally finding that the subjective burden appears to become more significant as caregivers age. Overall, the review found considerable evidence that the increased dependence on families for the informal care of mentally ill adults has resulted in increased caregiver burden and stigma stress, compromising the quality of life, and that this problem grows worse in time. The review also found that this additional dependence on families for care presents itself as a special dilemma to older parents of mentally ill adult children, who may themselves be in need of health care or be concerned about what will happen to the cared-for adult child if they pass on.

<center>Erickson's Developmental Model</center>

In 1950, Erik Erickson published *Childhood and Society* in which he presented a model of identity development using a psychosocial model. He described a journey of identity development that unfolded across a lifespan from infancy to old age in eight stages. He reported that in the eighth stage of life, elderly persons, facing aging and mortality, struggle with integrity versus despair. According to Erickson, if older adults can successfully bring together the events of their lives and produce a sense of meaning and understanding, they can achieve integrity. If they are successful in integrating these memories and feelings into a meaningful whole, they can resolve conflict and attain wisdom (Erickson, 1997). Erickson's model describes continuing development in the identity of an aging person within a framework that shows progression across a lifespan. Each person has a purpose and a struggle with an age appropriate developmental task

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before him/her. For aging parents of adult mentally ill children, attaining a sense of meaning in old age, while struggling with issues of despair has little research. The potential for creating meaning based on resilience is unknown.

Caring for Adult Persons with Disabilities: The Family Response

Caregiver Burden

Family-based caregivers to adults are termed informal caregivers. A considerable body of evidence has indicated that these caregivers, whose care is critical to the quality of life of care recipients, experience stress due to the burden of care, as well as psychological morbidity, social isolation, physical ill-health, and financial hardship (Brodaty & Donkin, 2009; Eisner & Johnson, 2008; Gordon, 2009). Brodaty and Donkin (2009) suggested that psychosocial interventions can help relieve the burden of care, depression, and early entry into nursing homes for caregivers vulnerable to adverse effects of care. .

Brodaty and Donkin (2009) discussed this problem in terms of older adults caring for adult children with dementia. In dementia, the typical profile of the caregiver is a middle-aged or older female child or spouse of the patient, though sometimes a parent can be the caregiver. Most informal caregivers, the research has found, care for their adult loved ones due to a sense of duty, guilt, and social pressure. Caregivers who view their care more positively tend to experience fewer negative effects of care. If the main caregiver can share care giving with others in the family, this reduces the burden.

Brodaty and Donkin (2009) also made use of the distinction between objective burden (the actual level of care required) and subjective burden (the caregiver's appraisal of the burden). Caregiver burden has been found to vary based on a number of

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variables, including race, type of residence, co-residence, and other factors. Siegler, Brummett, Williams, Haney, and Dilworth-Anderson (2010) studied the degree to which the race and age of the caregiver, whether Caucasian or black, older or younger, impacted caregiver burden. Eighty-seven intergenerational families with caregiver dyads of African American and Caucasian parents and children or adults drawn from the Duke Caregiver Study were studied using the Center for Epidemiologic Studies Depression Scale, subscales for neighborhood and health factors, and the Clinical Dementia Rating to measure objective caregiver burden. Race, living arrangements, age, gender, education, income, health status, cultural justification for care giving, crime concerns, blood pressure level, and other health issues were studied. The study sought to bring together a number of factors studied in other research, for example, the role of cultural implications on the psychosocial response of caregivers to the burden of care (generally found to lessen care burden perceptions in African Americans). The results found that, by and large, Caucasian caregivers reported more depression than black caregivers, and they reported more depression if the cared-for person was living apart from them, which increased their worry. If, however, the dyads lived together, then black caregivers reported more depressive symptoms. Thus, Siegler et al. (2010) concluded that in addition to taking race into account when measuring caregiver burden, the way that race interacts with living arrangements is also important to consider. A broader appraising of the full dimension of caregiver burden is encouraged (Siegler et al., 2010).

Steadman, Tremont, and Davis (2007) explored still another factor which may or may not influence the perception of caregiver burden: the caregiver's prior

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relationship satisfaction with the person being cared for. Steadman et al. (2007) surveyed 72 live-in caregivers for persons with dementia in Providence, Rhode Island, using psychosocial measures categorized as either characterized by high or low satisfaction, the Burns Relationship Satisfaction Scale, focusing on intimacy and closeness, the Activities of Daily Living Questionnaire, the Zarit Burden Interview, and Revised Memory and Behavior Problem Checklist. Not surprisingly, it was found that where the caregiver had a positive or high satisfaction relationship with the person receiving care from a time before the onset of the care need, they perceived the caregiver burden as much less and as a result exhibited better problem-solving skills, more effective communication, and generally offered a higher quality care. The study was based on research which has found that the quality of prior relationship with the cared-for person influenced caregiver burden. The importance of the quality of the relationship before disease onset is so important that it even overrides the severity of the disease of the person being cared for. By contrast, caregivers with a negative relationship with the cared for person prior to the onset of disease are more likely to have a negative response to their caregiver burden.

Caregiver burden as a construct has been increasingly associated with other problems which can compromise the health of the caregivers. Caregiver burden has been found to be a problem for an increasing number of persons as the population ages and health care systems usually leave most care at an informal level (Rospenda, Minich, Milner, & Richman, 2010). Rospenda et al. (2010) conceptualized caregiver burden as the tasks required in the course of care giving, and the way in which the caregiver appraises the tasks, that is, both objective and subjective caregiver burden. Adults

caring for adults with mental illness report that as a result of caregiver burden they have worse physical health and more frequent visits to doctor offices. Caregivers as a group generally report a higher percentage of depression and anxiety than the general population and also tend to report a poor overall quality of life. The Caregiver Burden Inventory helped in the study of caregiver burden by including five subscales which measured time-dependence burden, developmental burden, physical burden, social burden, and emotional burden.

Smith, Hong, Seltzer, Greenberg, Almeida, and Bishop (2010) provided some concrete evidence of the extent to which mothers caring for either adults or adolescents with autism spectrum disorder (ASD) have a greater burden of care by examining the daily lives and activities of these women. The results found that mothers with adult or adolescent children with ASD spent "significantly more time" providing childcare, doing chores, and generally caring for and thinking about caring for their children with ASD than mothers without ASD children. They also had much less time to devote to leisure activities or self care. This also resulted in these mothers reporting more fatigue, arguments with their children, and stressful events in their lives. Overall, mothers of children, either adult or adolescent, with ASD, reported fatigue on 50% of the days, in contrast with mothers without ASD children reporting fatigue only 25% of the time. Smith et al. (2010) reported that this reflects another finding that mothers with children with ASD were three times more likely to experience stressful events on any given day and, of course, as noted, spend much more time on childcare than mothers of children without ASD. It was also found that mothers of ASD children are so taxed emotionally than they struggle to provide or receive emotional support from others. Overall, Smith

et al. (2010) argued that the findings indicate a need for more support services for mothers of ASD children, adult or adolescent.

Still another dimension of caregiver burden that has received some attention is the fact that adults taking care of persons with mental illness often suffer from sleep disturbance. Two-thirds of adult caregivers experience some form of sleep disturbance, which in turn compromises their ability to care for the person and to maintain their own health. At the same time, some research has found that while caregivers complained of poor sleep, the amount of sleep they experienced was not objectively different from normal levels. Using the 3P model, McCurry et al. (2007) discussed three major contributors to sleep disturbance: (a) the fact that the caregiver's sleep routines have been disrupted by the demands of care; (b) caregiver burden and depression, in which case worry keeps the caregiver up at night; and (c) the caregiver's physical health status, which, if compromised, can reduce sleep. Though the purpose of the McCurry et al. (2007) study was simply to develop some practice points for physicians to help adult caregivers overcome sleep disturbances, their study nonetheless adds sleep disturbance to the list of symptoms which contribute to or suffer from caregiver burden of mentally ill persons.

In sum, the research into caregiver burden in families in general has found that caregiver burden varies by ethnicity of caregivers, with African American caregivers appearing to handle care better than Caucasians (Brodaty & Donkin, 2009), that caregiver burden by older persons can lead to depression (Siegler et al., 2010), as well as chronic sorrow (Gordon, 2009), that caring for some conditions is worse than others, and that many conditions are often co morbid with others (Carey et al., 2007). It was

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also determined that the caregiver burden can restrict one's time socializing (Smith et al., 2010), that care giving can lead to sleep disturbance (McCurry et al., 2007), that coping mechanisms are of critical importance to the management of caregiver burden, that the quality of the caregiver's prior relationship with the cared for person is important to the character of the subjective burden (Steadman et al., 2007), and that family members may contribute to the quality of care by the nature of their emotional response to the condition being cared for (Baker et al., 2011). Overall, the general research into caregiver burden by family members of persons with mental illness paints a picture of stress that requires intervention and support.

<div align="center">Vulnerability</div>

There are many terms to describe vulnerable persons/populations including: underserved, disadvantaged, poor, stigmatized, underprivileged, and distressed. Aday (2001) suggests, "to be vulnerable is to be in a position of being hurt or ignored, as well as helped by others. As members of a human community we are all potentially vulnerable" (p. 1). As such, de Chesnay (2012) suggests, "Vulnerability may be explored on two levels…both as an individual and group concept" (p. 12). Persons within vulnerable populations may or may not see themselves as vulnerable and persons within less vulnerable populations may describe themselves as very vulnerable. Mentally ill persons and aging populations are identified as a vulnerable. However, aging parents, in fact families in general, of persons diagnosed with mental illness have rarely been specifically identified as vulnerable populations. Karp and Tanarugsachock (2000) suggest mentally ill people may engage in behaviors considered socially repugnant, deny they are ill, and frequently treat their caregivers with hostility instead

of gratitude. Aging parents are experiencing change processes that may leave them increasingly physically and financially frail while co-existing with an identified vulnerable population. Further exploration of vulnerability is an interesting consideration.

Capital Resources

Human capital is one of the resources identified as a factor in assessing vulnerable populations (Aday, 2001). Human capital is operationalized as income, education, jobs, and housing (Flaskerud & Winslow, 1998). The Richardson, Cobham, Murray and McDermott (2011) qualitative review of 12 studies, reported most participants in these studies were Caucasian, members of support groups, middle income, and older parents of an adult mentally ill child who was primarily male and diagnosed with schizophrenia. Leighninger and Speier (1996) reported demographic information on 250 family members of persons with mental illness in Louisiana as part of a larger study on family support and burden. These findings were compared with demographic data from the National Alliance for the Mentally Ill (NAMI) conducted in 1992 by Skinner, Steinwachs, and Kasper (Leighninger & Speier, 1996). Differences were found between support group family members and those who were not in support groups. The researchers found that 66.4% of the mentally ill adults studied lived with families who were not members of a support group, while only 42.6% lived with families who were in support groups (Leighninger & Speir, 1996). Of families involved in support groups, 22% reported their mentally ill family member was employed in some capacity. On the other hand, in non-member families only 9.8% reported the mentally ill family member was employed. Families that were involved in a support

group had an average annual income of $35,000 per year, while average income of non-member families was $15,000. Jungbauer, Stelling, Dietrich, and Angermeyer (2004) reported, "parents had a growing impression that patients who had experienced schizophrenia for a long period of time and whose employment status had not changed would remain permanently dependent on their family's financial support" (p. 609). These demographic differences between support group member and non-member families raise the possibility that parents who are not part of NAMI or a support group may have a different experience with their adult child's mental illness as it relates to employment, housing, and financial resources (Leighninger & Speir, 1996).

Chatterton, Ke, Lewis, Rajagopalan, and Lazarus (2008) examined the financial burden on a family who had a family member with BPD. The reported results suggest that families with a member diagnosed with BPD experienced more outpatient physician visits. The family with a person diagnosed with BPD made 24 outpatient visits compared to eight per year in the general population. The findings indicate, in total that families caring for a member with BPD, had medical costs that were three times those of families without BPD, with an average of $4,664 per year compared to $1,376 per year, which is 239% higher costs compared to control families. As a result, Chatterton et al. (2008) concluded that having a family member with BPD had a "significant financial impact" on families, in addition to the other factors related to care burden. Even though they did not study indirect financial costs, such as loss of work time due to care, Chatterton et al. (2008), therefore, found that financial burden adds to the care burden of families with a member with BPD.

As parents age, financial burden, housing, and income reduction are major concerns for themselves and their adult child. It is often suggested that persons with mental illness are part of a larger homeless population because state hospital populations have declined. Sullivan, Burnam, and Koegel (2000) found that persons with mental illness were over-represented among the homeless, relative to the general population, and concluded that mental illness was most likely one of many vulnerabilities that conferred risk for homelessness. Overall, the jobs and incomes of the parents of adult persons with a mental health diagnosis remain unexplored.

Stigma

One of the most complex and difficult problems for mentally ill persons is stigma (Corrigan & Shapiro, 2010; Kroska & Harkness, 2011; Logonathan & Murthy, 2008; Logonathan, 2011). Gonzalez-Torres, Oraa, Aristuegui, Fernandez-Rivas and Guimon (2007) noted that data on the extent to which patients with schizophrenia, and their families, experience stigma and its negative effects is relatively scarce. They reported research has found that stigma causes mentally ill persons to curtail their social life, acting as a second illness, thus greatly reducing their change of clinical improvement and recovery. For that reason, the authors developed a qualitative study in which schizophrenic outpatients and their families were interviewed about their experience and side effects of stigma, including prejudice relating to a sense of danger, daily social discrimination, over-protection and infantilization by caregivers, discrimination in health care, and avoidance and social isolation as a result. Relatives were asked to describe witnessed incidents of stigma towards their schizophrenia siblings or offspring, as well as discrimination they also experienced due to stigma. The

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study included a total of 44 persons, 18 patients and 26 family members, with data collected by audio and video. The results found that both patients and families reported high levels of experience of discrimination due to stigma in all areas of life, including health care. They reported that people often responded to their illness as if it was merely them being lazy, that they were called names, that they were daily treated differently, as oddballs or with pity, and that even in the health care system their physical symptoms were routinely minimized by staff and believed to be a somatic problem.

The most common response to stigma in both patients and relatives was self-isolation and avoidance of society. Gonzalez-Torres et al. (2007) argued that stigma greatly contributes to caregiver burden and leads to isolation, which indirectly degrades their overall quality of life and, potentially, the quality of care. The authors suggest efforts must be made to publicize the reality of stigmatizing behavior and potential interventions to counteract it.

Stigma studies about mental illness have explored the possible origins for the stigma, though generally finding them to be deep-seated. For example, Boyd, Katz, Link, and Phelan (2010) studied the fact that someone who is related to a person who has been at one time hospitalized for mental illness can be stigmatized as a result of beliefs in the genetics of mental illness. This sort of stigma could dramatically compromise care and recovery of persons of mental illness and their families by contributing to discrimination and fear. When stigma is expressed broadly and publicly, patients tend to internalize it, reducing the likelihood that they will seek out care they need. While acknowledging social distance as a generalized consequence of stigma, Boyd et al. (2010) sought to determine whether this stigmatizing behavior extended into

friends and family. They suggested that previous contact with the person and in-group

bias in favor of the person would possibly reduce the effect of stigma and result in less

negative attitudes towards the person with mental illness. A random study with 1,416

respondents was conducted by phone using a vignette format to determine the degree to

which contact and in-group bias mediated stigma in response to persons previously

hospitalized for mental illness. Measures were used to determine contact, anger,

sympathy, perceived persistence, perceived seriousness, social distance, and

reproductive restriction. Boyd et al. (2010) confirmed in their study that having had

previous contact with a person with mental illness resulted in less stigmatizing concerns

about the individual person. The findings suggested that having contact with persons

with mental illness may serve to reduce the overall effect of stigma on the care for the

mentally ill (Boyd et al., 2010).

Grausgruber, Meise, Katschnig, Schony, and Fleischhacker (2007) examined the

differences in stigma behavior towards persons with schizophrenia among the general

public, family members, and medical staff, to determine how deep stigma against

schizophrenics was in Austrian society. They conducted a study of members of the

general public, 385 relatives of people suffering from mental illness, and 1,479 medical

personnel, from nurses to doctors, caring for persons with mental illness. They found

that the general public, family members, and medical staff had widely varying

perceptions and attitudes towards persons with schizophrenia, including different causal

attributions of schizophrenia, different perceptions of treatment success of persons,

different fears linked to dangerousness of schizophrenics, and a different level of

willingness to interact with persons with schizophrenia. While half of the general public

felt that persons with schizophrenia were dangerous, only a quarter of staff and a third of relatives believed so. The general public also had a pessimistic appraisal of treatment success while staff and relatives held more positive views. Not surprisingly, it is the general public who held the most negative views and engaged in the most stigmatizing behavior, including social distancing. Staff did identify, more than the public, that a cause of schizophrenia was an unhappy family situation. Interestingly, it is unclear if the unhappy family situation could result from the stressors associated chronic mental illness or if it was assumed to be fault of the family. Social distancing as a strategy resulting from stigma was found to be strongly influenced by the general public's perception that persons with schizophrenia are dangerous. While the Grausgruber et al. (2007) results were promising, and would suggest that contact as a strategy to reduce stigma does in fact do so, the intractability of public attitudes about mental illness, with half still believing that schizophrenics are dangerous, presents a significant risk of being stigmatized for any person or family member caring for persons diagnosed with schizophrenia.

Wong, Davidson, Anglin, Link, Gerson, Malaspina, McGlashan, and Corcoran (2009) examined how quickly stigma comes to negatively affect a family, by means of associative stigma, after the diagnosis or onset of a psychotic disorder among any family member. They examined early onset cases of family stigma to determine whether the stigma in early stages of the diseases prevented families from help-seeking behavior on behalf of the cared for person. Their research was grounded in findings that individuals with schizophrenia, in particular, were stigmatized soon after onset of their illness, and that stigma had negative effects not only on them but also on their care and

their families, and their families' ability to care for them as well. The theory behind

family member stigma is that either courtesy or associative stigma is experienced by

families as being isolated and excluded socially as a result of the diagnosis of mental

illness in a family. This study compared 11 individuals who were at high risk of onset

but not yet diagnosed with nine patients with a recent onset of psychosis for the

presence of stigma against themselves and family members. The Opinions about Mental

Illness scale and the Family Experiences Interview Schedule were used to obtain

results. In general, Wong et al. (2009) found that in cases of recent onset it appears that

stigma had not fully set in as most family members still espoused positive and

supportive values encouraging the cared-for person with recent onset psychosis to

participate in life. Family members, at this point of the diagnosis, still believed that the

patient should work, remain connected with society and not be penalized for their

problem. All participants felt that the patients should also be entitled to parity in health

care with persons having physical problems. Family members' perceptions of stigma

seemed to change, however, after the experience of a high-stress psychotic episode, in

which case stigma appeared to evolve from self-stigmatizing realization that they will

have to deal with a disease like schizophrenia for the rest of their lives. Wong et al.

(2009) also found that ethnic minority families with persons with recent onset psychosis

expressed a sense of shame and a desire to conceal the patient's condition from others.

Because stigma was found to be relatively low during the early phases of psychosis

Wong et al. (2009) argued that this would be an opportune time to intervene to prevent

stigma from forming around the family, and, if ethnic differences persisted, to develop a

culturally sensitive intervention that would help to reduce the amount of stigma experienced by family members of ethnic families.

Kroska and Harkness (2011) constructed a computer simulation demonstration which focused on the degree to which modified labeling theory of mental illness described the behavior of persons with mental illness. According to this theory, stigma or negative societal conceptions of mental illness only become personally relevant when one is diagnosed, in which case one's self-concept can be damaged. As a result, patients cope either by concealing their treatment history, educating others including family members about their illness, or withdrawing from social interaction. Kroska and Harkness (2011) demonstrated that both the severity of the mental illness diagnosed and the general diagnostic category in which the illness is placed, ranging from affective to schizophrenia, shapes patients' response to the diagnosis and resulting coping behaviors. Thus, stigma resulting from diagnosis itself also shapes patient response to mental illness, with indirect impact on family members as well.

Angermeyer, Schulze, and Dietrich (2003) noted in focus group discussions with families of mentally ill persons that they referred to stigmatization experiences of the mentally ill member when asked for their own experiences. It appeared difficult for relatives to draw the line between negative reactions targeted at themselves and those targeted at their mentally ill family member. During the early stages of mental illness, families reported their emotional agony increased when statements by the diagnosed family member, and some mental health professionals, suggested they (the families) might be the essential cause of the problem (Karp & Tanarugsachock, 2000). Family members reported relationships with professionals resulted in a sense of stigma because

of the lack of interest in their fears, problems, and worries (Angermeyer et al., 2003).

Drapalski, Marshall, Seybolt, Medoff, Peer, Leith, and Dixon (2008) reported "family members who felt stigmatized by mental health providers consistently experienced greater needs in all areas" (p. 10). Associative stigma is a challenge for families, and parents, in particular, could be prone to feelings of shame and blame for the onset of their child's mental illness.

In sum, the research into stigma finds that not only is stigma about mental illness persistent in society, contributing to the isolation of individuals with various mental illnesses, but that family members who care for these persons often continue to be stigmatized by association. In accordance with Goffman's original model of stigma, family members end up stigmatizing themselves (Boyd et al., 2010), and a diagnosis of schizophrenia is particularly stigmatized in society (Grausgruber et al., 2007), all of which adds to the caregiver burden of family members of mentally ill persons. Aging parents' underlying belief they are the cause of the problem or have increased the problem through expressed emotion may reduce their ability to connect socially with resources when they are most in need. The research into stigma suggests stigma can be countered by encouraging more contact between persons with mental illness and the general population, and that friends and family members, in fact, stigmatize these persons less than do strangers (Nadeem, Lange & Miranda, 2009).

Care Quality

Environmental resources are operationalized as access to health care and quality of care (Flaskerud & Winslow, 1998). Stigma and discrimination are experienced by relatives of persons with mental illness through imbalances and injustices inherent in

social structures, political decisions, and legal regulations (Angermeyer et al., 2003).

Lack of coordination, health care coverage, community mental health professionals, and

confidentiality laws limits access and quality of health care for persons with mental

illness. The poor quality of mental health care is one of the main stigmatization

experiences for relatives of the mentally ill (Angermeyer et al., 2003). These

researchers also found that laws, particularly confidentiality laws, were barriers to

health care. Parents of individuals with mental illness are faced with the sometimes

unpredictable behavior of their loved one. Therefore, they must have an on-going

relationship with a health care system. Changes in diagnosis and treatment

recommendations, as well as difficulty in obtaining information from professionals due

to conflicts over confidentiality, are continuing frustrations for family members of

individuals with mental illness. Frustration also results from encounters with

professionals who give conflicting advice to family members. Another frustration for

parents who have been denied access to information about their loved one's treatment is

that they are called upon to file a petition for commitment and/or provide follow-up

care.

As parents develop chronic illnesses, their health might disrupt their usual

patterns or routines as physically ill people are ordinarily involved in getting well or

adapting (Karp & Tanarugsachock, 2000). To the extent that there are predictable

moments in the unfolding of a family member's illness, there will be a parallel family

care giving career for the family (Karp & Tanarugsachock, 2000). Australian

researchers reported respite care for mentally ill adults with older caregivers was

inadequate (Jeon, Brodaty, O'Neill, & Chesterton, 2006). Mental illness, with

exacerbations and remissions, is relentless in its demands on family members. Care quality for mentally ill adult children is a challenge and the issue of the same care for families has not been addressed.

Relative Risk

Relative risk is considered to be the ratio of risk of poor health among groups who do not receive resources and are exposed to risk factors compared to those who receive resources and are not exposed to risk factors (Aday, 2001). Vulnerable populations are at risk of poor physical, psychological, and/or social health (Aday, 2001). While everyone is at risk for impairments in health, some individuals or groups are more likely to be at risk at given points in time (Aday, 2001). Relative risk reflects the differential vulnerability of groups to poor health and the likelihood of exposure to identified risk factors. The "differential vulnerability hypothesis argues that negative or stressful life events hurt some people more than others" (Aday, 2001, p. 4). Risk factors include exposure to stressful events as well as lifestyle choices, health screening and health promotion, and prevention. In describing the stressful events that decrease family members' social connection, increased stress, grief, guilt, and isolation have been identified as risk factors. Aging parents confront both the challenge of caregiver demands and the need to cope with aging. Barker, Greenberg, Mailick-Seltzer, and Almeida (2011) state,

> The results of the current study adds to a growing body of evidence that the long-term effects of parenting an adult with a disability has a biological impact on aging parents and support the need for family interventions across adulthood and into old age for parents of individuals with SMI. (para.1)

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In studying the problem of older adults taking care of adult mentally ill children, the health care behavior of the older person factors in and contributes to caregiver burden (Magana & Ghosh, 2010). For example, Conner, Copeland, Grote, Rosen, Albert, McMurray, Reynolds, Brown, and Koeske (2010) noted that older adults are more vulnerable to the effects of depression and yet are less likely to seek care for depression. Indeed, Conner et al. (2010) reported that depression is the most prevalent diagnosis, in terms of mental health problems, for older persons, and that 17% of men over 65 and 11% of women over 65 suffer from depressive symptoms. Given the fact that the elder population is swelling, due to the aging of the Baby Boomers, it is expected that the prevalence of elder depression is likely to double in the next 20 years.

While these statistics acknowledge that depression remains worse and more commonly diagnosed among older persons, it is also true that older persons with depression are much less likely to seek help for their depression. Among the half of all elders who receive help for their mental health problems, those with depression are very low on the help-seeking scale. If an elder happens to be caring for an adult child with a physical or mental illness, and the caregiver burden causes them to experience depression, the fact that they are less likely to seek care for that problem increases the risk of reduced quality of care to the older caregiver as opposed to younger parental or family caregivers.

In an early study on this particular caregiver dynamic, Greenberg, Seltzer, Krauss, Chou, and Hong (2004) examined the problem of maternal well-being in mothers caring for adult children with disabilities including schizophrenia, autism, and Down syndrome. They also studied whether the impact of care burden on maternal

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well-being was mediated by dispositional optimism. Some 126 mothers caring for adult children with Down syndrome, 292 mothers caring for adult children with schizophrenia, and 102 mothers caring for adult children with autism were surveyed. The study was undertaken based on research that the relationships between older parents and adult children are fairly positive and supportive and that in cases when the parent is frail or elderly, the closeness of the relationship between caregiver and care recipient also enhances caregiver well-being. The study was also based on findings that maternal care for adult children with mental illness was more pessimistic and had poorer mother-child. The study used the scale of psychological well-being, the CES-D Depression Scale, the Positive Affect Scale, and the Life Orientation Test to measure dispositional optimism. The results found that mothers of adults with schizophrenia and autism had better psychological well-being, with the effect mediated by optimism. By focusing on optimism, the study looked at pathways by which the quality of mother-child relationships is affected by mediating factors. Greenberg et al. (2004) commented at the time that this was an important finding, as dispositional optimism had been ignored as a mediating factor contributing to resiliency in caregivers of adults with mental illness. That is, the findings "contributed to the emerging body of research documenting the documenting the positive and supportive role played by persons with disabilities within their family" (Greenberg et al., p. 23).

It is also acknowledged that parental response to these illnesses varies related to the different times in life in which the diagnosis is made, with schizophrenia being distinct as in young adulthood, thus making parental response to its onset more difficult and jarring, based on previous experience. At the same time, the unpredictable and

cyclical nature of schizophrenia also creates more complex caretaking. Copeland and

Heilemann (2008) used Vulnerable Populations Conceptual Model (VPCM) as a

framework for conceptualizing family members' vulnerability related to violence in

mentally persons. She reported "family members are at increased risk of being victims

if their mentally ill relative becomes violent" (p. 972). Dixon, Stewart, Burland,

Delahanty, Lucksted, and Hoffman (2001) found family members who completed a

Family to Family Education Program experienced enhanced empowerment and reduced

subjective burden. However, attending did not reduce parents' actual, tangible sense of

workload nor did it affect their self esteem (Dixon et al., 2001). The literature is not

clear on how family members connect with support and at which point in the illness

trajectory connecting with a support group is helpful and reduces risk.

Data on actual risk rates for parents is unavailable. In describing the stressful

events that decrease family members' social connection, increased stress, grief, guilt,

financial burden, and isolation have been identified as risk factors. Positive pathways

such as dispositional optimism have early exploration. There is little literature that

outlines prevalence rates for health problems experienced by family members or aging

parents related to caring for or involvement with a mentally ill family member. No

literature was found on health promotion, screening, or prevention for aging parents of

persons with mental illness.

<div align="center">Parental and Family Response</div>

Chronic Sorrow

When care involves a parent and an adolescent or adult person the response of

the parent to the illness can influence the course and quality of care. Chronic sorrow,

distinct from grief or depression, is a construct developed to describe the emotional

response to the fact that their child has a permanent physical, developmental,

behavioral, or emotional disorder (Gordon, 2009). Chronic sorrow as a construct was

originally introduced in the early 1960s to describe "the normal pervasive psychological

response in the suffering of parents dealing with mentally disabled children" (Gordon,

p. 115). Chronic sorrow is defined as deriving from a living loss, that is, a diagnosis of a

child or relative with major illness. Research on parents of children with Down

Syndrome, for example, found that chronic sorrow can progress through life, and

recovery is sometimes gradual and steady or filled with peaks and valleys. However,

research has also indicated that chronic sorrow not only can lead to depression but also

can add to the caregiver burden of parents with mentally ill children as they mature into

adulthood. The Burke/NCRCS Chronic Sorrow Questionnaire was developed to assess

parental state of sorrow, and interventions which give parents license to vent their

sorrows or develop empathy were developed. While the purpose of Gordon's (2009)

study was to provide nurses with ways to identify and respond to chronic sorrow in

parents, the construct as a whole supports the notion that parental response to care of

mentally ill children contributes to caregiver burden.

Expressed Emotion

One of the primary predictors of BPD is expressed emotion (EE). Interventions

over the years have sought to reduce EE levels in BPD, in order to make care more

manageable. The concept of EE is defined as "critical, hostile, or emotionally over

involved attitudes toward a relative with a psychiatric disorder" (Eisner & Johnson,

2008, p. 375). EE has repeatedly been linked with poor outcomes in treatment of

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persons with mental illness, strongly indicating that persons with mental illness respond negatively to EE from family members and that BPD relapse, in particular, is often sparked by family EE. The dynamics of EE are theoretically explained when persons become angry at others when they feel they are responsible for their actions, with EE most often expressed by family members who believe that a mental illness is still within a person's control. Research has shown that EE often results from blaming attributions leveled against patients by families or in family contexts. For this reason, Eisner & Johnson (2008) developed a psycho education intervention designed to introduce an element of acceptance of the presence of BPD in the family in order to reduce the anger and blaming among family members, as a way to reduce incidence of EE. The theoretical foundation of psycho education models is that an increase in knowledge of the disease can also increase family support, reduce family burden, increase caregiver self-confidence, and as a result, reduce the number of relapses in mental illness a family must go through. To reduce the level of anger in EEs, elements of integrative behavioral couple therapy were also incorporated into the intervention. The unified detachment technique of IBCT was focused upon, the technique allowing persons to talk about problems without getting angry. With regard to BPD, these interventions would help family members recognize aspects of BPD which are not changeable and must be accepted in some form.

The intervention entailed having 28 family members of families with BPD individuals attend multifamily group workshops and then complete an assessment one week later. The assessments included the Understanding Mood Disorders Questionnaire, the Five Minute Speech Sample designed to assess criticism and

dissatisfaction, the Causal Dimension Scale, reviewing perceptions, and the State Trait

Anger Expression Inventory. Though the assessment revealed that as a result of the

intervention family members demonstrated more knowledge about BPD, they were not

able to reduce blaming attributions and criticism, indicating to Eisner and Johnson

(2008) once again that EE is very difficult to change. Finally, Eisner and Johnson

(2008) conjectured that small sample size or the use of self-report instruments for anger

may have been the cause of this disappointing finding.

Grief

Although grief work – the process of withdrawing attachment and working

through the pain of loss – has been studied by health professionals, most studies have

examined the experience of grief over loss due to death rather than loss due to a chronic

illness (Kaplan, Sadock, & Grebb, 2003). The concept of "facing loss" has relevance for

the study of the families of the seriously mentally ill; "facing loss" correlates with

ongoing grief that family members face in learning to live with a member who has a

mental illness. Families must let go of their former way of life and relationships that

used to be because they do not know what to expect. Rose, Mallinson, and

Walton-Moss, (2002) found evidence that family members of persons with serious

mental illness experienced emotions and behavior of grief similar to those experienced

by bereaved persons. Family members watch the gradual mental and functional decline

of the mentally ill family member, and they experience the loss of the "person" they

once knew, as well as grief (Atkinson, 1994; Davis & Schultz, 1994; Eakes, 1995;

Goddress et al. 2005; Miller, Dworkin, Ward, & Barone, 1990; Richardson, Cobham,

Murry, & McDermott, 2011; Rose et al., 2002; Solomon & Draine, 1996).

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In early work, Brown and Powell-Cope (1993) found caregivers faced the reality of what chronic illness changed in terms of dreams for the future, personal freedoms, previous lifestyles, and interpersonal relationships. The concept of "facing loss" has relevance for the study of families of the seriously mentally ill; it correlates with the grief family members face in learning to live with a member who has a mental illness. The concept of grief as a response to chronic illness is described for family members with a seriously mentally ill member (MacGregor, 1994; Finkelman, 1997) and studied (Atkinson, 1994; Miller et al., 1990; Solomon & Drain, 1996; Godress, Ozgul, Owen, & Foley-Evans, 2005). Miller et al. (1990) believed that studying the grief reaction of family members of persons with chronic mental illness would help identify interventions to increase coping skills for family members. They developed the Mental Illness Version of the Texas Inventory of Grief (MIVr-TIG) to measure the emotional and behavioral grief responses of family members experiencing the mental illness diagnosis of a family member. The investigators administered the MIVr-TIG to family members of patients with schizophrenia and BPD and found measurable grief reactions similar to grief reactions after the death of a family member. When attempting to establish predictors of grief, the investigators found no significant difference by diagnosis, degree of chronicity or severity, strength of the relationship, or degree of responsibility for the care of the mentally ill person. Although it was an important initial study, generalizability was limited by a small sample size (n=48) of self selected attendees of psycho educational workshops and support groups for family members of the mentally ill. The median range of illness was two to five years; thus, the length of time the families had been coping with the illness was not long.

Solomon and Draine (1996) also studied the grief response in family members of persons with serious mental illness. They used the MIVr-TIG but focused on social support and objective and subjective burden. The family subjects (n=225) experienced a longer time period since initial diagnosis (an average of 12.7 years.). This study varied from previous studies in that 51% of the family members had never participated in a family support group and 58.3% had never been members of the National Alliance for the Mentally Ill (NAMI). The results of the study showed that there was a greater degree of grief associated with family members who were Caucasian and had less education, but when looking at severity of illness more years of illness were associated with less grief. Although the researchers did not specifically consider age, the suggestion of longer illness could suggest that grief would decline with age. The researchers also reported that a smaller social network was associated with a greater degree of grief. Burden, both objective and subjective, was measured by interview and rated by both the family member and the interviewer. Findings supported the hypothesis that burden is an important factor in explaining the grief expressed by family members of the seriously mentally ill.

Finkelman (1997) stressed the importance of including all members of a family unit when researching the grief response. The dynamic interaction between the various subsets within the family may dramatically influence the grief response for each particular family member who has a relative with serious mental illness. Sadness, frustration, and anxiety were the most frequently reported emotions of the family members as a whole; when analyzed by subsets according to relationship, a slightly different picture of the emotions of grief emerged.

Ryan (1993), in an ethnographic study of five mothers from a support group, reported a strong sense of loss and grief as their children did not experience adult developmental goals. Atkinson (1994) compared the grief response of three groups: (a) parents who had an adult child with schizophrenia, (b) parents who lost an adult child through death, and (c) parents who "lost" an adult child through a head injury resulting in an organic personality disorder. She used the Beck Depression Inventory, the Hamilton Anxiety Scale, the Michigan Drug and Alcohol Screening Scale, the Texas Revised Inventory of Grief (TRIG), and the Mental Illness Version of the Texas Inventory of Grief (MIVr-TIG). Atikinson found that parents of children who have schizophrenia had significant increases in their grief scores on the MIVr-TIG from the time the child became ill to the present, a number of years later. Parents whose child had died showed a dramatic decrease in grief over time, while the parents whose child had organic personality disorder showed a less dramatic decrease in grief. Atkinson concluded that the parental loss of a child through schizophrenia led to a pattern of chronic grief but not to an increase in depression or anxiety. Although Atkinson did compare three different groups of parents, the number of participants in each group was only 25, a small sample. The participants were all members of a support group and self selected; thus, generalizability was limited. Eakes (1995) interviewed parents whose ages ranged from 54-75 years regarding their parenting experience of their mentally ill child. She found the majority of subjects described their feelings as less intense than at the time of diagnosis, which was in contrast to Miller et al. (1990) and Atkinson (1994). Eakes (1995) also suggested that, in theory, practitioners acknowledge that anger is an

integral part of grief. However, parents reported they did not feel professionals acknowledged these feelings in practice.

In describing their lived experience, twelve fathers felt the care giving and parenting of schizophrenic adult children was the most difficult event of their life (Howard, 1998). Further research was recommended with different ethnic groups and use of chronic sorrow as a framework in investigating parental care of adult children with severe mental illness. Davis and Schultz (1998) compared 78 mother/father dyads to validate grief, explore whether hours of parental contact with the child influenced grief, and explore whether parental relationship differed in grief reaction. They found the respondents who volunteered to participate in the study were older (62 years of age on average) and both parents reported grieving. The number of hours of parental contact was not found to influence grief.

Hatfield (2002) surveyed 210 older caregivers regarding end of life planning. The researcher found only 18% of elderly caregivers of relatives with mental illness had completed any kind of end of life planning. A majority of respondents reported emotional barriers as obstacles to planning. Of these barriers, 63% reported anxiety and 31% reported unresolved grief and pain as the barriers preventing them from making decisions about end of life plans.

Wilson, Hemmesch, Kaas and Lewis (1998) thesis study of 72 family members reported the feelings of grief most frequently reported by all family respondents, as measured by the MIVr-TIG, were sadness, frustration, and anxiety. While other feelings were reported to decrease over time, these feelings remained strong, albeit to varying degrees among family members. Sadness was the strongest emotion reported by the

respondents for this study. Although the percent of family members who reported feeling sad diminished with the passing of time, the feeling of sadness continued to dominate the family members' emotions. Respondents reported a significant decrease in disbelief, indicating they had an increase in their level of acceptance over time. In comparison with Miller et al. (1990), whose respondents had lived with the effects of the illness for two to five years, respondents in the Wilson et al. (1998) study had lived with the illness for 14.7 years. In addition, Wilson et al. (1998) reported spontaneous written letters from older parents, primarily mothers, expressing grief and sorrow over "what will happen to my child when I die." Godress et al. (2005) surveyed 62 mothers and nine fathers using the MIVr-TIG and Impact of Event Scale. Findings included parental reports of difficulties adapting to and distress associated with reminders of the illness, reduced levels of grief over time, and reduced levels of parents' health and well being.

Richardson, Cobham, Murray, and McDermott (2011) conducted a qualitative review of published literature, report that family members of persons who are mentally ill grieve in complex ways. They report grief is related to the adult child's relationship with the parent and impacts the parent's physical and psychological health. The authors suggest current research is sparse with additional research required. This research could "unveil important and unanswered questions about parent and family members' grieving process" (Richardson, Cobham, Murray, & McDermott, 2011, p. 41). The literature supports a grief response of family members to the "loss" of the person they knew prior to a diagnosis with serious mental illness (SMI). In five studies (Atkinson, 1994; Miller et al., 1990; Solomon & Drain, 1996; Godress, Ozgul, Owen, & Foley-

Evans, 2005) the grief response of family members of persons with SMI was reported as changing over time. In the Atkinson (1994) and Miller et al. (1990) studies the grief response had increased over time; in the Solomon and Draine (1996) and Goddress et al. (2005) studies the grief response had decreased over time.

Case Studies of Problems in Care of Mentally Ill
Adult Children by Aging Parents

Aschbrenner, Greenberg & Seltzer (2009) studied the care burden experienced by older parents of adult children with BPD. BPD was studied as it begins in early adulthood and the severity and frequency of its episodes can increase, unlike other mental illnesses in which symptoms may decline over time. As a result, a diagnosis of BPD can eventually lead to loss of work, increased healthcare costs, poorer overall functioning, and a growing burden on caregivers. Research has shown that parents who must care for children with BPD for decades often are beset by numerous challenges, and also that the particular problems related to BPD are shaped by the fluctuating and unpredictable nature of the disorder and the frequency of transitions between acute periods and periods of uncertainty between episodes. Long-term care of persons with BPD has been linked to poor physical and mental health among older adults with limited social support. Aschbrenner et al. (2009), while acknowledging prior research, found that too many previous studies failed to differentiate between the adult child with BPD and the mental illness problems of the caregiver, as research has found that first-degree relatives of patients with BPD often also suffer from mental health problems. They studied 145 older parents, average age of 65, of adult children with BPD to determine, based on several measures of psychological well-being, if whether their care

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burden had compromised their own health. The subjects were drawn from the Wisconsin Longitudinal Study which has followed the life course of high school seniors from 1957 with mental illness across 50 years. The psychological well-being of the older parents, most of them in their 60s, was measured with the Psychological Well-Being Scale, while other factors were measured with the Marital Satisfaction for Older Adults Scale and the Composite of International Diagnostic Interview.

It was found that these older parents had a more compromised profile in terms of their personal mental and physical health as a result of their care burden, as well as more problems with their marriage and work-life balance issues, including higher divorce rates and lower employment level. Parents with a higher level of education, however, generally fared better than those with a lower level of education, while men, though reporting that their health, both physically and mentally, was worse than women's, in fact fared better than women in terms of mental health. The problems experienced by older parents taking care of older children with mental illness also, in turn, often led to mental illness in the caregiver. In this case the problems they experienced were even more serious than those of older parents who had not developed mental illness. Specifically, older parents of adult mentally ill children who had experienced depression reported less self-acceptance and environmental mastery, contributing to their subjective care burden. Overall, Aschbrenner et al. (2009) found that older parents of adult mentally ill children are negatively affected by their care burden in numerous ways. At the same time, however, Aschbrenner et al. (2009) found a good deal of resiliency in these families, including instances of well-being, purpose in life, positive personal relationships, and growth in those relationships. This was

especially true if the older parent felt that they had a support group and could confide in others. However, many of these gains are lost in parents with a previous history of depression, suggesting that this group of older parents of adult children with BPD is especially at risk of mental illness and in most need of support and services.

In another study, Aschbrenner, Greenberg, Allen, and Seltzer (2010) studied the long-term stressors, and also the resources and gains, experienced by older parents of adults with serious mental illness. Aschbrenner et al. (2010) described the dimensions of the subjective burden of this kind of care as rooted in the fact that caring for an adult child with schizophrenia or BPD may extend over decades, that is, it may never be possible to establish independent living for the adult child and that older parents must continue with this care even as they begin to cope with their own aging and changes in health, including physical disability. It has also been found that, with the onset of older age, parents of adult children with mental illness begin to worry more about the future care of their child after they die. The study was based on previous research into this particular care dynamic, generally finding that older parents of adult mentally ill children experience higher levels of burden and elevated mental and physical health concerns and problems, often as a direct result of the care burden. Subjective burden as a concept is defined as "the range of negative emotional reactions to care giving" (Aschbrenner et al., p. 605). Aschbrenner et al. (2010), however, argued that the research thus far has focused too much on the negative aspects of care in this situation and not given enough attention to the potential for personal growth which ongoing care giving offers an older person.

In addition to providing older persons with major challenges, it is also true that caring for an adult child with mental illness may "present unique opportunities for positive parenting experiences, including personal growth and greater awareness of family strengths" (Aschbrenner et al., p. 606). Research has, in fact, found that many family members coping with the mental illness of family members have experienced a deeper sense of awareness, inner strength, more tolerance, increased sensitivity, and empathy. For this reason, Aschbrenner et al. (2010) argued that interventions to help older parents with adult mentally ill children to cope should focus on positively trying to enhance the caregiving experience, rather than entirely relieving parents of the burden of care. To frame this kind of response, the notion of subjective response has been rearticulated to also include what is known as the objective care giving burden, which entails direct ongoing hands-on support with the activities of daily living. Research into the role that this kind of care has on increasing or decreasing the subjective burden of care has, to date, been inconclusive, with one school of thought finding that the need for greater help in daily living increases the subjective burden, while another finding that being involved directly on a daily level reduces the subjective burden. Overall, however, this line of research has found that context is predictive of the level of subjective burden, with, for example, mothers of adult mentally ill children reporting that when their cared-for child moved out of the house their sense of the subjective burden of the care was reduced.

While Aschbrenner et al. (2010) sought to explore the positive side of care, he acknowledged that personal gains derived from care are usually only possible based on an adequate level of social support, and that supportive resources are required to make

the burden of care for an adult mentally ill child acceptable. The usual pattern of care giving is that a family will try to manage care by themselves, then turn to advice and support from others going through similar experiences. This later strategy has been found to foster a climate where they can feel supported and this in turn promotes an increased sense of mastery of the situation and resulting personal growth. Direct support group participation, for example, has been associated with reduction of subjective burden in older adults caring for the mentally ill. If the adult child with schizophrenia is able to reciprocate and undertake tasks related to their own care now, this, too, can provide older parent caregivers with a sense of support. For all of these reasons, Aschbrenner et al. (2010) sought to determine which factors were most closely associated with older parents of adult mentally ill children experiencing personal gains as a result of their care. They hypothesized that parental stressors, such as the child's poorer level of health, greater amount of care needed, and the co-residence of the parent and child will all lead to increased subjective burden, while parental resources, including assistance from the child to the parent, the presence of confidants, and support groups will be related to personal gains.

Some 111 older adults with mentally ill adult children were studied in the state of Wisconsin, with subjects derived from the Wisconsin Longitudinal Study which has followed the life course of high school students with mental illness and their siblings and parents over the course of fifty years. The average age of the parent involved in the study was 63 while the average age of the adult mentally ill child in the program was 37. Subjective burden was measured using the Zarit Burden Interview; three parental stressors and three measures of social support were also measured. The results of the

study found a strong correlation between stressors and the adult parent's sense of subjective burden, which was reduced if the adult child could do some tasks by themselves, or if the adult parent received more assistance. The study also found that older parents also experienced a number of gains from their care burden, especially if they engaged in more activities in daily life with the adult child with mental illness. In particular, subjective burden was, in fact, reduced if the older parents had a number of persons around them who acted as confidants and were members of a support group. The fact that more not less care was associated with personal gain for the older parent indicated to Aschbrenner et al. (2010) that reciprocity resulted in reduction of subjective burden. That is, objective burden, living with the child, having confidants and belonging to a support group also counteracted the negative aspects of subjective burden and provided older parents caring for adult mentally ill children with gains. The key ingredient in this mix appeared to be receiving some reciprocal help from the adult mentally ill child him- or herself, with reciprocity playing an important role in reducing stress. Aschbrenner et al. (2010) concluded by asserting that a recovery-oriented approach to care for adult mentally ill children of older parents would reduce subjective burden by helping older parents find ways to cope more effectively with care giving.

Johansson, Anderzen-Carlsson, Ahlin, and Andershed (2010) interviewed sixteen mothers with adult children with long-term mental illness to determine their feelings about their care burden. The study was undertaken based on prior research into the degree to which caregiver burden can lead to mental illness for family members caring long-term for mentally ill adult children. A constant level of high burden has been associated with feelings of grief, worry, anguish, guilt, and shame. These parents

also report less satisfaction with their quality of life, and this puts them at greater risk of mental and physical health problems as well. Research has also established that mothers assume the majority of the burden and often have to adapt their lives to take care of their adult mentally ill children, leading them to experience mental health problems and feelings of isolation and disenfranchisement. Using the concept of mothering, describing a fluctuating relationship over time in which sometimes care is given and at other times independence is encouraged, Johansson et al. (2010) sought to determine how mothers experience daily life of care of adult mentally ill children. All of the mothers were Swedish, 14 older than 50 (eight older than 60), and most had a low level of education but were employed. The adult mentally ill children were as old as 49. Through content analysis of their responses three themes were identified: (a) they were living under a constant strain; (b) they were living with an emotional burden; or (c) they had the ability to see the light in the darkness despite the number of difficulties they were living with. Those who lived with constant strain reported that the uncertainty negatively affected their daily life and that the child was permanently present in their lives. Maternal response to the onset of mental illness in the adult child ranged from shock to denial. Episodes of mental illness in the child resulted in exhaustion and need of support and rest in the parents as well. The fact that they felt they always had to be vigilant, described by one mother as living with a time bomb, also exerted tremendous stress on the aging parent. Many of the mothers described caring for an adult child with mental illness as "more demanding than the infant period" (Johansson et al., p. 695). Mothers reported not leaving home in order to stay with the adult child and discomfort at having to take them along on social outings. This not only compromised their own

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friendships but reduced their interest in socializing, resulting in extreme loneliness. With regard to the emotional burden of care, the interviewed mothers reported a feeling of constant sorrow, of being exposed as a bad mother and feeling that their whole family life had been negatively affected by the problem. Many reported having to rely on social workers or police, but did so as a last resort because they found this level of care poor and unhelpful. Some mothers reported "telephone terror" from their adult children who would threaten suicide or say offensive things to them.

At the same time, some mothers were able to find some positive side-effects of the situation including an ability to handle the situation, hope that things were getting better, and a stronger bond in the family as a result of the need for all to care for the mentally ill person. This was especially true if the adult child took some degree of responsibility for their own care. If the mothers in the context of care sought out or came in contact with other caregivers this support was found to greatly help them (Johansson et al., 2010). Overall, however, Johansson et al. (2010) found that the caregiver burden of mothers of adult mentally ill children was very high, and that this would negatively influence their own well-being, meaning that they must learn to take a break from caring "in order to increase psychological well-being and protect themselves from acute stress" (Johansson et al., p. 702).

Research into the care burden of parents with adult children with mental illness also has taken into consideration variation of response due to type of illness and ethnicity of the parent-child dyad. In this line of research, Magana and Ghosh (2010) explored the differences in depressive symptoms and psychological well-being in a group of Latina mothers caring for adult children with either autism or schizophrenia.

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While autism is characterized by impaired reciprocal social interaction and restricted or repetitive behaviors, in adulthood it can lead to aversion to social life and negative response to stimulation of a social nature. Schizophrenia in adults, by contrast, is manifest in delusions and hallucinations as well as behaviors often perceived as embarrassing or offensive to others including flat affect, poverty of speech, and inability to initiate or direct activities. In public, both types of mentally ill persons can hurt others, embarrass their caregivers, and be offensive to them as well. In both cases, caregivers of adults with either problem are at elevated risk of themselves experiencing mental health problems such as depression. Specific sub factors studied included whether or not the mother and adult child lived together, and how the care situation affected the mother's overall well-being. Other factors related to the mother being Latina include the fact that many Latinas are low-SES, have poor housing, poorer health, and limited access to health insurance. Research has also found that Latinas caring for mentally ill adult children suffer more depression than others. At the same time, in accordance with Latina values of familism, they seek care within the family more often and have larger networks of informal social support from which they draw support. It is also true that mentally ill adults are more likely to live with their parents if they are Latino or African American than if they are Caucasian, with 75% of such persons co-residing with parents as opposed to 33% among non-Latino Caucasian families.

Out of home placement occurs only when behavior becomes unmanageable in the home or when the caregiver suffers declining physical capacity. Whether or not the end of co-residence improves or worsens health for the caregiver is a contested issue.

The subjects were taken from a study of aging mothers of adults with a diagnosis of autism or schizophrenia in Wisconsin and Massachusetts. Psychological distress was measured using Radloff's Depression Scale, a psychological well-being measure, and the Inventory for Client and Agency planning to measure maladaptive behaviors. The results found that mothers with adult children with schizophrenia experienced lower levels of psychological well-being as compared with mothers of adult children with autism. Overall, however, both groups of mothers experienced less psychological stress if they lived with their adult child. Those mothers who had had to live apart from their adult children, due either to extreme behavioral problems or their own health problems, experienced a deep sense of sadness about the current living arrangements of their son or daughter with mental illness. One reason for the lower sense of psychological well-being in aging parents of schizophrenic adult children is that the diagnosis comes later in life. Parents have not adjusted to it; therefore. It comes as a shock and has a greater sense of interrupting a life that previously did not have to deal with this problem, whereas autism parents have had to address the problem since a very early age in their child's life.

Summary

In sum, it was determined through the literature review that caregiver burden by older persons can lead to depression (Siegler et al., 2010) as well as chronic sorrow (Gordon, 2009) and grief (Goddress et al., 2005), that caring for some conditions is worse than others, and that many conditions are often co- morbid with others (Carey et al., 2007). It was also determined that the caregiver burden can reduce time socializing (Smith et al., 2010), that care giving can lead to sleep disturbance (McCurry et al.,

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2007), that coping mechanisms are of critical importance to the management of caregiver burden, that the quality of the caregiver's prior relationship with the cared for person is important to the character of the subjective burden (Steadman et al., 2007), that the financial burden for long-term care giving is a major cause of caregiver burden stress (Chatterton et al., 2008), and that family members can contribute to the quality of care by the nature of their emotional response to the condition being cared for (Baker et al., 2011). Overall, the general research into caregiver burden by family members of persons with mental illness paints a picture of stress that requires intervention and support. The experience of aging parents is a cumulative process of caregiver burden, stress and continuous relationship. The process of parents to create meaning of this experience as they age is unknown.

CHAPTER III

METHODOLOGY

Introduction

This chapter provides an overview of Classic Grounded Theory as a general

research methodology and provides rationale for its selection as an appropriate

methodology for this study. The chapter begins by addressing the origin of grounded

theory methodology and its philosophical foundations. The chapter addresses the data

sources, methods of data collection and analysis, and ethical consideration. The chapter

provides information on the researcher's entry into the field, perspective as a researcher,

and a description of the researcher's process of learning Classic Grounded Theory under

the mentorship of Dr. Barney Glaser (2008 & 2009).

To create new knowledge (theory), the realist paradigm necessitates

methodology that enables the researcher to "enter the field and collect and analyze

whatever data are available in a way that transcends particularistic detail, thereby

enabling the emergence and conceptualization of the latent patterns" (Glaser, 1998,

p. 26-27). Classic Grounded Theory methodology (Glaser & Strauss, 1967; Glaser,

1978, 1998, 2001, 2003, 2005) provides a systematic process for the abstract

conceptualization of patterns of social reality. "Reality as found and collected shapes an

emergent theory" (Glaser, 2003, p. 82).

Choosing Grounded Theory Methodology

The decision to use Classic Grounded Theory methodology was driven by the researcher's wish to explore main concerns and coping mechanisms of aging parents of adult mentally ill children. The researcher's initial introduction to grounded theory was in reading *Discovery* (Glaser & Strauss, 1967). The researcher was attracted by the combination of systematic procedure and the outcome of a theoretical model: a combination of structure that supports holism. In 2007, the researcher attended the *Grounded Theory Jamboree* taught by Dr. Phyllis Stern and Dr. Paul Wishart. At that point even the language of grounded theory was foreign. The students and faculty, however, were bright and interesting. The topics the students were considering for research were relevant and riveting. The researcher felt she had entered a world of practical brilliance. The selection of Grounded Theory was additionally supported by the established reputation of the methodology in the professional field of nursing (Lomborg & Kirkevold, 2003; Morse, 2001; Stern & Parr, 2011).

The particular value of Grounded Theory lies in providing a conceptual overview of the phenomenon under study - what is actually going on. The theory focuses on participant perspectives, providing "opportunities to articulate their thoughts about issues they consider important, allowing them to reflect on these issues of concern to gain understanding and acquire new insights" (Glaser, 1998, p 32). This conceptual overview does not result in a superior methodology to either quantitative or qualitative but rather, is complementary.

Origins of the Grounded Theory Methodology

Grounded Theory is a general methodology of analysis linked with data

collection "using a systematically applied set of methods to generate an inductive theory

about a substantive area" (Glaser, 2002, p. 16). The methodology is emergent, with the

researcher entering the field open to explore a substantive area and allow the main

concerns of participants to guide the emergence of a core issue or problem to be

resolved. The conceptualization of the core problem becomes the basis for the

articulation of a grounded theory that explains the problem and its resolution. The

methodology originated in the mid 1960s with the groundbreaking work in medical

sociology of Barney Glaser and Anselm Strauss (Glaser & Strauss, 1965, 1970, 1971,

1974, 1975) and the publication of *The Discovery of Grounded Theory* (Glaser &

Strauss, 1967), the initial published documentation of the methodology. The blending of

backgrounds included Glaser's quantitative and qualitative math under Lazarfeld at

Columbia University and Strauss' study of symbolic interactionism with Blumer at the

University of Chicago (Glaser, 1998; Glaser & Strauss, 1967). They produced a counter

view that the only scientifically sound form of inquiry was quantitative (Glaser &

Strauss, 1967).

Grounded Theory is a form that gives structure to qualitative research as it exists

today. Glaser continued to build and teach what he reports is Classic Grounded Theory

(Grounded Theory Seminar, 2008 and 2009), while Strauss and Corbin (1990, 1998)

designed a considerably different structural approach. Charmez (2002) agrees with

Glaser that he has remained true to the original design of grounded theory methodology.

Glaser contends, "it is a simple, effective method that gets mangled by methodologists"

(Glaser, personal conversation, May 23, 2008). "Since its inception, grounded theory methodology has achieved canonical status in the research world" (Locke, 2001, p. 1). Qualitative researchers, in particular, "have embraced grounded theory, often without sufficient scholarship in the methodology" (Partington, 2000, p. 93; 2002, p. 136).

This results in researchers being unable to perceive Grounded Theory as a general methodology and an alternative to qualitative and quantitative research paradigms (Glaser, 2003). The result is philosophical confusion and an often unconscious remodeling of the original methodology (Partington, 2000). While some view the remodeling as an inevitable and productive evolution (Charmaz, 2002; Locke 2001), Glaser (Grounded Theory Seminar, 2008 and 2009) views it as an erosion of the power of the original methodology.

Charmaz (2000) cited six reasons for the revolutionary status accorded to *The Discovery of Grounded Theory* at the time of its publication, including its challenge to the,

> (A)rbitrary division between theory and research, views of qualitative research as preliminary precursor to more 'rigorous quantitative methods, claims that the quest for rigor made qualitative research illegitimate, beliefs that qualitative methods are impressionistic and unsystematic, separation of data collection and analysis, and assumptions that qualitative research could produce only descriptive case studies rather than theory development. (p. 510-511)

The schism in the collaboration between Glaser and Strauss occurred with the publication of *Basics of Qualitative Research* (Strauss & Corbin, 1990). Glaser (1992) responded with the publication of *Grounded Theory: Emergence versus Forcing*. His

intent was to distinguish the original methodology from Strauss and Corbin's work which he clearly regarded as a remodeled method that he termed "full conceptual description" (p. 123). His continuing concern with the eroding impact of various subsequent "remodeling" of the original methodology motivated him to produce additional publications in which he endeavored to clarify the purpose, principles, and procedures that together constitute Classic or Glaserian grounded theory (Glaser, 2001, 2002a, 2003, 2004, 2006, 2008, 2011; Glaser & Holton, 2004).

The purpose of classic grounded theory is to generate a theory related to how a population resolves a main concern. This main concern becomes a core category that is of central concern to the participants in the study. "A core is not a preconceived sociological interest or professional concern" (Glaser, 1978, p. 94). Glaser (1992) asserted, "since a core category accounts for most of the variation in pattern of behavior, it has several important functions for generating grounded theory: integration, density, saturation, completeness and delimiting focus" (p. 75). The researcher enters the field with as few predetermined ideas as possible while asking what accounts for the continual resolving of this concern (Glaser, 1998). Classic Grounded Theory allows the researcher to explore perspectives of aging parents of adult persons diagnosed with mental illness. The focus of the study will be on their main concerns and how they coped related to those concerns.

<div align="center">Sample</div>

Size

Non-probability sampling is appropriate for grounded theory inquiry (Glaser & Strauss, 1967; Glaser, 1968) as members of particular groups are more aware of

information than others. This type of sampling is not intended to be representative in the quantitative method, but as a qualitative method, as each member represents the group. Subjects are initially selected because they can illuminate the phenomenon. Subsequent sampling is done from the findings emerging from the study. The process continues until saturation is met. When grounded theory methodology is used, sample size cannot be definitely established in advance of the fieldwork; rather, the sample size will emerge as the study progresses. However, sample size for IRB approval was established as up to 20 parents over 65 years old who identify themselves as parents of adult mentally ill children. The actual sample size consisted of 13 parents and 25 interviews.

Entering the Field

I am a Caucasian Master's prepared psychiatric nurse with 35 years of work experience, 15 of those years specifically working in the mental health field and the rest in administration and education. I led the evidence based practice and research initiatives for St. Cloud Hospital as part of the 2008 Magnet re-designation, which earned exemplar feedback. I attended a *Grounded Theory Jamboree* in Canada in 2007. I subsequently contacted Dr. Barney Glaser to buy a book in 2008 and was invited to apply and attend his *Grounded Theory Seminars*. These three day seminars, including one to one mentoring, were attended in spring 2008 and fall 2009. During the seminars, I had the opportunity to engage in learning Classic Grounded Theory from Dr. Barney Glaser and his daughter, Jill Rhine. The spirited, caring, rigorous, and yet innovative approach to research confirmed my selection of this methodology to discover aging parents' perspectives and patterns.

I am a Faculty Learning about Geriatrics (FLAG) program member who attended the first week long course at the University of Minnesota in summer 2008. This program, offered by The Minnesota Hartford Center of Geriatric Nursing Excellence (MnHCGNE) was established in 2008 with funding from the John A. Hartford Foundation. I have also established a partnership with the Angel Foundation and Coborn Cancer Center to offer education for parents and grandparents diagnosed with cancer who have children or grandchildren under the age of 18.

My initial study for my Master's thesis measured the grief response over time of family members of persons who are mentally ill. The subsequent presentations of this data at the University of North Dakota, the Central Minnesota Alliance for the Mentally Ill, Whitney Senior Center, St. Cloud State University, Sigma Theta Tau Kappa Phi Chapter, and St. Cloud Hospital gave me the opportunity to engage in multiple conversations with family members and parents of persons diagnosed with mental illness. These discussions led to further understanding of the parenting experience in various stages of life for family members of persons diagnosed with a mental illness.

Grounded Theory methodology is easier to use when the researcher is sensitive to the area of study, as this sensitivity facilitates contextual understanding (Glaser, 1978). Glaser (1978; 1998) noted that researchers are often motivated to engage in grounded theory studies because of a life cycle interest of a personal or professional nature. My interest in the aging parents rose from previous research, letters from parents, my work in psych-mental health nursing, and parenting experiences. My initial curiosity was aroused from a specific letter I received from an older mother who wrote me saying she appreciated the recognition of grief and a family response, and was very

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sad because she wondered what would happen to her son if she died. The contents of

this letter stayed with me for years

Recruitment and Sampling Procedures

Formal letters of cooperation were obtained from the Alliance for the Mentally

Ill, Country Manor Senior Housing, and the Whitney Senior Center. I initially attempted

to recruit parents via presentations at Whitney Senior Center as well as posted flyers at

senior housing, support group newsletters, church newsletters, in conversations with

minority group pastors, and in mental health services. I contacted the Alliance for the

Mentally Ill in St. Cloud and Brainerd, St. Cloud area group homes, and Veterans

Administration Advance Practice Nurses to see if they had ideas for further parental

recruitment. However, no participants were identified or recruited from these methods.

Actual recruitment occurred from community dwelling adults who heard about the

study from friends who were nurses or providers who told them about my study. All of

them contacted me initially directly or through one of their adult children. Each

participant was contacted and received a private explanation of the study, benefits, and

consent process. Of those contacted, 13 decided to participate. All 13 participants lived

in their own homes, did not live with their adult child, were cognitively intact, and

engaged in the interview process. Each participant had the opportunity to meet in a

public setting or at their home. All wished to meet in their home.

Two additional parents contacted me with an interest in the study. One contacted

me via her friend and indicated she wanted to participate. She reported she and her

husband had spent years dealing with the mental health system to try and place and

support their son. The results had been dismal and very frustrating for the couple. The

son, while refusing treatment, subsequently committed a very violent act and she had not seen him in years. She had just started visiting him again in prison and felt the study would be important for health care professionals to better understand her role as an aging parent. However, in the end, she contacted me again via her friend and said she just could not talk about the violence as it caused her to relive it. Another parent called me after hearing about the study from a psychiatrist. We spent over an hour on the phone as she asked questions about the study and my background interest. She wanted to participate but decided she could not "live through her story again". She has called me twice since to let me know it is important work and that even learning about the topic was healing to her, but she felt she could not formally interview.

*Timelin*e

This study was approved by the Institutional Review Board of the University of North Dakota in August 2008 and then subsequently each year as an annual review. Interviews, data gathering, field notes and memoing started after the first interview in fall 2008 with the final interview conducted in November 2011. Coding was initiated in 2008 and occurred interactively over the period of years. As codes and memos developed, theoretical sampling was done with further memoing and coding, consistent with the constant comparative method.

Sample Demographics

I used chronological age, an arbitrary measure of age to define aging parents. There are descriptions of aging populations as young old (65-74), middle old (75-84) and old-old (85 and older). The sample included two young old, 10 middle old, and one old-old. Of the parents, eight persons were part of a married couple; each was

interviewed separately but shared parenting of one mentally ill adult. Four of the subjects were males and nine were females. All of the respondents were Caucasian. Attempts to recruit minority participants through religious leaders were unsuccessful. Each male volunteered after his spouse had initially been interviewed. Parents had a variety of educational backgrounds; five had a high school diploma, four had a bachelor's degree, three had a master's degree, and one had a doctorate. One person was currently employed in a professional field and the other 12 were all retired.

Mental illness was defined as BPD, schizophrenia, and a major depressive disorder. The focus was to select populations most likely to provide rich information on the experience of parenting a child with mental illness throughout life into older age. If the married parents were considered as group, there were nine adult children: two diagnosed with schizophrenia, five with BPD, and two with major depression. All of the participants' children who were diagnosed with major depression were also diagnosed with a chemical dependency disorder. Of the adults diagnosed with BPD, four of the five respondents' children had been treated for alcoholism or addiction. If chemical dependency had been excluded, it would have been difficult to find a sample population.

Of the nine adult children, all lived independent of the parent. One of the adult children moved in and out of the parent's house but did not permanently live with the parent. Ages ranged from 35 to 50 years of age; the average age was 40 years old. All were Caucasian. Seven were female and two were male. Eight of the adult children had children, resulting in the participant parents collectively having 17 grandchildren whose parents were mentally ill. Only one adult child lived with her children. One set of

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grandparents had obtained custody of a grandchild. The other fourteen grandchildren all lived with the divorced spouses.

<div align="center">Procedures</div>

Glaser (1978) and Stern and Parr (2011) outline processes, not *necessarily linear*, in grounded theory analysis. The process includes data collection, open coding, constant comparison, generating memos, selective coding, theoretical sampling, memoing, theoretical coding, and emergence of a core category and processes. This core category is the basis for further theoretical sampling, coding, and memoing. These steps occur simultaneously and end with the writing of a substantive or formal grounded theory. Data collection focused on open ended interviews with aging parents of persons diagnosed with mental illness to explore their main concerns and resolution of those concerns. Glaser (2006) reports "taping can inhibit participants who may resort to "proper lining" data (p. 110). The four types of interview data identified by Glaser (1998) are: (a) baseline, the participant's best or honest description; (b) properline, what the participant thinks is the proper thing to say; (c) interpreted, the trained professional's viewpoint; and (d) vaguing out - vagueries given when the participant has no interest in sharing the information. He suggests taping contributes to proper lining, in particular. Glaser (1998) suggests field notes capture the essence of an interview and allow the participant to feel safe resulting in a "spill" of truth. Additional issues with taping include pages and pages of transcripts making constant comparisons more difficult and less likely to reveal relevant processes. Field notes were written during the interview and after in order to reveal relevant processes and allow the researcher to see the whole.

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Glaser (2006) stated, "there are many forms of interviews in theoretical sampling. They vary from long interviews to quick questions on the fly" (p. 19). The interview style for this study was open-ended so as not to indicate preferred responses. The first two interviews were taped with the rest were conducted using field notes. The data for three of the interviews (formally transcribed and field notes) were reviewed in the Grounded Theory Seminar in 2008. In grounded theory interviews, Simmons and Gregory (2004) advised beginning as openly as possible, with a general "grand tour" type of question, formulated so as not to indicate a preferred response, such as "tell me about a day in your life" or "tell me something about what it is like to." Rather than forcing a framework onto the data, grounded theorists collect data by listening for meaning, grasping the participant's perspective, and studying the participant's concerns and motivations (Glaser, 1992; 1998). The questions in subsequent interviews relate directly to emerging concepts. I used less of a guide as I adjusted to the process and obtained feedback during the *Grounded Theory Seminar* and from my advisor, Dr. Marcia Gragert. The initial interview was more leading than subsequent interviews as I understood the process of field notes and memoing.

Observations about the environments in which the interviews took place were also made. Establishing rapport initially was part of the process and included casual conversation chat early in the meeting. I provided a description of the study, obtained consent, and answered any questions the participants had. Interviews lasted one to one and one half hours in the participants' homes. Preliminary data gathered included parent's gender, race, education, marital status, age, medical diagnoses, adult child's mental health diagnosis, age, and home or living status. Participants were initially

superficial, but all "spilled," particularly after I shared the topics of my previous research. Each person had much to tell.

Data Analysis

Conceptual development begins with data collection, coding, and analysis. Coding is the fracturing of data into conceptual codes, or abstract views (Glaser, 2004). Field notes were written to support capture of incidents revealed by participants in addressing their main concern and how they resolved the concern. These incidents, as indicators of a concept, become the units of the analysis in the constant comparison process that is part of the grounded theory methodology. Initially, incidents are compared to other incidents to generate conceptual codes. Additional incidents are then compared to the generated concepts to further define conceptual properties and dimensions. Data was organized into concepts and then categories which are then integrated into the theory. The researcher then continues to go back to the data to illustrate and confirm the theory.

Analysis is a simultaneous process. The initial data is analyzed by reading an interview line by line, coding each line, and comparing it to field notes and writing memos. Memos were created related to further questions or developing concepts. As interviews progressed, the data from one interview to the next was compared, which led to theoretical sampling, memoing, and further constant comparison. As the process proceeds, a core social or psychological process is beginning to emerge, establishing a foundation for further comparison. The researcher wrote codes with memos on sticky notes and grouped and regrouped concepts. The core category of *parenting to posthumous* began to emerge.

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During initial coding, categories tend to emerge quickly. Glaser (1978) reported, "the procedure of open coding is to find the core variable" (p. 409). Glaser (2005) stated, "without a core category, an effort at grounded theory will drift in relevance and workability" (p. 2). To establish the core variable, the researcher looks to see whether a) it is central, relating to as many of the coded categories and their properties as possible, and b) it accounts for a large portion of the variation in a pattern of behavior (Glaser, 1978). Simmons (1994) advised, "once a reasonably clear picture of relevant issues or problems emerges, then begin selective coding" (p. 29). Glaser (2004) noted that selective coding occurs only when the researcher feels certain she has discovered the core variable. Analysis of the core variable requires saturation, relevance, and workability (Glaser, 2005). This is called constant comparative analysis.

Memo writing is essential in grounded theory. "Memos are theoretical notes about the data and the conceptual connection between categories" (Glaser, 2004, p. 17). Memos consist of writing up ideas about substantive codes and the relationships that emerge. Stern (2007) used the analogy, "if data are the building blocks of the developing theory, memos are the mortar" (p. 119). Initial sorting was completed with sticky notes, with later sorting supported by Word Outline feature. Glaser (1978) reported "the procedure of sorting refers not just to the data sorting, but also to the conceptual sorting of memos and accompanying data" (p. 210). Glaser (1998) explained:

> At the start, the researcher faces virtually one large pile of memos. He should enter the pile anywhere, no matter and pick a memo. Place the memo on the table; it does not matter where. Then pick another memo and see how comparing

it is related to the first one picked….As integration emerges, re-sorting the

memos occurs as they fit somewhat differently. (p. 189)

Glaser (2004) suggested that as the researcher sorts she questions herself to help

develop theoretical sensitivity. Questions to ask include:

1) What is this data a study of?

2) What category did this incident indicate?

3) What is actually happening in the data?

4) What accounts for the continual resolving of this concern? (p. 13).

An example of a memo used in this study is as follows:

How do the parents view money…what could the money do for the child? What

do they fear the consequences will be? Balancing the 'good' (?) the money

could do if it were protected v. the harm the message would do.

Glaser and Strauss (1967) defined theoretical sampling as "the process of data

collection for generating theory, whereby the analyst jointly collects, codes and

analyzes his data and decides what data to collect next and where to find them" (p. 45).

Theoretical sampling requires additional interviews or re-interviewing focusing on

emerging main concerns and codes. As interviews were progressing, I used theoretical

sampling. Original participants were asked further questions as memos and concepts

developed. I conducted a total of 25 interviews over a period of three years. I had long

periods between some of the interviews, but the topic was always on my mind. For

instance, when Congresswomen Gabrielle Gifford was shot, I listened carefully to the

media storm related to the shooter, his mental status, and information about the parents.

In the study, as codes and memos accumulate, the researcher will start the process of theoretical coding (Glaser, 2005). Holton (2001) stated, "there are two types of coding in a classic grounded theory study, substantive coding, which includes both open and selective coding procedures, and theoretical coding" (p. 265). Glaser (2005) asserted theoretical codes are on a higher conceptual level than substantive concepts, as they represent more general phenomena. When theoretical codes fit well, "analysts suddenly become acutely aware of the power of the emerging codes and how they integrate the substantive categories and their properties into a modeled theory" (Glaser, 2005, p. 134). Emergent theoretical codes that fit best reflect which categories and properties are more relevant, which are less relevant, and which are non-relevant to the emerging theory (Glaser, 2005). In this study, as data became saturated and the relationships became clearer, the core category *Parenting to Posthumous* effectively synthesized, organized, and transcended what is known about aging and parenting a person diagnosed with a mental illness.

Methods for Rigor

Glaser outlines the criteria of fit, work, relevance and modifiability as the basis for determining rigor. Credibility relates to the question of reality representing the multiple viewpoints of informants. The suggestion is the truth is found by the subjects, not defined by the researcher. Sandelowski (1986) states the "value of qualitative research generally resides in the discovery of human phenomena or experiences as they are lived and perceived by subjects, rather than in verification of a priori conception of those experiences" (p. 30). When the core concept is credible to the participants Glaser (1978) calls it "grab". Lincoln and Gruba (1985) propose credibility with more

extensive interaction with participants in which there is time to learn the culture, build trust, and test misinformation. An example of in this study is an original thought of the core category *Posthumous Parenting*. It was concise, and the words were beginning to describe what I was seeing. However, the first three participants I discussed this with disliked it immediately as "they were not yet dead." The concept of *Parenting to Posthumous*, on the other hand, was confirmed to transcend the total of their experiences as a parent in this phase of their life. Relevance is achieved by allowing the concepts to emerge from the data, rather than from a preconceived concept. In this research that preconceived concept was grief, which was part of the concepts found, but certainly not the whole. Modifiability is the process of correcting as the comparisons occur. Glaser also argues that transferability is part of grounded theory. He writes,

> …these deducted hypotheses are not forced on the data when they fit poorly, they are discarded and others emerge in their place by constant comparative analysis. This method underlines and assumes the fact that the interpretations of patterns must be researched and grounded just as much as the interpretations themselves. (Glaser, 1978, p. 40)

He suggests because the data is transferred to a concept it is abstractive of time, place and people. Thus, a theory of aging parenting could be transferable or tested with other parent populations, including parenting adult children with disabilities or active addictions, or adult children generally. Glaser (1998) suggests the categories of the theory should fit the data, not be preconceived or discarded in attempt to keep exant theory intact.

Dependability consists of audit trails that the investigator tracks related to the process of interviewing and field notes, memoing, interpretations and coding and recommendations. Confirmability includes an audit trail. Since Glaser (1998) discouraged taping and also qualitative data management systems, the audit trail is fairly simple. The trail includes field notes, coding field notes, memos, lists of potential codes and categories and the written theory. In this study, for archival purposes, interview transcripts, field notes, and memos were assigned numbers that correlate to the date on which the data was collected. Similarly, date-correlated numbers were assigned to conceptual memos developed through coding and analysis of the data. A list of codes was kept within the notebooks related to the study and the written theory is presented within the dissertation.

<div align="center">Human Subject Protection</div>

The rich description and small sample sizes used in qualitative studies raise the potential for inadvertent disclosure of participant identity and other ethical violations. Anticipating and addressing issues of ethical conduct are requirements of researchers engaging in using qualitative data. Qualitative data in the form of personal interviews requires protection. Human subject protection is required and essential. Internal Review Board approval was initially received in 2008 and then updated annually. The following ethical considerations were observed;

Informed consent – Before participating in the study, individuals were advised of the research purpose, process, intended outcomes, and details regarding participation. Participants were asked to sign a consent form prior to their participation in the study.

Voluntary participation – Those participating in in-depth interviews were advised of the details of the study as well as the voluntary participation in the project prior to the researcher coming for the interview.

CHAPTER IV

RESULTS

He is in the business of the conceptual construction of induction. It will be complex. The learning curve of a theory is a delayed action one. Now he will discover that all the months of research work, the realizations, however, delayed in coming will come through the writing up his sorts. The yield will be conceptual (Glaser, 1998, p. 193).

This chapter presents a substantive grounded theory from data collected and analyzed using grounded theory developed by Glaser and Strauss (1967) and Glaser (1965, 1978, 1992, 1998, 2001, 2002, 2004, 2008, 2011). The purpose of this research was to generate a grounded theory that explains the main concerns and coping strategies of aging parents of adult mentally ill children. The specific objectives of this study are: (a) explore the individual experiences and perceptions of aging parents of adult mentally children to develop a conceptual understanding of how they resolve these concerns; (b) build a grounded theory of parenting adult mentally ill children as part of an aging process; and (c) identify characteristics of the conceptual process aging parents use to support and sustain them.

The interviews were comfortable and generally lasted an hour or longer. It was apparent from initial phones calls and interview process that parents were willing to share the rich life long experience and current process of parenting. All parents expressed gratitude for the ability to talk through this experience within their lives. Each

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described the shame of feeling blamed and the relief of sharing when they felt heard. The basic social process of *Parenting to Posthumous* is referred to in text. The substantive theory is depicted in Figure 1and briefly described in the following paragraphs.

Parents of adults diagnosed with a mental illness move into the aging experience with a foundation of *complicated caring* that is tightly formed and turbulent. The parenting experience formed in this base includes *loving, care coordinating, rescuing, and diminishing. Loving* includes maintaining a caring presence in the mentally ill adult's life. *Care coordinating* is navigating a complex system. Parents describe consistent *rescuing* in order to prevent or reduce financial, legal, and housing problems. The shame associated with stigma and parental anger creates *diminishing* expectations of the adult mentally ill child and *diminishing* views of themselves in their parental role. As the parent's health and/or energy change, *shifting* occurs in the intense psychological and/or physical caretaking they have provided. The actual caretaking role cannot be accomplished with the health priorities and energy changes the person or their spouse is experiencing. The person begins *reducing* his/her active caretaking role. As time is more available and the person is aware they are in the last third of their life, they begin a process of *expanding* spiritual caretaking and a perceptual view of the mentally ill adult child. The parent is also *examining* parental experiences to determine whether different approaches would have changed outcomes. The parent is *analyzing* their parenting, with a focus on their role in the losses the child has experienced. Parents are thinking about, but *hiding,* memories they don't plan to share, particularly those that created humiliating scenarios resulting in shame and blame as a secondary stigma of

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earlier years. As the parent examines their role, they also begin *releasing* some of the blame and guilt and the responsibility to care take. As mortality is faced, the parent thinks about *transitioning* possessions and the sense of family. The issue of *keeping* the adult mentally ill person included in family events and holidays weighs on their minds. As the parent thinks about his/her mortality and keeping the family together, he or she also wonders about the process of *giving* material possessions to his and/or her children and grandchildren. Parents consider what their adult mentally ill children will feel after the parent's death about inheritance of money as a form of *messaging.* Financial concerns about a mentally ill adult person's ability to handle money or reducing their loved one's eligibility for public services engenders *agonizing* about the outcomes of these decisions. Money and possessions have meaning, and a final exclusion or different treatment feels like one final message that the child is different. On the other hand, most parents report the adult child has not handled money well which is a cause for concern related to long-term stability, housing, health insurance, and other needs. All of these concerns cause *agonizing* thought processes for these parents, much of which remains unresolved.

Complicated Caring

Each parent described experiencing turbulent parental years beginning with young adulthood and continuing to the present. All of the parents felt their children's childhood years were "normal." Each of the parents described adolescent parenting years that involved stressors from typical adolescent rebellion. None of the parents talked about those years as being more difficult for them than for their friends who may

Parenting to Posthumous

Figure 1. Parenting to Posthumous is a five-stage interactive process that is synergistic and non-linear. The circle has a foundation of connecting and caretaking. However, the circle could be rotated as each concept could begin from this foundation or in a more sequential process. Much of this process is internal and the dimensions or subcategories may not be immediately visible from an external view.

have also had challenging teenagers. Each described a parental journey into young

adulthood that included dawning recognition of a significant diagnosis followed by

frantically trying to offer therapy, interventions, or treatment for a child who did not

follow the "typical path." Of the nine children of aging parents, eight had married and all were divorced with no remarriages. Seven of the children had children and the aging parents had 17 grandchildren. None of the children had had steady income producing jobs since their early 20s, and only one adult child had maintained custody of her children. Concepts of managing during this time included *loving, care coordinating, rescuing, and diminishing.*

Loving

Loving includes the continual presence of the parent in the adult child's life, often becoming the sole or dual presence of caring, albeit frustrated caring, in the adult's life on a lifelong basis. Typical reflections include,

> I tried so hard to provide her with a sense that we loved her in spite of her differences. I always called and when she didn't or couldn't respond I would send cards. I kept in contact with her children and never said bad things about her even when I knew it was not good.

Another comment included,

> I was trying to go to court to get custody of her child and yet trying to tell her I loved her. I don't know sometimes how we did it, but we raised him ***and*** we still see her almost every week.

Care Coordinating

Coordinating includes a navigator role inevitably described by parents who were the sole consistent person for long periods of time in this person's life. This consists of researching treatments, scheduling appointments, arranging social opportunities, facilitating employment opportunities, transporting, serving as the contact person for

mental health community, and checking on the person's follow up. This follow up as well as crisis events led to rescuing.

Rescuing

Rescuing is traveling to bring the adult out of difficult or unsafe situations, supplying money for rent, food, clothing, and entertainment, providing child care, cleaning, using social contacts to obtain employment, going to pick up at jail, and presenting the child positively to others. One parent said,

> I had no idea what was happening and then I get this phone call that she has
>
> tried to kill herself. It was the beginning of dreading calls and yet responding
>
> over and over again trying to find that one combination that would work.

Diminishing

The process of *diminishing* is a long painful journey for parents. All parents describe the feeling of loss, consistent with the grief and sorrow literature, of the person they knew, of the hope, and of dreams and expectations. Parents also described a diminishing sense of self as a parent. Encounters with health care professionals, law enforcement, and friends left them feeling blamed and shamed. Perceptions of parental blame were reinforced by self criticism related to yelling, screaming, and shaming the adult child during moments of great stress. A reflection includes,

> He didn't pay his rent and I screamed at him so loud the neighbors came out of
>
> the apartment. I called him names. I felt like we were the only ones trying to help
>
> him or save him and we reached breaking points.
>
> or

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I didn't sleep thinking of what I said and then when I talked to her again and

listened to all of her stupid decisions…you know…I felt that anger and then

shame for both of us all over again.

Shifting

Each parent described a process of changing priorities related to physical health

changes and a reduction in overall energy. Parents could not physically or

psychologically stay as involved with problem-solving and care coordinating for their

adult mentally ill children. The process of managing their own health increased as a

burden with parents needing time for decompressing and attending to their own

appointments.

Reducing

Parents described *reducing* their caretaking role in the lives of their adult

children. "I have so many doctors' appointments, I just can't go to see or take care of

her things like I used to". All of the parents discussed having less ability to help their

adult children financially, given pressures they felt to provide for their own care,

particularly as they aged. If parents attempted to stay involved, adult siblings intervened

creating conflicts, with parents already reducing their roles and yet feeling the need to

defend their mentally ill adult children from sibling anger.

Expanding

All parents shared feelings of love for their mentally ill adult children; often

complexly intertwined with anger and anxiety over their behaviors, addictions, or their

handling of money and grandchildren. Parents clung to their role as a parent but the

form of parenting changed, from hands-on helping to an *expanding* spiritual holding of

their children. Each parent described praying for the long term health and safety of their children. While parents acknowledged they prayed for their other children and grandchildren, most shared an increase in private time spent praying for their adult mentally ill children. One parent beautifully described her prayer,

I just can't do what I did before for her but I sit here for hours and look at the pond and hold her in God's sight. I know she will always be ill but I am putting her in the hands of God to walk with her.

This spiritual dimension was part of a letting go that was perhaps forced on parents but was also a way of achieving peace. Parents also described *expanding* positive relationships with their mentally ill adult children. Other adult children were described as busy with their careers and children's activities. Often grandchildren had reached adolescence and had reduced adoration of their grandparents. A parent's words included,

My son comes to see me and calls me every day. He still always has some commotion but I know that won't change. He and I laugh about some old things and I feel like he truly is a person who cares if I am here, even as decrepit as I am. It is different but kind of nice. He helps me with some small things I could not do before.

Examining

All of the parents talked about *examining* what they felt they did well and what could have been done differently. All felt they had committed themselves as parents to the process of doing what younger parents do, including preparing meals, assistance with clothing and school, and involvement with friends and church. Parents mentally

compared themselves to internal standards formed from their experiences and cultural norms within their community.

Analyzing

Loving includes regrets, and these parents verbalized this in many ways. Parents talked about looking over and over again at "how this could have happened," remembering warm family times and less proud parental moments. Warm family times included young family experiences of spending time together enjoying vacations as well as involved parenting. As the parents aged and adult children began to miss developmental targets of young adulthood, parents described fear and anger, including unkind words, fighting, and belittling. One father said,

> We did all the right things and still I had a daughter in jail. I can't believe it today. I wonder if I was too strict. I was very harsh as she acted so crazy and we had the police….all involved. It was horrible.

Many of the parents had thought about these issues for years and told analogies of their experiences such as,

> It is like searching for an agate on the North Shore. You pick up rocks and look for that one perfect agate. I think things over and wonder if we did do anything to cause this. But I know I will never know.

Hiding

Every parent talked about one good friend who knew "most of the story." Yet each parent felt there was much to hide from friends and family about their child's behavior, particularly the incidents that involved law enforcement. All of the parents had witnessed or been involved with law enforcement either from actual criminal

behavior or emergency holds. Many of the stories involved addiction or alcoholic behavior in conjunction with mental illness, or not taking prescribed medication. All parents experienced a sense of shame, particularly concerning these incidents, as the media or police presence may have been involved. Four parents described the huge decision to visit a jail. Each noted that those days were over but the vivid memory was a source of deep shame they still thought about. One parent described an incident where his adult daughter was sexually inappropriate in a health care setting. He said he would still go to a different hospital if he had any choice and "we never told my son. It will go to the grave with me." Parents also described *hiding* their role in caretaking from siblings and some of their decisions from friends and family. One father said his daughter did some illegal activity within his house and he just could not "turn it in." The only parent who could describe an effective health care interaction said,

> Dr. W. asked me every year how my daughter is. He doesn't ask about my son, but always my daughter. He will always be my doctor because he was kind, and remembered her. Most people don't ask about her anymore and if they do it isn't out of kindness.

Releasing

Parents described a process of *releasing* and giving up control of the feeling that the mental illness was all their fault and also that they could actually impact the outcome. They discussed a process of gradually realizing this was not within their control. Having described this, each of them discussed relapses of illness and the emotional surge that occurred for them in a short period of time. The parents were

generally poetic in the use of analogy to describe some of their long-lasting, intense feelings. One mother said,

> I have this dark cave and it is fire red inside. When I go there I feel all that heat and anger again and all the things I said to her. You know I was so mad at her and I loved her and it all mixed up. Sometimes I think of myself as a bird flying out of the cave because I can't change what happened. I am just flying.

Transitioning

All parents talked about transitioning caring and care coordinating to siblings, grandchildren, or county workers. "I hope someone will love him like I did, but then I don't want them to get all caught up." Transitioning aspects of care to county workers or siblings was a thought. The way each parent approached this transition was very different but the main concept of *transitioning* was present for all participants.

Keeping

Three males and one female worried about what their adult children would do on holidays, but did not want the siblings or grandchildren to experience the chaos the parents had lived with. The other nine participants had hopes siblings or grandchildren would consider *keeping* their mentally ill adult family members involved in holidays and family events. One mother said she would always love her sister because she invited her son to every family event. "She sent him an invitation even if he was in the shelter. I will never forget her kindness." The ambivalence in approaching transitioning can be seen in these two examples:

> I told my grandson I expected him to take his mother to Christmas and remember Mother's day …all those things. He said it was not fair. I said …not fair! … life

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is not fair. I didn't want my husband to die and leave me with children at a young

age. But now you think all is about being fair. It is not. She is part of your family

and you don't have to do a lot but you do have to do this. You need to stand in

for me.

The opposite thought was raised by four participants,

I hope my child dies before I do. I *hate to* think he will be alone on holidays, but

I don't want my other children to feel they have to "go get him". It is sad, but

there is always tension when he is here and then he does act odd. I just never

thought I would say this but I hope he dies. I don't want him to be alone but I

don't want to say this has to happen.

Other parents were less strong and all did describe ambivalence about this expectation.

Only one parent had actually talked to a grandson and laid out the expectation. A

mother said,

It really makes you a better person. My son talks about being a Christian, and he

is and we are; but this is real Christianity, when you reach out to the one who is

hard and maybe unlikable…but …still you love him and you include him.

No parent could describe any discussions surrounding this issue with other health care

professionals of nursing or physicians. However, of the nine children of the participants,

four were involved with county case management and received SSI. Of those parents,

discussions had occurred with county social workers.

Messaging

The topic of how adult children would receive money and belongings occurred as

well for all parents, with differing outcomes. Three of the four males felt larger sums of

money should be distributed to the adult mentally ill child through a trust or with an executor who could manage the money. All participants described fears that the adult child would spend the money in a way that would be reckless. Even though three of the four males felt a trust should be in place, only three of 13 participants had a trust that outlined specific supervision for a particular child. One was a married couple and the other a single mother. Parents worried about how the distribution of money created *messagin*g for the child.

> My daughter spent $900,000 in 2 years after she was divorced and now she is near homelessness. I just can't make myself write something that will once again tell her she is different. I care about the money but then I don't. She has always been different and I can't tell her that one more time.

Another parent more graphically described this as, "One is the criminal and one is the cop. She will always remember we didn't think she was adult enough to handle this either. Do I have to tell her this one more time? I don't think I will".

Agonizing

The mental ambivalence of thinking about creating messaging is agonizing for parents. They recognize the logical step is to establish formal ways to safeguard money for the overall safety of their mentally ill adult child. Having recognized this, they do not take steps to formalize this process as it seems so active in leaving a message of difference. The agony immobilizes them in relation to future planning.

CHAPTER V

SUMMARY, DISCUSSION, AND RECOMMENDATIONS

Introduction

This chapter compares and contrasts *Parenting to Posthumous* to the literature and empirical research, offers conclusions from the study findings, and addresses the contributions of the study to knowledge in relation to theory, practice, and research method. The chapter concludes with findings, limitations, and implications.

Compares *Parenting to Posthumous* to the Literature

In Chapter I, the purpose of the research was described as developing a formal or substantive theory by: (a) exploring individual experiences and perceptions of aging parents who have mentally ill adult children to develop a conceptual understanding of how they resolve their concerns; (b) building a grounded theory of parenting mentally ill adult children as part of this parent population's aging process; and (c) identifying characteristics of the conceptual process aging parents of mentally ill adult children use to support and sustain themselves. The substantive grounded theory of *Parenting to Posthumous* is compared to literature from the findings that emerged from this study, the expansion of previous literature, and any challenges to preconceived theories.

The literature review presented in Chapter II offers an overview of families and parent responses as informal caregivers for adult mentally ill children. This review was initiated prior to grounded theory data gathering and analysis. As data analysis

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progressed, caregiver burden, grief, and stigma substantiated the theory of *Parenting to Posthumous,* but did not emerge as the core category. The family response literature review failed to thoroughly illuminate the dynamics of parenting over a lifetime that emerged from the present study. For grounded theory, the researcher should do a literature review during sorting and writing when the grounded theory is nearly completed (Stern & Porr, 2011). The literature search can be intertwined into the theory as data for constant comparison. This process leaves the researcher open to discovery of concepts, problems, and interpretations that emerge from the data (Glaser, 1998). The researcher made a conscious effort to place the literature review, particularly the grief, sorrow, stigma, and burden literature, aside to see what emerged as a grounded theory. The passage of time aided this process, since months passed between the initial literature review and data gathering. When interviews began, the participants were able to lead the researcher as open questions were asked. It soon became evident that there was much more going on than the descriptions of grief, sorrow, stigma, and burden. While the literature on stigma outlines courtesy and associated stigma, there is not literature on the personal shame (*diminishing, examining, and hiding)* parents feel at their own reactions. Theoretical sampling yielded very consistent descriptions of these stages. Austrom and Lu (2009) suggested one aspect of long-term care family members must prepare themselves for is the development of more serious symptoms over time. They used Kaplan's model of family response and emotional adjustment to the diagnosis was used to pinpoint issues in family response to long-term care, including denial, over involvement, anger, guilt, and acceptance. While this literature is consistent with the findings, it also describes part of the shame created for parents with the

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wording of "over involvement and anger". These concepts were true but do not singularly appreciate the complexity of a silent process growing within parents. The process of internalizing shame based on stigma and lack of support must be considered as part of a parenting trajectory that is carried from one stage to the next. Family responses, like EE, should be situated within the context of the lack of societal, public, healthcare, and family support. The suggested educational interventions to reduce EE have potential to further stigmatize parents. The parent understands the biological underpinning of BPD, (s)he has few releases from the relentless pressure, and then is educated on how this anger may further trigger BPD. The research on how to address these singular problems does not address the broad, contextual issues nor place them in the trajectory of the disease.

Context, relationships, and conditions are essential to understand. The parents' internal processes do produce positive outcomes for parents through expanding their view of parenting, changing their paradigm of the child, and releasing or forgiving themselves. Therefore it was a rich topic for study. The process of *Parenting to Posthumous* goes beyond current concepts with an interactive view of aging parents of mentally ill adult children, which has the potential to challenge professional approaches, societal norms, and the absent work of nursing in the area of parenting over a lifetime. It is a more complete holistic accounting of what is going on in this substantive area.

For the most part *complicated caring* including *loving, care coordinating, rescuing*, *and diminishing* are supported by the literature of burden and stigma (Brodaty & Donkin, 2009; Eisner & Johnson, 2008; Gordon, 2009). Jungbauer et al. (2004) reported parents were very involved in the daily lives of adult mentally ill children

including supervision, medication, finances, appointments, personal hygiene, meal preparation, and paperwork. In addition, parents reported they looked for ways to create pleasant and positive experiences for their child (Jungbauer et al., 2004). Jungbauer et al. (2004) suggested support is needed for issues related to developmental problems, especially in detachment as developmental tasks related to attachment are challenged by this intense caretaking role. Hastrup, Van Den Berg, & Gryd-Hansen, 2011 reported care can also lead to family disruptions, psychological stress, physical fatigue, social isolation, and financial and legal issues. The complexity of care navigation over a long period of time is documented. The concept of coming to a period of life while loving a person who has required complicated caring with resulting resentments and shame is not clearly established. Overall, the previous literature suggests caretaking problems grow worse in time, and present as a special dilemma to older parents of mentally ill adult children, who themselves may be in need of health care or are concerned about what will happen to the cared-for adult child if they pass on. *Parenting to Posthumous* findings were not consistent with caretaking increasing over time; rather the parent reduced their responses and had expanding spiritually transforming times that provided a sense of peace. Parents do wonder what will happen to their child, but more specifically as it relates to keeping family rather than generic care. Finally, parents understand estate planning is important, but are immobilized by the ambivalence surrounding messaging. There is not literature on this phenomenon in the nursing or psychology literature.

Erickson (1997) suggested elderly persons, facing aging and mortality, struggle with integrity versus despair. According to Erickson, if older adults can successfully

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bring together the events of their lives and produce a sense of meaning and understanding, they can achieve integrity. If they are successful in integrating these memories and feelings into a meaningful whole, they can resolve conflict and attain wisdom (Erickson, 1997). *Parenting to Posthumous* is consistent with this model in the role of shifting and examining. The *Parenting to Posthumous* model develops further in identifying the idea of loving beyond living through the form of messaging.

Ingersoll-Dayton, Dunkle, Chadiha, Lawrence-Jacobson, Li, and Weir and Sartorius (2011) researched how older parents with adult mentally ill children cope with their caregiver burden by exploring a mediating factor in their perception of care: intergenerational ambivalence. Intergenerational ambivalence theory was developed by gerontologists to identify the fact that family members often have conflicting emotions and expectations of other family members. The theory is structured by two constructs, sociological ambivalence, which occurs when conflicting normative expectations are placed on a social role, with pressure brought to bear by expectations leading to ambivalence, and ambivalence management, which involves how one tries to manage these feelings. Sociological ambivalence develops in aging parents as they struggle between two competing societal norms, intergenerational solidarity and intergenerational independence. This ambivalence develops because older parents feel obligated to help their adult children but at the same time feel like their children should be establishing their independence. Ambivalence management entails the mechanisms by which the ambivalence is managed, either by choosing one norm and ignoring the other, rationalizing the amount of assistance received, or accepting that such ambivalence itself is normal. Aging parents of adult children have been found to engage

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in only a minimal amount of confrontation, undoubtedly out of fear to rupture relations. This problem is complicated in the dyad of an older parent and an adult child with mental illness insofar as caring for the adult child becomes complicated by aging itself and the increased need for care oneself. Study of this dyad has found that it can bring with it a host of responses ranging from self-blame, guilt, neglect, intimacy, gratification, sensitivity, and support. The theory was used by Ingersoll-Dayton et al. (2011) to examine the extent to which aging mothers of adult daughters who are mentally ill had contradictory expectations. Data was obtained by interviewing 22 mothers between the ages of 52 and 90 who expressed "considerable sociological ambivalence" about caring for their grown daughters. The study identified four different strategies by which aging mothers managed their ambivalence: excusing behaviors, reducing expectations, adjusting help-giving, and confronting. Ingersoll-Dayton et al. (2011) argued that by attending to the presence of intergenerational ambivalence in aging mothers of adult mentally ill daughters, service providers can target management strategies to improve the quality of their support. In particular aging mothers felt they should support their daughters, but at the same time worried about compromising their independence.

Mothers expressed pressure from other family members not to help daughters with depression but a continued feeling of that, in an emergency, they would do so anyway. Another group of mothers expressed ambivalence over the fact that just as they were expecting their daughters to be their safety net, they now had to be their daughters' safety net. Excusing behavior entailed believing that the depression did not derive from their daughters but by another cause, with someone else to blame. By imagining that

their mentally ill daughters still had good mothers, aging mothers held out hope that they might expect some care from them at some point too. Mothers often reduced their expectations of their daughter's helping them as a way to rationalize their ambivalence, that is, if they appreciated what little the daughter could do for them they would not be so upset that the generational support dynamic had become reversed in their care for an adult mentally ill daughter. In this way, many mothers protected themselves from the disappointment they really felt at having to care for their daughters at this time in their lives. Reducing expectations also entailed not telling their daughters about their own health problems, and allowed them to exhibit intergenerational solidarity without overwhelming ambivalence.

Other mothers began to limit the amount of help they provided their daughters, a kind of setting limits and establishing boundaries as a means to protect themselves from care giving demands. Overall, then, Ingersoll-Dayton et al. (2011) found that, while the general research on older parents caring for mentally ill adult children focuses on both the positive and negative effects of care, few have examined the contradictory expectations experienced by these families, and, by applying intergenerational ambivalence theory into the dyad of older mothers and mentally ill adult daughter, uncovered some of the ways in which older parents manage the positive and negative aspects of care through ambivalence management strategies that may mediate the effects of care burden on them. Most importantly, the study also identified fundamental intergenerational ambivalence, caught between feelings like they need to help while at the same time feeling that the adult child should be independent, as contributing to the difficulties experienced by aging parents. On the basis of the findings, Ingersoll-Dayton

et al. (2011) argued that family practitioners dealing with aging parents with adult mentally ill children should factor in this ambivalence as a normal part of the dyadic relationship and consider ways to help aging parents manage or accept their ambivalence to help them better cope with their care burden. In this way, the strategies can be identified as adaptive or maladaptive and thus altered to ensure that harmonious relationships are maintained between aging parent and adult mentally ill child. In comparison, *Parenting to Posthumous* grounded theory, supports the concept of ambivalence, excusing behaviors, reducing expectations, adjusting help-giving, and confronting. The movement of the parent within the spiritual realm and the ambivalence of transitioning and messaging further expand the concepts found in Ingersoll-Dayton et al. (2011) research.

Conclusions

The grounded theory of *Parenting to Posthumous*, which emerged from the present study, is supported by extant research and theory. Furthermore, *Parenting to Posthumous* explains more clearly and thoroughly the process that occurs when parents struggle with burden, stigma, and shame as they move into older age. *Parenting to Posthumous* explains the impact of those earlier experiences on the concerns and actions of parents related to transitioning and messaging. Telling the story emerged as a process of reflecting and as a data gathering method that complements grounded theory.

Contributions and Implications for Practice

As noted in the literature, providers may also stigmatize parents. In the *Parenting to Posthumous* findings, parents did not identify health care providers as a source of support. They also did not identify support groups as an effective intervention. Friends

and relatives who were not judgmental and invited their child to events created a sense of caring. Findings from this study suggest parents are under tremendous pressure and could use psychological support and understanding that their responses, while negative at times, are not abnormal and in fact could be reduced by kindness on the part of providers, friends, and law enforcement. Family meetings or therapy with professionals skilled in understanding the trajectory of the disease process, the trajectory of parenting processes, and family dynamics have potential to bring secrets into the open. This could potentially, with skilled facilitation, create opportunities for parents to discuss ways of family keeping and inclusion that are sensitive to creating a sense of the importance of the mentally ill adult child in the family. Health care professionals can be sensitized to the grief family members experience as adult mentally ill persons struggle with employment, parenting, finances, and addiction. Approaching a parent considering their grief trajectory is different from approaching a parent to "set boundaries." Understanding the impact of dual diagnosis is another finding from the *Parenting to Posthumous* study. Caregiver burden is proven to be worse when mental health diagnosis is co-morbid with patient substance abuse, complicating care (Carey, Leontieva, Dimmock, Maisto, & Batki, 2007). Understanding the impact of the dual diagnosis is key for stigma reduction as well.

Reduction of stigma early in the parent experience has the potential to increase overall quality of life through the parenting trajectory. Having identified stigma and the fact that it interferes with the treatment of mental illness, Corrigan and Shapiro (2010) noted that a number of interventions have been created to try to reduce public stigmatizing behavior about mental illness. At present, however, there is little evidence

that these programs have been effective in reducing mental health-related stigma. For that reason, Corrigan and Shapiro (2010) reviewed three different anti-stigma strategies - protest, education and contact - in order to determine whether any approach was better for reducing public stigma of mental illness. They focused on stigma and also self-stigma, whereby a person internalizes the stigmas based on stereotypes and thus endorses the "why try effect" in terms of help-seeking or fighting against the stigma. Protest strategies against stigma generally protest publicly against any sign that stigma is in operation in public response to a problem. This can involve forcing TV networks from cancelling TV shows stereotyping the mentally ill, or public protest against evidence that stigma was at play in policy about mental illness in any number of sites. The evidence thus far indicates that while in some cases protest helps, in other instances it does not. Education strategies seek to replace inaccurate stereotypes with factual information that goes against the myths that underlie most stigmatizing behavior. These can range from public service announcements, to books and movies, to web pages and podcasts and other media.

Here, too, while in some cases education programs have reduced stigma, in other cases, as for example when the biological roots of mental illness are discussed openly, it only adds more fuel to the fire of stigmatizing behavior, likely because the participants do not fully understand the educational material or because they are hardwired to hold certain beliefs about diseases. Finally, contact strategies involve having people come in more contact with mentally ill people, which have proven to reduce prejudice. At the same time, there is considerable question as to whether or not this strategy works, insofar as people who work with the mentally ill often have the most stigmatizing

attitudes about them. Indeed, if the contact is negative, then it is likely to reinforce

stigma. In addition to these approaches, Corrigan and Shapiro (2010) argued that more

targeted and local campaigns on all levels might be more effective in reducing stigma.

Corrigan and Shapiro (2010) assessed a number of interventions in terms of the

measured use to determine stigma, the domains of assessment addressed and the

validity of the instruments involved. Measurement of behavior change as a result of the

intervention was also assessed. While the purpose of the report was to determine

whether a number of interventions were valid based on assessing aspects of their

protocols and procedures, by and large Corrigan and Shapiro (2010) concluded that

anti-stigma campaigns of any kind can only be effective when targeted at the local

level, and when outcomes are modestly measured without too great of expectations of

reduction of stigma. In sum, at present, it appears that interventions to reduce stigma

remain effective in a case-by-case basis.

In addition to documenting the burden of caring for adults with dementia and

other mental illnesses, research has also explored factors which may mitigate the

burden. Sayegh and Knight (2010) argued that more study is needed of the dynamics by

which ethnicity and care giving intersect to affect the quality of care offered to adults

with mental illness. The sociocultural stress and coping model for caregivers is a

conceptual framework which provides the basis for conceptualizing how care varies

across ethnic groups. The model argues that the stress of care is mediated by several

variables, including one's appraisal of the burden, coping style and social support.

Cultural values can also moderate negative effects of long-term care. They suggested

that three different factors are critical to determining the overall effect of familism:

(a) family obligations, perceived support from the family and family as referents, or the perception of obligation to provide support; (b) expectations one has of receiving support from family members; and (c) the extent to which family is consulted in care. The results found that family obligations negatively affects both the mental and subjective physical health of caregivers by forcing them to engage in avoidant coping. This finding correlated with other studies which have found that family obligation results in dysfunctional thoughts and depressive symptomology in caregivers. At the same time, expected help from other family members did not have any measurable impact on the caregiver's health. Cultural justifications resulted in both active and avoidant coping. In sum, Sayegh and Knight (2010) concluded that while familism in general is a positive value in some ethnic families, if care of an adult with mental illness is undertaken out of a sense of family obligation rather than familial solidarity or support, this will have an adverse effect on the caregiver by causing them to engage in avoidant coping.

This is consistent with the findings in the *Parenting to Posthumous* study. The parents described largely isolated caretaking, which was impacted by sibling concern for the parents, not the mentally ill adult. Parents described hiding many of their rescuing actions, but continuing them as they felt like the often sole source of caring. Engaging siblings in understanding the process of mental illness and the parenting response may facilitate clearer understanding and support. Chow, Law, Andermann, Yang, Leszcz, Wong, and Sadavoy (2010) sought to combine a multi-family psycho-education group protocol into an assertive community treatment team practice in order to assess, before and after, the well-being of family members taking care of adult clients

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who suffered from severe mental illness, including their perception of the burden of care and acceptance of cared-for persons. The study was based on research which has increasingly found that family interventions are to be considered a critical element of most efforts to treat schizophrenia. The elements of the program, especially education about the disease, was found to greatly improve family care levels, and reduce the perception of caregiver burden, insofar as families were better able to detect signs and symptoms of relapses or problems and address them in a more immediate way, reducing the stress involved in these aspects of care in schizophrenia.

Therapeutic jurisprudence is defined as "law that is primarily focused upon psychological well being…the absolute parameters of promoting psychological well being and preventing psychological dysfunction" (Stolle, 1996, p. 463). Given the ambivalence of parents over transitioning and messaging, there is an opportunity for nurses and other health care providers to work with lawyers to create processes that go beyond the standard checklists and incorporates facilitated discussions among parents and their children. Programs on medical shared decision making could be replicated and expanded to include health care *and* estate planning, with facilitated standardized sessions with parents and their families. If discussions are standardized with trained nursing and legal professionals, a dialogue could be created with the parents and each or all siblings as a precursor to communicating love but handling money differently.

Contributions and Implications for Theory and Research Method

The current study identifies a powerful, unidentified basic social process. The theory is powerful because it has fit and relevance, and it works. Congruent with Glaser (1998), concepts and categories of *Parenting to Posthumous* emerged from stories told

by aging parents (fit); emergent concepts relate to true issues of the parents interviewed (relevance); the stages account for most of the variation of parents' behavior (work); and, the theory can be constantly modified to fit and work with relevance. This theory, which is grounded in data, is easily understandable which creates trust. *Parenting to Posthumous* is an original theory that establishes connections—making familiar ideas relevant, while giving integrative scope and a new perspective. Because the theory is very broad, it provides excellent opportunities for future research that can move in many directions.

The theory calls for programs of research that will further explore and more fully develop its concepts and begin to identify causes, comparisons and predictions. Further theoretical sampling is needed to: (a) allow a more thorough and useful understanding of the stages of *complicated caring, shifting, examining, transitioning,* and *messaging* and different ways that parents might progress through them; (b) provide a better understanding of core feelings and actions of parents in the context of societal and professional norms; and (c) modify the theory to include different populations of parents, including aging parents of adults with disabilities, addiction, and diverse populations.

<div align="center">Limitations</div>

The Grounded Theory of *Parenting to Posthumous* is a newly identified basic social process. This study was methodologically true to Glaserian Grounded Theory. There are important opportunities for future research in nursing and other disciplines including:

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1. The volunteer sample consisted of a homogeneous group of Caucasian parents. The study does not attempt to discover incidence of the process, merely to describe it, so that it is not known to what degree the model represents the collective experience of parents or different populations of parents.

2. The volunteer sample consisted of participants who were willing to talk about parenting a mentally ill adult child. Parents who have not remained engaged with their children or who are not willing to share are not represented in the theory.

3. The grounded theory of *Parenting to Posthumous* is an initial work of the researcher. Further grounded investigation of the process will create a theory with more depth and explanatory nature.

4. The stages of *complicated caring, shifting, examining, transitioning, and messaging* have not been specifically identified in the literature; thus, overall comparisons were not possible. However, comparisons were made to the literature on topics such as burden, stigma, and grief. Further theoretical sampling is needed to more fully describe the stages.

5. The theory is so broad as to touch only superficially on several important concepts. Further theoretical sampling is needed to more fully describe the concepts.
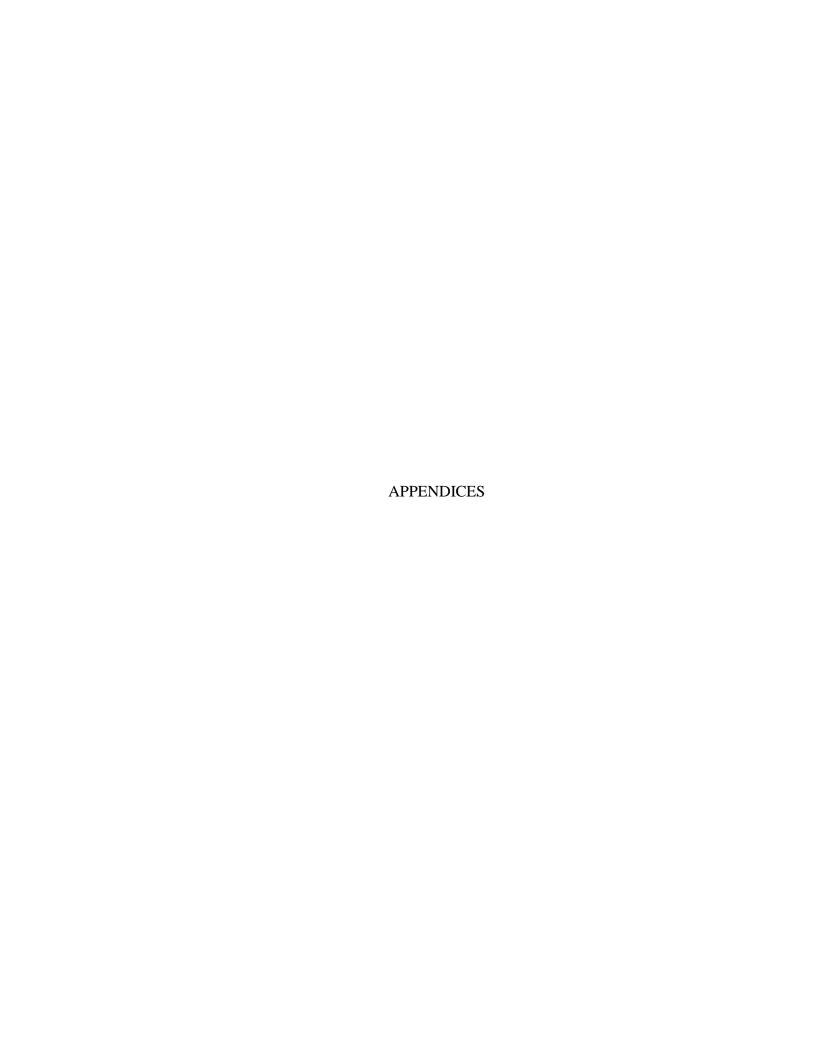
Discussion

The grounded theory of *Parenting to Posthumous* in nursing, which emerged from the present study, is supported by extant research and theory. Furthermore,

Parenting to Posthumous explains more clearly and thoroughly the process that occurs when parents struggle with complicated caregiving that includes loving, social and self-judgment, expanding spirituality, positive paradigms, and ambivalence. The grounded theory is the first to identify this holistic process which includes the stages of complicated caregiving, shifting, examining, transitioning, and messaging. *Parenting to Posthumous* is a call for professionals to treat patients and their families as part of a whole, both as a family member and over a trajectory of parenting. Telling the story emerged as integral to the process of reflecting, a method that complements grounded theory. Interestingly, all parents discussed the process as healing for them personally. Complicating family issues in the care of persons with mental illness is that there remains a dearth of studies of how, for example, dual disorders negatively impact family members in their social environment. In dealing with many mental illnesses, it is acknowledged that family members are ill-prepared and unsupported to deal with all of the resulting problems. This study offers a holistic paradigm that is sensitive to the experience of the parent in a changing process.

The experience of parenting as an aging person has been minimally explored in research. The concept of shifting priorities may change dependent on age, finances, and health. Still, the aging parent, as a wise, resilient person within a complex family, experiencing a difficult stigmatized illness and behavior, **is an unheard voice**. In this research the aging parent was not able to provide the same level of complicated care coordination as health changes occur. On the other hand, the intense connection remained and parents described some interactions with adult mentally ill children as useful and meaningful. The dynamic interaction of developmental tasks and roles with

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an overlay of complex needs and care giving creates a wonderful opportunity for nursing to approach parents in a more holistic manner, including an understanding of the need for emotional resources respect. These are parents who have been unrecognized, but given the intense cycles of their parenting, the tenacity they have displayed, and the courage and committed loving they have demonstrated, require respect for parenting well, in spite of barriers at every step. Nursing has the opportunity to understand these steps and stages and come to care with understanding and compassion for the challenges and joys of these roles. The single intervention identified as significant by a parent was a doctor asking each and every visit how her daughter was. We can do more than that. Aging persons have a wealth of wisdom to share. Aging parents of adult mentally ill children have loved in every way they could and are still considering how to love beyond living. As nurses, we need to reduce singular episodes of care approaches for aging and parenting difficult children. Parents have made mistakes but they have persevered and loved. This model allows parents to teach us. Let us as nurses continue this learning.

"Do small things with great love" Mother Teresa

APPENDICES

Interview Guide

Background Information;

Date and place of birth

Ethnicity

Relationship Status: Single, Married, Divorced, Partner

Level of education:

Number of children:

Number of children diagnosed with mental illness:

Psychiatric diagnosis of child diagnosed with mental illness:

- Can you tell me about chronic conditions you have that impact your daily life?

- Tell me about changes you noticed in your life as you have gotten older.

- As you have aged, describe assistance you need.

- Describe how aging has changed your relationship with your children.

- Tell me about parenting an adult mentally child as you age.

- Describe the difference in your relationships between you and your mentally ill

  child and your other children.

- Describe concerns you have as a parent of a mentally ill child.

- Describe how you handle changes at this point in your life.

- Describe how you have planned for the end of your life.

- Describe how your planning has been influenced by having a mentally ill child.

- Describe reactions from your other children related to your planning.

- Describe things that help your planning or change your planning.

- Describe your accomplishments in parenting a mentally ill adult.

- Describe your sorrows in parenting a mentally ill adult.

- Describe plans to involve other people in caring for your mentally ill child.

- Describe how thinking about your own death or disability has changed your
  parenting.

- What are a few words you would use to describe the process of parenting as you
  age? Are they different words for a mentally ill child?

- You are an expert on the experience of aging and parenting adult mentally ill
  children. What advice would you have for your other children or family
  members?

- What advice would you have for doctors, nurses and social workers?

- What else do you think is important for me to know about aging and parenting
  mentally ill children?

- Do you have any questions?

Appendix B

Informed Consent

I have asked you to be part of a research study. My name is Roxanne Wilson. I am a
Master's prepared nurse, completing a doctoral program at the University of North
Dakota. I am studying aging parents' response to parenting adult mentally ill children.
Through this study, I hope to learn what aging parents' concerns are in response to
parenting mentally ill adult children. I hope to learn how aging parents cope with these
concerns

If you agree to talk to me, the interview will take about one to one and one half hours. I
might need to meet with you once or twice after the first interview, as I learn more
about aging parents. This research will take place from May 2011 to May 2012.

I will take notes during the interview. Your information will remain confidential. Code
names will be used and your real name will not be used. Your statements will not
identify you in the written summaries of my research.

I understand talking about aging and your parenting experiences might be difficult.
Your story will be treated with respect. I am a nurse researcher. I am not a therapist or
counselor. If you or I feel the interview is too uncomfortable, either of us can stop the
interview. I have emergency mental health numbers and support groups as contacts if
bringing up parenting issues causes you to feel you need professional support. You do
not have to answer questions that you do not want to. You can end the interview
without any concerns on my part. If you end the interview, that will be confidential.

Being part of this study may or may not provide direct benefit to you. It may help in the
future as we learn more about the needs of aging parents of adult mentally ill persons. It
may be helpful to have a person listen to your story. There is no payment for this and no
cost to you.

Any data I obtain in this study will be confidential. It will be shared only with your
permission. There are some exceptions to this. I am required by law to report previously
unreported child abuse or abuse of mentally ill or developmentally disabled persons or
abuse of vulnerable adults or intent to harm or kill yourself or someone else.

The data will be locked in file cabinets in my office. The data will be kept for three
years. The data will then be shredded. The data will be seen by the teachers who guide
me in my research and a typist. Your real name will not be shared with teachers or
typists.

Participating in a study is voluntary. You can stop at any time. I will answer any
questions you have about this research. Please call me or email me if you have any
questions. I am happy to talk to you about this study. My email is wilsonr@jetup.net.

You may call me at 320-249-1777. You can contact my advisor, Dr. Elizabeth Tyree, at 701-777-4552. If you have any further concerns, please call the University of North Dakota Office of Research and Program Development at 701-777-4279.

I have read this consent form. I have had all my questions answered by Roxanne Wilson. I agree to be part of this study.

Signature of participant _____

Printed name _____

Date signed _____

You will receive a copy of this consent.

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