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The Impact of Perceived Mental Illness Stigma on Caregivers' Desire to Relinquish Care

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

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Abstract

THE IMPACT OF PERCEIVED MENTAL ILLNESS STIGMA ON CAREGIVERS' DESIRE TO RELINQUISH CARE

By Tyler Rogers Corson, MS

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

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Caregiving can be stressful, and older adults' health and well-being may be impacted by the roles and responsibilities they assume as caregivers for persons with serious mental illness (SMI). This study is the first to apply the Stress Process Model of Caregiving (SPM) in an attempt to understand how mental illness stigma influences caregiver outcomes, specifically their desire to relinquish care. The intent of this study was to call attention to care relinquishment as an under-studied stress process outcome and to explore stress factors, with a focus on mental illness stigma, that contribute to SMI caregivers' desire to relinquish care. Using convenience sampling, members of the National Alliance on Mental Illness in the eastern U.S. were invited to participate in an online survey, resulting in a sample of n = 285. Regression analysis findings suggest that caregivers' partnership status, exposure to problematic behaviors, and perceptions of courtesy stigma predicted desire to relinquish care. Neither age nor caregiver sense of mastery moderated the relationship between perceived courtesy stigma and relinquishment desire.

Perceptions of stigma were negatively associated with caregiver health, sense of mastery, and social support levels, indicating stigma's role in the erosion of caregiver resources. This study provides information that can inform the development of educational and supportive services that may help caregivers better cope with the stressors associated with SMI caregiving. With caregiving stressors diminished, older caregivers will be able to better apply their resources toward self-care and maintaining their quality of life.

Keywords: serious mental illness, caregiver, courtesy stigma, Stress Process Model of Caregiving, care relinquishment, older adults

Chapter One: Introduction

Chapter Overview

The purpose of this study is to understand the impact of perceived stigma on caregivers' desire to relinquish care for their loved ones with serious or severe and persistent mental illness (SMI and SPMI respectively). The study uses the stress process model of caregiving as a framework to guide understanding of how stigma can impact caregiver outcomes. Study results will help fill a gap in the caregiver literature concerning care relinquishment decisions and will help direct attention to important personal and policy consequences of these decisions.

Chapter one provides a brief background on the issue and includes a statement of the problem. The study purpose and study significance are then summarized, followed by a brief introduction to the theoretical framework and data sources. The chapter concludes with an overview of the remaining chapters in the proposal.

Background

Mental illness is a significant public health issue. In 2014, almost ten million Americans, representing 4.2% of the population, suffered from a serious mental illness (SMI) (Center for Behavioral Health Statistics and Quality, 2015). Serious mental illnesses include schizophrenia, bipolar disorder, major depressive disorders, and other mental or psychotic disorders (Development Services Group, 2016). The functional impairments that accompany SMI may impede an individual's capacity for self-care and independent living. Estimates indicate that up to 75% of adults with SMI live with family members (Ghosh, Greenberg, & Seltzer, 2012;

Goodman, 2005; Kaufman, Scogin, Macneil, Leeper, & Wimberly, 2010) who provide financial and emotional support, housing, advocacy, treatment supervision, and de facto case management (Dixon et al., 2001). As such, these informal caregivers provide a critical network of care for this vulnerable population.

The stress of caregiving is widely documented in the literature. Providing care for a person with SMI exacts a toll in caregiver well-being (Aschbrenner, Greenberg, Allen, & Seltzer, 2010; Bass & Noelker, 1987; Llewellyn, Gething, Kendig, & Cant, 2004). The responsibilities associated with caregiving can lead to an assortment of biopsychosocial liabilities for the caregiver, including increased mental and physical health symptoms, financial and marital strains, and reduced social networks (Botsford & Rule, 2004; Goodman, 2005; Lefley & Hatfield, 1999; Shpigner, Possick, & Buchbinder, 2013). Caregiver stress has been shown to derive from many sources, including the physical demands of care, time demands that impinge on other work and family obligations, and damage to caregiver's self-concepts (Aneshensel, Pearlin, Mullen, Zarit, & Whitlatch, 1995; Pearlin, Mullan, Semple, & Skaff, 1990). Caregivers for persons with SMI also face a unique stressor: the widespread stigmatization of mental illness.

Goffman (1963) described stigma as occurring when a particular feature of an individual causes him to be excluded from full social acceptance. Link and Phelan (2001; 2013) have outlined a process through which people with mental illness are treated differently than other members of society. According to Link and Phelan (2001), the stigmatization of mental illness initially involves the labeling of differences that are deemed to be socially relevant. Stereotyping then links the mentally ill person's differences to undesirable characteristics. Once stereotyped groups are "separated" from other people, they are subject to status loss and discrimination in society. Discrimination may include devaluation, rejection, and exclusion that lead to unequal outcomes for persons with SMI (Link & Phelan, 2001). These outcomes can spill over into the lives of persons associated with SMI (i.e. friends, family, care providers) in a phenomenon known as *courtesy stigma*. Courtesy stigma may result in families being blamed, socially isolated, and discriminated against (Larson & Corrigan, 2008). As a result, family members may become depressed or reclusive (Ali, Hassiotis, Strydom, & King, 2012). While there is a considerable body of research concerning mental illness stigma's impact on families, existing research focuses almost exclusively on psychosocial outcomes. This has left a gap in the research concerning caregivers' behavioral responses to the stress of stigma, including their decisions to relinquish care.

Statement of the Problem

When stress reaches intolerable levels, caregivers may feel they have no choice but to relinquish their caregiving responsibilities. These decisions to relinquish care have important implications for both parties of the caregiving dyad. Abandoned by their caregivers, adults with SMI may destabilize and turn to public care systems (e.g. prisons, emergency departments, and homeless shelters) that are financially and organizationally unprepared to assume long-term care responsibilities for them. Caregivers themselves may experience significant grief, sorrow, and/or guilt. They also may face the loss of a future beneficial relationship with the care recipient (Veltman, Cameron, & Stewart, 2002). A gap exists in the literature concerning this population's motivation to relinquish care; closing that gap will help stakeholders design interventions and supports that preclude expensive and onerous outcomes for both dyad members.

Study Purpose

The purpose of this study is to survey caregivers of persons with SMI to ascertain their perceptions of the stigma they face and how those perceptions contribute to care relinquishment desire. Successful completion of this study will allow for the identification of key points in the caregiver stress process that influence desire to relinquish care, and will inform the discussion about how to best invest scarce public resources to alleviate the most burdensome caregiver stressors. The long-term goal is to identify points in the caregiving process where targeted interventions and fortifying supports can prolong caregiving capacities.

Study Significance

This study adds to the existing literature by looking beyond the mental health outcomes that are typically examined in caregiver stress studies. Aneshensel (1996) argues that a mental health focus assigns a medical orientation to a social problem. This medical orientation derives from funding sources (Aneshensel, 1996; Purkis & Ceci, 2015) that support disease-specific inquiries. While mental health outcomes are important, they are only a sample of the eventualities that can result from psychosocial stress. For caregivers of persons with SMI, there are critical outcomes associated with stress that are unrelated to the caregivers' psychopathology. By investigating caregivers' desire to relinquish care, this study adds the significant personal and societal implications of relinquishment decisions to the conversation about caregiving stress process outcomes for this population.

The inclusion of stigma as an independent stressor variable is a novel approach in caregiver stress studies. Unlike many physical ailments, mental illnesses are widely stigmatized. Outdated causational theories often attribute SMI to family influences and behaviors (Goodman, 2005; Milliken, 2001), which may lead to blame and stigma for parents. While SMIs are now known to be biologically and genetically based, outdated practitioner and public views still contribute to widespread stigmatization of individuals with SMI, which extends to families as courtesy stigma. This study is the first to investigate stigma as a contributing stress factor in care relinquishment decisions for this population.

Introduction to Theoretical Framework

The stress process model of caregiving (SPM) (Pearlin et al., 1990) forms the theoretical framework for this study. The SPM includes four important components: caregiving context, stressors, mediators, and outcomes. The *caregiving context* includes demographic caregiver characteristics that influence stress exposure as well as coping resources (Aneshensel et al., 1995). *Stressors* are problematic conditions that result from a discrepancy between the demands on a person and his ability to respond to those demands (Pearlin, Lieberman, Menaghan, & Mullan, 1981). When faced with stress, people call on their personal resources to counteract the stressful conditions. These resources, called *mediators*, can include social supports and coping skills that caregivers activate to combat stress. *Outcomes* are the consequences of stress processes. The SPM posits that outcomes may not result from any one particular stressor, but may emanate from a chain of stressors. This is the concept of *stress proliferation*, wherein individual stressors create or intensify stress in other areas of the caregiver's life that are unassociated with direct care. Using the SPM as a guiding framework, this study investigates whether caregivers' perceptions of mental illness stigma influence their desire to relinquish care, which can contribute to important caregiver and care recipient outcomes.

Assumptions

A key assumption of this study is that caregiving for a person with SMI is stressful. This assumption does not discount the benefits that some caregivers are known to derive from providing care for a loved one. Another assumption is that caregivers are voluntarily providing care because they feel a close personal connection to the person for whom they are providing care. The study further assumes that caregivers will provide open and honest answers to survey questions.

Delimitations

This study's survey will take place in early 2017 and is targeted toward adults who provide informal (i.e. unpaid) care for another adult who has been clinically diagnosed with SMI. As the study's dependent variable measures a caregiver's current desire to relinquish care, caregivers who are not presently providing care are not included. Caregivers for adults whose only mental illness diagnosis is either substance abuse disorder or dementia are also excluded from this study, as those populations face unique caregiving stressors that are outside the scope of this study.

Summary of Data Sources

Using a cross-sectional survey design, this study will collect primary data via distribution of an online caregiver survey. The Research Electronic Data Capture (REDCap) system, available through Virginia Commonwealth University's (VCU's) Center for Clinical and Translational Research, will host the survey. Online respondents will be recruited from a convenience sample of members of the National Alliance on Mental Illness (NAMI) Virginia. The survey link will initially be included in the electronic and print newsletters of local and state affiliates in the state of Virginia. If additional subjects are necessary to meet recruitment goals, NAMI affiliates in other states will be approached to disseminate the survey link. Snowball sampling will also be used, as various individuals and organizations (e.g. community mental health support groups, targeted online forums) will distribute or redistribute the survey link. Survey respondents are the primary unit of analysis for this investigation.

The survey questions will be derived from SPM constructs. Information about caregiving context, including kinship and cohabitation status, will shed light on the personal linkages between caregivers and recipients. Questions concerning stressors will be guided by prior studies that have identified objective and subjective stressors important to this population. Similarly, past studies underscore the importance of caregiver resources within the stress process; as such, data will be collected to measure the constructs of caregiver social supports and sense of mastery.

Definition of Terms

The following definitions, which are from the Oxford English Dictionary (2000) unless otherwise noted, clarify the meaning of terms as they are used within this study.

- <u>Stigma:</u> An attribute of a person that is deeply discrediting and that reduces the person to a tainted or devalued status within society (Goffman, 1963).
- <u>Blame:</u> To find fault with; to fix the responsibility on; the imputation of demerit on account of a fault or blemish.
- <u>Shame:</u> The painful emotion arising from the consciousness of something dishonoring, ridiculous, or indecorous in one's own conduct or circumstances (or in those of others whose honor or disgrace one regards as one's own).
- <u>Embarrassment:</u> Intense emotional or social discomfort caused by an awkward situation or by an awareness that one's own or another's words or actions are inappropriate or compromising, or that they reveal inadequacy or foolishness; awkwardness, self-consciousness.

- Guilt: Responsibility for an action or event; the 'fault' of (some person); the fact of having committed, or of being guilty of, some specified or implied offence.

Current terminology for mental disorders requiring regular management includes *serious mental illness* and *severe and persistent mental illness* (Development services Group, 2016). In the interest of simplicity, the term SMI caregiver is used in this research, however, the sample population includes persons caring for adults with either SMI or SPMI.

- Serious mental illness (SMI): Federal regulations define serious mental illness as a condition that impacts "persons aged 18 or older who currently or at any time in the past year have had a diagnosable mental, behavioral, or emotional disorder (excluding developmental and substance use disorders) of sufficient duration to meet diagnostic criteria…that has resulted in serious functional impairment, which substantially interferes with or limits one or more major life activities" (Substance Abuse and Mental Health Services Administration, 2013).
- Severe and persistent mental illness (SPMI): SMI and SPMI are discrete terms. While persons with SMI may have some disablement, treatment and recovery supports have the potential to improve their functional capacities. SPMI, however, is persistent (i.e. chronic) and always disabling (Development Services Group, 2016).

Chapter Summary and Overview of Remaining Chapters

Chapter one has described the need to fortify caregivers in their roles supporting persons with SMI in order to avoid negative outcomes for both parties of this caregiving dyad. The chapter has also highlighted the need to advance the conversation around caregivers' stress processes beyond pathological outcomes to other significant caregiver responses to the stresses of providing care to a person with mental illness. The importance of considering mental illness stigma within the caregiving stress processes for this population was also discussed.

The remainder of the proposal follows in chapters two and three. Chapter two presents a review of the literature, including a discussion of what is known about the topic, and identification of gaps in the literature that point to the need for the current study. Chapter two also more fully explains the theoretical underpinnings for the study. Chapter three describes the study sample, including a power analysis, and delineates the study's research design and methodology. References and appendices conclude the study proposal.

Chapter Two: Literature Review

Chapter Overview

The symptoms of SMI can limit an individual's ability to function independently. As such, loved ones of persons with SMI are often called on to provide care. This chapter reviews the literature concerning caregiving for persons with SMI. The review begins with an overview of the issue, including the impact of the deinstitutionalization movement on SMI caregiving. Caregiving stress is defined, followed by a summary of studies that highlight mental illness stigma as a unique source of caregiving stress. The next section elaborates on the SPM, followed by an application of the model to the population of SMI caregivers. The chapter concludes by outlining dissertation aims and related hypotheses.

Background

In 2013, an estimated 4.2 percent of American adults experienced a serious mental illness (Substance Abuse and Mental Health Services Administration, 2014). Serious mental illnesses include schizophrenia, schizoaffective disorder, bipolar disorder, and major depressive disorders (Cohen et al., 2000; Hert et al., 2011). SMI also encompasses mood, paranoid, panic, or other severe anxiety disorders, personality disorders, somatoform disorders, and other mental or psychotic disorders that may lead to a chronic disability (excluding dementia) (U.S. Government Printing Office, 2014). These illnesses can substantially impede self-care capacity. A survey by the AARP Public Policy Institute (2015) estimates that 8.4 million caregivers currently provide informal care for an adult with a mental health condition. Nearly nine in ten caregivers of individuals with SMI are caring for a family member, and almost half are caring for their adult children (National Alliance for Caregiving, 2016). These informal caregivers provide essential assistance to their loved ones, including, but not limited to: emotional and financial support, housing, advocacy, treatment supervision, and de facto case management services (Dixon et al., 2001). As such, they provide an important network of care for this vulnerable population.

A unique caregiving population. The SMI caregiving career is distinct from that of other caregivers. The average caregiver of a person with mental illness is 54.3 (National Alliance for Caregiving, 2016), 5 years older than the average age of all U.S. caregivers (49.2) (AARP Public Policy Institute, 2015). Like the rest of the aging population, these caregivers may face age-associated biopsychosocial changes, and these changes may influence their caregiving capacities (Lefley, 1987). SMI caregivers are likely to have loved ones who are abruptly diagnosed with psychotic illnesses in early adulthood after living almost a generation with no outward signs of illness (Greenberg, Seltzer, & Greenley, 1993) such that caregivers are simultaneously addressing the impacts of psychotic illness (e.g. hospitalization, treatment management) and grieving the loss of the pre-illness individual that they knew and loved (Ghosh et al., 2012; Goodman, 2005; Johansson, Anderzen-Carlsson, Åhlin, & Andershed, 2010). Unlike stable (e.g. intellectual disabilities) or degenerative (e.g. Alzheimer's) illnesses, SMIs are cyclical, and the fluctuating symptoms and periods of remission lead to caregiver uncertainty and feelings of constantly "walking on eggshells" (Goodman, 2005; Lefley, 1987) in anticipation of exacerbated illness symptoms that activate caregiving needs and precipitate taxing caregiver responsibilities.

Differences in available community care options also distinguish the SMI caregiver population, who perceive a lack of accessible and appropriate care alternatives for their loved ones (Hatfield & Lefley, 2000). Although families of developmentally and intellectually disabled (DD and ID respectively) children can often count on siblings to help with current and future care, research suggests that poor sibling relationships and heavy caregiving responsibilities discourage this care pathway for families impacted by SMI (Lefley, 1987; Lefley & Hatfield, 1999). In addition, Medicaid community-based care waiver programs available to families impacted by ID and DD are not typically accessible for SMI, increasing the financial burden of care for these families. Certain caregivers have access to nursing homes for their chronically impaired loved ones, however the younger population of persons with SMI may be averse to nursing home placement and face admission barriers as well (Lane, McCoy, & Ewashen, 2010). While raised awareness of the difficulties facing individuals and families experiencing Alzheimer's disease has led to the growth of residential memory care centers, the number of residential psychiatric facilities has greatly diminished due to the deinstitutionalization movement of the last half-century (Mowbray & Holter, 2002). SMI caregivers also contend with the limited availability of appropriate public housing for their loved ones, as housing options are often transitional and located in neighborhoods where judgment-impaired individuals may be at higher risk of victimization (Hatfield & Lefley, 2000; Lefley, 1989).

Housing and care accessibility limitations put additional onus on family members to provide community-based care themselves. Cohabitation rates are high for this population. Forty-five percent of SMI caregivers co-reside with the care recipient in the community, a significantly higher rate than that of caregivers for adults without mental illness (34%) (AARP Public Policy Institute, 2015; National Alliance for Caregiving, 2016). Another 27% of SMI caregivers live within 20 minutes of the person for whom they provide care (National Alliance for Caregiving, 2016). These caregivers provide assistance an average of 32 hours per week, with one in five devoting more than 40 hours each week to caregiving responsibilities (National Alliance for Caregiving, 2016). Clearly, this group is providing a substantial amount of community-based care, without access to many of the supports available to other caregiving populations.

Deinstitutionalization. Community based care has not always been normative for individuals living with SMI in the United States. The movement away from institutional toward community-based mental health care began in the 1950s and 60s and grew out of converging social and scientific issues at that time (Becker, Stiles, & Schonfeld, 2002). At mid-century, stakeholders were optimistic that newly developed antipsychotic medications would allow individuals with SMI to leave psychiatric hospitals and function in their communities (Mowbray & Holter, 2002). The Civil Rights Movement of the 1960s led to a clarion call for individuals with mental illness to be cared for in the least restrictive setting, an appeal that was federally mandated by *Olmstead v. L.C.* (1999) at the end of the century. In response to the push for community-based care, the psychiatric hospital inpatient population fell from 560,000 in 1955 to around 35,000 in 2014 (Public Broadcasting Service, 2002; Torrey et al., 2014). While the belief in recovery and home-based support was hopeful, many individuals with SMI were discharged from residential facilities before communities could build sufficient and appropriate support systems, and family members were left to fill the care void.

In addition to being seen as too restrictive, state psychiatric hospitals were also expensive. Deinstitutionalization meant relocating persons with SMI back to their communities for care and shifted funding responsibility from state-supported institutions to community health centers and other federally funded programs (Mowbray & Holter, 2002). Unfortunately, the community mental health supports that were promised as part of the deinstitutionalization movement never fully materialized, leaving untrained and unprepared family members to provide care for a very vulnerable and challenging population (Goodman, 2005; Kaufman et al., 2010). In 2015, four in ten caregivers reported that they had no education or training to support them in their complicated and critical caregiving roles (National Alliance for Caregiving, 2016). Providing care for a complex population with little training and limited resources contributes to caregiver stress and leads to negative consequences for caregivers and their loved ones.

Stress of caregiving. Stress occurs when individuals perceive that the demands of their environment exceed their personal capacity to cope with the situation (Aneshensel, 1996; Lazarus, 1981). The stressors associated with providing care for a person with SMI can have negative impacts on caregivers, and the toll of caregiving may increase with age (Aschbrenner et al., 2010; Bass & Noelker, 1987; Llewellyn et al., 2004). Biopsychosocial challenges associated with caregiving include increased mental and physical health symptoms, financial, family, and marital strains, and reduced social networks (Botsford & Rule, 2004; Goodman, 2005; Lefley & Hatfield, 1999; Shpigner et al., 2013). Cook, Lefley, Pickett, and Cohler (1994) posit that caregivers of different ages may have unique concerns, and that it is reasonable to expect that stressors will change as caregivers age. SMI caregivers are often older adults in their 50s and 60s (Aschbrenner et al., 2010; Botsford & Rule, 2004; National Alliance for Caregiving, 2016). Like other older adults, aging SMI caregivers may experience increased physical frailty, compromised mental health, limited financial resources in retirement, or other age-associated changes that diminish or preclude some caregiving capabilities and add to caregiving stresses (Arling, 1987; Ghosh et al., 2012; Perlick, Hohenstein, Clarkin, Kaczynski, & Rosenheck, 2005). Older caregivers may also experience losses that make it more difficult to cope with the stresses and strains of caregiving, including the loss of meaningful work, the deaths of loved ones, and declining social supports (Hatfield & Lefley, 2000; Lefley & Hatfield, 1999). Life expectancies are increasing for both caregivers and persons with SMI, and the combined impacts of aging and perpetual caregiving responsibilities result in distinctive stressors for the SMI caregiver population. Despite these stressors, many SMI caregivers continue in their caring roles, contributing an important share of the estimated $450 billion dollars worth of informal care provided in the U.S. annually (Feinberg, Reinhard, Houser, & Choula, 2011). In order to sustain aging caregivers in their roles and support the well-being of both members of the care dyad, it is important that we understand the impacts of providing care so as to prepare for and support positive outcomes.

Studies of caregiving and stress in gerontology. Gerontologists have long been interested in the impacts of stress on the aging process, and the relationship between stress and caregiving issues has received wide attention in the gerontological literature. For example, in a review of eight major journals of aging and sociology, stress process and stress and coping models formed the second most frequently employed paradigmatic approach in aging research (after life-course theory) from 2000-2004 (Alley, Putney, Rice, & Bengtson, 2010). According to Alley, Putney, Rice, and Bengtson (2010), three additional paradigms that address issues of caregiving and aging (hierarchical selection, task specificity, and substitution hypothesis) were also among the most frequently cited models in gerontological publications of that period. Gerontologists as well as researchers in other age-associated disciplines (e.g. psychology, sociology) have used these theories to investigate the caregiving process and identify caregiving stressors (Dilworth-Anderson, Williams, & Gibson, 2002; Hilgeman et al., 2009; Messeri, Silverstein, & Litwak, 1993; Yogtiba, 1998).

Using the aforementioned and other theoretical paradigms, researchers have created a considerable body of literature depicting the issues facing older SMI caregivers. In an early article entitled "Aging Parents as Caregivers of Mentally Ill Adult Children: An Emerging Social Problem," Lefley (1987) brought the issues relative to aging and SMI caregiving to the forefront. Subsequent qualitative studies describe the lived experience of older SMI caregivers (Avieli, Smeloy, & Band-Winterstein, 2015; Johansson et al., 2010; Kropf & Kelly, 1995; Pejlert, 2001; Shpigner et al., 2013; J. Smith, 2012). Quantitative investigations of aging SMI caregiver topics range from their future planning needs (Botsford & Rule, 2004; Hatfield & Lefley, 2000; G. C. Smith, Hatfield, & Miller, 2000; G. C. Smith, 2004) to caregiver health and health care access issues (Dixon et al., 2001; Ghosh & Greenberg, 2009; Llewellyn et al., 2004; S. Magaña, Smith, & Taylor, 2006; Perlick et al., 2005). Caregiver stress for this population has been investigated and shown to derive from many sources, including the physical and emotional demands of care, time and energy demands that impinge on other work and family obligations, and damage to caregiver's self-concepts (Aneshensel et al., 1995; Aschbrenner et al., 2010; Ghosh et al., 2012; Kaufman et al., 2010; Pejlert, 2001; Saunders, 2003; Tessler & Gamache, 2000). In addition to challenges related to both aging and providing care, SMI caregivers also face a unique stressor: the stigmatization of mental illness.

Mental Illness Stigma

Stigma is defined in the Oxford English Dictionary (2000) as "a distinguishing mark or characteristic (of a bad or objectionable kind)." The term stigma was first used in ancient Greek society, where cut or burn marks in the skin, called stigmas, were used to publicly identify criminals or traitors. Goffman's (1963) seminal tome *Stigma, Notes on the Management of a Spoiled Identity* defines stigma as more than just the outward mark of a particular trait, but as a deeply discrediting personal attribute that reduces an individual "in [others'] minds from a whole and usual person to a tainted, discounted one" (p. 3). Goffman (1963) argues that stigma spreads from stigmatized persons to individuals who are linked to them through social structures (e.g. kinship, friendship) by way of a phenomenon known as *courtesy stigma*. While the outward cues identifying an individual with SMI may include unusual behaviors or taking certain medications, families are marked simply by their association with a person who experiences mental illness. Through this association, parents, siblings, spouses, neighbors, friends, and health care providers of persons with SMI may face negative consequences resulting from the stigmatization of mental illness (Corrigan & Miller, 2004; Francis, 2012; Goffman, 1963; Mak & Cheung, 2008; National Alliance for Caregiving, 2016).

Building on Goffman's work, Link and Phelan (2001) describe stigma as a process through which people associated with mental illness (or other stigmatized traits) are treated differently than other members of society. Mechanisms in this multidimensional process include labeling, stereotyping, separation, status loss, and discrimination. The stigmatization of mental illness begins with the *labeling* of differences that are deemed to be socially relevant. Marks that link an individual to mental illness range from the ill person's unusual behaviors to being seen accompanying an individual with SMI to a mental health court hearing or psychiatrist's office. Once the person is labeled as having a direct or indirect association with mental illness, *stereotyping* then links the differences to undesirable characteristics. Stereotypes are cognitive attributions used to categorize individuals, and these categories are then applied to differentiate between "us" and "them" (Byrne, 2000). Persons with SMI are stereotypically thought to have violent tendencies; their families are stereotyped as having caused or contributed to their loved one's illness (Angermeyer, Schulze, & Dietrich, 2003; Corrigan & Miller, 2004; Shibre et al., 2001).

Once differences are labeled and the stereotyped group is *separated* from others, the stigmatized persons experience a *loss of social status* and are subjected to societal *discrimination* (Link & Phelan, 2001). Such discrimination reduces life opportunities and leads to adverse social and emotional outcomes for persons associated with SMI (Goffman, 1963; Green, Davis, Karshmer, Marsh, & Straight, 2005). Research shows that individuals with SMI have reduced opportunities in the areas of work, education, housing, and relationships (Angermeyer et al., 2003). Not only do individuals with SMI face limitations due to stigma and discrimination, there is evidence that their associates are also negatively impacted by mental illness stigma (Goffman, 1963).

Link and Phelan, joined by Yang and Collins (2004), have refined their delineation of the stigmatizing process to include the concept of *emotional reactions*. Link and colleagues (2004) argue that the behaviors of all parties involved in the stigma process are driven by their emotions, making consideration of emotional reactions integral for stigma researchers. Within the stigma process, the separation between the in group (us, or the stigmatizers) and out group (them, or the stigmatized) evokes emotional reactions in members of both groups. According to attribution theory, the in group's emotional responses to stigma (e.g. fear, pity, anger) drive their behaviors toward the out group, with pity driving more helping behaviors and anger driving punishing behaviors (Corrigan, 2000). Emotions are important for the out group as well. Stigmatized persons can detect stigmatizers' emotional reactions and may tailor their behaviors accordingly (Link et al., 2004). For example, an SMI caregiver who senses reprobation from a health care provider may avoid future care visits. The perception of stigmatizing behaviors and attitudes can evoke a wide range of intense feelings for the caregiver, including but not limited to embarrassment, shame, guilt, anger, helplessness, alienation, confusion, frustration, regret, hurt, and disappointment (Angermeyer et al., 2003; Byrne, 2000; Chang & Horrocks, 2006; Chou, Pu, Lee, Lin, & Kröger, 2009; Corrigan & Miller, 2004; Corrigan, Watson, & Miller, 2006; Karnieli-Miller et al., 2013; Lefley, 1992; Wight, Aneshensel, Murphy, Miller-Martinez, & Beals, 2006). These negative emotions threaten caregivers' emotional well-being and reduce their chances for successful aging (Freund & Baltes, 1998).

Consequences of Stigma

This section reviews the stigma literature, revealing caregiver consequences that include blame and shame, social isolation and loneliness, and discrimination. These outcomes can have wide-ranging caregiver impacts.

Blame and shame.

Twentieth century causational theories attributed SMI to family influences and behaviors, which led to blame and stigma for many caregivers (Goodman, 2005; Milliken, 2001). Parents, and especially mothers, are typically held responsible for their offspring's conduct. In the mid-1900s, just as the deinstitutionalization movement was gaining traction and persons with mental illness were being sent home, the blame for the occurrence of SMI was placed more strongly on the parents, especially mothers (Francis, 2012). The psychiatric profession was not immune to mother-blaming, and coined the term *schizophrenogenic mother* to attribute the onset of SMI to parental behaviors (Milliken, 2001). While SMIs are now known to be biologically based and influenced by genetic factors, outdated views persist, and care providers may still view parents as over-involved and contributing to the child's SMI (Goodman, 2005; Lefley, 1989; Pejlert, 2001). In a focus group study by Angermeyer (2003), families impacted by SMI reported feeling that health care professionals looked down on them and excluded them from the treatment team. They also felt devalued by care professionals, who dismissed their caregiving experience and care competence. The lasting stigmatization of mental illness has created barriers between families and the health care system and led to mistrust, underutilization of services, and frustration in encounters with the system (Dixon et al., 2001; Lefley, 1989). These outcomes threaten the health and well-being of caregivers and their loved ones.

Health professionals are not alone in blaming families for a relative's mental illness. Despite medical models that explain the occurrence of SMI, families report being blamed by grandparents, spouses, siblings, the ill family member, friends, strangers, and educational professionals (Angermeyer et al., 2003; Corrigan & Miller, 2004; Francis, 2012; Green, 2004). Corrigan and Miller (2004) have found that family blame is a heterogeneous construct that depends on an individual's level of kinship with the ill person. Parents are typically blamed for poor parenting that caused the mental illness; siblings are more likely to be blamed for not helping to control the symptoms and for the exacerbation of their relative's illness (Corrigan & Miller, 2004; Corrigan et al., 2006). Children of parents with SMI may be seen as contaminated by the parent's illness and resultantly viewed as having a devalued social identity (Corrigan & Miller, 2004; Goffman, 1963).

As a result of blame, family members may feel shame over their association with mental illness (Larson & Corrigan, 2008; Perlick et al., 2007). Shame is a painful emotion that arises from a person's awareness of having behaviors or characteristics that others find offensive. Byrne (2000) finds that family members use secrecy as a response mechanism to feelings of shame. Caregivers may waste valuable resources hiding their loved one's illness in order to avoid stigmatization and discrimination. In addition, efforts to conceal a loved one's mental illness status may lead to increased social isolation for caregivers.

Social isolation and loneliness. Social barriers erected by mental illness stigma can surround whole families and alienate and isolate them from community supports and services (Kropf & Kelly, 1995; Lefley, 1989; Veltman et al., 2002). Caregivers benefit from social supports; caregivers with smaller social networks are likely to feel increased caregiver burden (Aschbrenner et al., 2010; Kaufman et al., 2010). Social isolation can also add to the emotional burden for SMI caregivers, as embarrassed and ashamed caregivers may not participate in self-care and social activities (e.g. exercise classes, meals with friends) that can stave off depression and reduce stress (Kropf & Kelly, 1995; Perlick et al., 2007). By threatening caregivers' well-being, the social isolation resulting from mental illness stigma may negatively impact their ability to provide effective care.

For those caregivers whose loved ones with SMI are severely psychotic, the ill person's bizarre or disruptive behaviors may lead to increased social isolation because outsiders avoid contact that feels uncomfortable, or because families self-isolate to avoid embarrassment and stigma (Lefley, 1989; Shpigner et al., 2013). Two types of stigma are described in the literature: felt and enacted. According to Green, Davis, Karshmer, Marsh and Straight (2005), *felt stigma* occurs when individuals perceive that they are associated with a stigmatizing trait, exposed to disapprobation, and experience social distance. Caregivers of persons with SMI may avoid contact due to the anticipation of stigma or they may actually be socially rejected and isolated by others due to stigmatization. *Enacted stigma* refers to an occasion when a person with a stigmatized attribute loses status or experiences overt discrimination (Green et al., 2005). Either pathway results in reduced social support networks for vulnerable caregivers.

Social rejection and isolation due to mental illness stigma can make SMI caregivers especially vulnerable to loneliness. Loneliness is a subjective state wherein a person feels isolated, without companionship, or has a sense of not belonging (Perissinotto, Stijacic Cenzer, & Covinsky, 2012; Russell, 2009). Loneliness is not equivalent to being alone or having few intimate relationships, as people can be content by themselves or with small social networks. Instead, loneliness occurs when a person desires a greater number of relationships than he currently has (Perissinotto et al., 2012). Loneliness has been associated with poor health outcomes, including declines in activities of daily living, mobility declines, sleep dysfunction, and increased morbidity and mortality for older adults (Cacioppo et al., 2002; Cornwell & Waite, 2009; Perissinotto et al., 2012). Ekwall, Sivberg, and Halberg (2005) found that both smaller social networks and loneliness were associated with lower quality of life for caregivers. While social integration can alleviate an individual's sense of loneliness (Rote, Hill, & Ellison, 2013), persons with stigmatizing conditions are likely to be excluded from social interaction at some level (Goffman, 1963). Taken together, the socially isolating impacts of mental illness stigma and the potentially deleterious effects of loneliness for older adults highlight the need for investigations of the impacts of mental illness stigma on outcomes for this caregiving population.

Discrimination. Link and Phelan (2001) describe discrimination as behaviors that lead to unequal outcomes and disadvantages for stigmatized persons. Discrimination against caregivers may take the form of negative interpersonal interactions such as defamation, assignment of guilt, negative reactions, and social ostracism (Corrigan, Watson, & Barr, 2006; Larson & Corrigan, 2008; Perlick et al., 2011; Wight et al., 2006). Caregivers may also face structural discrimination by way of policies and regulations that limit the opportunities for persons impacted by mental illness, such as limitations on funding streams for supported housing, or confidentiality laws (e.g. HIPAA) that inhibit caregivers from being part of their relative's care team. Discrimination increases the stressors and burdens facing this caregiver population.

Despite the established impacts that mental illness stigma has on caregivers, its role is relatively unexplored in the literature on caregiver stress. The purpose of this study is to investigate stigma as a stressor within the SPM to determine its influence on caregiver outcomes, specifically caregivers' desire to relinquish their caregiving responsibilities.

Stigma and the Aging Caregiver

There is a paucity of research investigating aging caregivers' experiences with mental illness stigma. Without this information, stakeholders are unable to develop targeted, supportive interventions for this population. The lack of evidence also makes it difficult to efficiently allocate scarce public mental health resources. Existing studies are summarized in Table 1. Three of these four studies were performed outside of the U.S., in countries where unique cultural and religious concepts surrounding mental illness may impede international generalizability (Mak & Cheung, 2012). Atheoretical investigative approaches are also limitations in these studies. Given this gap in the literature, this study proposes to investigate caregiver age as a potentially important variable in the relationship between caregivers' perceived stigma and their desire to relinquish care.

Emotions, stigma, and older adults. As described above, the process of stigma includes an important emotional component. There is a wide range of emotional intensity that people potentially feel when they perceive themselves as subjected to stigma. People with more intense emotions may have greater responses to stigma than people with less intense emotions. Emotions initiate physiological responses in the body's cardiovascular, endocrine, and

Table 1

Summary of Literature Regarding Aging Caregivers and Mental Illness Stigma

Study	Subjects	Results	Limitations
Chou (2009)	Older (55+) Taiwanese ID caregivers (n=350) and SMI caregivers (n=66)	Perceived stigma has stronger impact on caregiver quality of life for SMI vs. ID caregivers	Comparison of two groups of aging female caregivers. Did not investigate impact of age/aging on perceptions of stigma
Mak & Cheung (2008)	Chinese ID caregivers (n=210) and SMI caregivers (n=110)	Significant relationship between affiliate stigma and caregiver age (r=0.27, p<0.05)	Measures affiliate vs. courtesy stigma; Cultural sense of *losing face* may influence results for older Chinese caregivers
Perlick, et al. (2007)	American caregivers for persons with bipolar disorder (n=500)	Perceived stigma positively associated with depressive symptoms. Overall patterns of associations between stigma, support and coping, and depression did not differ among caregiver age groups	Age group associative patterns including stigma were investigated using exploratory (vs. hypothesized) analyses.
Shibre et al. (2001)	Relatives of Ethiopians with schizophrenia or affective disorders (n=178)	75% of relatives reported felt or enacted stigma. Older (45+) and urban Ethiopians more likely to perceive stigma as problematic	Almost 30% of respondents attribute SMI to supernatural forces, which may influence older adults' perceptions. Participants did not necessarily provide care.

neurological systems; an individual must exert physical and psychological effort to counteract the emotional effects and return the body to baseline functioning (Charles & Carstensen, 2007). Carstensen, Pasupathi, Mayr, and Nesselroade (2000) found that older and younger adults experience similar levels of emotional intensity. However, older adults may have enhanced capabilities and strategies for managing their emotions in the face of stigma. Charles and Carstensen (2007) posit that while age-associated biological changes occur and may challenge an older person's physical responses, there are contemporaneous changes in emotion regulation strategies that can offset these challenges to maintain or even improve older adults' ability to regulate emotional responses.

Socioemotional selectivity theory. Socioemotional selectivity theory (SST) is a lifespan theory of motivation which posits that humans' concepts of time and of their position in the lifespan combine to influence their life goals (Carstensen, Isaacowitz, & Charles, 1999; Charles, 2011; Charles & Carstensen, 2007). SST asserts that human goals can be subdivided into two basic categories: knowledge-based goals that focus on gaining information, and emotion-based goals, which emphasize a person's emotional fulfillment and well-being. According to the theory, as humans perceive that their lifespan is limited (regardless of chronological age), they are motivated to shift their focus from knowledge- to emotion-based goals (Carstensen et al., 1999; Carstensen et al., 2000). SST further postulates that in order to optimize their emotional well-being, older adults develop emotion regulation strategies to minimize negative affect and maximize positive affect (Charles & Carstensen, 2007). They do this in at least two ways: avoiding what they perceive as negative interactions, or viewing those interactions in a more positive light.

Older adults use their accumulated experiences in social settings to avoid negative social encounters, or to minimize their emotional reactions to those encounters, tactics which lead them to report less negative impact from their negative social interactions than younger adults (Birditt, 2014). SST posits that older adults use *situation selection* and *situation modification* as emotion regulation strategies to avoid or cognitively reframe (i.e. change their perceptions of) socially toxic or damaging relationships (Carstensen, Gross, & Fung, 1997). Older adults are more likely than their younger counterparts to employ these avoidance techniques in response to interpersonal problems (Birditt, Fingerman, & Almeida, 2005; Birditt & Fingerman, 2005).

Goffman (1963) asserts that individuals who are repeatedly faced with stigma can develop skills to manage stigmatizing situations. It is expectable that older caregivers with a history of stigma exposure would employ emotion regulation strategies to avoid stigmatizing individuals and environments that provoke negative interactions and emotions. For example, older adults may employ their positive attentional mechanisms to ignore sidelong looks from strangers, or they may use situation selection tactics to avoid businesses where employees demonstrate negative attitudes and behaviors toward their loved one with SMI.

In addition to managing their social interactions to avoid negativity, older adults are likely to focus on positive aspects of their lives. According to SST, aging individuals are increasingly motivated to pay attention to positive stimuli, to make more positive assessments of situations, and to recall information in ways that promote emotional well-being (Charles & Carstensen, 2007). This refocus in aging from a negative toward a more positive outlook is known within the SST framework as the *positivity effect* (Carstensen & Mikels, 2005; Mather & Carstensen, 2005). Several studies validate the existence of the positivity effect in aging. Mather and Carstensen (2003) found that older adults showed an attentional bias toward positive information that was not present in younger adults. In the same study, older adults had better recall of positive versus negative information (Mather & Carstensen, 2003). In their investigation of adults aged 25 to 74 (n = 2,727), Mroczek and Kolarz (1998) found that older adults self-reported higher positive affect and lower negative affect than younger adults. A national study of daily stressors revealed that older adults (ages 60 to 74) not only reported lower frequency of stressors, but also were less apt than their younger counterparts to perceive the stressors as influential over other people's feelings toward them (Almeida, 2005). In other words, compared to younger adults, older adults felt that others would be less judgmental towards them in certain stressful circumstances. Given older adults' penchant for positive versus negative information and social situations, it is reasonable to think that they may use the emotion regulation strategies proposed by SST to shift their time, attention, and recall efforts away from negative attitudes and interactions caused by mental illness stigma. As such, perceived stigma may have less impact on caregiver outcomes for older adults than for younger ones. Investigation of this proposition is one aim of the current study.

Stress Process Model of Caregiving

Model overview. Researchers have proposed various theoretical frameworks to explain the caregiving process. The SPM has been successfully applied in various care settings and has been used to investigate a wide array of variables associated with the model's constructs (Noyes et al., 2010; Seeher, Low, Reppermund, & Brodaty, 2013). Studies empirically testing the model range from investigations of intergenerational stress proliferation (Bierman & Milkie, 2008) to those of stress process differences among caregivers of different ethnicities (Hilgeman et al., 2009). The SPM proposes that caregiver health and behavioral outcomes are influenced by the confluence of their personal characteristics, the stressors to which they are exposed, and the personal resources that they bring to bear in the stress equation. In order to create policies and programs that reduce the most salient SMI caregiver stressors, we need a more complete understanding of the stress processes of this caregiving population. The SPM allows us to test the proposition that perceived mental illness stigma impacts caregivers' desire to relinquish care.

Sociological studies of stress began in the mid-20th century, and constructs arising from thematic data analysis led to the emergence of theories to describe the stress process (Avison, 2010). Leonard Pearlin and his colleagues began to conceptualize stress as a process in the early 1980s in an article highlighting the impact of social structures on stressors and on factors that mediate stress (Pearlin et al., 1981). Pearlin, Mullan, Semple, and Skaff (1990) further elaborated the SPM constructs. In their explanation of the model, Pearlin and his colleagues identify stress as a process that may be triggered by a particular stressor, but goes beyond just that one stressor and involves the context in which the stress takes place. The SPM considers the caregiver's whole environment, including socioeconomic factors, family relationships, and personal histories, as an important influence on the caregiver's stress process (Aneshensel et al., 1995; Pearlin et al., 1990). Inclusion of caregiving context in the SPM acknowledges that caregivers do not manage stressors singularly, but in tandem with all the other aspects of their lives.

Model concepts and constructs. There are four main components of the SPM: caregiving background and context, stressors, mediators, and outcomes.

Background and contextual factors. The responsibilities associated with caregiving are not inherently stressful. Caregivers feel stress when they perceive their caregiving duties as onerous in some way, and these perceptions are influenced by caregivers' personal characteristics (Turner & Roszell, 1994). Pearlin (1989) argues that in order to understand the stress process, researchers must investigate caregivers' social and economic characteristics to establish the background and context of the caregiving environment. Studies show that exposure to stress within a caregiving dyad is influenced by the unique characteristics of each of its members, as well as the members' relationship status and care environment (Aneshensel et al., 1995; Morycz, 1985; Pearlin, 1999). Nankervis, Rosewarne, and Vassos (2011) investigated the decisions of caregivers (n = 32) for family members with intellectual disabilities to relinquish care to respite facilities. In the resulting thematic analysis, factors influencing relinquishment decisions fell into three categories: characteristics of the person with disability, characteristics of the caregiver, and characteristics of the environment. In a sample of Alzheimer's caregivers by Aneshensel, Pearlin, and Schuler (1993), the risk for institutionalization of the care recipient was dependent on specific personal characteristics of dyad members, including financial status, care recipient age, and impairment level. In that study (Aneshensel et al., 1993), younger care recipient age was associated with more feelings of role captivity for caregivers; it is reasonable to think that these caregiver emotions might translate to the SMI caregiver population, as caregivers who are caring for a younger person (e.g. a parent caring for an adult child) can expect years or decades of caregiving responsibilities to come (Goodman, 2005). These studies confirm the importance of specific background and contextual characteristics in the stress process.

Stressors. Stressors are problematic circumstances facing caregivers that call into play one's capacity to adapt to difficult conditions. Aneshensel et al. (1995) define stressors as "conditions, experiences and activities that are problematic to people, threatening them, thwarting their efforts, fatiguing them, and defeating their dreams" (p. 69). Stress arises from a conflict between individuals and their environments, where difficulties arise as result of incompatibility of a person's setting and his characteristics (Aneshensel, 1996). In other words, stress develops when there is a mismatch between the demands on a caregiver and the caregiver's perception of his ability to respond to the demands (Aneshensel et al., 1995; Pearlin et al., 1981). The SPM subdivides stressors into primary and secondary categories.

Primary stressors. Primary stressors derive directly from the routine performance of care duties (Aneshensel et al., 1993). The SPM differentiates between objective and subjective primary stressors. *Objective stressors* result directly from care responsibilities associated with the care recipient's needs and behaviors (e.g. assisting with personal care, driving to appointments, calming the recipient). These stressors require the caregiver to take physical action. *Subjective stressors* derive from caregivers' emotional, cognitive, and attitudinal responses to their caregiving responsibilities and can cause psychological distress for caregivers (Aneshensel et al., 1995; Zarit, 2006). These stressors deal with caregivers' thoughts and feelings, (e.g. feeling trapped in the caregiving role, or sadness about their loved one's condition).

Secondary stressors. Secondary stressors are unrelated to direct care provision, but instead arise when the demands of care impinge on caregivers' social roles, social networks, and self-concepts (Aneshensel et al., 1993). Despite their name, secondary stressors do not have reduced impacts within the model; the terminology simply indicates that these stressors emanate from primary tasks and responsibilities associated with care. Secondary stressors are subdivided within the model as *role strains* and *intrapsychic strains*. Role strains refer to the conflicts and tensions associated with caregivers' work or family relationships, or with financial problems associated with caregiving (Zarit, 2006). Role strain stressors result from conflict between a caregiver's roles (e.g. need to take excessive work leave to provide care), or role overload, which can lead to caregiver exhaustion or burnout (Morycz, 1985). Intrapsychic strains involve caregivers' self-concepts, which may be negatively impacted by the enduring and taxing responsibilities of providing care (Pearlin et al., 1990; Zarit, 2006). The categorizations of stressors within the SPM allow the model to illuminate the widespread and complex impacts that reverberate throughout the lives of not only caregivers, but within the lives of those who are connected to the caregivers through extended social, employment, or kinship networks.

Mediators. Caregivers are a heterogeneous group with unique sets of personal coping resources, and as such they respond differently to specific conditions and environments

(Aneshensel, 1996; Pearlin, 1999). What causes stress for some individuals may not be a source of difficulty for others. Differences in caregiver responses are partially explained within the SPM's construct of *mediators*. SPM mediators are psychosocial resources that militate against the deleterious impacts of stressful life circumstances (Aneshensel et al., 1995; Pearlin, Turner, & Semple, 1989). Two important coping resources that help regulate the relationships between caregiver stressors and outcomes are mastery and social support (Pearlin et al., 1990; Turner & Noh, 1988).

It is critical to note that while caregiver psychosocial resources are typically called mediators within the SPM, they have not always been considered as having statistically mediating effects. In revisiting the SPM almost two decades after its inception, Pearlin (1999) postulated that these resources are not inherently mediating or moderating variables, but should be considered in light of the other components of the particular stress process under consideration. SPM mediators have been considered as having statistically moderating and/or mediating effects in various studies (Aneshensel et al., 1995; G. C. Smith, 2004; Wight, Aneshensel, LeBlanc, & Beals, 2008). Within the current study, the caregiver resource variables of mastery and social support are investigated as statistical mediators or moderators based on the considered nature of the predictor-criterion relationship.

Mastery. A person's sense of mastery is a key factor in his ability to regulate stress (Turner & Noh, 1988) and plays a critical role in the SPM. Mastery represents an individual's perception of how much control he exerts on the forces that impact his life. Mastery influences how caregivers expect their personal attributes (e.g. ability, effort) to impact their life outcomes (Aneshensel et al., 1995; Pearlin et al., 1990; Pearlin et al., 1981). Studies show that persons with increased mastery experience better caregiver outcomes, including lower levels of depression and better overall mental health and well-being (Green, 2004; Pearlin et al., 1981; Wong, 2000). Individuals with higher mastery may interpret stressors as less menacing than those with low mastery, or they may be better able to activate their personal resources against stress, both of which can explain at least some of the variability in outcomes (Pearlin, 1999).

Research reveals an association between age and sense of mastery such that older adults report lower levels of mastery than younger adults (Jang, Borenstein-Graves, Haley, Small, & Mortimer, 2003; Mirowsky, 1995; Ross & Mirowsky, 2002). Studies further indicate that changes in perceptions of control may be related to older adults' health outcomes through their influence on stress and coping capabilities, physiological reaction, and health behaviors (Rodin, 1986). Rodin (1986) postulates a triad of potential influences on older individuals' sense of control: 1) more frequent experiences related to control (e.g. retirement, negative stereotypes of aging), 2) an enhanced link between health and sense of control in aging, and 3) increased contact with a health care system that limits opportunities for control. In a study of randomly selected U.S. residents (*n* = 2030), Mirowsky (1995) found that adults' sense of control was comparably high and stable between ages 18 and 50, after which participants' reported sense of control decreased progressively with age. The lowest levels of mastery were observed in the oldest (80 and older) age group. Other studies confirm that perceived control decreases with age (Lachman, Rosnick, & Röcke, 2009; Schieman & Turner, 1998; Wolinsky, Wyrwich, Babu, Kroenke, & Tierney, 2003). While a full exploration of mastery is beyond the scope of this study, the mastery construct is influenced by many factors in addition to age, including health, income level, social supports, race, gender, religiosity, and socioeconomic status (Gadalla, 2009; Jang et al., 2003; Schieman & Turner, 1998; Schieman, Nguyen, & Elliott, 2003; Skaff, Pearlin, & Mullan, 1996). That said, older age (recall that the average SMI caregiver is 54), may indicate that certain SMI caregivers have lower levels of mastery, a key psychosocial resource that is postulated in the SPM to combat the stressors of caregiving. These individuals may be especially vulnerable to the impacts of caregiving stressors.

Perceived social support. When faced with stressful conditions, people will often turn to others in their social networks for support and succor. Individuals who perceive that they are valued by and connected to other people gain strength from those relationships. This strength is an important personal resource that militates against stress. Social support can be measured objectively or subjectively. Objective reports of *received support* can be plagued by conflicting agreement (typically 50-60%) between persons who provide vs. receive support (Sarason I.G., Pierce, & Sarason, 1994). Sarason, Pierce, and Sarason (1994) argue that the impact of social support within the stress process derives not so much from direct actions of support, but from caregivers' perception that they are cared about and valued by others in their environment. Research indicates that subjective measures of *perceived support* are tied to caregiver stress process outcomes including burden, psychological outcomes, and quality of life (Aschbrenner et al., 2010; Chou et al., 2009; Lefley & Hatfield, 1999).

Aging SMI caregivers may experience enhanced vulnerabilities vis-à-vis perceived social supports. The social supports available to older adults typically diminish with age, attributable in part to their retirement from work, children leaving home, or deaths of family and friends (Saunders, 2003). In addition, courtesy stigma may inhibit perceived support levels, because caregivers' fear of rejection or uncomfortable social situations causes them to preemptively avoid contacts or discourages them from asking for help from potential supporters (Goffman, 1963). The impacts of ageism may pose a further impediment to perceived support levels. Societal stereotypes of aging and ageist attitudes may influence the amount of support that aging caregivers feel they can access. Ageist stereotypes impact social interactions in two ways: through their influence on people's behaviors (e.g. discrimination) toward older adults, and via their influence on individuals' self-concepts as they age (Kornadt & Rothermund, 2015; Levy, Slade, & Kasl, 2002). Levy's (2009) stereotype embodiment theory proposes a process through which individuals, often unconsciously, internalize cultural stereotypes of aging and define their own aging via these concepts. As such, stereotypes of aging can become self-fulfilling prophecies, wherein older adults begin to take on the stereotypical characteristics and attitudes (Kornadt & Rothermund, 2015; Levy, 2009; Levy et al., 2002). Stereotypes of and attitudes toward aging can be positive or negative, and may lead to benefits or disadvantages for older caregivers (Kornadt & Rothermund, 2015). In the case of perceived social support, Ramirez and Palacios-Espinosa (2016) found a positive correlation ($r = 0.21$, $p < .01$) between positive stereotypes of aging and perceived social support among older adults. Conversely, caregivers with fewer positive stereotypes and who hold negative perceptions of aging may feel that they have less support in their communities.

Stress proliferation. An important concept within the SPM is the idea of *stress proliferation*, which posits that stressors can create or intensify stress in other facets of a caregiver's life that are unassociated with care responsibilities (Aneshensel, 1996; Pearlin, Schieman, Fazio, & Meersman, 2005). Stress proliferation recognizes that the difficulties associated with providing care to another person do not happen in a vacuum; care responsibilities can spill over into a caregiver's work and family lives, and can affect the caregiver's self-perceptions. The process by which primary stressors proliferate into other areas of caregivers' lives within the SPM is depicted in Figure 1.

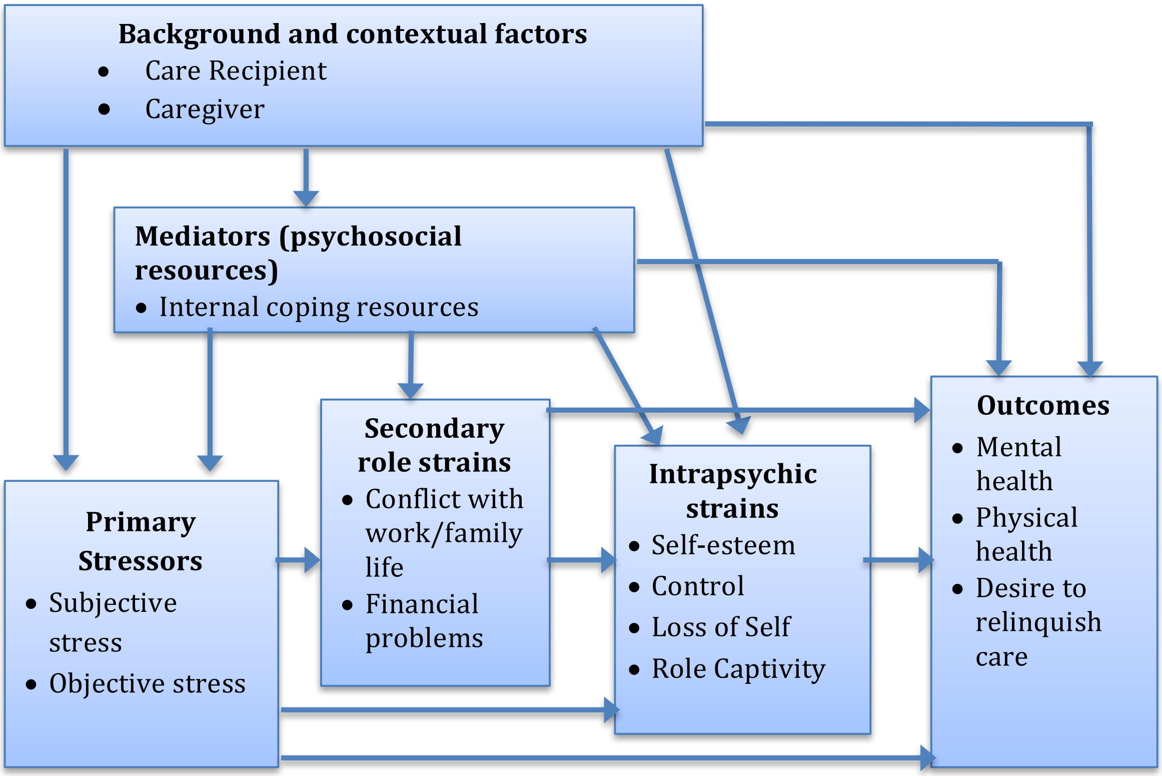

Figure 1. Stress Process Model of Caregiving

Caregiver outcomes. The ultimate construct within the SPM is caregiver *outcomes*, which are the consequences of stressors. There has been an evolution of thinking vis-à-vis the outcomes of the stress process within the SPM. In their early treatise on the stress process, Pearlin, Lieberman, Menaghan, and Mullan (1981) highlighted researchers' disagreements about which outcomes could appropriately be considered the "real" results of stress. These authors argued that outcomes might be "biochemical, physiological, or emotional," as manifested in the diagnosis of specific physical or psychological diseases (p. 341). In that particular study, Pearlin and colleagues (1981) limited their investigation to a single indicator of stress: depression. Several years later, Pearlin (1989) argued that by focusing on biological outcomes and medical diagnoses, sociologists were missing the opportunity to investigate the wider impacts of stress. Pearlin advocated for using a wider outcomes lens, and offered a more inclusive list of valid stress process outcome variables, including substance abuse, inability to fulfill role obligations, or ruptured relationships (Pearlin, 1989). Six years later, Pearlin and his colleagues defined SPM outcomes even more broadly: effects on caregiver mental and physical health, timing of transitional caregiving events, and caregiver behavioral changes, such as relinquishing a portion or all of their caring responsibilities (Aneshensel et al., 1995). The authors also considered the evolution of post-caregiving life as an outcome in the model, acknowledging that the consequences of caregiving are not confined to the duration of care, but can have long-lasting effects across the life-course. By considering a range of outcomes, the SPM accounts for the multiple and enduring manifestations of stress among caregivers with unique background characteristics and caregiving environments. A caregiver's desire to relinquish care is a potential stress outcome with considerable impacts.

Desire to Relinquish Care as a Stress Process Outcome

In accordance with the SPM's early emphasis on biological and medical stress outcomes, caregiver health has typically been investigated as the dependent variable (DV) in caregiver stress studies. Extant studies have correlated caregiver stress with negative physical and mental health outcomes (Aschbrenner, Greenberg, & Seltzer, 2009; Gallagher & Mechanic, 1996; Ghosh & Greenberg, 2009; S. M. Magaña, Greenberg, & Seltzer, 2004; Perlick et al., 2005; Suro & Mamani, 2013). While health outcomes are valid and valuable measurements in the caregiving stress process, the disproportionate focus on biomedical outcomes limits investigation of other manifestations of stress for SMI caregivers, including caregivers' behavioral responses to what they perceive are stressful environments.

Critical components in the stress equation are the individual and the environment. As noted above, stress can occur when the individual perceives his environment to be damaging or undesirable. In considering the universe of stress outcomes, Aneshensel (1996) posits that when stress occurs due to conflicts between the person and the environment, there are impacts for both components. Stress studies have typically focused on impacts to the person in the stress equation, including heavy emphasis on individual's physical and mental health outcomes. The impacts of stress on the environmental component are understudied. Individuals may manage stress by limiting their exposure to stressors, i.e. changing their environment (Aneshensel, 1996; Pearlin & Schooler, 1978; Pearlin & Aneshensel, 1986). Within the population of SMI caregivers confronted with stressful caregiving circumstances, some will choose to endure the strain and any associated biopsychosocial outcomes. However, others may choose to cope with the stress by avoiding the stressful caregiving environment. In other words, these caregivers may have some desire to relinquish their caregiving roles.

An individual's perception of and reaction to a potentially stressful environment is formulated in light of his personal characteristics, but larger socioenvironmental forces may also come into play (Aneshensel et al., 1995; Aneshensel, 1996; Pearlin, 1989; Zarit, 2006). Stigma is one such force. In addition to the consequences of stigma already discussed, Goffman (1963) posits that stigma can cause persons to avoid relationships with labeled persons, or to terminate existing relationships (p. 30). Accordingly, the stigmatization of mental illness may contribute to caregivers' desire to relinquish (i.e. terminate) their caregiving relationships.

Impacts of care relinquishment. As has been discussed, the impacts of mental illness stigma can heighten caregiver stress levels and when stress reaches intolerable levels, caregivers may feel they have no choice but to relinquish their caregiving responsibilities. These decisions may have long-term impacts for caregivers, who experience feelings of guilt, shame, worry, and loss, and who also relinquish future benefits that have been associated with a continued dyadic relationship, ranging from enhanced caregiver self-concepts to instrumental assistance from the care recipient (Aschbrenner et al., 2010; Goodman, 2005; Johansson et al., 2010; Pejlert, 2001). Relinquishment decisions also have important repercussions in the provision of care for the functionally impaired adults with SMI who depend on the caregiver. Without their caregivers, adults with SMI may destabilize and turn to public care systems (e.g. prisons, emergency departments, and homeless shelters) that are financially and organizationally unprepared to assume long-term care responsibilities for persons with SMI. Therefore, the impacts of relinquishment decisions on public systems may be significant.

In 2012, an estimated 356,268 jail and prison inmates experienced mental illness (Torrey et al., 2014). Prisoners with mental illness stay in jail longer than typical inmates, and are costlier to incarcerate: Washington state reportedly spends an additional $70,000 per year for prisoners with SMI versus those without mental illness (Torrey et al., 2014). Hospital systems are impacted as well. In the wake of deinstitutionalization, there are less than 50,000 inpatient psychiatric beds in the United States, forcing emergency departments (EDs) to serve as the de facto safety net for persons with SMI (Emergency Medicine Practice Committee, 2014). Psychiatric patients have longer ED stays, and boarding them in EDs as they await available psychiatric beds has negative impacts on hospital operations, finances, and care quality (Emergency Medicine Practice Committee, 2014). Without caregiver support, individuals with SMI may be also forced into homelessness. Anecdotal reports from confidential sources to this study's author indicate that exasperated, stressed caregivers may drop their adult children with SMI off at homeless shelters in hopes that at least one and hopefully both parties can find relief from what has become an insufferable caregiving environment. These caregivers are ultimately driven to alter their caregiving environments, by yielding their care roles, to reduce stress levels.

In light of the personal and societal costs of care relinquishment, research is needed to understand the predictors of these decisions. This study contributes to an underdeveloped perspective in the literature by focusing on a behavioral stress outcome, care relinquishment, that impacts both caregivers and care recipients.

Extant care relinquishment studies. A limited number of stress studies have investigated care relinquishment in other caregiver populations and are summarized in Table 2. Aneshensel, Pearlin, and Schuler (1993) and Morycz (1985) each explore the relinquishment decisions of caregivers for persons with Alzheimer’s disease or other dementias, finding that caregiver stressors predict the duration of in-home care and caregivers’ desire to relinquish their roles. Chene (2006) qualitatively investigated the lived experience of dementia caregivers, finding that their care relinquishment decisions led to feelings of loss, sadness, and resignation. In another qualitative study, Caron and Bowers (2003) focused on shifts in dyadic relationships caused by care recipients’ cognitive impairments. They found that caregivers’ acceptance of formal care assistance (i.e. relinquishment of care duties) was tied to their purpose in providing care (e.g. relationship maintenance or practical assistance). While these studies are material, the unique career trajectories of Alzheimer’s and SMI caregivers limit generalizability across these populations. Salient differences include: duration of caregiving due to earlier diagnosis of SMI, different funding sources for formal care, kinship of the dyad, disparate disease trajectories, and a more developed institutional care system for Alzheimer’s patients (i.e. memory care facilities). This last difference points to a limitation of these studies vis-à-vis the current project: existing studies conceptualize relinquishment in terms of *placement* decisions wherein caregivers relinquish care to formal care institutions (e.g. nursing homes, respite care facilities, group homes). The desire to relinquish care in the current study does not assume any caregiver plan for

Table 2

Summary of Care Relinquishment Literature

Study	Subjects	Results	Limitations
Aneshensel, Pearlin, and Schuler (1993)	Alzheimer's caregivers, n=555 mostly spouses and adult children	Caregiver psychological distress increases placement risk	Limited generalizability to other illnesses and caregiver kinships; decisions involve placement v. relinquishment
Caron (2003)	Qualitative study of n=16 caregivers of aging relatives, most with dementia;	Caregivers' decisions about formal help tied to their purpose in providing care	Focus on relationship shifts caused by cognitive impairments
Chene (2006)	Dementia carers (n=20) who had relinquished full-time care	Relinquishment decisions led to caregiver feelings of loss, sadness, resignation;	Population limits generalizability to SMI caregivers
Green (2004)	Mothers of young children with developmental disabilities (n=81)	Perceptions of stigma influenced willingness to consider placement	Limited generalizability to SMI caregivers; decisions involve placement vs. relinquishment
Morycz (1985)	Alzheimer's caregivers n=80	Mental and emotional burden, widowhood, and living alone predicted desire to institutionalize	Limited generalizability to SMI caregivers; decisions involve placement v. relinquishment
Nankervis, Rosewarne, and Vassos (2011)	Australian caregivers of persons with disabilities (n=32)	Characteristics of caregiver, care recipient and care context influence relinquishment	Relinquishment to formal out-of-home care system
Rimmerman and Keren (1995)	Israeli parents of children with psychiatric disabilities	Parents with low stress were more likely to think about placement	Decisions involve placement v. relinquishment
Seltzer, Greenberg, Wyngaarden Krauss, and Hong (1997)	Caregiving mothers of adults with SMI (n=73)	Caregiver stress predicted end of co-residence	Unclear which member of caregiving dyad initiated end of co-residence

the care recipient's future care. The considerable differences between caregiver populations and dependent variable specifics warrant direct investigation of the desire of caregivers for persons with SMI to relinquish care.

Application of the Stress Process Model of Caregiving

In accordance with the SPM presented in the conceptual framework (Figure 2), this study investigates caregivers' desire to relinquish care through examination of the caregiving context, primary stressors, and the influence of mediators and moderators within the stress process.

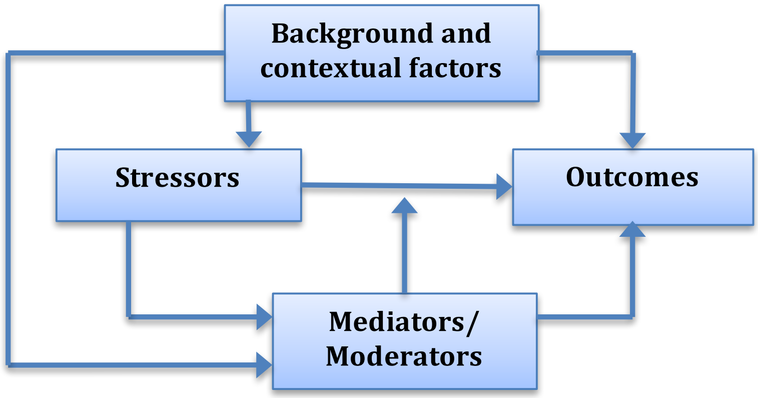

Figure 2. Conceptual Framework. Adapted from Aneshensel et al. (1995)

While secondary stressors and proliferation of stressors are important components of the SPM, this study focuses on the occurrence of stressors associated directly with providing care to a person with SMI, (i.e. primary stressors). The following section summarizes dissertation aims, elaborates on each of the relevant model domains, and derives study hypotheses.

Research Questions

The stresses of providing care comprise only one aspect of the caregiving environment. The concept of stress as a *process* acknowledges the influence of many factors that combine to create a difficult or problematic situation. This study has five major research questions that investigate caregiver's desire to relinquish care for their loved one with SMI. The research questions, as well as the dissertation aims and hypotheses, derive from three main SPM constructs that combine to influence caregiver outcomes: caregiving context, primary stressors, and mediating resources.

Question 1: How do caregiver background and contextual factors influence caregivers' desire to relinquish their caregiving responsibilities for adults with SMI?

Question 2: What is the impact of care recipients' problematic behaviors on caregivers' desire to relinquish care?

Question 3: What is the impact of perceived stigma on caregivers' desire to relinquish care?

Question 4: Does caregiver age moderate the impact of perceived stigma on desire to relinquish care?

Question 5: How do caregiver psychosocial resources (mastery, perceived social support) impact on the relationship between perceived stigma and desire to relinquish care? Questions 1-3 will be considered together using hierarchical regression modeling described in Chapter 3. A significant finding for the relationship between perceived stigma and desire to relinquish care will trigger moderation and mediation analyses as indicated in questions 4-5.

Dissertation Aims and Hypotheses

The study aims and hypotheses are summarized in Figure 3. Chapter three includes details of study methods, including associated measurements and statistical analysis techniques, which will center on hierarchical regression modeling.

Aim 1: Identify how caregiver background and contextual factors influence caregivers' desire to relinquish their caregiving responsibilities for adults with SMI.

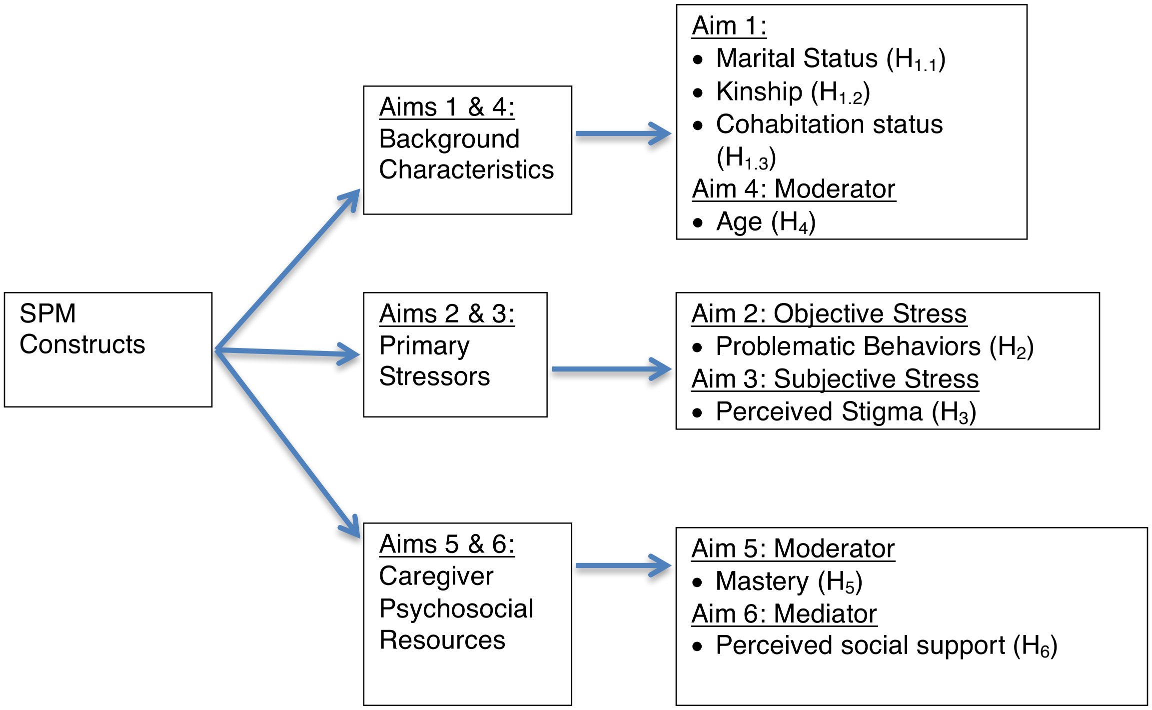

Figure 3. Conceptual framework with study aims and hypotheses.

Background and contextual factors. Hypotheses one through three investigate specific dyadic characteristics for the population of SMI caregivers. The independent variables chosen for hypothesized relationships arise from the relevant literature.

Caregiver marital status. Several studies of caregiver stress have identified marital status as contributing to outcomes. An early study of parent/child dyads impacted by SMI identified marital status as a predictor of caregiver burden (Pickett, Cook, Cohler, & Solomon, 1997). Nankervis and colleagues (2011) found that single parent caregivers could become overwhelmed with the responsibilities of caring for persons with ID and that being single contributed to caregivers' relinquishment decisions. In a study of Israeli caregivers for children with ID, Rimmerman (1991) found that single parents were more likely to apply for out-of-home placement for their children. While caution should be used in generalizing from these caregiver populations' relinquishment decisions, it is reasonable to think that caregivers of persons with

SMI who are not supported by a spouse or partner in the household might have higher stress levels and be more likely to relinquish care.

$H_{1.1.}$ Single caregivers will have more desire to relinquish care than married caregivers.

Kinship. Another salient caregiver characteristic is kinship with the care recipient. Human lives are lived interdependently, and linkages between lives imply that individual experiences and their ramifications can impact each of the linked network members (Elder, 1998). When family members or friends experience significant health challenges, the impacts reverberate through households, and members may need to devote time and energy to adjusting to the changes (Gallagher & Mechanic, 1996; McLean & Link, 1994). These adjustments may be stress inducing, and stress levels may be heightened in more closely connected relationships. Providing care in more normative care relationships (e.g. caring for a spouse or aging parent) is more expectable, and may be less stressful for caregivers (Gallagher & Mechanic, 1996). In a study of kinship and caregiver health outcomes, parents living with an adult child with SMI reported significantly poorer health than participants living with spouses with SMI (Gallagher & Mechanic, 1996). In that study, parental caregivers were also more likely to report activity limitations than spousal caregivers.

Due to the nature of this particular dyad's parent-child relationship, with its inherent sense of parental responsibility and the vulnerability of the child with SMI, parents caring for their offspring with SMI may be especially susceptible to the stresses of caregiving. These parents may to see their caregiving role as an enduring, even life-long endeavor (Kim, Greenberg, Seltzer, & Krauss, 2003). As has been discussed, these families may have been blamed for causing their child's illness, and some may question their own culpability in contributing to the illness. They may feel that their children would benefit from spending time in an environment sans parents. In line with normative parenting roles, parents may take on care duties that other caregiving kin would leave to the adult care recipient. These additional self-imposed responsibilities may increase caregivers' sense of burden. Parents may also have other children or grandchildren whom they neglect due to caregiving responsibilities, leading to caregiver feelings of guilt or regret. All of these factors may combine to make parents more likely to consider care relinquishment.

$H_{1.2.}$ Parental caregivers will have stronger desire to relinquish care than other kin relationships.

Cohabitation status. Living with a person who experiences SMI can present an especially stressful environment for caregivers. In cohabitating dyads, the caregiver is never fully relieved of caring duties. Aschbrenner, Greenberg, Allen, and Seltzer (2010) found that cohabitation was associated with increased stress among older parents of adults with SMI. In addition, research finds that families impacted by SMI have more difficulty coping with stress when they co-reside with their ill relative (Hatfield, 1981). Because SMIs may be associated with difficult behaviors that range from embarrassing to threatening for the caregiver, residing in the same household exposes the caregiver to a constant strain of worry and emotional upheaval (Seltzer et al., 1997; Tessler & Gamache, 2000). Increased household stress may influence the likelihood that caregivers will want alternative living arrangements for their loved one. As such, dyad cohabitation will predict stronger desire to relinquish care.

$H_{1.3.}$ Caregiver desire to relinquish care will be stronger when dyad members cohabitate.

<u>Aim 2:</u> Determine the impact of care recipient behaviors on caregivers' decisions to relinquish care.

Primary objective stressor: problematic behaviors. Objective stressors in the SPM are described in terms of care recipient behaviors and needs. Individuals with SMI typically do not need help with basic activities of self-care such as bathing, toileting, eating, and dressing that can be stressful for caregivers. For this population of caregivers, the wide range of problematic behaviors exhibited by individuals with SMI is more commonly a source of stress (Kaufman et al., 2010; Tessler & Gamache, 2000). As these behaviors are also often the identifying marks of mental illness, they are particularly salient within a study of mental illness stigma. Problematic behaviors can include, but are not limited to: delusions, hallucinations, poor personal hygiene, violence and aggression, inappropriate sexual behaviors, medication non-compliance, suicide threats and attempts, financial irresponsibility, and nocturnal disturbances (Goodman, 2005; Katz-Saltzman, Biegel, & Townsend, 2008; Kaufman et al., 2010; Kropf & Kelly, 1995; Lefley, 1989; Tessler & Gamache, 2000). Caregivers spend a considerable amount of time and energy attempting to prevent these behaviors and managing their consequences. Caregiver responses to problematic behaviors might include pleading, arguing, or threatening the individual with mental illness, or caregivers may need to involve outside parties such as other family members, case managers, lawyers, or even law enforcement (Tessler & Gamache, 2000). Symptomatic behaviors are established as causing caregiver distress (Kaufman et al., 2010; Tessler & Gamache, 2000; Zarit, 2006). Anecdotal reports from confidential sources to this study's author indicate that SMI caregivers feel stress when they have to: miss work for court dates with their loved one, manage interactions with law enforcement, maintain vigilant suicide watches, deal with angry neighbors, or manage other situations resulting from the care recipient's disruptive behaviors.

Because of their heavy caregiver impact, the behavioral problems of persons with SMI are among the most commonly investigated research variables for this population (Saunders, 2003). Problematic care recipient behaviors have been correlated with caregiver distress (Kaufman et al., 2010; Lefley, 1987; Mak & Cheung, 2008; Tessler & Gamache, 2000) and caregiver burden (Dyck, Short, & Vitaliano, 1999; Mak & Cheung, 2008; G. C. Smith, 2004) in families impacted by SMI. Research also indicates that caregiver symptoms of depression rise in tandem with recipients' problematic behaviors (Song, Biegel, & Milligan, 1997). A few studies have looked at the relationship between care recipient behavioral problems and care relinquishment. Aneshensel et al. (1993) found that problematic behaviors of Alzheimer's patients were significant predictors of care relinquishment, but the effect was reduced when other stressors were added to the equation (i.e. there may have been mediating variables). However, generalization of those results to the current study is difficult, as the illness trajectories of Alzheimer's and SMI are quite different in that problematic patient behaviors typically drop off in later disease stages of Alzheimer's, whereas they may occur cyclically over the lifetime of a person with SMI. Nankervis et al. (2011) found that among families (*n* = 32) who had relinquished care of their loved one with ID to the respite care system, 74% reported problematic recipient behaviors. Seltzer et al. (1997) found that behavioral problems predicted the end of co-resident caregiving for dyads (*n* = 73) impacted by SMI. In accordance with these findings:

$H_{2.}$ Care recipient problematic behaviors will predict caregiver desire to relinquish care such that increased problematic behaviors will be associated with more desire to relinquish care.

Aim 3: Determine the impact of perceived stigma on caregivers' decisions to relinquish care.

Primary subjective stressor: perceived stigma. A caregiver's perception of stigmatizing social attitudes regarding mental illness represents subjective primary stress within the SPM paradigm (Figure 1). That caregiving is demanding and stress inducing is well documented, but caregivers assume additional burdens when they feel that they are stigmatized and subsequently devalued within their communities (Avison & Gotlib, 1994; Struening et al., 2001). Subjective perceptions of stigma may evoke a range of negative emotions and attitudes including frustration, resentment, anxiety, and helplessness. Perceived stigma is also associated with increased perceived burden, and with reductions in caregivers' subjective interpretations of both their quality of life and perceived benefits from caregiving (Tsang, Tam, Chan, Cheung, & Chang, 2003). Given the additional burden, reduced quality of life, and emotional distress associated with perceptions of stigma, caregivers are working in a stressful environment (Chou et al., 2009; Green, 2007); relinquishing care is one route for the caregiver to change that environment. As such, increased perceptions of stigma are hypothesized to impact care relinquishment desire.

$H_{3.}$ Perceived stigma will predict desire to relinquish care such that caregivers with higher levels of perceived stigma will have more desire to relinquish care.

<u>Aim 4:</u> If there is support for hypothesis H_3, and perceived stigma significantly predicts desire to relinquish care, the fourth aim will investigate whether caregiver age moderates the impact of perceived stigma on desire to relinquish care.

Age as a moderator. According to socioemotional selectivity theory, and as elaborated above, older adults use emotion regulation strategies to manipulate their social interactions and focus on emotionally rewarding interactions (Charles & Carstensen, 2007). It is reasonable to think that older adults might have developed tactics to avoid people and situations that increase their exposure to stigma. In addition, the positivity effect described above may encourage older adults to place less emphasis on other people's negative stigmatizing attitudes about mental illness so that they can focus on more positive aspects of their emotional lives. The combination of reduced exposure to and less focus on stigmatizing attitudes may help reduce the relationship between perceived stigma and desire to relinquish care for older adults as compared to younger adults. The hypothesized moderating relationship exerted by age is depicted in Figure 4.

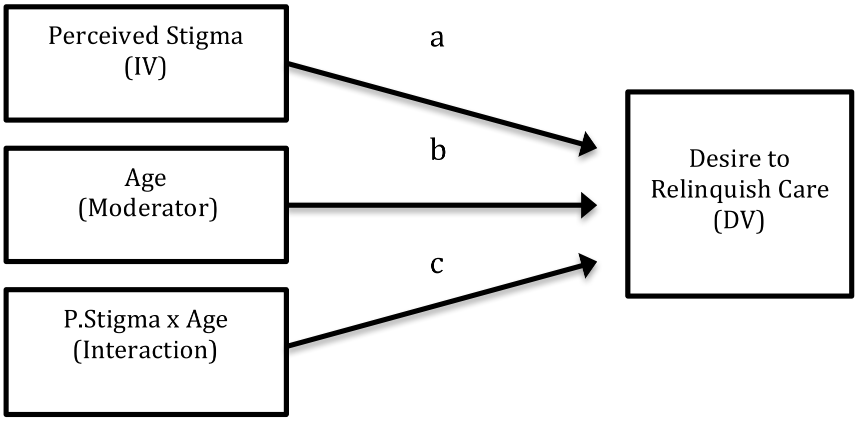

Figure 4. Hypothesized study moderation model: Age (on the basis of MacKinnon, 2011).

Testing age as a potential moderating variable investigates whether perceived stigma and desire to relinquish care have the same relationship across caregivers of different age groups (MacKinnon, 2011). The three arrows in Figure 4 represent causal pathways impacting the DV: paths a and b represent the main effects of the independent variable (IV) and moderating variable, respectively, with path c denoting the interaction of those variables (perceived stigma X age) (Baron & Kenny, 1986). The significance of path c within the hierarchical regression equation will support the hypothesized moderating relationship.

$H_{4.}$ Perceived stigma will have less impact on desire to relinquish care for older caregivers than for younger caregivers.

Aim 5: If there is support for hypothesis H_3, and perceived stigma significantly predicts desire to relinquish care, the fifth aim will investigate whether caregiver sense of mastery moderates the impact of perceived stigma on desire to relinquish care.

Mastery as a moderator. As discussed above, a person's sense of mastery influences his interpretation of stressors. Caregivers who feel a heightened sense of control over their own environments may not feel as vulnerable to the negative impacts of SMI stigma. Testing mastery's potential as a moderating variable investigates whether perceived stigma and desire to relinquish care have the same relationship across caregivers with different mastery levels (MacKinnon, 2011). The hypothesized moderating relationship involving mastery is depicted in Figure 5.

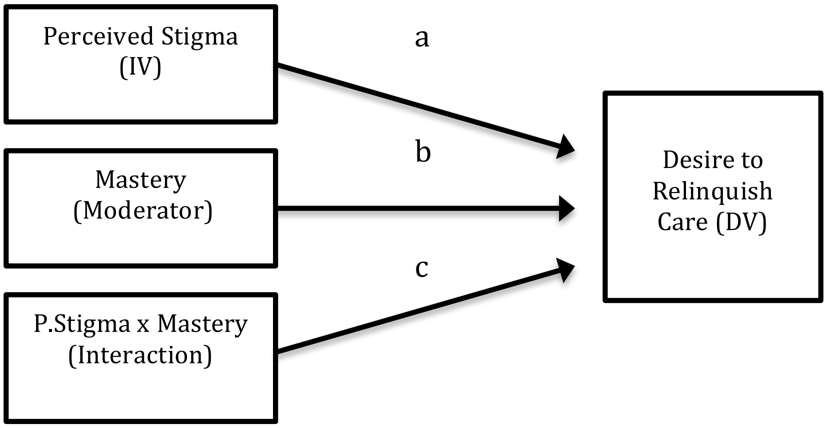

Figure 5. Hypothesized study moderation model: Mastery (on the basis of MacKinnon, 2011).

$H_{5.}$ Perceived stigma will have less impact on desire to relinquish care for caregivers who score high on the mastery scale than for those with lower scores.

Aim 6: If there is support for hypothesis H_3, and perceived stigma significantly predicts desire to relinquish care, the sixth aim is to determine whether caregivers' perceptions of social support mediate in the relationship between stigma and desire to relinquish care.

Perceived social support as a mediator. Mediating variables in the SPM are seen as mutable, and can be enhanced or eroded by the stressors under consideration (Pearlin, 1999). Caregivers of persons with SMI have smaller social networks than other caregiver populations, and a portion of that diminishment is attributable to mental illness stigma (Aneshensel et al., 1995; Lefley & Hatfield, 1999). Link, Cullen, Struening, Shrout, and Dohrenwend (1989) posit that because they fear social rejection, people associated with a stigmatizing condition may preemptively withdraw from social contacts, concomitantly reducing their access to vital supports. People in a caregiver's social network may withdraw or reduce their support due to their perceptions of SMI as discomfiting. SMI is known colloquially among impacted persons as "the no-casserole disease," as mental illness stigma often intervenes in relationships and precludes the normative offers of informal supports that accompany other illness diagnoses such as cancer or heart attack.

It seems reasonable that caregivers who perceive mental illness to be highly stigmatized might also perceive actual or anticipated reductions to their social support networks due to that stigmatization. As such, it is hypothesized that perceived social support will mediate between perceived stigma and desire to relinquish care. The concept of statistical mediation refers to a relationship wherein the hypothesized mediating variable is: 1) associated with both the IV and DV, and 2) the proposed mediator reduces the IV-DV relationship (Baron & Kenny, 1986). Figure 6 depicts the mediating relationship among study variables. If the combined pathways a (IV to mediator) and b (mediator to DV) explain some of the effect of perceived stigma on desire to relinquish care (pathway c), a mediating relationship is indicated. Pathway c' in Figure 6 represents the mediated relationship between the IV and the DV considering the mediating variable of social support.

$H_{6.}$ Perceived social support will mediate between perceived stigma and desire to relinquish care, such that the association between perceived stigma and desire to relinquish care will be lower for individuals who have higher levels of perceived social support.

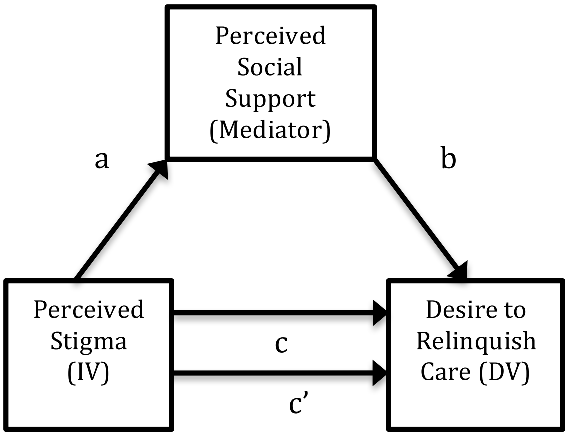

Figure 6. Hypothesized study mediation model: Social support (on the basis of Baron & Kenny, 1986).

Chapter Summary

Providing care to an individual with SMI is stressful, and the stressors associated with caregiving may increase as caregivers age. Aging caregivers may face increased mental and physical health problems, financial strains, reduced social networks, and other age-associated challenges. In addition, the unique symptoms and trajectories associated with mental illness, including problematic behaviors, timing of illness, duration of care, and the reliance on community-based care in the wake of deinstitutionalization all contribute to caregiver stress. Another singular source of stress for the SMI caregiver population is mental illness stigma. The stigmatization of mental illness has negative consequences for caregivers, such as negative emotions, social isolation and loneliness, and discrimination. These outcomes add to the stressors of aging and caregiving, and when stress reaches untenable levels, caregivers may have some desire to relinquish their caregiving responsibilities. Care relinquishment can have negative outcomes: caregivers incur emotional burdens associated with relinquishment, and they give up a potential future relationship with the care recipient. Relinquishment decisions can also leave vulnerable care recipients without reliable care supports. The purpose of this study is to investigate the relationship between caregivers’ perceptions of stigma and their desire to relinquish care in order to better understand the stress process for this population and begin to build evidence for meaningful supports that can stave off care relinquishment decisions.

Chapter Three: Methodology

Chapter Overview

Chapter three describes the study's research methodology, including research design, population, and sampling information. This information is followed by a detailed description of the study measurements and instrumentation and an overview of data collection and procedures, including survey development. The data analysis plan and study limitations conclude this chapter of the proposal.

The purpose of this study is to examine the impact of perceived stigma on caregivers' desire to relinquish care. The stress process model of caregiving (SPM) described in chapter two provides the theoretical framework and informs study variables. The SPM focuses on the relationship between caregiver stressors, potential psychosocial resources available to mitigate stress, and caregiver outcomes. The framework's constructs and relationships will guide evaluation of the study data.

Research Design

A cross-sectional, descriptive, correlational design is planned to achieve the project aims. Cross-sectional research collects all measurements simultaneously, without any longitudinal follow up (Hulley, Cummings, & Newman, 2013). Correlational research investigates variable interrelationships that are not subject to researcher intervention (Polit & Beck, 2012). While experimental design is the gold standard for demonstrating cause-and-effect relationships between variables, this study's variables (e.g. objective stress and caregiver social supports) cannot ethically or technically be manipulated. As such, the study is inherently pre-experimental. Pre-experimental designs do not include mechanisms to compensate for the absence of a control group or randomization within the design (Polit & Hungler, 1999). A descriptive correlational study allows for examination of the relationships between caregiver stressors and outcomes. However, without experimental manipulation of the independent variables, a correlational study does not establish causal pathways (Hulley, Cummings, Browner, Grady, & Newman, 2013; Polit & Beck, 2012). The current study, with the objective of filling a gap in the care relinquishment research, will lay the groundwork for future investigations.

Population and Sample

Target population. This study is aimed at the population of adult caregivers who are providing informal (i.e. unpaid) care for another adult who has been clinically diagnosed with SMI.

Sampling strategy. A sample of 850 caregivers will be recruited to participate in an online survey. Because this study investigates the experiences of a specific caregiver population, probability sampling methods are not feasible. Respondents will be recruited from a purposive convenience sample of persons who receive emails and/or newsletters from the National Alliance on Mental Illness (NAMI) in the state of Virginia. NAMI Virginia and the NAMI Virginia Beach affiliate have agreed to distribute the information in their newsletters. In the event that additional recruitment efforts are needed, NAMI affiliates in other states will be approached to disseminate the survey link. A copy of the email letter asking additional NAMI affiliate directors to help with survey recruitment appears in Appendix A. Purposive sampling allows researchers to direct recruitment efforts toward participants whom the researchers believe will provide the most pertinent data (Polit & Beck, 2012). As NAMI is a nationally known advocacy and educational group for this caregiver population, and NAMI Virginia served almost 22,000 Virginians last year, their newsletter distribution list should directly target a large number of caregivers who meet the study criteria. Snowball sampling will also be used, as various individuals and organizations (e.g. community mental health support groups and targeted online forums) will distribute the online survey link. Snowball sampling has several advantages over convenience sampling in that it is cost-efficient, targeted directly at persons with the desired study characteristic, and referrals from persons or organizations known to the recruit may help establish trust in the research (Polit & Beck, 2012). Recruitment fliers will be posted at local mental health organizations in the Hampton Roads area of southeast Virginia, to include local mental health departments and hospital psychiatric service departments. A copy of the flyer is included in Appendix B. Due to the inability to track how many times the survey link is re-distributed or the flyer is viewed, it will not be possible to accurately calculate a response rate. Additionally, because NAMI serves both caregivers and persons living with mental illness, it will not be known how many caregivers receive the survey invitation. As a result, a calculated response rate for this subgroup is not feasible.

Eligibility criteria. Table 3 provides study inclusion and exclusion criteria for caregivers. The rationale for including caregivers who provide unpaid care is that there are likely to be appreciable differences in informal versus formal caregivers' desire to relinquish care that fall outside the scope of this study. The criterion related to clinical diagnosis is aimed toward ensuring that caregivers' responses are correlated specifically with SMI and the resulting care needs and responsibilities. There are two reasons to specify that the care recipient is an adult: 1) relationships and caregiving decisions between caregivers and minor children are likely to be singularly influenced by age of the child, and 2) this study is particularly interested in older

Table 3

Inclusion and Exclusion Criteria

Caregiver Inclusion Criteria:	**Caregiver Exclusion Criteria:**
Care recipient clinically diagnosed with SMI	Care recipient's *only* mental illness diagnosis is either substance abuse disorder or dementia
Currently providing unpaid care	
Caregiver is >18 years old	
Care recipient is >18 years old	

caregivers. Because many caregivers in this population are maternal parents, a large number of mothers providing care for their children (particularly adult sons) are likely to respond to this survey. However, caregivers of any relationship with the adult receiving care (e.g. siblings, friends, adult children) are welcomed and encouraged in recruitment efforts.

Caregivers for persons whose only mental illness diagnosis is either dementia or substance abuse disorders are excluded from the current study. Due to considerable differences in symptoms, treatments, and disease trajectories between SMI and these conditions, caregiving responsibilities and environments among these populations are likely to be significantly different and are outside the study scope. An initial series of survey screening questions will ensure that caregivers meet study inclusion criteria. Data will be excluded for cases that do not meet study criteria. The study protocol was approved by VCU's Institutional Review Board (IRB) prior to subject recruitment.

Power analysis. Power analysis is a technique used to reduce the risk of Type II errors (false negative outcomes), and to increase the statistical conclusion validity of a study (Polit & Beck, 2012). An *a priori* power analysis was completed using G*Power software v. 3.1.9.2, which calculates sample size n as a function of power level ($1 - \beta$), significance level α, and the estimated population effect size (Faul, Erdfelder, Buchner, & Lang, 2014). For the multiple regression power analysis, which also considers number of predictors, nine caregiver demographic variables and two stressor variables were used to estimate the required sample sizes per effect. Required sample sizes are listed by Cohen's f^2 effect size in Table 4. Based on similar research considering caregivers' desire to place care recipients into institutional care, a small to medium effect ($0.24 < r^2 < 0.38$) is expected in this study (Green, 2004; Morycz, 1985; Wight et al., 2008). As such, this study aims to recruit 850 participants. In the event that the indicated *n* or anticipated effect size were not achieved, the power of the study would be reduced below 0.80. To maintain power with reduced *n*, the number of predictors could be reduced by including only those caregiver background variables that show significance ($p < 0.10$) in the baseline multiple regression equation as predictors in subsequent equations. In that event, comparison of the full and reduced models of caregiver background variables would be inspected to ensure comparability.

Table 4

Required Sample Sizes Calculated by Effect Size

R^2	**Cohen's f^2**	**Effect size**	**Required *n***
$0.1 < r^2 < 0.3$	.02	Small	850
$0.3 < r^2 < 0.5$	.15	Medium	123
$r^2 > 0.5$	.35	Large	59

Note: Power calculated using β=0.8; α=0.05

Variables and Instrumentation

Study variables are informed by the literature and by the SPM framework. The variables include information relative to: caregiver demographics and context, caregiving stressors, stress mediators, and caregiver outcomes.

Background and contextual variables. Caregiving does not happen in a vacuum. People bring with them to the caregiving experience a unique set of personal characteristics that influence their potential exposure to stressors, the resources they have to counteract those stressors, and the range of potential stress outcomes (Aneshensel et al., 1995; Aneshensel et al., 1993; Pearlin et al., 1981). These characteristics generally include caregiver sociodemographics. However, within the context of the caregiving dyad, there are additional considerations that may relate to a caregiver's desire to relinquish care. According to Zarit (2006), the relationship between the caregiver and care recipient (e.g. kin, friend) may be the most important indicator of care commitment. The residential context for this dyad is also important, as cohabitation is known to influence caregiver burden levels (Aschbrenner et al., 2010; Pickett et al., 1997; Wedenoja, 1996). A list of caregiver background and contextual variables for this study includes important dyadic characteristics, and is included in Table 5. Response categories and coding for the study variables are included in Appendix F.

Stressor variables. As noted in chapter two, the SPM differentiates between objective and subjective stressors.

Objective stressor: care recipient behaviors. Care recipients' problematic behaviors are a confounding variable within this study. Confounding variables are correlated with both the independent and dependent variables within a study, correlations that can distort the relationship

Table 5

Study Variables

Variable	**Type**	**Data Type**
Background and contextual variables		
Caregiver age	Moderating variable	Continuous
Caregiver race	Covariate	Categorical
Caregiver education	Covariate	Continuous
Caregiver employment	Covariate	Categorical
Caregiver self-rated health	Covariate	Ordinal
Relationship to care recipient	Covariate	Categorical
Caregiver household size	Covariate	Continuous
Caregiver marital status	Covariate	Categorical
Recipient gender	Covariate	Dichotomous
Recipient residence type	Covariate	Categorical
Stressor Variables		
Care recipient behaviors	Confounding covariate	Continuous
Perceived stigma	Independent variable	Continuous
Mediating variables: Caregiver resources		
Mastery	Moderating variable	Continuous
Social Support	Mediating variable	Continuous
Outcome		
Desire to relinquish care	Dependent variable	Continuous

between those variables (Pourhoseingholi, Baghestani, & Vahedi, 2012). The problematic behaviors of a person with SMI, especially those that caregivers identify as embarrassing because others observe them, may engender stigmatization and influence a caregiver's perceptions of stigma (Tessler & Gamache, 2000). Problematic behaviors are also likely to be correlated with SMI caregivers' desire to relinquish care, as these variables have been correlated in other caregiver populations (Aneshensel et al., 1993; Nankervis et al., 2011; Seltzer et al., 1997). The confounding influence of care recipients' problematic behaviors will be controlled in this study to better isolate the relationship between perceived stigma and desire to relinquish care. In non-experimental studies, confounding effects must be controlled statistically (Pourhoseingholi et al., 2012). As such, the confounding variable of problematic behaviors will serve as a control in the study's multiple regression analysis; in other words, it will be entered into the regression equation prior to the independent variable of perceived stigma.

To measure problematic behaviors, caregivers are asked to report how often they personally deal with seven individual behaviors that Tessler and Gamache (2000) identified as most problematic for caregivers of persons with SMI. Care recipient behavior questions are listed in Table 6. It is important to note that the scale measures the behaviors as they involve the caregiver; the simple fact that the recipient displayed the behavior does not in and of itself imply caregiver impact. Response categories are *never* (0), *rarely* (1), *sometimes* (2), *quite frequently* (3), or *nearly always* (4). Reliability represents how dependable a scale is in measuring a particular attribute as well as its reproducibility (Kane, 2006; Polit & Beck, 2012). Internal consistency, measured by Cronbach's alpha, is one aspect of reliability, indicating how each scale item is related to the overall scale (Kane, 2006). Alpha is an estimation of how much variation in scores is attributable to true scores versus error. Acceptable alpha values are in the range of .70 to .80 (Nunnally & Bernstein, 1994). Cronbach's alpha will be reported to indicate internal consistency for this section of the survey. Values for Cronbach's alpha range from zero (representing no correlation between any of the possible scale item pairs) to one, with higher values representing higher internal consistency (Kane, 2006; Polit & Beck, 2012).

Table 6

Questions Measuring Stress Due to Care Recipient Behaviors

How often do you personally have to deal with the following behaviors of your (relative)? (Responses are 0=never, 1=rarely, 2=sometimes, 3=quite frequently, 4=nearly always)
1. Attention-seeking behaviors, including excessive demands on your time and attention, interrupting your activities, calling you on the phone, or other actions that bother you and take up your time
2. Embarrassing behaviors, including improper sexual behaviors, poor personal grooming habits, inappropriate language, bizarre movements, or other actions that embarrass you in public or in front of company
3. Disturbing you or your household at night
4. Alcohol abuse
5. Violence, or threats of violence
6. Drug abuse
7. Threats of suicide or suicide attempt

Subjective stressor: perceived stigma. The independent variable emphasized in this study is perceived stigma. This study uses the combined Devaluation of Consumers and Consumer Families Scale (Link et al., 1989) to measure perceived mental illness stigma. The combined scale has two components; the first measures the extent to which caregivers feel that most people devalue individuals with SMI, the second part measures caregivers' beliefs that people devalue the family members of persons with SMI. This duality is relevant for caregivers of persons with mental illness, particularly because of the linked lives of the caregiving dyad. Due to the close relationship between caregiver and care recipient, caregivers are likely to be emotionally affected by their perceptions that their loved one is being labeled, devalued, and/or discriminated against because of an illness. In a study by Struening et al. (2001) that employed the combined scales, almost 70% of caregivers believed that most people devalue individuals with SMI, and 43% of caregivers felt that most people also devalue the families of persons with SMI.

The Devaluation Scale in this study contains fifteen questions. Likert scale responses range from 1 to 4, representing strongly disagree, disagree, agree, and strongly agree. Five of the fifteen items are reverse-scored. Summed scores range from 15 to 60, with higher scores representing more perceived stigma. The first eight items comprise the Devaluation of Consumers Scale and operationally define the perceived devaluation of individuals with SMI. The ensuing seven items constitute the Devaluation of Consumer Families Scale, and operationally reflect caregivers' belief that most people devalue families with a family member who lives with SMI. In a study of 461 caregivers of persons with SMI, Struening and colleagues (2001), identified coefficient alpha of .82 and .77 for the Consumer and Family scales, respectively. The Devaluation and Discrimination Scale items are included in Appendix C.

Mediators: caregiver resources. The SPM conceptualizes *mastery* and *social supports* as important mediators between stress and caregiver outcomes (Pearlin et al., 1990). As discussed in chapter two, SPM mediators can have a variety of statistical impacts on the IV-DV relationship.

Mastery. This study employs the Pearlin Mastery scale to measure caregivers' sense of mastery. The scale contains seven items that are rated from strongly disagree (1) to strongly agree (4). Five of the seven items are negatively worded and will be reverse coded prior to analysis. The items are summed for a total mastery score ranging from 7 to 28, with higher scores indicating increased mastery levels. Cronbach's alpha (α=0.75 - 0.83) indicates good internal consistency for caregiver populations (Aneshensel et al., 1995; Wight et al., 2008). The mastery scale items are included in Appendix D.

Social support. Perceived social support is measured in this study using an adaptation of questions used by Green (2004) in an inquiry of how perceptions of stigma impact maternal attitudes toward residential care placement for their children with intellectual or developmental disabilities. Nine questions from Green's original measure inquire whether there is a person outside the household to whom caregivers feel they could turn for support in a variety of situations. Because support groups comprise an integral part of this study population's social support network (Aschbrenner et al., 2010; Goodman, 2005), one additional question was added to determine if respondents belong to a caregiver support group. Table 7 includes a listing of the ten social support items. All responses are binary (yes/no) and the summed score divided by number of questions represents a composite index of social supports, with zero representing no support and one representing support for all ten items (Green, 2004).

Table 7

Questions Measuring Caregiver Social Support

Do you have someone who lives outside your home that: (answer yes or no)
1.. …would take care of your home while you are out of town?
2. …you talk to about work or other life issues?
3. …helps you with household tasks (like yardwork, cleaning, chores)?
4. …you would ask for advice on important decisions?
5. …you socialize with (going to movies, having dinner together, hanging out, talking on phone)?
6. …you would talk to about your personal worries?
7. …you could borrow money from?
8. …could take care of your loved one with mental illness while you are out?
9. …helps you with routine tasks of caring for your loved one with mental illness?
10. Do you belong to a caregiver support group?

Outcome: desire to relinquish care. Caregiver desire to relinquish care is this study's dependent variable. Measurement of the dependent variable is based on an adaptation of Morycz's (1985) Desire to Institutionalize (DTI) Scale. The DTI Scale has been used to measure a caregiver's desire to relinquish care for a person with Alzheimer's disease by facilitating placement in long-term care institutions (Mccaskill, Burgio, Decoster, & Roff, 2011; Morycz, 1985). The DTI is a Guttman-type scale that contains six dichotomous response (yes/no) questions about placement decisions. Guttman scaling is hierarchical, meaning that respondents who agree with one question on the test are likely to agree with the previous questions (Kane, 2006). Each positive response is counted as one point on the scale, ergo scores range from zero to six, with higher scores representing greater desire to place the care recipient. The Kuder-Richardson coefficient of reliability measures the reliability of dichotomously scored items (Thompson, 2010). In a study of caregivers by Morycz (1985), the KR-20 reliability coefficient of the DTI scale was .71, indicating moderate reliability (Polit & Beck, 2012). McCaskill, Burgio, Decoster, and Roff (2011) adapted the Morycz scale for use with yielding of caregiving roles, and report a KR-20 range of .694 - .767 across three ethnicities. In a longitudinal study, Morycz (1985) found that caregivers' desire to institutionalize was significantly associated with actual placement in an institution ($r = 0.53$, $p < 0.001$), making it a reasonable proxy for caregivers' decisions.

In the second question of the original DTI hierarchy, caregivers of persons with Alzheimer's disease are asked whether they feel the care *recipient* would be better off if placed in a care institution. While caregivers for Alzheimer's patients feel concern for their ability to care for the impaired individual that can impact their relinquishment decisions, caregivers for adults with SMI typically consider care relinquishment because they are experiencing difficulties caring for the *caregiver*, i.e. themselves. Thus, the second question is modified in order to ascertain whether the caregiver feels that the *caregiver* would be better off after relinquishing care. In the current study, caregiver desire to relinquish care is measured based on the revised questions of the DTI as outlined in Table 8. Questions 1-6 will be used to calculate the scale

Table 8

Desire to Relinquish Care Scale

Item (responses are yes/no)
1. Have you ever considered giving up all of your care responsibilities for your (relationship)?
2. Have you ever felt that you would be better off if you stopped providing care for your (relationship)?
3. Have you ever talked to your family, friends, or anyone else about giving up your care responsibilities for your (relationship)?
4. Have you ever talked to your (relationship) about giving up your care responsibilities for (him/her)?
5. Are you likely to give up providing care for your (relationship)?
6. Have you taken any steps toward giving up your care responsibilities for your (relationship)?
7. Have you ever felt that your (relationship) would be better off if you stopped providing care for (him/her)? [a]

[a] Item not included in composite scale scoring. Adapted from "Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development," by R.K. Morycz, 1985, *Research on Aging, 7*(3), 329-361.

score (range 0-6). The seventh question is added to ascertain the caregivers' expectation concerning the care recipient's well-being if care is relinquished and will be analyzed separately.

Data Collection

Study survey. Study data will be collected and managed using Research Electronic Data Capture (REDCap) tools hosted at VCU. REDCap is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources (Harris et al., 2009).

Primary data will be collected through an online caregiver survey. REDCap issues a unique survey URL (e.g. www.redcap.vcu.edu/rc/surveys/example999) which users can click on to access the survey. Survey respondents will initially be asked to read the study's online survey information sheet (Appendix E). Respondents' full completion of the survey (i.e. clicking "submit") will indicate that they have read and understood accurate information about the research in which they are participating and know that their participation is voluntary.

Sometimes thinking about a loved one's mental illness can cause people to become emotionally upset, therefore, respondents will be assured that they can stop the survey at any time. The survey contains a maximum of 68 forced choice questions (depending on branching logic), and should take about 15 minutes to complete. A copy of the survey is available in Appendix F. Study consent processes, survey questions, and study protocol will have prior approval from VCU's IRB. The study is being submitted to the IRB for an exempt review, category two. Category two exempt research includes survey procedures that do not collect identifiable information, nor would disclosure of responses reasonably place participants at any risk. All study recruitment materials and the information sheet embedded in the survey advise potential participants that their responses are anonymous.

Piloting the survey. The study survey was preliminarily piloted. Four caregivers of adults with SMI were emailed the survey link and asked give feedback on survey length (approximately 15 minutes), clarity of instructions, and technical or other issues. To gauge the survey content's face validity, caregivers were also asked to answer two questions: 1) Are there any questions that you feel should be deleted from the survey for any reason? and 2) Are there any additional questions that you feel would add valuable information to the study? Pilot feedback was incorporated into the survey and is summarized in Table 9. One caregiver, also a licensed clinical social worker, provided an unsolicited feedback list of stressors facing SMI caregivers. In review, these stress sources were already considered in the literature review (e.g. lack of knowledge about mental illness), included in the survey (e.g. caregiver embarrassment),

Table 9

Summary of Feedback from Preliminary Survey Pilot

Feedback	**Resolution/Revision**
Screening question about substance abuse/dementia diagnosis confusing	Revised from one to two questions
Duration of care question unclear	Revised: How many years have you been providing care for your [relation] *since he or she first started having symptoms of mental illness?*
Choices insufficient for living arrangements	…lives independently in private home *or apartment*
Punctuation suggestion	No revision made after review
List of caregiver stress sources	Review confirmed face validity of caregiver stress sources covered in literature review/study methods

Note. Survey question wording revisions noted in italics.

or deemed outside of the study scope (e.g. difficulty finding optimal treatment). The survey link was distributed to potential study participants as described in the sampling strategy above. Once sufficient *n* was achieved, study data was exported directly from REDCap into the Statistical Package for Social Sciences (SPSS) version 23 for data analysis.

Data Analysis

Data cleaning. Data will be cleaned prior to statistical procedures using data screening techniques described in Tabachnick and Fidell (2013) and summarized in Table 10. An SPSS missing value analysis (MVA) procedure will be run to identify missing data; Little's MCAR test will determine the randomness of missing data patterns. Intercorrelational analysis will also be performed to inspect relationships among study variables. Significant correlations among both continuous and categorical variables will be assessed using collinearity diagnostics within the SPSS regression analysis; inflated condition indices and variance proportion values will shed light on multicollinearity (Tabachnick & Fidell, 2013). In the event of collinearity, variables will be reviewed for deletion or combination to maintain the coherence of the regression analysis.

Table 10

Data Screening Procedures

Data Cleaning Steps:
Verify accuracy of input using descriptive statistics
Identify magnitude and randomness of missing data; take corrective action
Evaluate for nonlinearity and heteroscedasticity
Identify and redress non-normal variables and data outliers
Identify and deal with multivariate outliers
Evaluate variables for multicollinearity and singularity

Note. Adapted from *Using Multivariate Statistics (6th ed),* by B.B. Tabachnick and L.S. Fidell, 2013, Boston: Pearson Education.

Descriptive statistics. Descriptive statistics including (as appropriate) number of occurrences *n* and corresponding percentages, means, standard deviations, and ranges will be calculated and tabled for demographic, predicting, mediating, and moderating variables. The individual item responses for the dependent variable will also be tabled, with an indication of the number and percentages of participants who agreed with each item on the Guttman-style desire to relinquish care scale, along with the overall mean score and standard deviation. As this is the first known study to investigate this population’s desire to relinquish care, this information will be important both for the current study and to inform future research on this topic.

Multivariate analysis: multiple regression. Multiple linear regression techniques will assess the impact of perceived stigma and other predictor variables on caregivers’ desire to relinquish care. Linear regression models are appropriate for either experimental or correlational studies and are versatile enough to accommodate both categorical and continuous predictors (Liu, 2014). Prior to regression analyses, the assumptions for multiple regression methods will be tested using techniques described by Tabachnick and Fidell (2013) and outlined in Table 11. Any changes that are made to cases during the assumptions testing in order to meet the necessary assumptions will be reported in the results write-up.

Table 11

Assumptions of Multivariate Regression

Assumption	Assessment Technique
Ratio of cases to IVs	*A priori* power analysis
Absence of multicollinearity	Inspection of correlation matrices to identify variables that are too highly correlated (>0.9, Tolerance value >.10)
	Multicollinear predictors will be inspected for deletion or averaging
No significant multivariate outliers	Screening using SPSS REGRESSSION>Mahalanobis values; cases with large Mahalanobis values will be examined individually and modified or deleted as indicated
Normality, linearity, and homoscedasticity	The SPSS REGRESSION procedure produces residuals scatterplots that will be examined to determine if residuals are *normally* distributed around the predicted DV scores, that the residuals are *linearly* related to DVs, and that the variance of the residuals is consistent across all predicted DV scores, indicating *homoscedasticity*.
	If residual scatterplots indicate assumptions violations, skewness and kurtosis values and P-P plots will be reviewed to further identify assumptions violations. Any data manipulated to meet assumptions will be described in the study analysis.

Note. Adapted from *Using Multivariate Statistics (6th ed),* by B.B. Tabachnick and L.S. Fidell, 2013, Boston: Pearson Education.

Hierarchical regression procedures. Hierarchical regression techniques allow researchers to use theory or logic to determine the sequence in which predictors are entered into the regression equation (Tabachnick & Fidell, 2013). To achieve the study aims, variables will be entered into the hierarchical regression model in three blocks based on the prioritized logic of the SPM: background and contextual variables will be entered first, followed by primary stressors, then potential mediators.

Aim one: background variables. To achieve study aim one, desire to relinquish care will be regressed on background and contextual variables. Hypotheses 1.1 through 1.3 will be investigated in this initial regression block. These hypotheses respectively predict that single (vs. coupled) caregivers, parental (vs. other kinship) caregivers, and those who reside with the care recipient (vs. those who do not) will have more desire to relinquish care. Statistically significant correlation coefficients for these variables that occur in the hypothesized direction (based on variable coding) will indicate support for these hypotheses. While categorical variables will be fully reported by category in descriptive statistics (for categories, see Appendix F), the marital status and kinship variables will be dichotomized (single/partnered and parental/other, respectively) prior to entry into the model.

Aims two and three: stressor variables. Study aims two and three examine primary stressor variables and will be investigated in the second block of the regression model. In order to maintain parsimony, and to increase the case-to-variable ratio for additional statistical power, only those background and contextual variables that achieve significance ($p \leq 0.10$) in the first model will be retained for entry in subsequent models (Green, 2004). To investigate hypotheses two and three, the primary stressors of *care recipient behaviors*, and *perceived stigma* will be stepped into the equation individually and in that order. Because care recipients' problematic behaviors are known to impact caregiver outcomes (Lefley, 1989; G. C. Smith, 2004; Tessler & Gamache, 2000) it is important to control for this variable in the regression equation in order to better isolate the predictive ability of perceived stigma. Increases in both care recipient problematic behaviors (hypothesis 2) and perceived stigma (hypothesis 3) are hypothesized to predict increased desire to relinquish care. As with background variables, the statistical significance of the regression correlation coefficients will be the indication of hypothesis support. The impact of each of these variables in the regression equation is reported as the increase in R^2, along with the associated F change statistic and p-value (Tabachnick & Fidell, 2013).

Aims four and five: moderators. Hypothesis four predicts that age is a moderating variable between perceived stigma and desire to relinquish care, i.e. stigma will have different influence on the DV for caregivers of different ages (Figure 4). Hypothesis five postulates that a caregivers' sense of mastery moderates between perceived stigma and the DV (Figure 5). Moderating variables affect the strength or direction of the IV/DV relationship (MacKinnon, 2011; Polit & Beck, 2012). To assess caregiver age as a moderating variable (Study Aim 3) within the stress process, desire to relinquish care will be regressed on a multiplicative interaction term of *perceived stigma* X *caregiver age*, controlling for variables already in the equation. Prior to this analysis, the variables perceived stigma and caregiver age will be centered (i.e. converted so that the mean of each variable is zero) to avoid any problems associated with multicollinearity when the interaction is entered into the equation (Tabachnick & Fidell, 2013). The hypothesis of moderation will be supported if the interaction term is statistically significant ($p \leq 0.05$) and increases the predictive capacity of the equation. Significance of the interaction will trigger simple effects testing to inspect the bivariate correlations between the DV and perceived stigma for different age groups (Baron & Kenny, 1986; Tabachnick & Fidell, 2013). Similar procedures will be used to assess mastery as a moderating variable.

Aim six: mediating variable. The concluding aim in this study is to investigate caregivers' social support as a mediating variable between stigma and desire to relinquish care (Figure 6) as proposed in hypothesis six. In a hypothetical causal chain of three variables, the center variable may exert an indirect effect on the dependent variable (Tabachnick & Fidell, 2013). According to Tabachnick and Fidell (2013, p160), four conditions must be met to confirm a mediating variable: 1) a significant IV/mediator relationship, 2) a significant IV/DV relationship, 3) the proposed mediator predicts the DV when IV is controlled, and 4) the IV/DV relationship is reduced when the mediator is added to the equation. Social support will be analyzed against these conditions to test the hypothesis that this individual caregiver resource mediates in the IV-DV relationship. Baron and Kenny (1986) suggest a series of regression models to test mediation. Following the Baron and Kenny model (1986), the following regression equations will be entered in SPSS REGRESSION modeling to test *social support* as a mediator: 1) regression of social support on stigma, 2) regression of desire to relinquish care on stigma, and 3) regressing desire to relinquish care on both perceived stigma and social support.

Study Validity

There are many challenges when planning rigorous research methods that will accurately depict the issue under investigation. Validity is a criterion that reflects a study's "soundness," or whether the researchers have controlled sources of bias and used solid research design techniques (Polit & Beck, 2012). Due to its exploratory nature, this study uses a pre-experimental design, which has fewer intrinsic controls against potential threats to validity than experimental designs. However, potential threats to internal and external validity of this study have been considered and minimized to the extent possible with corresponding research design methods.

Potential threats and controls. This study builds on prior research into caregiver outcomes of the stress process. While this investigation has the potential to shed light on caregiver outcomes that are as yet unexplored, there are several possible threats to study validity outlined in Table 12. The use of purposive convenience sampling may limit generalizability of study results. Because NAMI Virginia will distribute the survey link through their distribution channels, with the potential to reach thousands of caregivers, NAMI affiliated caregivers are

Table 12

Methodological Threats and Controls

Design Aspect	**Threat**	**Threatens:**	**Control**
Convenience Sampling	Non-representative sample	External validity/ Generalizability	Distributing survey through multiple channels: NAMI, mental health service providers and organizations, online forums
Online Survey	Self-report bias	Internal validity	Anonymous survey should encourage honest responses
	Self-selection bias	External validity	Report limitation in study results
	Limited to caregivers with internet access	External validity	Survey will be accessible on multiple digital platforms (computers, smartphones, tablets) to increase respondent diversity
	Unable to calculate response rate	External validity	Report limitation in study results
Cross-sectional study	Desire to relinquish care may not correspond with actual care relinquishment, an SPM outcome	Construct validity	Use of Morycz scale, for which desire to relinquish care has been correlated with actual care relinquishment for Alzheimer's caregivers
	Moderating impact of caregiver age may be due to cohort vs. age differences	Internal validity	Report limitation in study results
	Difficult to gauge causality among variables	Internal validity	Use of the well-tested SPM guides interpretation of study results
Confounding variables	May contaminate results of IV-DV investigation	Internal validity	Control for confounding variable in statistical analysis

Table 12. Continued

Design Aspect	Threat	Threatens:	Control
Insufficient survey respondents	Low statistical power	Statistical conclusion validity	*A priori* power analysis indicates study recruitment goal; teaming with NAMI provides access to large population of targeted SMI caregivers
More than one caregiver of a single care recipient responds to survey	Independence of cases	Statistical conclusion validity	Report limitation in study results

likely to be overrepresented within this study. The study attempts to mitigate this bias toward NAMI membership by posting the survey link on internet-based caregiver discussion boards that are unassociated with NAMI and distributing recruitment flyers through other organizations that support this caregiver population. As it is not possible to know how many persons received the online survey link or viewed the flyers, calculating a survey response rate is not feasible. Additionally, the study may not attract caregivers who are overwhelmed with caring responsibilities and who do not have time to complete the survey. This points to the potential for self-selection bias, as caregivers who choose to participate may be inherently different from non-participants vis-à-vis study variables.

Online surveys are useful for generating large inclusive samples, and data is collected quickly and efficiently from large audiences (Wyatt, 2000). However, there are limitations to electronically collected data. Respondents are limited to caregivers who have access to electronic devices on which to complete the survey, and they may differ in significant ways from caregivers who are not electronically connected. Making the survey accessible on multiple digital platforms will help mitigate this source of response bias and encourage a more diverse sample. As with any self-report instrument, there is a risk of response bias. Caregivers may be reticent to admit their true feelings about their caregiving experiences, particularly if they feel their emotions are not socially acceptable (e.g. wanting to lock your child out of the house). However, study data is collected anonymously, which should minimize the effect of social response bias. Participants who volunteer to answer questions about stigma and care relinquishment may feel more comfortable than non-participants reflecting on and sharing their personal experiences as caregivers. Finally, the survey may not have collected information on all variables that are exerting impacts on the study outcome.

A cross-sectional design, necessary because of resource constraints, may threaten study validity. However, controls are planned to limit the threats. While a caregiver may express desire to relinquish care, intervening conditions may prevent the desired relinquishment from translating to actual relinquishment. Use of the adapted DTI scale (Morycz, 1985), for which desire to yield care has been correlated in longitudinal studies to actual yielding of care, helps to control for this threat to construct validity. Cross-sectional designs make it difficult to establish causality among variables (Polit & Beck, 2012) which may call into question the hypothesized mediation equation. Use of the well-tested SPM variable relationships bolsters the directionality of the potential mediation. In addition, cross-sectional design cannot establish causality between variables, i.e. caregivers' perceived stigma might not cause changes in their desire to relinquish care. However, the use of an established stress-process paradigm allows us to make informed estimations of the directionality between the variables.

Chapter Summary

This chapter summarized the methodological details for this study, to include research design and planned data analysis methods. Detailed information was presented concerning design, population, sampling techniques, variables and instrumentation, and survey development.

The analysis plan, including main effects and potential mediation and moderation were presented, followed by a section on limitations and corresponding controls.

Chapter Four: Results

Chapter Overview

This chapter presents research results, beginning with a review of variables and data collection followed by a summary of data preparation and descriptive statistics. Data cleaning processes and statistical procedures assumptions are then described, and data analysis results presented relative to study aims and hypotheses.

Data Collection

The purpose of this study was to identify factors that influence caregivers' desire to relinquish care for their loved ones with SMI. In accordance with the SPM, caregiver contextual factors and stressors were considered for their potential correlation with the dependent variable: caregiver desire to relinquish care.

The study employed a cross-sectional, descriptive, correlational research design. Data was collected from a purposive convenience sample of caregivers of adults with SMI via an online survey. Personalized recruitment emails were initially sent to all NAMI affiliates in 11 eastern U.S. states (MD, NC, VA, WV, SC, GA, FL, TN, KY, MS, LA). To increase sample size, additional emails were sent two weeks later to an additional 11 eastern states (DE, NJ, PA, VT, ME, OH, CT, RI, MA, NH, NY) and the District of Columbia. The NAMI Virginia state affiliate and several local affiliates in Virginia and other states embedded the survey link in their online newsletters. As expected, snowball sampling occurred, as the link was also shared through affiliate and personal emails and was posted on personal and NAMI affiliates' social media accounts (e.g. Facebook, Twitter). As such, it is not feasible to calculate a response rate.

Data collection lasted approximately six weeks. A total of 414 survey responses were recorded in REDCap. Screening question responses indicated failure to meet inclusion criteria (n = 85) and incomplete surveys (n = 44), resulting in a final sample of n = 285 caregivers. A portion (n = 38) of the incomplete surveys were blank; the remaining incomplete surveys (n = 6) did not include responses for the dependent variable. Several cases (n = 10) responded positively to one or both screening questions "Is your loved one's only mental illness diagnosis Alzheimer's disease?" or "Is your loved one's only mental illness substance abuse?" but also indicated a primary mental illness diagnosis other than these two excluded conditions. These ten cases were retained in the analysis on the basis of the indicated SMI diagnosis.

Data cleaning and Preparation

Data entries were verified for accuracy and reasonableness. Variable names and labels were updated as needed for clarity in the analysis. Numeric variable fields were corrected to avoid string entries, e.g. "college" was recoded to "16" or "5+" was recoded to "5". Five new dichotomous variables were created by collapsing categories in the caregiver demographic variables of race, employment, relationship to the care recipient, marital status, and care recipient residential status; these characteristics were dichotomized into minority, employed, parental, partnered, and cohabitation status variables, respectively. Items in the Mastery scale and Devaluation and Discrimination scale were reverse coded as necessary, and total scale scores were calculated through summation of individual scale item values. All dichotomous predictors were inspected to ensure that they had better than 90% - 10% splits between categories (i.e. neither category contained 10% or less of the data).

Missing values analysis. Missing values were determined by Little's MCAR to be missing at random ($\chi^2 = 126.8$, df = 126, $p = .462$). No variable had more than 5% of cases missing values. The most missing cases for any variable was mastery, with $n = 10$ (3.5%) missing. Missing values were replaced with EM estimated mean values for each variable.

Univariate outliers. Univariate outliers are cases with extreme values for one variable that distort statistical analysis (Tabachnick & Fidell, 2013). A case is considered an outlier if it has a standardized score more than three standard deviations above or below the mean. Standardized scores for continuous variables were inspected, and for those cases with Z scores > 3.29, the outlying scores were recoded into the next lowest value minus one, or the next highest value plus one, as appropriate. Because only one person scored "very bad" on the self-rated health scale, that category was collapsed with the rating "bad". A total of 9 outliers were recoded.

Study Variable Intercorrelations

Collinearity assessment. Bivariate correlations analysis through SPSS examined relationships between continuous independent and dependent study variables. While a number of variable correlations were significant at the $p < .05$ and $p < .01$ level, correlations did not approach the level indicated for problematic collinearity ($r > .70$), indicating that study variables were appropriate for entry into the regression analysis. Expectable exceptions were the relationships between the individual subscales of the Devaluation and Discrimination scale and the total scale. To avoid multicollinearity, the individual subscales and total scale were not entered concurrently in any regression model. Correlations between study variables are summarized in Table 13.

Table 13

Correlations between Study Variables

	2	3	4	5	6	7	8	9	10	11
1. Age	-.063	.425**	.259**	-0.077	0.003	-0.111	-0.061	-0.094	-0.016	-0.076
2. Health		-.017	.031	-.154**	-.091	-.213**	-.173**	.336**	.266**	-.061
3. Care Duration			.474**	0.041	0.081	0.034	0.065	-0.033	-0.022	-0.058
4. Time Ill				-0.048	-0.025	-0.059	-0.048	.136*	0.027	0.053
5. Problem Behaviors					.238**	.250**	.278**	-.372**	-.265**	.351**
6. Consumer stigma						.544**	.879**	-.290**	-.210**	0.103
7. Caregiver stigma							.879**	-.236**	-.226**	.240**
8. Ttl Stigma								-.299**	-.248**	.195**
9. Mastery									.382**	-.124*
10. Social Support										-0.079
11. DTR										--

Note. DTR = Desire to Relinquish Care
** $p < 0.01$. *$p < .05$

Notable variable correlations. There were several notable correlations in the study. Age was positively associated with the length of time that the respondent had been providing care ($r = .425, p < .01$) and the length of time that their loved one had been ill ($r = .259, p < .01$), indicating that older adults had been providing care for longer than their younger counterparts. Problematic behaviors, which may serve as the stigmatizing "mark" of SMI, were positively correlated with caregivers' perceptions concerning stigma directed at persons with SMI ($r = .238, p < .01$), courtesy stigma ($r = .250, p < .01$), and total perceived stigma ($r = .278, p < .01$). Problem behaviors were also positively correlated with the dependent variable, desire to relinquish care, such that increases in caregiver exposure to problem behaviors were associated with increased desire to relinquish care ($r = .351, p < .01$). Problem behaviors were negatively associated with caregiver sense of mastery ($r = -.372, p < .01$) and social support ($r = -.265, p < .01$).

In addition to being negatively correlated with problem behaviors, caregiver mastery was negatively correlated with caregivers' perceptions concerning direct SMI stigma ($r = -.290, p < .01$), courtesy stigma ($r = -.236, p < .01$), and total perceived stigma ($r = -.299, p < .01$). There was no significant correlation between age and mastery within the study sample. Social support was negatively correlated with both stigma subscale scores ($r = -.210, p < .01$ and $r = -.226, p < .01$), and total perceived stigma ($r = -.248, p < .01$). Caregiver sense of mastery was positively associated with social support ($r = .382, p < .01$) an indication that caregivers with higher mastery scores also reported higher levels of support from a person outside of their home. Caregiver desire to relinquish care, the dependent variable in the study, was positively correlated with total perceived stigma ($r = .195, p < .01$). This correlation derived mainly from respondents' scores on the subscale measuring courtesy stigma ($r = .240$, $p < .01$), as there was not a significant correlation between the direct (i.e. consumer) stigma subscale scores and the DV. Finally, the correlation between caregiver sense of mastery and desire to relinquish care was negative ($r = -.124$, $p < .05$), indicating that people who reported lower mastery had higher desire to relinquish care.

Caregiver self-rated health showed significant positive correlations with both caregiver sense of mastery ($r = .336$, $p < .01$) and social supports ($r = .226$, $p < .01$). Participants' reports of their health were negatively correlated with their loved one's level of problematic behaviors ($r = -.154$, $p < .01$), and total perceived stigma ($r = -.173$, $p < .01$). Interestingly, while there was a negative correlation between self-rated health and perceptions of courtesy stigma ($r = -.213$, $p < .01$), the relationship between direct SMI stigma and self-rated health was insignificant.

Descriptive Statistics

This section presents descriptive statistics for independent and dependent study variables. The data is described in terms of stress process model constructs and summarized in Table 14.

Background and contextual factors. Contextual factors from the SPM can be divided into three categories: characteristics of the caregiver, characteristics of the care recipient, and characteristics of the caregiving environment. This section describes the relevant contextual study variables.

Caregiver characteristics. The sample was largely female ($n = 242$, 84%,) and white ($n = 249$, 87%). Black or African American caregivers were the largest minority group ($n = 13$, 5%) represented. The sample was overwhelmingly college-educated, with an average of 16.3 (SD = 2.61) years of schooling. More than a third of respondents held a bachelor's degree ($n = 108$, 38%) and an additional 40% ($n = 115$) had graduate degrees. Only 4 respondents

Table 14

Description of Subjects in Terms of Stress Process Model Constructs

	Mean	Standard Deviation
Background and contextual factors:		
Caregiver age (years)	60.02	10.52
Caregiver education (years schooling)	16.30	2.61
Caregiver self-rated health (scale 1-5)	3.99	0.83
Caregiver household size	2.69	1.04
Years providing care	12.57	8.97
Recipient age (years)	39.03	15.84
Recipient illness duration (years)	18.50	12.89
Stressors:		
Problematic behaviors (scale 0-28)	9.26	5.12
Perceived consumer stigma (scale 8-32) [a]	24.12	3.61
Perceived caregiver stigma (scale 7-28) [a]	18.14	3.61
Total perceived stigma (scale 15-60)	42.26	6.34
Mediators		
Mastery (scale 7-28)	18.57	3.66
Social support (scale 0-1)	0.63	0.24
Outcome		
Desire to relinquish care (scale 0-6)	1.81	1.78

Note. Higher scores indicate increased problematic behaviors, perceived stigma, feelings of mastery, social supports, and desire to relinquish care.
[a] Subscale of Devaluation and Discrimination scale used to measure perceived stigma

had less than a high school education. Over half of the caregivers were working full- (*n* = 97, 34%) or part-time (*n* = 65, 23%), while almost one-third were retired (*n* = 88, 31%). Of the 10% (*n* = 27) of sampled caregivers who were unemployed, 40% (*n* = 11) were currently looking for work. Only 5% (*n* = 13) of caregivers reported being in “bad” (*n* = 12; 4%) or “very bad” (*n* = 1) health, with nearly three-quarters (74%) indicating that they were in “good” (*n* = 128, 45%) or “very good” health (*n* = 83, 29%). Three percent (*n* = 7) of caregivers were disabled and unable to work. Caregivers reported being married/partnered (*n* = 206, 72%), separated/divorced (*n* = 50, 18%), widowed (*n* = 21, 7%) or never married/partnered (*n* = 8, 3%).

Caregivers in the study sample ranged from a 22-year-old woman caring for her 20-year-old sister, to an 82-year-old man caring for his 48-year-old son. The average caregiver age was 60.02 (SD = 10.52). Caregiver ages are summarized in Table 15. Almost three-quarters (*n* = 207, 73%) of caregivers were in their 50s and 60s. This data meshes with the fact that 74% of the sample reported caring for a son (*n* = 145, 51%) or daughter (*n* = 66, 23%). The average age of these sons/daughters was 32.49 (SD = 8.48), representing a mean generational distance of 28 years from their parents. Sampled caregivers had been providing care for an average of 12.57 years, and the standard deviation (8.97) indicates considerable variation in care duration. Twenty-eight percent of caregivers had been providing care for 5 years or less; 22% (*n* = 63) reported being in the caregiving role for 20 years or more, and 6% (*n* = 16) had been providing care for more than 3 decades.

Table 15

Caregiver Ages within the Sample

Age range (years)	N	Percent
< 31	6	2
31=40	9	3
41-50	22	9
51-60	103	36
61-70	104	36
71-80	37	13
80 and up	4	1
Total	**285**	**100**

Care recipient characteristics. Care recipients were more likely to be male (*n* = 187, 66%) than female (*n* = 98, 34%). Fourteen mental illness diagnoses were reported in the survey (Table 16), with bipolar disorder (*n* = 96, 34%), schizophrenia (*n* = 62, 22%), schizophreniform disorder (*n* = 59, 21%), and depression (*n* = 22, 8%) reported most frequently. Borderline personality disorder, anxiety, and post-traumatic stress disorder (PTSD) each accounted for 4%

Table 16

Study Mental Illness Diagnoses

Diagnosis	N	Percent
Anxiety disorder	11	3.9
Bipolar disorder	96	33.7
Borderline personality disorder	11	3.9
Depression	22	7.7
Eating disorder (Anorexia, Bulimia, Binge Eating Disorder)	2	.7
Obsessive-compulsive disorder (OCD)	1	.4
Personality Disorder	1	.4
Phobia	1	.4
Post-Traumatic Stress Disorder (PTSD)	11	3.9
Schizoaffective disorder	59	20.7
Schizophrenia	62	21.8
Schizophreniform Disorder	3	1.1
Other	5	1.8
Total	285	100

(*n* = 11) of the sample. SMI diagnoses in the “other” category were unspecified psychoses and depersonalization and derealization disorder.

Characteristics of the caregiving environment. Respondents hailed from 24 U.S. states, with one respondent from outside of the continental U.S. One quarter of respondents (*n* = 71) were from Virginia, and 39% were from the combined southeastern states of South Carolina (*n* = 38, 13%), Florida (*n* = 25), and Georgia (*n* = 22, 8%), Tennessee (*n* = 16, 6%), and North Carolina (*n* = 10, 4%). New York (n = 24, 8%) and New Jersey (*n* = 16, 6%) were the largest northeastern states responding, accounting for 14% of responses. No other state (AL, AZ, CA, CO, CT, KS, KY, LA, MD, MA, MI, NH, OH, OR, PA, VT, outside U.S.) had double-digit respondents. More than half (*n* = 155, 54%) of the sampled caregivers live with the person for whom they are caring. Another 24% (*n* = 67) care for a person who lives in a private home or apartment, and 7% (*n* = 21) care for a person living in supported housing. Several respondents (*n* = 7, 2%) indicated that they were providing care for their loved ones who were currently hospitalized or imprisoned.

Stressors. This study included two variables that represent stress for SMI caregivers: problematic behaviors and perceived mental illness stigma. Descriptive statistics (means, standard deviations) for these two variables are included in Table 14.

Problematic behaviors. Problematic behaviors were measured using caregivers' reports on how often they personally had to deal with individual behaviors that Tessler and Gamache (2000) identified as most problematic for caregivers of persons with SMI. Using SPSS scale reliability analysis, Cronbach's alpha for the 7-item problematic behaviors scale was calculated as $\alpha = 0.786$, indicating acceptable (> 0.70) internal consistency.

The most frequently occurring problematic behavior reported by caregivers was attention-seeking, such as excessive demands on the caregiver's time and attention, interruptions to caregiver activities, calling on the phone, or other activities that bother caregivers and take up their time. The percentages of caregivers who reported that their loved ones exhibit specific problematic behaviors are summarized in Table 17 along with descriptive statistics by category. Half of caregivers (*n* = 142, 50%) reported that these behaviors occurred frequently or quite frequently, and another 27% (*n* = 78) reported that they occur sometimes. Embarrassing behaviors occurred often as well, with 30% (*n* = 84) of caregivers reporting dealing with these behaviors quite frequently or nearly always, and another third (*n* = 96, 34%) dealing with them sometimes. Drug and alcohol abuse were the least frequently reported behaviors, with 62% (*n* = 176) and 58% (*n* = 164) of caregivers reporting that their loved ones never abused drugs or alcohol, respectively.

Table 17

Percentage of Caregivers Reporting Problematic Behaviors

Behavior category	Never	Rarely	Some-times	Quite frequently	Nearly always	Total	Mean (SD)
Attention seeking	9	14	27	35	15	100	2.33 (1.15)
Embarrassing	11	26	34	19	11	100	1.92 (1.15)
Nocturnal disturbances	19	33	28	16	4	100	1.52 (1.10)
Alcohol abuse	58	18	13	9	2	100	0.80 (1.11)
Drug abuse	62	12	15	7	4	100	0.80 (1.18)
Violence/ threats of violence	51	23	17	8	1	100	0.86 (1.04)
Suicide/ threats of suicide	40	28	25	5	2	100	1.03 (1.04)

Note. Scores rated with responses: 0 = "never"; 1 = "rarely"; 2 = "sometimes"; 3 = "quite frequently"; 4 = "nearly always"

While violent and suicidal behaviors were reported slightly more frequently than substance abuse, these variables were highly positively skewed (Figures 7 and 8), indicating that caregivers were more likely to report that these behaviors never or rarely occurred. That said, considerable percentages of sampled caregivers reported having had to deal with suicidal (*n* = 172, 60%) or violent (*n* = 140, 49%) behaviors at some level in their current caregiving career.

Perceived stigma. Cronbach's alpha for the overall Devaluation and Discrimination scale, which measures perceived stigma, was 0.863. Items 1 through 8 of the Devaluation and Discrimination scale constitute the Devaluation of Consumers subscale ($\alpha = .788$); items 9 through 15 constitute the Devaluation of Consumer Families subscale ($\alpha = .829$).

Stigma directed toward individuals with SMI. A majority (ranging from 67% to 90%) of survey respondents reported "agree" or "strongly agree" on every item in the Devaluation of

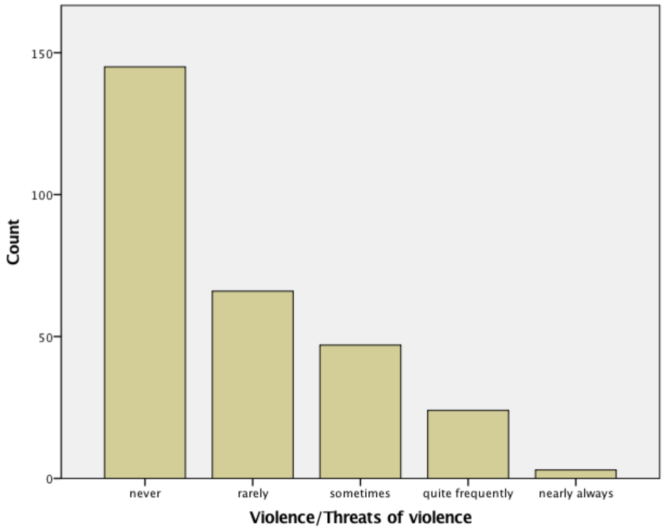

Figure 7. Frequency of reported violent problematic behaviors.

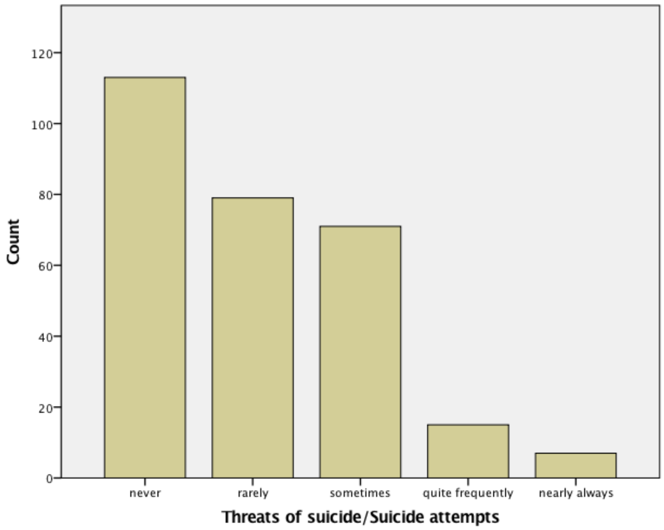

Figure 8. Frequency of reported suicidal problematic behaviors.

Consumers subscale (Table 18), indicating that they perceive that their loved ones with mental illness are stigmatized. Two-thirds or more of respondents agreed that most people: believe that having a mental illness is worse than being drug-addicted (*n* = 191, 67%), would not befriend a person with SMI (*n* = 202, 71%), or considered psychiatric treatment a sign of personal failure (*n* = 203, 71%). Four in five respondents agreed that most people would not hire (*n* = 229, 80%) or marry (*n* = 231, 81%) a person with mental illness. Almost 9 in 10 caregivers reported feeling

Table 18

Response Percentages for Devaluation of Consumers Subscale Items

Scale Item	Strongly Disagree	Disagree	Agree	Strongly Agree
Most people would not accept a person who once had a serious mental illness as a close friend.[a]	4.9	24.2	52.3	18.6
Most people think that a person with serious mental illness is dangerous and unpredictable.	1.8	11.2	60.7	26.3
Most people feel that having a mental illness is worse than being addicted to drugs.	2.5	30.5	46.0	21.1
Most people look down on someone who once was a patient in a mental hospital.	2.8	8.7	54.0	34.4
Most employers will not hire a person who once has a serious mental illness if he or she is qualified for the job.[a]	1.1	18.6	55.0	25.3
Most people think less of someone who has been a patient in a mental hospital.	1.4	9.5	57.9	31.2
Most people feel that entering psychiatric treatment is a sign of personal failure.	3.2	25.6	49.5	21.8
Most young women would not marry a man who has been treated for a serious mental disorder.	1.4	17.5	63.5	17.5

[a] Item was reversed in analysis

that most people consider mentally ill persons dangerous (*n* = 248, 87%), and would look down on (*n* = 252, 88%) or think less of (*n* = 254, 89%) a former psychiatric hospital patient.

Courtesy stigma. Courtesy stigma extends beyond the person with the stigmatizing condition to individuals who are associated with them, such as caregivers or family members. Caregivers in this study indicated that they perceived stigmatization of family members due to their association with mental illness, although the perception was less pronounced for courtesy stigma than for stigma directed towards individuals with SMI. Respondents indicated that parents might shoulder guilt and blame for their loved one's illness; more than one-third of caregivers (*n* = 103, 36%) agreed or strongly agreed that most people believe parents of individuals with SMI are not as caring and responsible as other parents, and over half (*n* = 150, 53%) felt that parents were blamed for their child's SMI. Survey data reveal caregivers' concerns about social isolation and reduced social networks as well. Respondents agreed that most people would not be friends with (*n* = 131, 46%), and would rather not visit (*n* = 187, 65%) families that have a member who is mentally ill, even if their family member were hospitalized (*n* = 162, 57%). A majority of caregivers (*n* = 157, 55%) indicated their consensus that families impacted by mental illness are looked down on by others as well. Table 19 summarizes caregivers' responses to each item on the Devaluation of Consumer Families subscale.

Table 19

Response Percentages for Devaluation of Consumer Families Subscale Items

Scale Item	Strongly Disagree	Disagree	Agree	Strongly Agree
Most people in my community would rather not be friends with families that have a relative who is mentally ill living with them.	4.6	49.1	36.8	9.5
Most people believe that parents of children with a mental illness are not as responsible and caring as other parents. [a]	11.6	52.3	31.2	4.9
Most people look down on families that have a member who is mentally ill living with them.	5.3	39.6	44.2	10.9
Most people believe their friends would not visit them as often if a member of their family were hospitalized for a serious mental illness.	3.9	39.3	46.0	10.9
Most people would not treat families with a member who is mentally ill the same way they treat other families. [a]	3.5	30.5	51.2	14.7
Most people blame parents for the mental illness of their children. [a]	6.0	41.4	41.1	11.6
Most people would rather not visit families that have a member who is mentally ill.	2.8	31.6	55.4	10.2

[a] Item was reversed in analysis

Combined stigma scores. The overall scores for the Devaluation and Discrimination scale reflect the perceptions of stigma indicated in the subscales. The scale is scored on a range from 15 to 60, where 37.5 is the midpoint of the scale (i.e. where agreement = disagreement).

The mean score (standard deviation) in this study was 42.26 (6.34), indicating that respondents were more likely to perceive mental illness stigma than not. In fact, 78% of caregivers' responses were greater than the scale midpoint, and 28% scored in the scale's highest quartile (> 45).

Psychosocial resources that mediate stress. This study considered both the caregiver's sense of mastery and the level of available social supports as potential influences on caregiver outcomes.

Mastery. Cronbach's alpha for the Mastery scale within this study, calculated via SPSS scale reliability analysis, was .796. The Mastery scale consisted of seven items, and possible responses ranged from 7 to 28, with higher scores indicating a higher caregiver sense of mastery. The midpoint of the scale is 17.5. Two-thirds of the sample (*n* = 191, 67%) scored higher than the midpoint, and 13% (*n* = 38) of respondents scored in the top quartile of possible scores (23 or greater), indicating in general a positive sense of mastery in sampled caregivers. The mean for the Mastery scales scores was 18.57 (SD = 3.66).

Social Supports. Cronbach's alpha for the social supports scale within this study was .747, indicating acceptable scale reliability. Social support was measured by determining the percentage of nine tasks for which caregivers had outside help, plus an added item to determine caregiver support group participation. For each of the ten items, scores were coded 0 for "no" and 1 for "yes". The summed responses were divided by 10 to form a composite index of support with scores ranging from zero (help with no tasks and no support group participation) to one (help with all 9 tasks and participation in a support group). Descriptive statistics for Social Support scale items and the complete scale are presented in Table 20 and indicate that on average, caregivers indicated support on 6 of the 10 items. Support levels were lowest for

Table 20

Descriptive Statistics for Social Support Scale Items and Scale Total

Do you have someone who lives outside your home that:	**Mean (SD)**
….would take care of your home while you are out of town?	.62 (.485)
…you talk to about work or other life issues?	.87 (.337)
…helps you with household tasks (like yardwork, cleaning, chores)?	.43 (.496)
…you would ask for advice on important decisions?	.81 (.390)
…you socialize with (going to movies, having dinner together, hanging out, talking on phone)?	.85 (.355)
…you would talk to about your personal worries?	.83 (.375)
…you could borrow money from?	.55 (.498)
…could take care of your loved one with mental illness while you are out?	.45 (.498)
…helps you with routine tasks of caring for your loved one with mental illness?	.31 (.462)
Do you belong to a caregiver support group?	.51 (.501)
Social support scale total	**.63 (.241)**

Note. Score response scale: "no" = 0; "yes" = 1.

assistance with day-to-day tasks, as less than half of respondents indicated they had help with routine caregiving tasks (*n* = 87, 31%), household chores (*n* = 123, 43%), and respite care (*n* = 127, 45%). Study participants were more likely to report emotional supports such as asking advice (*n* = 232, 81%), discussing worries (*n* = 236, 83%), socializing (*n* = 243, 85%), or talking about work-life issues with someone (*n* = 248, 87%).

Outcome: Desire to relinquish care. Caregiver desire to relinquish care was measured using the Desire to Relinquish Care (DTR) scale, an adaptation of Morycz's Desire to Institutionalize (DTI) scale. Potential scores range from zero (no desire to relinquish care) to six, with higher scores indicating increased desire. Scale reliability was calculated using SPSS scale reliability analysis for Guttman scaling. This analysis produces six Guttman's lower bounds coefficients (lambda 1-6); lambda 3 (λ3) is equivalent to Cronbach's alpha (Garson, 2009). For this study, λ3 was calculated as .755, indicating acceptable scale reliability (> .70).

The DTR scale is hierarchical, meaning that respondents who agree with one question on the test are likely to agree with the previous questions (Kane, 2006). This expectation was borne out in the current study, as more caregivers responded positively to the earlier than later scale questions (Table 21). One notable discrepancy occurred wherein only 7% of respondents (*n* = 20) indicated that they were likely to stop providing care, yet 22% of respondents (*n* = 62) had taken some steps toward giving up care.

Table 21

Desire to Relinquish Care Scale Item Responses

Scale Item	**N**	**%**
Caregiver indicates that they:		
….have considered giving up all their care responsibilities.	117	41.1
…have felt they would be better off if they stopped providing care.	129	45.3
…have talked to friends, family, or anyone else about giving up all their care responsibilities.	100	35.1
…have talked to their ill relative about no longer providing care for them.	89	31.2
…are likely to stop providing care for their relative.	20	7.0
…have taken steps toward giving up care	62	21.7
Scale mean	1.81	
Scale standard deviation	1.78	

Note. Score response scale: “no” = 0; “yes” = 1.

While not part of the scaled DTR score, study participants were asked if they felt that the care recipient would be better off if the caregiver stopped providing care, and 23% (*n* = 66) responded yes. Almost twice as many caregivers (*n* = 129, 45%) indicated that they thought the caregiver (i.e. the survey respondent him or herself) would be better off if they stopped providing care.

Caregiver desire to relinquish care was positively skewed (skewness/standard error of skewness = 4.17), indicating that scores were concentrated on the lower end of the DTR scale, largely due to the percentage of caregivers (*n* = 101, 35%) who indicated no desire to relinquish care. Almost two-thirds (*n* = 184, 65%) of caregivers indicated some desire to relinquish care, and 1 in 5 caregivers (*n* = 62, 21%) indicated that they had taken steps toward care relinquishment. Seven percent (*n* = 20) of sampled caregivers were likely to relinquish care. Table 22 presents a summary of desire to relinquish care scale score frequencies.

Table 22

Caregiver Desire to Relinquish Care of their Loved One with Serious Mental Illness

DTR Scale Total score	N	%
0	101	35.4
1	41	14.4
2	47	16.5
3	37	13.0
4	31	10.9
5	21	7.4
6	7	2.5
Total	285	100

Note. Higher scores indicate increased desire to relinquish care

Assumptions of Multiple Regression

This section reviews the processes used for validating the assumptions of multivariate regression as outlined by Tabachnick and Fidell (2013). Assumptions tested included ratio of cases to IVs, multicollinearity, multivariate outliers, normality, linearity, and homoscedasticity.

Ratio of cases to IVs. The a priori power analysis indicated that a sample size of *n* = 123 would be sufficient for detecting a large or medium study effect, so the current study's cases (*n* = 285) were sufficient to detect all but a small effect.

Linearity, homoscedasticity, and homogeneity of variance. The assumption of linearity is of a straight-line relationship between two variables. Bivariate scatterplots between variable pairs (IVs and DV) were inspected and no non-linear relationships were detected. Homoscedasticity assumes that for continuous variables, the variability in scores is approximately the same at all values of another continuous variable. The equivalent assumption for categorical data is homogeneity of variance, wherein the variability in the DV is expected to be the roughly the same for all levels of the grouping variable (Tabachnick & Fidell, 2013). Scatterplots between the individual IVs and DV revealed that assumptions of homoscedasticity and homogeneity of variance were met.

Normality. Tabachnick and Fidell (2013) indicate that screening continuous variables for normality is important in multivariate analysis, and that while normality is not always required for analysis, the solution improves when all variables in the analysis are normally distributed. Two concepts in normality are skewness, which indicates distribution symmetry, and kurtosis, which indicates the peakedness of the distribution. After adjusting for univariate outliers, histograms were inspected and indicated that some study variables were skewed and/or kurtotic. Variable distributions are considered skewed (kurtotic) if the skew (kurtosis) statistic divided by the standard error of that statistic is greater than 3.29. Corrections to univariate outliers improved the skewness of the health variable. Due to the skewness and/or kurtosis of several other variables, transformations were indicated.

Data Transformations. For data that do not meet the assumptions of a normal distribution, transformation of variables can improve the shape of the distribution and analysis results (Tabachnick & Fidell, 2013). To resolve their negative skewness, the variables of age and social support were first reflected (to avoid taking the square root of zero), and then the square root calculated. Due to their positive skewness, two variables, desire to relinquish care and problematic behaviors, were transformed by taking the square root of the variable value plus one (added to avoid taking square root of zero). These transformations brought the skewness and kurtosis levels of these variables in line with normality assumptions (< 3.29) with the exception of kurtosis (-4.396) for the DV, desire to relinquish care. According to Waternaux (1976), the underestimation of variance associated with negative kurtosis disappears when $n > 200$.

The subscales associated with the stigma IV, measured by the Devaluation and Discrimination scale, were also analyzed for normality. Skewness and kurtosis for both the Devaluation of Consumers and Devaluation of Consumer Families subscales were within normal limits (< 3.29) and histograms indicated normal distribution curves for both scales.

Two variables in the analysis had extreme non-normality. After resolution of outliers, the number of household members was severely positively skewed (6.68) and education was severely negatively skewed (-6.46). Even with common transformation techniques (e.g. square root, logarithm), these variables remained non-normal. A considerable majority ($n = 223$, 78%) of the sample had a college education or higher, precluding analysis of differently educated groups. The mean caregiver household, including the caregiver, totaled 3.99 (SD = .831) persons. Due to their extreme non-normality, low level of importance to the analysis, and the challenges of dichotomizing, the decision was made to drop the education and household size variables from the analysis. Scatterplots for the transformed variables against the DV were examined and linearity and homoscedasticity were reconfirmed. Table 23 summarizes the post-transformation skew/kurtosis statistics and variable transformation methods.

Multivariate outliers. Multivariate outliers indicate cases with an unusual combination of scores on two or more variables, and these cases have inflated Mahalanobis distances. Mahalanobis distances were generated in the regression analysis and no value exceeded the critical value ($\chi^2 = 29.59$, 10 df, $p < .001$) indicating no multivariate outliers.

Multicollinearity. Multicollinearity of variables in the analysis was assessed using SPSS multicollinearity diagnostics procedures. Multicollinearity criteria include the combination of a

Table 23

Skewness and Kurtosis of Transformed Study Variables

Variable	Skew	SE of skew	Skew/ SE skew	Kurtosis	SE of kurt.	Kurt/SE kurtosis	Transform Method
Age	-0.337	0.144	-2.340	0.812	0.288	2.819	Square root
Education (years)	--	--	--	--	--	--	Dropped from analysis
Health	-0.456	0.144	-3.167	-0.406	0.288	-1.41	None
# Household members	--	--	--	--	--	--	Dropped from analysis
Problem Behaviors	-0.184	0.144	-1.278	0.291	0.288	1.010	Square root
Perceived Stigma	-.009	0.144	-.0625	-.167	0.288	-.580	None
Mastery	.014	0.144	0.97	.356	0.288	1.24	None
Social Support	0.033	0.144	0.229	0.021	0.288	0.073	Square root
Desire to Relinquish	-0.244	0.144	-1.694	0.625	0.288	2.170	Square root

condition index greater than 30 and two or more variance proportions higher than .50 for one dimension (Belsley, 1980). Regression analysis indicted that no dimension of the regression model met the criteria for multicollinearity.

Data Analysis: Hypothesis Testing

This section describes the procedures used for testing study hypotheses using hierarchical multiple regression analysis. In accordance with the specific aims of the study, which reflect SPM constructs, predictors were entered into the regression model in a series of blocks.

Specific aim one. The first aim of the study was to identify how caregiver background and contextual factors influence caregivers' desire to relinquish their caregiving responsibilities for adults with SMI. Hypotheses 1.1 through 1.3 explored the impact of specific caregiver demographic variables. Sequential regression was used to determine if the addition of caregiver partnered, parental, or cohabitation status variables improved prediction of desire to relinquish care beyond that of the control variables. The control variables, including caregiver age, race, employment status, self-rated health, and care recipient gender were entered at the first step of the regression model. The remaining predictor variables were stepped into the equation in this order: partnered, parental, and cohabitation status. The dependent variable was the transformed version of the DV, i.e. the squareroot of a caregiver's summed score on the DTR scale. The initial regression model including the caregiver demographic covariates was not significant (R^2 = .010, F_{inc} (5, 279) = .573, p = .720), an indication that this group of covariates did not explain a significant portion of the variance in desire to relinquish care. Table 24 displays statistical analysis results after entry of control (step 1) and caregiver contextual and background variables (steps 2-4) into the regression equation.

Table 24

Regression of Desire to Relinquish Care on Control and Contextual Variables

DV: Desire to Relinquish Care		
Predictor	**ΔR^2**	**β**
Step 1	.010	
Age		.064
Minority		-.073
Employed		.004
Health		-.031
Adult gender		.011
Step 2	.036**	
Partnered		-.197**
Step 3	.009	
Parental		-.100
Step 4	.000	
Cohabitating		.018
Total R^2	.056*	
F	2.047*	
N	285	

Note. Beta weights listed are from the full model (through step 4)
* $p < .05$ ** $p < .01$

$H_{1.1.}$ Single caregivers will have more desire to relinquish care than partnered caregivers. After step 2, with partnered status added to the covariates, $R^2 = .047$, $F_{\text{inc}}(1, 278) = 10.61$, $p < .01$. Addition of partnered status to the equation already containing the covariates resulted in a significant increment in R^2. Partnered status was coded 0 = single, 1 = partnered. As such, the negative standardized regression coefficient ($\beta = -.197$) of the partnered variable in step 2 indicates that partnered caregivers had lower desire to relinquish care and supports hypothesis 1.1.

$H_{1.2.}$ Parental caregivers will have stronger desire to relinquish care than other kin relationships. After step 3, with parental status added to the equation, $R^2 = .056$, $F_{\text{inc}}(1, 277) = 2.68$, $p = .103$. Addition of parental status did not reliably improve R^2, therefore hypothesis 1.2 was not supported.

$H_{1.3.}$ Caregiver desire to relinquish care will be stronger when dyad members cohabitate. Cohabitation status was added to the model in step 4, after which $R^2 = .056$, $F_{\text{inc}}(1, 276) = .093$, $p = .761$. The addition of cohabitation status did not improve the model fit, and hypotheses 1.3 was not supported. Table 24 displays the statistical results of regression after entry of parental and cohabitation status variables.

Specific aims two and three. The second and third aims of the study were to determine the impact of care recipient behaviors and perceived stigma on caregivers' desire to relinquish care**.** These aims were investigated by stepping problematic behavior and perceived stigma, in that order, into the regression model.

$H_{2.}$ Care recipient problematic behaviors will predict caregiver desire to relinquish care such that increased problematic behaviors will be associated with more desire to relinquish care. Problematic behavior was added to the model in step 5, after which $R^2 = .159$, $F_{\text{inc}}(1, 275) =$

33.65, $p < .01$. Addition of problematic behaviors to the equation with caregiver background and contextual variables resulted in a significant increase in R^2 and improved the predictive capacity of the model by 10.3 percent ($\Delta R^2 = .103$). The positive regression coefficient of problem behaviors ($\beta = .336$) indicates that increases in problematic behaviors correspond with increases in desire to relinquish care. Hypothesis two was fully supported.

Notably, with problematic behaviors in the equation, the regression coefficient for parental status ($\beta = -.027$) achieves significance in the model and the coefficient for partnered status ($\beta = -.129$) is reduced to significance at the .05 level. The significant negative coefficient of parental status (coded 0 = non-parental, 1 = parental) indicates that increased problematic behaviors are less likely to increase parental (vs. non-parental) caregivers' desire to relinquish care.

<u>H_3. Perceived stigma will predict desire to relinquish care such that caregivers with higher levels of perceived stigma will have more desire to relinquish care.</u> Caregivers' perceptions of stigma were measured in the study using the Devaluation and Discrimination scale, comprised of two subscales. The Devaluation of Consumers subscale measures the respondent's perception that persons who have mental illness will experience stigma associated with that illness. The Devaluation of Families of Consumers subscale measures the respondent's belief that persons *associated with* a person who has mental illness will experience stigma due to that association (i.e. courtesy stigma). To assess the impact of perceived stigma on desire to relinquish care, the subscales were simultaneously entered into the equation at step 6, resulting in $R^2 = .184$, $F_{\text{inc}}(1, 273) = 4.123$, $p < .05$. The addition of perceived stigma reduced the partnered status coefficient to insignificance, an indication that a caregivers' partnership status is not a significant consideration in predicting desire to relinquish care when perceived stigma is included in the full

model. In that the addition of perceived stigma significantly added to the predictive capability of the model ($\Delta R^2 = .025$), hypothesis three was supported. However, of the two subscales, only the Devaluation of Families of Consumers subscale was a significant predictor ($\beta = .191$, $p < .01$) in the equation, pointing to caregivers' perceptions of courtesy stigma as influential in their desire to relinquish care. Table 25 displays the statistical analysis results after entry of problematic behaviors (step 5), and perceived stigma (step 6) into the regression equation.

Table 25

Regression of Desire to Relinquish Care on Stressor Variables

DV: Desire to Relinquish Care		
Predictor	ΔR^2	**β**
Step 1	.010	
Age		.016
Minority		-.056
Employed		-.011
Health		.041
Adult gender		.037
Step 2	.036**	
Partnered		-.107
Step 3	.009	
Parental		-.135*
Step 4	.000	
Cohabitating		-.003
Step 5	.103**	
Problematic behaviors		.313**
Step 6	.025*	
Perceived stigma		
Devaluation of Consumers subscale		-.060
Devaluation of Families of Consumers subscale		.191**
Total R^2	.184**	
F	5.581**	
N	285	

Note. Beta weights listed are from the full model (through step 6)
*$p < .05$ ** $p < .01$

Specific aims four and five. Given the support for specific aim three, wherein perceived stigma significantly predicted desire to relinquish care, specific aims four and five respectively investigated whether the individual variables of caregiver age or caregiver sense of mastery moderated the impact of perceived stigma on desire to relinquish care. Due to its sole significance in the regression analysis evaluating stigma, the Devaluation of Families of Consumers subscale of the Devaluation and Discrimination scale served as the IV (perceived stigma) in the moderation equation. For those variables that were transformed for the main study regression analysis, the transformations were used (and centered, where appropriate) in the moderation analysis.

Moderation tests whether the regression coefficient of one IV varies over the range of another predictor. The IV (perceived stigma) and moderating variables (caregiver age and mastery) were centered prior to moderation analysis to reduce problems with multicollinearity. Centering converts values to deviation scores such that each variable has a mean of zero (Aiken & West, 1991). According to Tabachnick and Fidell (2013), centering an IV does not impact variable intercorrelations but does influence the IV interactions that are included in the moderation analysis. Centering DVs is not necessary (Tabachnick & Fidell, 2013). Interaction terms were calculated by multiplying the IV by each of the hypothesized moderators (i.e. perceived stigma X age, perceived stigma X mastery). Independent and moderating variables, as well as interactions terms, were inspected for accuracy and multicollinearity.

H_4. Perceived stigma will have less impact on desire to relinquish care for older caregivers than for younger caregivers. To test hypothesis 4, moderation analysis was conducted by regressing the DV on the centered IV (stigma), the centered moderating variable (age), and the interaction term (stigma X age), which were entered into the regression equation in that order. After step 3, with all variables/terms in the age moderation model, $R^2 = .069$, $F_{inc}(1, 281) = 2.717$, $p = .10$. Addition of the interaction term did not explain a significant amount of variance in the DV, therefore age did not moderate perceived stigma, and hypothesis 4 was not supported.

$H_{5.}$ Perceived stigma will have less impact on desire to relinquish care for caregivers who score high on the mastery scale than for those with lower scores. A similar regression analysis tested mastery as a moderating variable between perceived stigma and the DV, with stigma, mastery, and the interaction term (mastery X stigma) progressively stepped into the model. After the addition of the interaction term, R^2 = .054, F_{inc} (1, 281) = .417, p = .519. The mastery X stigma interaction term did not significantly increase the amount of variance explained by the model, indicating that mastery did not moderate between perceived stigma and desire to relinquish care. As such, hypothesis 5 was not supported. Table 26 summarizes moderation analysis results.

Table 26

Regression Analysis of Hypothesized Moderation Variables

DV: Desire to Relinquish Care

	B	SE B	β	sr^2 (Incremental)	R^2	Adjusted R^2
Perceived stigma	.034	.009	.233		.058**	.054
Age	.032	.027	.069	.002	.060	.053
Stigma X age	.016	.009	.097	.009	.069	.059
N=285						
Perceived stigma	.033	.009	.224		.058**	.054
Mastery	-.011	.009	-.078	.005	.062	.056
Stigma X mastery	.002	.002	.038	.001	.064	.054
N=285						

$^{**}p < .01$

Specific aim six. The sixth aim of the study was to determine whether caregivers' perceived social support mediates in the relationship between stigma and desire to relinquish care.

H_6. Perceived social support will mediate between perceived stigma and desire to relinquish care, such that the association between perceived stigma and desire to relinquish care will be lower for individuals who have higher levels of perceived social support. A series of regression models put forward by Baron and Kenny (1986) were analyzed to test for the potential mediating impact of social support. In the mediation analysis, the Devaluation of Families of Consumers subscale served as the IV (perceived stigma), and the transformed version of social support (square root) was the mediating variable. Data cleaning procedures confirmed the assumptions of mediation: normality and multivariate normality, multicollinearity, and homoscedasticity. An initial regression equation determined that the IV (stigma) had a significant impact on the DV ($\beta = .240$, $p < .001$). A second equation confirmed that the IV had a significant effect on the hypothesized mediator (social support) ($\beta = .226$, $p < .001$). Next, regression analysis was run to ensure that the presumptive mediator had a significant impact on the DV, controlling for the IV (perceived stigma). It is in this step of the mediation analysis that the conditions were not met, as social support did not have a significant impact on desire to relinquish care after controlling for the effect of perceived stigma ($\beta = .026$, $p = .656$). Therefore, the hypothesized mediating relationship of social support was not supported.

Summary of Findings

Findings relative to the study hypotheses are summarized in Table 27.

Hypothesis 1.1. Study findings indicate that caregivers who are partnered have lower desire to relinquish care than single caregivers ($\beta = -.197$, $p < .01$). Partnership status accounted for 4% of the regression model, and hypothesis one was supported.

Table 27

Summary of Study Findings

Hypothesis	**Supported**
1.1. Single caregivers will have more desire to relinquish care than partnered caregivers.	Yes
1.2. Parental caregivers will have stronger desire to relinquish care than other kin relationships.	No
1.3. Caregiver desire to relinquish care will be stronger when dyad members cohabitate.	No
2. Care recipient problematic behaviors will predict caregiver desire to relinquish care such that increased problematic behaviors will be associated with more desire to relinquish care.	Yes
3. Perceived stigma will predict desire to relinquish care such that caregivers with higher levels of perceived stigma will have more desire to relinquish care.	Yes
4. Perceived stigma will have less impact on desire to relinquish care for older caregivers than for younger caregivers.	No
5. Perceived stigma will have less impact on desire to relinquish care for caregivers who score high on the mastery scale than for those with lower scores	No
6. Perceived social support will mediate between perceived stigma and desire to relinquish care, such that the association between perceived stigma and desire to relinquish care will be lower for individuals who have higher levels of perceived social support.	No

Hypotheses 1.2 and 1.3. Neither caregiver parental status ($F_{\text{inc}}(1, 277) = 2.68, p = .103$) nor the caregiving dyad cohabitation status $F_{\text{inc}}(1, 276) = .093, p = .761$) increased the predictive ability of the regression equation for desire to relinquish care. The hypotheses that parental ($H_{1.2}$) and cohabitating ($H_{1.3}$) caregivers would have stronger desire to relinquish care were not supported.

Hypothesis 2. Analysis results indicated that problematic behaviors significantly predicted caregivers' desire to relinquish care for their loved ones with SMI. This step in the model accounted for 10.3% of the model, and hypothesis 2 was fully supported.

Hypothesis 3. Perceived stigma, when added to the regression equation, significantly increased the amount of variance in the DV explained by the model ($\Delta R^2 = .025$). Of note was the importance of caregivers' perceptions of courtesy stigma, as measured by the Devaluation of Families of Consumers subscale, as a significant predictor within the model ($\beta = .191$, $t = 2.801$, $p < .01$). Within the study sample, caregivers typically expressed higher perceptions of mental illness stigma directed toward consumers (i.e. persons with mental illness) than of courtesy stigma directed toward families. However, this direct stigma, as measured by the Devaluation of Consumers subscale, was not a significant predictor of desire to relinquish care.

Hypotheses 4 and 5. The study results did not support the hypothesized moderating relationships of caregiver age (H4) or mastery (H5). In separate regression analyses for moderating effects, neither interaction term, stigma X age or stigma X mastery, proved significant within the analysis.

Hypothesis 6. The investigation into the mediating relationship of caregiver social supports indicated that while perceived stigma had a significant effect on social support ($\beta = .226$, $p < .001$), social supports did not have the requisite impact on desire to relinquish care after controlling for the effects of perceived stigma. As the moderator did not meet the prerequisites for mediation analysis, hypothesis six was unsupported.

Chapter 5: Discussion

Chapter Introduction

This chapter provides a discussion of the research findings, including theoretical and practical implications of the study and recommendations for future research. The chapter also includes a summary of study limitations, followed by conclusions.

Overview

Caregiving can be stressful, and caregivers' health and well-being may be impacted by the roles and responsibilities they take on as caregivers. This work builds on existing research concerning the caregiver stress process and expands the research base by exploring mental illness stigma as a stressful part of SMI caregiving. The intent of this study was to call attention to care relinquishment as an under-studied stress process outcome and to explore stress factors, with a focus on mental illness stigma, that contribute to SMI caregivers' desire to relinquish care. The results of this study indicate that the stressors to which they are exposed as SMI caregivers affect older adults' lives. Constant, years-long exposure to the stress of caregiving is likely to be emotionally and mentally exhausting. Many sampled caregivers felt as though their lives would be improved if they relinquished their caregiving roles. Occupying an unwanted role can also be burdensome for aging caregivers, and time and attention devoted to roles they consider onerous can detract from their self-care capacities.

Study Results

Caregiving context. The average age of the current study's sample was 60, and almost a third of respondents were over the age of 65. On average, caregivers in this study had been providing care for more than 12 years, with 1 in 5 respondents occupying the caregiving role for more than 20 years, and 6% having provided care for over three decades. The adults with SMI for whom respondents were caring had been ill for an average of 18 years. These statistics reflect the decades-long implications of caring for someone with SMI and underscore the differences between this and other caregiving populations where care recipients may not live as long with an illness diagnosis (e.g. Alzheimer's disease) or the need for caregiving subsides (e.g. curable illnesses, injuries). This study confirms that SMI caregivers are a unique population that merits specific inquiry to understand how their caregiving roles mesh with the aging experience.

Background variables. An aim of this study was to investigate the influence of background and contextual variables on the caregiving stress process. The analysis included the demographic variables of caregiver age, race, employment status, health, and care recipient gender, none of which were significant predictors of desire to relinquish care. Of note, however, were the significant negative correlations between caregiver health and exposure to problematic behaviors, and between caregiver health and courtesy stigma perceptions. These findings are in line with prior research associating increased stressors with negative caregiver health outcomes (Aschbrenner, Greenberg, & Seltzer, 2009; Gallagher & Mechanic, 1996; Ghosh & Greenberg, 2009; Pearlin, Mullan, Semple, & Skaff, 1990). Healthier caregivers may be better positioned to combat caregiving stressors and may have access to different psychosocial resources than those in poor health.

Relationships between the contextual background of caregiving and relinquishment desire were also investigated. Caregivers' partnered status predicted desire to relinquish care, while being a parent of or cohabitating with the care recipient did not. Caregivers who were partnered reported less relinquishment desire. One explanation could be that partnered caregivers perceived or received more support than single caregivers, thus reducing the burden of caregiving and reducing relinquishment desire. Additional work is needed to investigate the specifics of these partnerships and to clarify their influence on care relinquishment.

Study results show that cohabitation of the caregiver with the adult for whom they provide care did not predict desire to relinquish care. However, more than half of the sampled caregivers live with the person for whom they provide care, an indication that the caregiver may occupy an around-the-clock caregiving role without respite from associated stressors. In those dyads who were not cohabitating, two thirds of the adults with SMI lived in private homes or supported housing, numbers that speak to the fact that caregivers continue to provide care to their loved ones with SMI even when they live separately and/or have formal supports. This study confirms that caregiving contextual and background factors are important considerations in this population's stress processes.

Problematic behaviors as a stressor. Caregivers expend considerable time and energy dealing with the problematic behaviors that individuals with SMI often exhibit (Tessler & Gamache, 2000). For example, the constant vigilance required monitoring a mentally ill person's violent or suicidal behaviors, or the lack of sleep incurred due to nighttime disturbances can be mentally, emotionally, and physically taxing for caregivers. Results from this study establish problematic behaviors as predictive of SMI caregivers' desire to relinquish care. These results mirror previous research with caregivers of individuals with Alzheimer's disease, which identified problematic behaviors as predictive of desire to relinquish care for a loved one with dementia (Morycz, 1985). However, differences in residential and community care options for persons with SMI and Alzheimer's are considerable and are likely to influence relinquishment desire. In 2010, 17% of all residential long-term care communities had dementia special care units containing 342,700 beds reserved for individuals with dementia (Park-Lee, Sengupta, & Harris-Kojetin, 2013). While memory care units are gaining popularity, the number of psychiatric beds is dropping, with just under 38,000 beds currently in U.S. state psychiatric hospitals (Fuller, Sinclair, Geller, Quanbeck, & Snook, 2016). While not every person with SMI will need inpatient psychiatric hospitalization, research indicates that the reductions in psychiatric beds are associated with increased pressures on hospital emergency departments and families to provide care (Fuller, Sinclair, Geller, Quanbeck, & Snook, 2016). Housing type has been shown to influence social supports, employment, reliance on public systems, and global functioning of individuals with SMI (Browne & Courtney, 2004; Martinez & Burt, 2006; Moxam, 2000). Barriers to supportive SMI housing include its scarcity, affordability, perceptions about its locale, and lack of public housing voucher access for the SMI population (Angermeyer et al., 2003; K. Ashby, personal communication, 2015; Hatfield & Lefley, 2000; Karaim, 2002; Lefley, 1989; NAMI, 2017). Individuals with SMI may also face admission barriers into medical models of residential care (e.g. nursing homes, assisted living communities) (Lane, McCoy, & Ewashen, 2010). Availability and accessibility of appropriate community housing options for adults with SMI are important considerations for future research into both cohabitation and relinquishment decisions for this caregiver population. Given the potential for mental illness stigma to impede entry into certain types of care and housing, it is an important aspect of accessibility as well, since the existence of these services may not equate to access for persons with SMI.

This study's findings indicate that exposure to their loved one's problematic behaviors is stressful for caregivers. Problematic behaviors were negatively correlated with caregiver health, sense of mastery, and social support levels, and positively correlated with desire to relinquish care. These results point to the need for supportive services that help caregivers cope with their loved ones' problematic behaviors. Appropriate supportive services could include programs that teach caregivers problem-solving techniques, including methods for defusing, responding to, and coping with problematic behaviors. These services are available in some communities through grass-roots organizations such as the National Alliance on Mental Illness (NAMI) and Mental Health America. However, services are constrained by funding and resources and are especially limited in rural areas.

Stigma as a stressor. Mental illness stigma is multi-faceted. Direct, or consumer stigma, is aimed directly at persons living with mental illness. Stigma may also be directed toward persons affiliated with those who have mental illness in a phenomenon known as courtesy stigma. Perceived stigma refers to individuals' beliefs about the existence of stigmatizing social attitudes regarding mental illness. Respondents in this study overwhelmingly believed that most people directly stigmatize mental illness, a result that is in line with decades of mental illness stigma research following Goffman's (1963) work on stigma. Important findings from this study are that SMI caregivers believe that they will be subjected to courtesy stigma, and that caregivers' perceptions of courtesy stigma are predictive of their desire to relinquish care. While perceptions of stigma are subjective and may not represent actualized stigmatization, the fear of being stigmatized may influence both caregiver behaviors and caregivers' feelings toward their caring responsibilities, thus potentially being as troublesome as actual stigmatization. The results of this study point to the need for courtesy stigma education programs. While anti-stigma initiatives exist, they tend to focus on reducing stigma toward individuals with the stigmatized 'mark.' Raising awareness of the phenomenon of courtesy stigma, especially via groups and publications that routinely interact with individuals who have or may become targets of courtesy stigma (e.g. NAMI, Mental Health America), can foster an understanding of this phenomenon and inform programs and practices to help prevent it and/or manage its effects.

Care relinquishment as a stress outcome. In the current analysis, almost two thirds of caregivers indicated some desire to relinquish their caregiving responsibilities, and 45% indicated that they would be better off after relinquishing care. Conversely, only 23% of caregivers thought that their loved one would be better off if the caregiver relinquished care. These numbers, coupled with the fact that only a small percentage (7%) of sampled caregivers reported being "likely to relinquish care," may indicate the amount of burden caregivers are willing to shoulder in order to support their loved one with SMI and protect them from additional difficulties that might derive if caregivers relinquish their care responsibilities. This study supports the use of care relinquishment as a predictable outcome of stress within the Stress Process Model of Caregiving (SPM). It also suggests the need for future investigation into additional SMI caregiving stress process factors that might add predictive ability for relinquishment desire.

An exception to the expected hierarchy of Desire to Relinquish (DTR) scale responses occurred when a smaller number (7%) of sampled caregivers responded that they were likely to relinquish care than the number (20%) indicating that they had taken steps toward care relinquishment. This may reflect barriers that caregivers encountered as they took action toward care relinquishment (e.g. lack of suitable housing options or caregiver emotional reactions to care relinquishment), which led them to understand that they were unlikely to actually stop care provision. Further investigation of this this discrepancy is warranted.

A substantial number of caregivers reported no desire to relinquish care. While these reports may reflect an actual absence of desire, responses may have also been biased by survey respondents' difficulty admitting to themselves or to researchers that they have some desire to stop providing care for their loved ones. This admission could be especially difficult for parents, who typically feel a unique responsibility for ensuring their child's well-being. Qualitative studies of SMI caregivers who have relinquished care are needed to shed light on the lived experience of care relinquishment for this population. That said, recruitment for studies of this type is difficult due to the sensitive and personal nature of care relinquishment decisions.

This study acknowledges that care relinquishment is a valid and appropriate option for some caregivers. Researchers investigating care relinquishment for this population should be careful not to imply that care relinquishment is always an undesirable stress outcome. Caregivers who fear being judged or stigmatized for their relinquishment decisions may incur additional stressors in trying to provide care beyond their capacities. These stressors can result in negative outcomes for both parties in the caregiving dyad, as well as for other members of the caregiver's extended social and familial networks. While there is evidence that caregivers and the adults they care for accrue emotional and practical rewards from the caregiving relationship (Aschbrenner, Greenberg, Allen, & Seltzer, 2010), there is also the potential for improved quality of life for either or both parties when caregivers relinquish care (Aneshensel, Pearlin, Mullen, Zarit, & Whitlatch, 1995; Morycz, 1985). Longitudinal studies with this caregiver population are needed to investigate both positive and negative caregiver outcomes of care relinquishment decisions.

Psychosocial resources. As noted, sample respondents were age 60 on average, with roughly a third of respondents over the age of 65. Older adults may be especially vulnerable to caregiving stressors as they experience age-associated changes (e.g. changes in social networks, health problems, less income) concurrently with their caregiving responsibilities. While the hypothesized effects of mastery and social supports were not supported, data illuminated several important relationships. Study results show that perceived mental illness stigma may contribute to older caregivers' social isolation, in that perceived stigma was associated with reductions in social support levels. Increased perceptions of stigma were also associated with lower sense of personal mastery, which may influence older adults' real or perceived capacity for self-care.

Limitations

While steps were taken to ensure the validity of this research, the study is not without its limitations. Survey participants were not randomly selected, but recruited through NAMI state and local affiliates. As such, sampled caregivers may have differed in ways salient to the study (e.g. sense of mastery, social support levels) from persons not connected to NAMI; these differences may have impacted study results. Within this study's sample, age was not significantly associated with health, perceptions of stigma, sense of mastery, or levels of social support. These findings may be influenced by the study's sampling strategy. The use of convenience sampling resulted in low diversity within the sample. A majority of survey respondents were in good health, college-educated, partnered, and white. Only five caregivers sampled in this study reported being in ‘bad’ or ‘very bad’ health. As this study included only current caregivers, it may have excluded caregivers who have already relinquished care due to their poor health. Increased health diversity in a future sample may be better suited for an investigation into caregiver well-being as a predictor of care relinquishment. The uniformity of the convenience sample also limited the study's ability to investigate differences in perceptions of stigma among caregivers of different ethnicities or education levels. More diverse samples are needed to better identify age-related differences among caregivers and may reveal subcultural differences in both perceptions of SMI stigma and attitudes toward relinquishment.

Data from this study did not support the hypothesis that perceived stigma would be less influential over older (versus younger) caregivers' relinquishment desire. The research design may have influenced this finding. Socioemotional selectivity theory (SST) posits that older adults use situation selection as a way to avoid socially toxic or damaging relationships (Carstensen, Gross, & Fung, 1997). Caregivers who may have already relinquished care (i.e. selected a new situation) were not eligible for the current study. Their exclusion may have impacted the analysis of age as a moderating factor between perceived stigma and relinquishment desire. Similarly, SST's positivity effect, wherein older adults have better recall of and focus on positive (versus negative) information, may have influenced survey results. When asked questions about problematic behaviors, perceptions of stigma, and social supports, older caregivers may have been biased toward more positive responses, thereby influencing analysis results.

Additionally, it is not possible to know how many people received survey emails or saw the survey on social media, so calculating a study response rate is not feasible. Study participants were self-selected, which can create sampling bias because only caregivers with certain views or qualities may choose to participate. That the survey was solely available online also creates sampling bias, as technology users may be different in some ways from their counterparts. Smith (2014) found that 41% of adults 65 and older do not use the internet. Older adults who do go online tend to be younger, more highly educated, and more affluent; non-users often have significant health challenges (Smith, 2014). Self-report bias is also a study limitation, as participants may not have been fully forthcoming in their responses given the sensitivity of care relinquishment decisions. The results of this study are not generalizable to the entire population of SMI caregivers, but to caregivers in the eastern United States with some connection (not necessarily membership) to NAMI or a similar mental health advocacy organization.

Other limitations derive from the study's cross-sectional, correlational design. On average the caregivers in this study had been providing care for more than a decade; it is possible that care relinquishment desire peaks (or actual relinquishment occurs) earlier in the caregiver role trajectory. In addition, the dependent variable in this study, desire to relinquish care, may not predict actual care relinquishment. Longitudinal research is needed to confirm the connection between desire and realized relinquishment decisions and future projects may want to include caregivers who are in earlier stages of their caregiving careers. Due to its correlational design, the study does not establish causal relationships, so it is not clear whether perceived mental illness stigma influences levels of social supports and mastery or vice versa. Future research may shed light on the directionality of these relationships.

Not every potential predictor for care relinquishment desire was considered in the current study. The accuracy of regression analysis results is impacted by the absence of relevant variables from the equation (Tabachnick and Fidell, 2013). As this is the first study of this population using desire to relinquish care as the DV, there may have been some important variables missing. Qualitative studies of SMI caregivers who currently desire to relinquish care, or who have already relinquished care, may shed light on additional factors for future consideration. Longitudinal studies focusing on specific caregiving dyads could illuminate the long-term impacts of courtesy stigma and care relinquishment on both the caregiver and the adult with SMI.

Conclusion

This study is the first to apply the SPM in an attempt to understand how stressors such as social situation and support, care recipient problematic behaviors, and perceived stigma influence caregiver outcomes, specifically their desire to relinquish care. The project contributes to gerontological research by exploring relationships among stressors facing older caregivers of persons with SMI. The impact of these stressors may be enhanced among older caregivers due to their concurrence with other age-associated circumstances that can cause stress. Study data confirm that older SMI caregivers occupy caring roles for long periods of time, that they are sensitive and reactive to mental illness stigma, and that stigma is associated with reduced caregiver psychosocial resources. These findings are important indicators of the difficulties facing older adults who provide SMI care.

Stress is an individual experience, yet there are common trajectories within the caregiving career that are predictable using existing stress process models. Understanding these trajectories is a first step in identifying critical points in the caregiving path where interventions would be helpful. This study provides information that can inform the development of educational and supportive services that may help caregivers better cope with the stressors associated with SMI caregiving, thereby supporting them in their caring roles, and potentially obviating or justifying difficult care relinquishment decisions. With caregiving stressors diminished, older caregivers will be able to better apply their resources toward self-care and maintaining their own quality of life. Less stress for caregivers may also imply an enhanced capacity for caregiving, a win-win situation for both parties of the SMI caregiving dyad.

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Appendix A

Study Recruitment Materials

Email for NAMI Affiliate Directors:

Subject line: Caregiver stress research project
Body:
Dear [NAMI Affiliate Director],

My name is Tyler Corson, and I am a member of the NAMI Virginia Beach affiliate. I am also a former student of and current facilitator for NAMI's Family-to-Family class. I am currently working on my PhD at VCU in the Gerontology department, and my research interests concern stressors facing older caregivers who provide care support for adults with severe mental illness. I am specifically interested in information about caregivers' perceptions of stigma and their thoughts about continuing in their caregiving roles.

To gather research data for my dissertation, I have an online survey that I would like to distribute to caregivers of adults with mental illness. I know that NAMI affiliates sometimes send out research survey links, and I wondered if you might consider distributing information about and a link to my survey in your newsletter and/or on your website. I am attaching a .pdf file of a short description of the research that could be included in your newsletter.

The ultimate goal of my research is to identify points in the caregiving stress process where targeted interventions might help alleviate stressors and enhance caregivers' capacity for care. I will certainly be happy to share the results of my research with your affiliate when it is complete.

The VCU Office of Research Subjects Protection has granted IRB approval for this study [Study #HM20008818]. The survey is completely anonymous, and takes about 15 minutes to complete. If you have any questions or concerns about this study, please email me at corsontr@vcu.edu or my dissertation supervisor, Dr. Tracey Gendron at tlgendro@vcu.edu

Thank you very much for considering my request. I will follow up in a week or so to see if you have any questions about my work.

Warm regards,

Tyler Corson, MS Gerontology

Draft of newsletter recruitment blurb:

Headline: Caregivers Needed for Stress Research Survey

Tyler Corson, a doctoral student at Virginia Commonwealth University and NAMI family member in Virginia Beach, is working on a research study about caregiver stress. If you are a caregiver for a person with serious mental illness, you are invited to participate in an anonymous online survey that takes about **15 minutes** to complete. The survey includes questions about mental illness stigma and your thoughts about providing care. Your participation in this survey will help us gather information that may be helpful in designing programs to reduce caregiver stress. Tyler will share the research results with NAMI when the study is complete.

Please follow this link to the survey: https://redcap.vcu.edu/surveys/?s=KDXHDYDT8X

Please pass the survey link on to other caregivers of persons with mental illness!

Appendix B

Study Recruitment Flyer

Research Study
Virginia Commonwealth University
Department of Gerontology

This study investigates caregivers’ experiences providing care for their loved ones with serious mental illness, including caregivers’ ability and desire to continue providing care. We are also interested in caregivers’ opinions about mental illness stigma.

Who is Eligible?

- **Current or former caregivers of adults with serious mental illness**
- **Does NOT include caregivers of persons with Alzheimer’s or dementia**

What will you be asked to do?

- **Participate in an anonymous online caregiver survey about your caregiving experience (takes about 15 minutes)**

Compensation

- **There is no direct compensation for your participation**
- **The information you provide may help in the development of future caregiver support programs**

Questions? Please contact:
Tyler Corson (703) 678-6876 or Email: corsontr@vcu.edu

CAREGIVER SURVEY https://redcap.vcu.edu/surveys /?s=KDXHDYDT8X	CAREGIVER SURVEY https://redcap.vcu.edu/surveys /?s=KDXHDYDT8	CAREGIVER SURVEY https://redcap.vcu.edu/surveys /?s=KDXHDYDT8	CAREGIVER SURVEY https://redcap.vcu.edu/surveys /?s=KDXHDYDT8	CAREGIVER SURVEY https://redcap.vcu.edu/surveys /?s=KDXHDYDT8	CAREGIVER SURVEY https://redcap.vcu.edu/surveys /?s=KDXHDYDT8	CAREGIVER SURVEY https://redcap.vcu.edu/surveys /?s=KDXHDYDT8	CAREGIVER SURVEY https://redcap.vcu.edu/surveys /?s=KDXHDYDT8

Appendix C

Devaluation and Discrimination Scale Questions

Likert scale scoring 1-4: strongly disagree, disagree, agree, strongly agree

Item[1]
1. Most people would not accept a person who once had a serious mental illness as a close friend.[2]
2. Most people think that a person with serious mental illness is dangerous and unpredictable.
3. Most people feel that having a mental illness is worse than being addicted to drugs.
4. Most people look down on someone who once was a patient in a mental hospital.
5. Most employers will not hire a person who once has a serious mental illness if he or she is qualified for the job.[2]
6. Most people think less of someone who has been a patient in a mental hospital.
7. Most people feel that entering psychiatric treatment is a sign of personal failure.
8. Most young women would not marry a man who has been treated for a serious mental disorder.
9. Most people in my community would rather not be friends with families that have a relative who is mentally ill living with them.
10. Most people believe that parents of children with a mental illness are not as responsible and caring as other parents.[2]
11. Most people look down on families that have a member who is mentally ill living with them.
12. Most people believe their friends would not visit them as often if a member of their family were hospitalized for a serious mental illness.
13. Most people would not treat families with a member who is mentally ill the same way they treat other families.[2]
14. Most people blame parents for the mental illness of their children.[2]
15. Most people would rather not visit families that have a member who is mentally ill.

[1] Items 1-8 constitute the Devaluation of Consumers Subscale; items 9-15 constitute the Devaluation of Consumer Families Subscale

[2] Reverse item in analysis

Appendix D

Pearlin Mastery Scale

The following questions are about how you see yourself as a person. How strongly do you agree or disagree with each of the following statements?

Response categories: 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree

Item[1]
1. There is really no way I can solve some of the problems I have.
2. Sometimes I feel I'm being pushed around in life.
3. I have little control over the things that happen to me.
4. I can do just about anything I really set my mind to.
5. I often feel helpless in dealing with the problems of my life.
6. What happens to me in the future mostly depends on me.
7. There is little I can do to change many of the important things in my life.

[1] Items 1, 2, 3, 5, and 7 are reverse coded.

Appendix E

Online Survey Information Sheet

You are invited to participate in a research study about the impacts of providing care to adults with serious mental illness. Tyler Corson, MSG from the Department of Gerontology at Virginia Commonwealth University is conducting this study.

In this study you will be asked to answer questions about your experiences and feelings about caring for your loved one with mental illness. Sometimes thinking about these feelings can cause people to become upset. You do not have to answer any questions that you do not want to answer, and you are free to stop the survey at any time.

You may not get any direct benefit from this study, but, the information we learn from people in this study may help us design better programs for caregivers and their loved ones. There are no costs to participate in the study.

This survey is anonymous and no IP addresses will be collected. No one will be able to identify you or your answers, and no one will know whether or not you participated in the study. Should the data be published, no individual information can or will be disclosed.

QUESTIONS? If you have any questions or concerns while completing the survey, please feel free to contact **Tyler Corson at corsontr@vcu.edu**

If you have any questions, complaints, or concerns about your participation in this research, contact:

Dr. Tracey Gendron
Department of Gerontology
730 E. Broad Street
P. O. Box 980228
Richmond, VA 23298-2018
Phone: (804) 828-1565
E-mail: tlgendro@vcu.edu

The researcher/study staff named above is the best person(s) to call for questions about your participation in this study.

If you have any general questions about your rights as a participant in this or any other research, you may contact:

Office of Research
Virginia Commonwealth University
800 East Leigh Street, Suite 3000
P.O. Box 980568
Richmond, VA 23298
Telephone: (804) 827-2157

You may also contact this number to ask general questions, to obtain information or offer input, and to express concerns or complaints about research. You may also call this number if you cannot reach the research team or if you wish to talk with someone else. General information about participation in research studies can also be found at http://www.research.vcu.edu/human_research/volunteers.htm.

Your participation in this study is voluntary. By completing this survey, you indicate that you have read and fully understand the above information.

Appendix F

Survey for Caregivers of Adults with Serious Mental Illness

Construct	**Item**	**Required?**	**Response Coding**
Screening Questions	1. Do you **currently** provide **unpaid** care for a relative or friend (over 18 years of age) who has been professionally diagnosed with mental illness? This care might include helping with personal needs or household chores. It could also mean managing a person's finances, visiting them to see how they are doing, or arranging for outside services. **[if no, branch to Q66]**	Yes	0=No 1=Yes
	2. Is your loved one's **only** mental illness diagnosis substance abuse disorder	Yes	0=No 1=Yes
	3. Is your loved one's **only** mental illness diagnosis Alzheimer's disease or another dementia?	Yes	0=No 1=Yes
Caregiver Demographics	4. What is your age?	Yes	Years
	5. Please specify your race/ethnicity:	No	1=White 2=Black/African American 3=AIAN 4=Asian 5=Latino Hispanic 6=Prefer not to answer 7=Other
	6. What state do you live in?	No	State
	7. What is your gender?	No	1=Male 2=Female
	8. Which category best describes your employment status?	No	1, Employed, working 40 or more hours per week 2, Employed, working 1-39 hours per week 3, Not employed, looking

			for work 4, Not employed, NOT looking for work 5, Retired 6, Disabled, not able to work
	9. How many years of schooling have you completed? (For example: 8th grade=8; high school or GED=12; college=16)	No	Years
	10. How would you rate your own health?	No	1, very bad 2, bad 3, fair 4, good 5, very good
	11. The person you are caring for is your:	No	1, Son 2, Daughter 3, Sister 4, Brother 5, Mother 6, Father 7, Wife 8, Husband 9, Partner/Companion 10, Aunt 11, Uncle 12, Grandmother/Grandmother-in-law 13, Grandfather/Grandfather-in-law 14, Granddaughter 15, Grandson 16, Niece 17, Nephew 18, Sister-in-law 19, Brother-in-law 20, Friend 21, Other, please specify
	12. How many years have you been providing care for your [relation] since he or she first started	No	Years

	having symptoms of mental illness? (If less than one year, please enter 0)		
	13. How many total people, including you, live in your home?	No	Number of persons
	14. What is your marital status?	No	1, Married or Partnered 2, Separated or Divorced 3, Widowed 4, Never Married or Partnered
Care Recipient Demographics	15. How old is your [relative]?	No	Years
	16. What is the PRIMARY mental illness diagnosis of the person you are caring for? (Your loved one may have multiple conditions, but please indicate the MAIN mental health problem)	Yes	1, Anxiety disorder 2, Bipolar disorder 3, Borderline personality disorder 4, Depression 5, Eating disorder (Anorexia, Bulimia, Binge Eating Disorder) 6, Hoarding 7, Multiple Personality Disorder 8, Obsessive-compulsive disorder (OCD) 9, Panic Disorder 10, Personality Disorder 11, Phobia 12, Post-Traumatic Stress Disorder (PTSD) 13, Schizoaffective disorder 14, Schizophrenia 15, Schizophreniform Disorder 16, Other, please specify
	17. Where does your [relation] live?	No	1, with me 2, independently in private home or apartment 3, in supported housing (for example, in assisted living or a group home) 4, moves from place to place with friends or family 5, homeless

			6, other, please specify
	18. How many years has your [relative] been ill? (Note: This may be longer than the time your [relative] has been formally diagnosed with mental illness.) [If less than one year, please enter zero.]	No	Years
Problematic behaviors	How often do you personally have to deal with the following behaviors of your relative?		1, never 2, rarely 3, sometimes 4, quite frequently 5, nearly always
	19. Attention-seeking behaviors, including excessive demands on your time and attention, interrupting your activities, calling you on the phone, or other actions that bother you and take up your time	Yes	
	20. Embarrassing behaviors, including improper sexual behaviors, poor personal grooming habits, inappropriate language, bizarre movements, or other actions that embarrass you in public or in front of company	Yes	
	21. Disturbing you or your household at night	Yes	
	22. Alcohol abuse	Yes	
	23. Violence or threats of violence	Yes	
	24. Drug abuse	Yes	
	25. Threats of suicide or suicide attempts	Yes	
Perceived Stigma	Please indicate how strongly you agree or disagree with the following statements:		1, strongly disagree 2, disagree

*Reverse item in analysis			3, agree 4, strongly agree
	26. Most people would accept a person who once had a serious mental illness as a close friend. *	Yes	
	27. Most people think that a person with serious mental illness is dangerous and unpredictable.	Yes	
	28. Most people feel that having a mental illness is worse than being addicted to drugs.	Yes	
	29. Most people look down on someone who once was a patient in a mental hospital.	Yes	
	30. Most employers will hire a person who once has a serious mental illness if he or she is qualified for the job. *	Yes	
	31. Most people think less of someone who has been a patient in a mental hospital.	Yes	
	32. Most people feel that entering psychiatric treatment is a sign of personal failure.	Yes	
	33. Most young women would not marry a man who has been treated for a serious mental disorder.	Yes	
	34. Most people in my community would rather not be friends with families that have a relative who is mentally ill living with them.	Yes	
	35. Most people believe that parents of children with	Yes	

	a mental illness are just as responsible and caring as other parents. *		
	36. Most people look down on families that have a member who is mentally ill living with them	Yes	
	37. Most people believe their friends would not visit them as often if a member of their family were hospitalized for a serious mental illness.	Yes	
	38. Most people would treat families with a member who is mentally ill the same way they treat other families. *	Yes	
	39. Most people would not blame parents for the mental illness of their children. *	Yes	
	40. Most people would rather not visit families that have a member who is mentally ill.	Yes	
Mastery Scale *Reverse item in analysis	Please indicate how strongly you disagree or agree with the following statements:		1, strongly disagree 2, disagree 3, agree 4, strongly agree
	41. There is really no way I can solve some of the problems I have. *	No	
	42. Sometimes I feel I’m being pushed around in life. *	No	
	43. I have little control over the things that happen to me. *	No	
	44. I can do just about anything I set my mind to.	No	
	45. I feel helpless in dealing with the problems of my	No	

	life. *		
	46. What happens in the future depends mostly on me.	No	
	47. There is little I can do to change many of the important things in my life. *	No	
Social Support	Do you have someone who lives outside your home that:		0=No 1=Yes
	48. ...would take care of your home while you are out of town?	No	
	49. ...you talk to about work or other life issues?	No	
	50. ...helps you with household tasks (like yard work, cleaning, chores)?	No	
	51. ...you would ask for advice on important decisions?	No	
	52. you socialize with (going to movies, having dinner together, talking on the phone)?	No	
	53. ...you would talk to about your personal worries?	No	
	54. ...you could borrow money from?	No	
	55. ...could take care of your [relate] with mental illness while you are out?	No	
	56. …helps you with the routine tasks of caring for your [relation] with mental illness?	No	
	57. Do you belong to a caregiver support group?	No	
Caregiver Burden	58. Overall, how burdened do you feel in caring for your [relation] with	No	1, not burdened at all 2, slightly burdened 3, somewhat burdened

	mental illness?		4, moderately
Desire to Relinquish Care	59. Have you ever considered giving up all of your care responsibilities for your [relation]?	Yes	
	60. Have you ever felt that you would be better off if you stopped providing care for your [relation]?	Yes	
	61. Have you ever talked to your family, friends, or anyone else about giving up your care responsibilities for your [relation]?	Yes	
	62. Have you ever talked to your [relation] about no longer providing care for him or her?	Yes	
	63. Are you likely to stop providing care for your [relation]?	Yes	
	64. Have you ever taken any steps toward giving up your care responsibilities for your [relation]?	Yes	
	65. Have you ever thought that your [relation] would be better off if you stopped providing care for him or her? **[Branch to Q67]**	Yes	
Prior Relinquishment Decisions	66. In the past, have you ever provided unpaid care for an adult with mental illness? **[if yes, go to question 64]**	No	0,No **(End survey)** 1,Yes
	67. While you were a caregiver, did you ever decide to stop providing care for your loved one? This might have been that you could not or would	No	0,No **(End survey)** 1,Yes

	not continue to provide support due to any number of personal reasons. **[if yes, go to question 68]**		
	68. Why did you stop providing care?	No	1, My loved one no longer needed my assistance. 2, My loved one went to jail/prison. **(End survey)** 3, My loved one left our area and we lost contact. 4, The responsibilities of caregiving were too much for me to manage. 5, I became ill and was no longer able to provide care. 6, My loved one died. **(End survey)** 7, Other, please specify
	69. What happened to the person you were caring for when you stopped providing care? He or she: Select all that apply.	No	1, lived alone or with other people without my help 2, became homeless 3, went to jail/prison 4, lived in supported housing without my help (for example mental health housing, nursing home, assisted living) 5, Other, please specify

Vita

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