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Health and Relationship Variables Impacting Psychological and Social Well-Being Among Predominantly White Middle Class Adults 65 and Older Who Receive Assistance with Their Care from Family Members

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HEALTH AND RELATIONSHIP VARIABLES IMPACTING PSYCHOLOGICAL AND
SOCIAL WELL-BEING AMONG PREDOMINANTLY WHITE MIDDLE
CLASS ADULTS 65 AND OLDER WHO RECEIVE ASSISTANCE
WITH THEIR CARE FROM FAMILY MEMBERS

by

Alyssa C. Ford

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Submitted to the
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Advisor: Mary Z. Anderson, Ph.D.

Western Michigan University
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HEALTH AND RELATIONSHIP VARIABLES IMPACTING PSYCHOLOGICAL AND SOCIAL WELL-BEING AMONG PREDOMINANTLY WHITE MIDDLE CLASS ADULTS 65 AND OLDER WHO RECEIVE ASSISTANCE WITH THEIR CARE FROM FAMILY MEMBERS

Alyssa C. Ford, Ph.D.

Western Michigan University, 2012

The majority of care to persons 65 and older in the United States is provided by family members. Previous research among older adults who receive assistance with their care from family or friends, while sparse, has identified variables that appear to impact the well-being of such persons. These variables include reciprocity, dignity, self-perceived burden, mental health status, and physical health or disability status. However, these variables have not been studied together. The purpose of this dissertation research was to examine these variables individually and collectively as they relate to well-being.

A sample of 71 adults, ages 68 to 97, who receive help or assistance from at least one family member participated in the study. Participants were recruited from senior living communities in Northern Indiana and Southwestern Michigan. Hierarchical regression analyses were utilized to examine the effects of reciprocity, dignity, self-perceived burden, anxiety, depression, and functional impairment on psychological well-being, and on social well-being. The results indicated: 1) Functional impairment, anxiety, depression, reciprocity, dignity, and self-perceived burden collectively impact both psychological and social well-being; 2) Dignity, reciprocity, and self-perceived burden collectively impact social well-being after controlling for depression, anxiety, and

functional impairment; and 3) Reciprocity contributed unique effects to the variance on social well-being. Findings and implications are discussed, and recommendations for future research are provided.

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This dissertation is dedicated to my partner Ben Ford and our daughter, Cordelia. I look forward to giving and receiving the care we will provide to one another throughout our lives, and hope that we continue to do so in ways that are dignifying and uplifting.

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CHAPTER I

REVIEW OF LITERATURE

As life expectancy and the number of older adults in the general population have increased (Werner, 2011), so has the population of older adults living with chronic and/or disabling health conditions (Hill, 2005). Older adults with physical and/or cognitive disabilities frequently rely on family members or close friends to provide assistance and care in addition to the care received by healthcare and other providers. Indeed, the vast majority of care to older adults—about 80%—is provided by family members (Curry, Walker & Hogstel, 2006). The family and friends who provide care are frequently referred to as informal caregivers in the literature, and a growing body of research inquiry has explored this topic area (Gallagher-Thompson & Coon, 2007).

While the experiences of caregivers have been emphasized in prior literature, the perspectives and experiences of care recipients are equally important. The purpose of this review is to provide an overview of previous findings about the experience of receiving care in later adulthood, critically evaluate the existing literature, integrate prior research into a coherent whole, and provide context for the present study. This review ultimately identifies relationship variables of dignity, self-perceived burden, and reciprocity as being the most salient variables that appear to impact the well-being of adults ages 65 and older who regularly receive assistance with their care from family members. The present study also includes exploration of the health variables of functional impairment, depression,

and anxiety on well-being, in an attempt to better understand how the relationship variables impact well-being above and beyond health status.

The following sections are: definitions, scope of the review, giving and receiving care within families, the experience of receiving care, and conclusions. The first three sections illustrate the broad context in which family care relationships occur, while the experience of receiving care section will highlight variables that prior research indicates as being particularly salient among persons age 65 and older who receive care from family members or close friends.

Definitions

The purpose of this section is to define the terms “care” and “family” in regard to this review, as these words have varying definitions across different circumstances and contexts. The way in which each study in this review defines nature of care and what is meant by family is explicitly described throughout the review.

Care. In this review, the term care is used broadly, and refers to a wide range of activities and interpersonal benefits. As is illustrated below, care is defined as assistance or help that addresses physical, psychological, and/or social needs.

Many studies define care as assistance with Activities of Daily Living (ADLs) and/or Instrumental Activities of Daily Living (IADLs), which encompass largely physical needs (e.g. Schumacher, Beck, & Marren, 2006; Newsom & Schulz, 1998). ADLs include bathing, dressing, toileting, being able to get out of bed and into a chair without assistance, continence, and feeding. In addition to basic ADLs, elders may require assistance with Instrumental Activities of Daily Living (IADLs): using the telephone, shopping, food preparation, housekeeping, laundry, transportation, medication

management, and handling one's finances. Beyond ADLs and IADLs, physical care from family members may include medical tasks such as administration of injections, and wound dressing. While exact figures are unknown, estimates indicate that 20% of persons older than 70 and 50% of persons older than 85 have disabilities that interfere with activities of daily living (Hill, 2005).

In addition to these physical needs, an emerging body of evidence is including psychological and social aspects of care as well. This newer body of literature addresses a previously identified gap in the caregiving literature, as Townsend (1993) observed that caregiving had often been defined according to the number of ADLs that care recipients need assistance with. In contrast, phenomena such as supervision, companionship and emotional support were rarely addressed by research studies (Townsend, 1993).

The more holistic emphasis is important, because the full extent of actual family care activities occur within the context of intimate personal relationships that have evolved over time and within a greater social system that includes friends and paid caregivers. Additionally, excluding the interpersonal benefits associated with receiving care ignores the possibility that a caregiver and care recipient are both giving and receiving something of value from one another. Studies that explore constructs such as reciprocity or mutuality (Finch & Mason, 1993; Schumacher et al., 2006; Lyons et al., 2007; Sebern, 2005), provide insight into the role of interpersonal factors in relation to the well-being of persons both providing and receiving care within families.

Family. While family is not generally defined in studies on family caregiving, types of families represented in the literature range from persons related either biologically, or legally by marriage or adoption, to close friends and others not

traditionally considered family. This broad definition is used in this review, as well as in the present study.

One of the limitations of the family care of elders literature is that participants have often been White and presumed to be heterosexual. Another limitation is that caregivers represented have often either been spouses or biological children of care recipients. These limitations makes it difficult to generalize prior research to individuals of color, those who are lesbian or gay, who live with but are not married to romantic partners, or who receive care from close friends.

Pointing out statistically likely care relationships, Thompson (2000) stated that older men requiring care are most likely to be cared for by their wives given that women have longer life expectancies and are more likely to be the younger member of a marriage, and that older women who have been widowed are most often cared for by their adult daughters due in part to a preference for gender constancy as well as gender role socialization. However, certain types of care relationships may be more prevalent among certain individuals according to variables such as gender, race and sexual orientation. The White participants in one study that explored such differences were often married and talked about their spouses providing help or influencing them (Gallant, Spitze, & Prohaska, 2007). In contrast, the Black elders interviewed were more likely to talk about adult children and grandchildren living nearby as well as church-related supports. Likewise, Fredriksen (1999) found gay and lesbian caregivers providing for ill and disabled adults reported that their care recipients were friends (61%), parents (16%), partners (13%), and other biological family members (10%). This finding is reflective that many gay and lesbian persons have “families of choice,” in addition to their families

of origin. Families of choice, church families, and other close social relationships might all be relevant to better understanding family care relationships. Therefore, while this review attempts to be inclusive of all elders and their families, the lack of consideration of multicultural factors and populations in the existing literature places inherent limits on this review.

Scope of the Review: Finding the Voices of Care Recipients

The majority of literature that examines care to elders within families focuses on the experience of providing the care and/or only considers the perspectives of the caregiver. The need for more inclusion of care recipient perspectives in the literature has been repeatedly pointed out by researchers during the last several decades (Horowitz, 1985; Purk & Richardson, 1994; Newsom, 1999; Brewer, 2002; Ready & Ott, 2008; Graham & Bassett, 2006). Rationale for such inclusion includes the perspective that evaluation of patient satisfaction with the care they received is the “ultimate validator” of quality of care (Chen et al, 2006).

From a larger historical perspective, research on caregiving appears to have followed the advent of discussions of caregiving in the popular media in the 1980s in discussions of public policy and long-term care (Zarit, Pearlin, & Schaie, 1993.) Pruchno, Burant, and Peters (1997) noted that the gerontological literature focused more upon the health and well-being of older people prior to the 1980s when a shift occurred that transferred the focus to those providing care to older adults. Many of the articles highlighted in this review refer to the need for more care recipient perspectives in the total literature and thus represent an effort to rebalance the greater body of knowledge and focus of inquiry into later life from across many disciplines, including psychology

(e.g. McPherson, Wilson, & Murray, 2007; Simmons, 2007; Cousineau, McDowell, Hotz, & Hebert, 2003; Newsom, 1999; Purk & Richardson, 1994).

Despite recognition of the lack of care recipient perspectives in the literature, the gap remains and continues to widen as published family care of elders literature continues to primarily focus on caregivers. Purk and Richardson (1994) suggested that one reason this gap exists is due to the number of studies that have focused on caregiving to recipients who are cognitively impaired, such as those with dementia. However, prior research indicates that integrating perspectives from patients with mild cognitive impairment and mild to moderate Alzheimer's disease and their caregivers or other close informants in clinical settings provides a more valid and reliable assessment of patient quality of life than only soliciting information from an informant generates (Ready & Ott, 2008; Menne, Tucke, Whitlatch, & Friss Feinberg, 2008; Russell, Bunting, & Gregory, 1997). Likewise, Menne and colleagues (2008) observed that prior research has indicated that persons with dementia are capable of providing insight into their preferences regarding their own care.

Additionally, Ready and Ott (2008) acknowledge that while data collected from cognitively impaired persons may be distorted by the participants' lack of insight, data provided from caregivers or other informants may be just as distorted due to factors such as their own experience of feeling burdened. Thus, further inquiry is needed to assess the reliability of integrated data gathered from both persons with dementia and one or more informants.

Another barrier to data collection from persons needing care may be related to a lack of accessibility to that population, especially among persons who are homebound

(Geron et al., 2000). Therefore, limited time and financial resources amongst researchers may also help to explain the paucity of care recipient perspectives in the overall literature.

A barrier encountered in constructing this review was that persons who receive family care may be referred to as care recipients, patients, or otherwise. This terminology issue may be related to the historically passive role assigned to all persons who receive care. Russell et al. (1997) cited Nightingale's (1969) perspective that has been foundational in nursing and other caring sciences that, "the chief function of a nurse was to put the patient in the best condition for nature to act upon him or her, while protecting the patient from any exertion." Such a philosophy assumes that care recipients are completely passive; however, Russell et al.'s findings, along with other work cited in this review, directly challenge that notion.

As a result, obtaining information about the experience of receiving care requires researchers to consider the myriad of ways that persons who receive care are discussed. For example, this review also considers literature about persons with dementia, stroke, and cancer in an attempt to more thoroughly capture information about the experience of receiving care across types of illness and disability. Additionally, literature focused on palliative care provided some rich information about receiving care in later life. Consideration of this larger body of literature resulted in reviewing several studies that examined care recipients from across the lifespan, despite this author's primary interest in learning about receiving care from a family member while in later life.

Giving and Receiving Care within Families

The studies described in this section provide fundamental information about receiving care from family members in later life that helps to lay the groundwork for more specific issues discussed later in this review. Just a small number of studies (N=2) are described here due to the limited research in this area. Both of these studies succeeded in collecting data from elders about the care they receive from family members, despite the logistical difficulties in obtaining data from persons who may be homebound or cognitively or physically impaired.

Brewer: A Qualitative Study of Family Caregiving Systems

Using semi-structured qualitative interviews, Brewer (2002) interviewed 22 older adults and their family caregiver(s) in an effort to explore differences between receiving care from a primary caregiver and receiving care from multiple family members. This study was noteworthy in that it included the perspectives of multiple parties in caregiving relationships – including elder care recipients and multiple caregivers, drew from a relatively large sample for a qualitative study of such depth, and provided preliminary information that can be used in the construction of understanding about receiving care from family members in later life.

Through exploratory semi-structured qualitative interviews, Brewer found that:

- (1) Caregiving approaches are influenced by multiple factors that include awareness of the need for care, willingness to act on behalf of a care recipient, and evolving circumstances;
- (2) Team caregivers were more likely to report no change or positive changes in personal well-being whereas primary caregivers indicated more problems associated with their own well-being;
- (3) Dissatisfaction with care by care recipients was

usually directed at formal caregivers rather than toward family caregivers; (4) satisfaction with care from a family member appeared to be related to a care recipient's perception of that family member's effort; and (5) Care recipients were unlikely to identify anything that could improve their situations but caregivers typically identified unmet needs of the care recipients. This study attempted to interview each party separately, but 15 (out of 22) care recipients were interviewed in the presence of a caregiver due to factors such as dwelling size and communication deficits, and four care recipients were not interviewed at all due to cognitive limitations.

The fact that only three of the care recipients in Brewer's (2002) study were interviewed privately appears to be a major limitation, given that these persons may have been reluctant to be critical of shortcomings in care while in the presence of the person(s) providing the care. This possibility seems likely, as older adults have been found to exhibit high rates of socially desirable response bias—the tendency to provide answers they assume the researcher wants to hear (Geron et al, 2000). Another explanation may be related to care recipients feeling concerned, and possibly guilty about the amount of assistance their caregivers were providing to them, as research about self-perceived burden (discussed in more detail later in this review) has found that receiving care from loved ones can lead to the feeling that one is creating hardships for others (McPherson et al, 2007). Despite these potential limitations, Brewer's study illuminates the importance of the quality of care being provided to elders, whether the care is being provided by family or more formal caregivers.

Purk and Richardson: Morale Levels of Stroke Patients and Their Caregivers

Purk and Richardson (1994) studied the morale of 44 married persons aged 60 and older who had suffered strokes and their spousal caregivers. Like the Brewer (2002) study, Purk and Richardson (1994) included the perspectives of care recipients and their caregivers. However, this study is narrower in focus in that all of the persons in need of care had similar medical circumstances and also differs in that correlational analyses were used to test hypotheses about how various factors affect the morale of both parties. By limiting this study to spousal caregivers, Purk and Richardson were able to identify factors that may be common within one caregiving context (i.e. spousal relationships post-stroke) that may not play a role in other family caregiving constellations, such as when an adult child takes care of an aging parent. Furthermore, this study's focus on caregiving after stroke provides information about caregiving relationships within a marriage that are initiated by a singular event, as contrasted with caregiving relationships that evolve gradually over time.

Purk and Richardson (1994) found that overall morale levels as measured by the Philadelphia Geriatric Center (PGC) Morale Scale of both care recipients and their caregiving spouses were strongly interrelated. The scale defines higher morale as having lower levels of agitation, lower levels of dissatisfaction, and more positive attitudes towards one's own aging. Attitudes towards one's own aging were highly correlated with overall morale for both caregivers and care recipients. There was not, however, a significant relationship between the agitation levels of care recipients and their spouses, indicating that the frustration of one member of a spousal care dyad does not necessarily cause the other to feel frustrated.

Purk and Richardson (1994) also studied other factors that may affect morale: functional independence, gender, and length of time since the stroke occurred. Length of time since the stroke showed no evidence of effect on morale, and gender showed only a minimal influence, with caregiving husbands reporting higher levels of agitation than caregiving wives. However, a positive relationship was found between care recipients' morale and aspects of functional independence associated with ADLs: the ability to provide one's own self-care (i.e. grooming and toileting), being able to transfer one's self from one surface to another, and locomotion (defined as ambulation and/or wheel-chair mobility). Caregivers' morale was lower when care recipients needed assistance with transfers or personal care, but not when they needed assistance with locomotion, such as being pushed in a wheelchair. Caregivers' morale was also not affected when care recipients had disabilities that hindered their communication abilities or social functioning. This finding calls for further inquiry as to how spousal caregiver morale is lowered by having to perform physical tasks, such as toileting assistance or bathing, when the ability to communicate with or socialize with their spouse is not compromised. Purk and Richardson hypothesized that this is explained by continuity and closeness of the marital relationship transcending the caregiving situation, but the reason could be more related to the nature of caregiving tasks *within* a marital relationship. For example, perhaps assisting a spouse with toileting is more upsetting than helping a parent or other relative with that task. This finding also raises the question of whether care recipients find receiving help with certain types of activities or receiving help from certain people to be more or less upsetting.

Purk and Richardson (1994) argued that omitting care recipients' perspectives is especially problematic in care relationships in which a spouse, as opposed to an adult child or other family member, provides the care because of the nature of committed marital relationships. While better understanding of care relationships in all types of family constellations is important, specifically understanding dynamics within spousal relationships is valuable because the majority of family care is provided by spouses. Typically wives care for their husbands (Brewer, 2002; Thompson, 2000), a phenomenon that is likely a natural byproduct of women having longer expected lifespans than men. Overall, Purk and Richardson's findings about morale levels among care recipients and their caregivers provides evidence that persons in relationships influence one another's well-being, a phenomenon that will be discussed in further detail later in this review.

Given the concern about the omission of care recipients' perspectives voiced by Purk and Richardson (1994), dimensions of satisfaction with paid care identified by Geron et al. (2000) are an appropriate starting point from which to consider what qualities elders might consider to be desirable to their care in general. Geron et al. used grounded theory with a sample of primarily low-income, disabled females (N=228) to identify dimensions of satisfaction with paid care. The eight dimensions identified by this research were: competency, humaneness, dependability, service adequacy, continuity of care, choice, accessibility and advocacy. This research is particularly notable in that persons who receive care were: 1) given a voice in the literature alongside the voices of experts and caregivers and, 2) were successful in identifying variables that contribute to their own well-being.

A key difference between paid and unpaid care is the lack of formal training to family members to provide caregiving tasks. Thus, care recipients, who are most frequently spouses or parents of caregivers, may have different expectations of quality of care from their loved ones as opposed to from paid home health aides or other care providers. Therefore, satisfaction dimensions identified by Geron et al., such as competency or advocacy, may appear different from a care recipient's perspective depending upon who is providing the care. Despite these potential differences, the eight dimensions identified by Geron et al. provide a starting point from which to consider satisfaction and quality of care in a family caregiving context.

Summary

Studies such as the two detailed above (Brewer, 2002; Purk & Richardson, 1994) indicate that receiving care from family members is a complex experience that may result in both positive and negative experiences for multiple parties in the caregiving relationship, and that the relationships between care recipients and their caregiver(s) is an important variable. While there are certainly notable examples to the contrary, the overall literature is limited by implicit endorsement of the overly simplistic notion that receiving care is a positive experience whereas giving it is generally negative in that it is burdensome.

Future research needs to solicit and integrate care recipient perspectives, especially when care recipients are not cognitively impaired. Even when mild to moderate cognitive impairment exists, it is still possible to solicit information from care recipients regarding their own perceived quality of life (Ready & Ott, 2008). Such perspectives are critical to establishing baseline information regarding the experience of

receiving care from family members while in later life. Furthermore, perspectives from elders receiving family care are necessary in the creation of instruments that assess quality of life and quality of care. Such instruments would better equip psychological and medical health providers to promote well-being among older adult care recipients and their caregivers and to prevent and intervene in cases of elder abuse and neglect.

Experiences of Care Recipients

Understanding the psychological experiences of elders who receive care from their family members is a complex task. This section begins by summarizing the results of a study (Gallant et al., 2007) that provides a basic framework for understanding the perspectives of elders regarding how their friends and family influence their care in direct as well as indirect ways. Next, the issues of maintaining dignity and feeling burdensome to one's caregivers are explored in the context of a greater body of literature that has often emphasized the burdens experienced by caregivers. This discussion of internal experience leads to the final section about caregiving relationships.

Gallant and Colleagues: Social Influences on Symptom Management in Later Life

Gallant and colleagues (2007) aimed to identify positive and negative influences from friends and family on older adults' (ages 65 and older) self-management of their symptoms related to arthritis, diabetes, and/or heart disease. The findings from this study are especially important as they were collected from persons who receive help from family and/or friends but may or may not actively see themselves as care recipients. As caregiving relationships often evolve over time from existing family relationships into ones in which there is an identified caregiver and care recipient (Radina, 2007), gathering care recipient perspectives from an earlier point in the continuum than is represented in

many of the other studies in this review helps to provide a more comprehensive sense of receiving care over time. Additionally, many of the other studies represented in this review focus on conditions such as stroke or cancer as opposed to the chronic illnesses that may be comorbid with or precursors to such diseases.

Gallant and colleagues (2007) conducted four focus groups with a total of 28 White women, five with a total of 32 African American women, three with a total of 19 White men, and one with five African American men. The researchers' difficulty in obtaining a larger sample of Black men may be reflective of the extreme disparity between life expectancy of Black men and that of other groups, highlighting the fact that non-Whites, and especially Black men, are not equally represented in the majority of the research discussed in this review.

The focus group data revealed that while having a social network generally contributed positively to chronic illness management, social networks could also contribute negatively as well. More specifically, Gallant et al. (2007) identified three main categories in which members of one's social network may either be a positive or negative influence: Disease Management Activities, Making Decisions About Care, and Psychosocial Coping.

The Disease Management category was further broken down into four subcategories: Medications and Testing, Diet, Exercise and Physical Activity, and Psychosocial Coping. Gallant and colleagues observed that taking medication was a component of care common to all of three types of chronic disease among the participants. Assistance in this arena almost always came from a family member and ranged from having someone who was primarily responsible for the elder's medication

schedule to having somebody who provided an occasional reminder, all of which care recipients generally experience as positive.

Gallant et al. (2007) found that diet was a dominant theme amongst participants, and influences could be either positive or negative. Positively, the elders reported that members of their households helped by cooking proper meals, following the same diet recommended for the participant, and monitoring participants' diets. However, the influence was negative when household members followed different diets or cooked foods that were not recommended for the chronically ill participants. Away from home, friends or family members negatively influenced disease management by tempting the elders to stray from their recommended diets (i.e. "One little piece won't hurt you") or by not accommodating their prescribed diets. As with diet, other people could provide motivation or a lack of motivation to follow prescribed recommendations regarding exercise. While both friends and family were sometimes cited as negative influences, friends were also cited as being positive in this regard by serving as walking partners or exercising with them in other ways.

Decision-making about Care was another major category identified by Gallant et al. (2007). In this arena, older adults with chronic illness were influenced by others in three main ways: through information-sharing (typically by friends), serving as a liaison with one's doctor or helping to facilitate medical care or treatment (typically a family member), and providing unwanted advice. Gallant et al. found that older adults with chronic disease generally experience unwanted advice as threats to their own independence, and thus described this as a negative influence.

The third category identified by Gallant et al. (2007), Psychosocial Coping, is especially relevant to the discussion of caregiving relationships later in this review. Talking with others, whether family or friends, about concerns was generally described as a positive experience, sometimes because such talks provided insight that others were worse off or that others experience similar struggles. The importance of having social supports with whom one can relate appears to be especially salient to the elders in this study; several participants distinguished between how they can laugh about age-related decline with a same-age peer but would find it unsatisfying to discuss with an adult child who finds little humor in it.

Generally, Gallant and colleagues (2007) found that participants' negative experiences with family and friends were the opposite of what was described as helpful or positive. These included a lack of understanding about what one is going through and having others expect them to act as if nothing is wrong when their illnesses or pain are not readily apparent. Interestingly, while some of the participants had cited talking with others about their common struggles as positive, others perceived such conversations as depressing — indicating that evaluating one's experience of care or assistance is often highly individualized.

While Gallant et al. (2007) separated focus groups according to race and gender primarily to facilitate more open discussion, some differences between groups were also gleaned. Differences between gender may also reflect differences between married and single persons as the majority of the men (68% of White men and 100% of Black men) were married whereas the majority of the women were single, divorced, or widowed (61% of White women and 88% of Black women), which is fairly representative of the

greater population. Group differences associated with gender included that women talked more about support from adult children, men mostly talked about support from wives, and married women talked more about their husbands than their children.

A key observed gender difference, that was common to both Black and White participants, was that only female participants discussed receiving unwanted advice, being motivated to talk by others, and being subjected to depressing talk. Black and White women differed, however, in that Black women spent more time talking about children and grandchildren who lived with them or very close by and talked about having worked outside the home throughout their lives. Both Black men and women discussed the importance of church in their lives to a much greater degree than did White participants. These findings highlight differences in support systems and care relationship constellations across both gender and race that may impact health behaviors and psychological functioning. Thus, understanding the unique contexts and needs of different groups is important as is identifying aspects of caregiving among families and friends that are more universal across various social backgrounds and circumstances. Gallant et al.'s (2007) findings also raise questions about how cumulative experiences of positive and negative influences from a given caregiver may contribute to various aspects of care relationships.

Maintenance of Dignity

Fearing the loss of independence in later adulthood (Gallant and colleagues, 2007) is likely related to the desire to maintain dignity, as is Purk and Richardson's (1994) finding that care recipients and their spousal caregivers reported lower morale when caregiving activities included help with personal care such as toileting. The need to

maintain dignity appears to be universal, appearing as a theme in American studies on caregiving, in several qualitative studies conducted in various European countries, and as a guiding principle of a Taiwanese study about quality of life in dying persons (Tang et al, 2008).

A Norwegian study (Mangset, Dahl, Forde, & Wyller, 2008) that explored satisfaction and dissatisfaction among 12 older persons (ages 60 to 87) with their stroke rehabilitation found that being treated with “respect and dignity” was a core component of whether the elders were satisfied with their rehabilitation. The subthemes of respect and dignity that emerged were: being treated with humanity, being acknowledged as individuals, having autonomy respected, having confidence and trust in the professionals treating them, and dialogue and exchange of information.

The relationship between dignity, often equated with feeling respected, and perceived quality of care may depend on context. Webster and Bryan (2009) found that British elders, in describing the care they received at hospitals, were sensitive to actions that compromised their dignity despite being generally satisfied with the care they received. This phenomenological study of 10 community-dwelling older adults (ages 73-83) resulted in the identification of five themes associated with maintaining dignity: respect of privacy, cleanliness (such as healthcare workers frequently washing their hands before touching the elders or having access to clean toilet facilities), not wanting to be treated differently as a result of age or being lumped together with elders with dementia or more severe problems than they had, communication (such as being ignored or talked down to), and independence and control.

The participants interviewed by Webster and Bryan (2009) expressed that maintaining independence was essential to preserving dignity. For participants who could use the toilet or bathe themselves, being able to do so alone was cited as important. Participants who needed more assistance with ADLs indicated that having choices regarding their care, such as which beverage to swallow a pill with, contributed to maintenance of dignity. This finding is consistent with Gallant and colleagues' (2007) study indicating that the preferences of elders are highly individualized, and thus require flexibility and adaptability by caregivers in attending to an older care recipient's needs.

The concerns about privacy and cleanliness that emerged in Webster and Bryan's (2009) work fit in with the need to have one's humanity respected in Mangset and colleagues' (2007) study. Similarly, Mangset and colleagues' subthemes of the need to have confidence and trust in care providers and the need to be treated as an individual are similar to Webster and Bryan's subtheme of not wanting to be treated differently as a result of age. The subthemes of communication/dialogue and independence and control/autonomy are virtually identical. Furthermore, these findings are consistent with a concept analysis of literature from 1990-2005 (N=53 studies) pertaining to dignity among older persons that revealed common dimensions of: individualized care, control restored, respect, advocacy, and sensitive listening (Anderberg, Lepp, Berglund, & Segesten, 2007). Therefore, the importance of dignity appears to be among the most well-established knowledge in existence regarding receiving care in later adulthood.

Interestingly, interviews about receiving care conducted with elders not yet in need of it yielded a similar concern about dignity but with different subthemes than did the studies with older persons who had been hospitalized or were in the midst of stroke

rehabilitation. Harrefors, Savenstedt, and Axelsson (2009) exposed 12 older couples in Northern Sweden, in which neither partner was currently receiving any ongoing professional healthcare, to vignettes in which the participants had to imagine needing various levels of healthcare due to increased illness and disability. All of the collected responses fell under the overarching theme of wanting to maintain the self and be cared for with dignity. However, the subthemes that emerged from this study included the desire to remain home for as long as possible, having access to institutional care if a condition were severe in order to avoid burdening one's spouse, and the fear of abandonment.

The contrast between the anticipatory subthemes identified by Harrefors and colleagues (2009) and the subthemes that emerged from participants who had recently been hospitalized or were receiving ongoing healthcare services has many implications regarding the choices that elders make regarding their future preferences for care, and how their preferences may change over time. The differences may also reflect that the researchers studying the persons already ill or disabled were questioning them regarding care from professional healthcare providers, whereas the healthy participants' responses indicated an anticipation of reliance on their spouses for some care. Further research is also needed to discern how having a healthy spouse, as did all of the participants in Harrefors and colleagues' study, or having a spouse at all, affects an elder's healthcare preferences in respect to dignity. These questions help to illuminate the need to better understand family care of elders from the relational context in which it occurs. Clearly, there is a great need for research that considers dignity in the context of receiving care from family members.

Burden and Self-perceived Burden

The construct of caregiver burden has been explored extensively in the literature focused on caregiving, and many studies that focus on caregivers and caregiving relationships consider the burden a caregiver experiences as the result of providing care to be a key variable of interest (Haley et al, 1995; Hughes and et al, 1999; Kim, Knight, & Flynn Longmire, 1997; Gottlieb, Kelloway, & Fraboni, 1994). A lesser studied, but arguably just as important phenomenon, is how elders may experience themselves as burdensome to the family members who care for them. This section will briefly discuss caregiver burden before describing studies that focus on perceived burden.

Burden

An important distinction when considering burden is whether subjective or objective burden is being examined. Subjective burden typically refers to the self-reported experience of whether an individual thinks or feels that something is burdensome. Objective burden refers to burden that is measured by considering how one's life is negatively impacted by something that may be burdensome, such as having fewer financial resources, less time, decreased self-care, neglect of other duties or responsibilities, impaired vocational functioning, and increased mental health or physical problems (Di Mattei et al., 2008).

Much information about burden in caregiving has been gathered by researchers focused on learning more about caregivers. While substantial evidence indicates that many family caregivers experience a sense of burden as a result of the care they provide (Di Mattei et al, 2008; Hughes et al, 1999; Lutzky & Knight, 1994; Reese et al, 1994;), there is also evidence that many family caregivers do not feel burdened, and may even

welcome the opportunity to provide care to an ill, disabled or dying loved one (Hash, 2007; Boerner, Schulz, & Horowitz, 2004).

Culture and Burden

One area of inquiry represented in the literature has been to examine demographic and cultural variables related to experiences of caregiver burden. Particularly, many researchers have found differences in caregiver burden or caregiver adjustment when comparing the experiences of White and non-White caregivers. Haley and colleagues (1995) found that providing care is associated with higher levels of depression in White family caregivers as compared with Whites not providing care to family members, but that depression levels do not differ between Blacks who provide care to family members and those who do not. Furthermore, Connell and Gibson (1997) found that Black caregivers experience lower levels of depression and stress related to caregiving and burden than do White caregivers. Hughes and colleagues (1999) also found evidence of lower levels of both subjective and objective burden in Black caregivers than in White caregivers.

More recent inquiry that has attempted to better understand the role of race, ethnicity and/or culture in the experience of providing care to family members has suggested that one's education level is a better predictor of whether a caregiver will experience burden than is one's race (Kim, Knight, & Flynn-Longmire, 2007). Using path analysis, Kim and colleagues (2007) found that when level of education was included, this variable replaced race as a predictor of caregiver burden. They speculated that education in the US is associated with increased levels of individualism, which increase one's perception of burden when caring for others. However, these findings

contradict previous research that found higher levels of burden among caregivers with less education (Hughes et al., 1999) and higher levels of burden among caregivers with lower incomes than those with higher incomes (Gottlieb, Kelloway, & Fraboni, 1994). Replication of the Kim and colleagues study and/or further research in this area is needed to draw more definitive conclusions regarding the relationships between demographic variables such as race, culture, education, and income, and burden.

Contextual Factors: Type of illness or disability.

Caregivers of care recipients with certain illness appear to experience different levels of burden and quality of life than do caregivers of other types of care recipients. Likewise, the prognosis of the illness or disability may have an impact on caregiver burden. Finally, as identified caregivers often have conditions of their own that require care from others, a caregiver's health status in concert with the care recipient's issues may contribute to caregiver burden.

Reese et al (1994) found that while caregivers of elder family members with either Alzheimer's Disease (AD) or stroke recovery both experienced higher levels of depression, higher levels of burden and less social interaction than a noncaregiving control group, the AD caregivers experienced less social interaction and more burden than the stroke caregivers. A distinct difference between AD and strokes is that, with a stroke, caregiving activities are typically initiated following the stroke and there is a period of recovery, as opposed to AD in which there is gradual cognitive decline prior to diagnosis and the care recipient requires more and more care over time. Related to this, Reese et al. (1994) noted that the AD caregivers in their study may have been providing care over a longer period of time than the stroke caregivers, and thus the cumulative

effects of caregiving over time may have contributed to the differences between the AD and stroke caregivers.

Di Mattei et al (2008) found that family caregivers of elders with dementia in Italy who have somatic disorders of their own experience significantly higher levels of burden than physically healthier family caregivers. Furthermore, this study found that characteristics associated with higher levels of burden in previous studies such as gender, ages of caregivers and care recipients, and availability of supports for caregivers were not significant. This finding suggests that caregiver burden may largely be related to caregivers needing their resources to take care of their own illnesses.

Burden may also be impacted by whether a care recipient's illness is terminal, chronic or temporary. Gilbar's (1994) mixed-methods inquiry found that the spouses of 32 Israeli cancer patients aged 65 and older experienced less burden when their spouses had better prognoses, suggesting that hope for care recipient improvement lessens the experience of burden among caregivers. From semi-structured interviews, Gilbar also obtained information regarding the nature of burden experienced by spouses of cancer patients, and found that most of the spouses reported experiencing increased anxiety and more thoughts about death and dying. Confirmation of these findings is needed, in addition to inquiry as to how different circumstances of illness or disability affect care recipients' experiences of themselves as burdensome.

Clearly, further research is needed to better understand the relationships between demographic variables such as education, race, ethnicity, and gender, and caregiver burden. Furthermore, exploration of such demographic variables in connection to self-perceived burden among elders who receive care, and whether there is congruence among

care recipients and their caregivers about the level of burden incurred as a result of care provision, will be important lines of future inquiry.

Self-perceived Burden

As with other facets of the family caregiving relationship that have neglected the perspectives of care recipients, less attention has been paid to care recipients' experiences of feeling like a burden to others (Cousineau, McDowell, Hotz, & Hebert, 2003; McPherson, Wilson, & Murray, 2007). Byock (1997) reports, based on his experience as a career hospice physician, that dying persons fear becoming burdensome to their loved ones, possibly as much or more than they fear death itself.

Definition and Prevalence

In the development of a measure of how much an ill person feels like a burden to others, Cousineau and colleagues (2003, p. 11) defined self-perceived burden as, "a multi-dimensional construct arising from the care-recipient's feelings of dependence and the resulting frustration and worry, which then may lead to negative feelings of guilt at being responsible for the caregiver's hardship."

More recently, McPherson and colleagues (2007) offered a revised definition of self-perceived burden as "empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished sense of self."

Self-perceived burden or other negative psychological experiences may be common among care recipients. In one of the few studies exploring negative reactions to receiving care from a family member, Newsom and Schulz (1998) found that 40% of the physically disabled older adult participants (mean age = 76.6) with a wide range of

assistance needed with ADLs and IADLs reported experiencing mental or emotional strain in response to receiving care from their spouses. This study found that greater physical impairment, age, fatalism, lower perceived control, and lower self-esteem each significantly predicted degree of self-reported mental or emotional strain in response to receiving help from spouses.

The experience of feeling burdensome may be even more common in some caregiving situations than is the experience of feeling burdened due to caring for a loved one. Kuijer et al.'s (1991) examined differences in equity between 80 healthy couples and 106 couples in which one spouse has cancer (care recipients ages ranged from 33-83). Kuijer et al. found that spouses with cancer, especially females, reported that they perceived inequity within their marital relationships since diagnosis or onset of illness—but their spouses did not. Specifically this perceived disruption of reciprocity among persons with cancer resulted in the persons with cancer feeling that they were receiving more than they were giving within the relationship. These results highlight the need for consideration of how relationships are affected by the reception and provision of care, as well as the possibility that one partner may perceive a disruption or change while the other one does not. Kuijer and colleagues's findings demonstrate the importance of developing better understanding of both self-perceived burden and of the experience of reciprocity (giving and receiving) within care relationships.

McPherson and Colleagues (2007): A Close-Up Look at Self-Perceived Burden

Among the most illuminating research regarding self-perceived burden has been McPherson and colleagues's (2007) interpretive phenomenological analysis of self-perceived burden among terminally ill persons with cancer. This qualitative study

revealed that participants' (N=15, ages ranging from 42 to 78) experiences of self-perceived burden fell primarily into two categories: Concern for Others and Implications for Self. A third, but less salient, category of Minimizing Burden also emerged. The findings from this study will be discussed in further detail as they highlight the importance of considering relational factors related to receiving and providing care, as well as how care recipients actively consider their own psychological and physical well-being within their experiences of self-perceived burden.

Within the arena of Concern for Others, McPherson and colleagues (2007) reported that participants felt they were imposing on others due to physical burdens typically associated with ADLs; social burdens, such as time taken from other responsibilities such as child-rearing or paid employment; emotional burdens such as making a caregiver sad, worried, stressed; and future concerns. Collectively, these findings demonstrate that care recipients often actively worry about a wide range of objective and subjective burdens that their caregivers may be experiencing.

The Future Concerns category identified by McPherson and colleagues (2007) includes care recipients' worry that the progressive nature of terminal illness eventually culminating in the care recipient's death will create an increasing amount of burden for their caregivers over time. McPherson and colleagues reported that care recipients were especially concerned about their caregivers having to decide whether to keep them at home or transfer them to institutional care. These findings also indicated that ambivalence regarding residence is common as care recipients often weighed the desire to be at home with their concerns about being a burden.

The Implications for Self category identified by McPherson and colleagues (2007) included three main themes: Emotions, Self-Blame and Self-Concept. The Emotions theme focused particularly on psychologically distressing emotions including guilt, regret, frustration and worry. McPherson and colleagues noted that Cousineau and colleagues (2003) had considered worry, guilt and frustration to be components of self-perceived burden, but that McPherson and colleagues' terminally ill participants also expressed sadness about the losses their caregivers would experience. Future research then, should consider whether sadness is a component of receiving care in most family care situations or is unique to receiving care at the end-stage of life when one's death is imminent.

The theme of Self-Blame identified by McPherson and colleagues (2007) appeared to revolve around participants feeling some responsibility for having developed cancer, such as those who had smoked tobacco. However, participants in this study who attributed developing cancer to external factors still experienced themselves as burdensome because of the sense that they were creating hardships for others.

The theme of Self-Concept appears to be consistent with the research examining both dignity and reciprocity within caregiving relationships that is discussed in this review. McPherson and colleagues (2007) found that care recipients often struggled with adjusting to needing help from others, and that experiences of being burdensome were connected to feeling dependent, especially among those who had considered themselves to be "strong and independent" prior to requiring care in relation to illness. Future research about how self-perceived burden is related to Self-Concept may then need to

consider the role of aging and expectations about one's abilities at different points in the lifespan.

Finally, McPherson and colleagues (2007) found that terminally ill care recipients with cancer were employing multiple strategies in an active attempt to cope with their perceptions of being burdensome to others. These strategies were divided into two broad categories of Alleviating Burden to Others and Reducing Perceptions of Burden to Self.

Alleviating Burden to Others included the subthemes of being active within their own care in an effort to preserve reciprocity, concealing or minimizing their own needs, attempting to manage the needs of others by providing emotional reassurance, and helping prepare caregivers both emotionally and practically for the impending deaths.

McPherson and colleagues (2007) found that reducing perceptions of burdens to self included cognitive avoidance strategies such as making an effort to not dwell on the impact they have on their caregivers, adopting a positive outlook about the experience of receiving care, and having an attitude of entitlement to the care they were receiving. The positive outlook category is of especial interest, as the care recipients whose responses fell into this category, "described how their relationship had been strengthened, their feelings for one another deepened, and communication opened up."

The McPherson and colleagues (2007) study represented the experiences of participants in mid and later life, included only persons with terminal cancer diagnoses, and recruited all participants through a palliative care team that specialized in symptom management. Thus, further phenomenological and other forms of research inquiry are needed in order to better understand how age, type of illness or disability, prognosis of condition, and types of treatment being provided impact self-perceived burden.

Nevertheless, McPherson and colleagues (2007) findings are consistent with other lines of research that have explored self-perceived burden and other related constructs suggesting that many of the themes identified in this study may be universal to receiving care across various contexts.

For example, Singer, Martin, and Kelner (1999) analyzed data from three previous studies (Martin, Thiel, & Singer, 1999; Singer and colleagues, 1998; and Kelner, 1995) using content analysis to identify themes of end-of-life experience among persons on dialysis, persons with AIDS, and residents of a long-term care facility (ages ranged from 20 to 85). This approach resulted in the identification of five domains: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones. In respect to burden, participants identified three specific types of burden they worried about: provision of physical care, witnessing their dying, and having to make decisions about life-sustaining treatment, each of which were mentioned by terminally ill care recipients with cancer in McPherson and colleagues (2007) study. Singer and colleagues also found that both relieving burdens and strengthening relationships were connected to having discussions about the dying process with their loved ones, indicating that communication decreases self-perceived burden. Further inquiry into the relationship between care recipients' communication with their caregivers is certainly warranted to confirm whether effective communication both decreases perceived burden and improves relationship quality.

Beyond Burden and Dignity: The Bigger Picture of Receiving Care in Relationships

The previous sections of this review provide an overview of the later life family care literature and discuss the state of the literature as it pertains to elders receiving care from family members in later life. As the majority of literature about care in later life focuses on caregiving, both receiving and giving care have been explored in this review. Two common areas of focus, self-perceived burden and dignity, have emerged as being especially salient to the experience of receiving care. Both of these experiences occur within a relational context. This section of the review will explore other aspects of relationships in which care is being provided.

The complexity of care relationships, and common experiences within them, are evident in two concepts from the nursing literature: protective care receiving (Russell, Bunting, and Gregory, 1997) and Shared Care (Sebern, 2005; 1996). Together, these concepts contribute to a framework from which multiple disciplines can better consider the active roles of care recipients and the importance of understanding care relationships.

Consideration of protective care receiving refutes the assumption discussed earlier in this review that persons who receive care are passive in regard to their care, and provides the perspective that elders with illness or disability not only act to impact themselves, but also actively impact others and their relationships with others. Shared Care theory posits that three elements—decision-making, communication, and reciprocity—are central to care relationships. These elements are discussed within the greater context of care literature.

Protective Care Receiving: The Active Roles of Care Recipients

The relationships between elders and the family members or friends who care for them are complex and dynamic (Brewer, 2002). This complexity has likely contributed to the struggle researchers have faced in attempting to operationalize caregiving and related constructs (Townsend, 1993). The work of Russell et al. (1997) provides a framework from which multiple disciplines can consider the active role care recipients play in their own care. Russell and colleagues used interpretive synthesis of qualitative data to integrate findings on “protective care-receiving” across three prior studies: Russell’s (1993) ethnographic exploration of care recipient’s care-seeking experiences including protection of self and others, Bunting’s (1992) interviews with persons with AIDS and their caregivers, and Gregory’s (1994) content analysis of interviews with persons being treated for cancer. The common themes identified across the three prior studies resulted in the conclusion that care recipients take an active role in shaping and influencing their care, caregivers, and care environments.

Regarding protection of self, Russell and colleagues (1997) identified four main goals coupled with common strategies used to meet those goals. For example, persons receiving care may work to protect themselves from needing future care by engaging in healthcare practices such as following recommended nutritional guidelines, making environmental adjustments that include recognizing and adapting to one’s limitations, and adopting an attitude of taking responsibility for one’s decisions. Another tactic may be to act in a way that will result in receiving the desired amount of care. Specifically, persons who seek more care may actively work to keep caregivers happy or exaggerate their levels of disability whereas care recipients who desire less care may obtain

equipment that promotes self-sufficiency and schedule or avoid activities in such a way as to avoid appearing incompetent. Finally, care recipients may actively obtain education about their conditions and needs, and work to maintain control of their own medical treatments and other decisions.

Russell et al. (1997) also identified four goals associated with protecting others. One way that care recipients protect their caregivers is by assuring their physical safety, such as by alerting them to caregiving practices that may be unsafe. Care recipients also attend to the psychological well-being of their caregivers by guarding caregiver's feelings and deferring to the preferences of caregivers rather than speaking up about their own preferences. Additionally, care recipients were found to actively protect their caregivers from potential consequences associated with caregiving, such as by helping to prepare the caregivers for death through conversation and advanced planning.

The third category identified by Russell et al. (1997) involves protecting self and others in ways that cannot be separated, often through altruistic acts that simultaneously benefit others and preserve one's sense of autonomy. Descriptions of elders' in this category included the example of elders who benefitted psychologically from providing help to their caregivers, often in the form of advice or encouragement. A particularly relevant implication was that elder care recipients appeared to experience a psychological benefit when they believed they were relieving or reducing caregiving-related burden. These categories of active ways in which care recipients protect themselves and others allude to relationship quality.

Whether the action protects self, others, or the relationship, common aspects of these themes are the preservation of dignity, avoiding being burdensome, and attempting to collaborate within or contribute to their care relationships.

Shared Care: A Framework for Optimal Care Relationships

Sebern's (2005, 1996) development of the term "Shared Care" to complexly describe successful care relationships between elders and their caregivers emphasizes the importance of relational factors to physical health outcomes in addition to social and psychological well-being. This subsection will describe Shared Care and its elements, including how these elements fit in with the greater body of care literature.

Sebern (1996) named the construct of Shared Care after using naturalistic inquiry to study symptoms of pressure ulcers, also known as bedsores, from the perspectives of dyads of elderly care recipients and their family caregivers. This process resulted in identifying two contrasting relationship patterns: one that Sebern labeled "Directed/Discrepant" that appeared to be associated with greater risk of development of pressure ulcers in the elder care recipient, and the Shared Care pattern that was associated with less risk of pressure ulcers. The Shared Care interaction pattern consisted of three elements: communication, decision-making, and reciprocity. While reciprocity seems to be an especially important theme, communication and decision-making will be discussed first as they may be conceptualized as components of reciprocity.

Communication

Communication in the initial study from which Shared Care was proposed (Sebern, 1996) referred specifically to clear communication about physical symptoms. In this case, care recipients communicated symptoms that precipitated the development of

bedsores, such as itchy or burning skin. In the dyads that demonstrated Shared Care, Sebern observed care recipients communicating their symptoms and their caregivers responding to them, interaction that resulted in forming an agreement about the meaning of the symptoms and how to best provide relief. In other words, the participants in this study were actively protecting their physical health in a manner that may be promoting their own psychological health by contributing to a sense of dignity, as well as promoting their own social well-being through collaboration with others.

Sebern (2005) later noted that in order to communicate, one must have intact sensory channels, cognitive structures, and the ability to comprehend, understand and interpret language. As discussed previously in this review, the presence of dementia or other severe cognitive deficits may hinder a care recipient's ability to communicate. However, previous research has established that persons with mild cognitive impairment are not only capable of providing information about their care but do so with more reliability and validity than collecting information from only a caregiver does (Ready & Ott, 2008; Menne, et al., 2008; Russell et al., 1997).

Congruence between care recipients and their caregivers may also aid the effectiveness of communication. Sebern (2005) cited Gayle and Preiss's (2002) work suggesting that interpersonal communication within a dyad is affected by the level of similarity in subjective perceptions, attitudes, and goals. A lack of similarity may be moderated by effective communication, as Sebern also stated that communication can modify the effects of dissimilar goals and result in agreement about goals. Sebern further supported this hypothesis by citing Horowitz et al's (2004) finding that disagreement

within a dyad regarding a care recipient's vision loss was associated with depression among both care recipients and their caregivers.

The importance of communication in care dyads has been established in other research as well (Tang et al, 2008; Cohen & Leis, 2002). Through qualitative interviews, Cohen and Leis found that communication was important to quality of life among persons diagnosed with terminal cancer, illustrating this finding with a participant's account of her frustration with her doctors for communicating more information to her husband than to her. This example reflects that care dyads occur in wider social networks that include paid caregivers, and that each member of a dyad's interactions with persons in the greater system can affect the care relationship. The relationship, in turn, impacts the psychological health of the person receiving care, which can also impact physical health.

Tang et al's (2008) survey of 1108 dyads (aged 18-91, mean= 61 years) of persons with terminal cancer diagnoses and their family caregivers recruited from 24 hospitals in Taiwan is especially compelling. The Tang et al. study found that quality of life of terminally ill persons with cancer, many of whom were elders, was significantly higher if they felt they were financially stable enough to make ends meet, were aware of the terminal nature of their prognosis, and agreed with their family caregiver about their place of death. Financial stability may be related to autonomy and dignity, further evidence of the importance of this variable.

These findings also illuminated the importance of communication about difficult topics within caregiving relationships, such as the impact of and logistics surrounding dying. Furthermore, Tang et al. (2008) concluded, based upon their findings, that cultural

reasons commonly cited in Taiwan, China and Japan for not informing a person that his or her illness is terminal should be avoided in order to promote best possible quality of life. Integration of such findings from various cultures is important within multi-ethnic societies like the US, where cultural sensitivity and competence is becoming an increasingly strong value within the healthcare system and greater culture.

Perhaps in the ultimate act of protective care receiving, communication about one's wishes may continue to be taken into consideration even after the ability to communicate is lost. Elliott et al. (2008) conducted focus groups with family members of severely impaired nursing home residents in Minnesota to better understand the ethical decision-making of family members about an incapacitated loved one's care. This study resulted in the finding that family members are more likely to use a loved one's life story to guide decisions, rather than principle-driven ethics. This suggests that relationship factors, including prior communication of a care recipient's wishes, continue to impact decision-making in care relationships even when a care recipient is no longer able to communicate his or her opinions.

Decision-Making

Sebern (1996) found that persons whose care relationships fell into the Shared Care paradigm often reported engaging in joint decision-making with their caregivers (Sebern, 1996), a process inextricably linked to communication. This section will discuss how care recipients participate in the decision-making process, as well as the psychological and social implications of this participation.

Russell et al.'s work (1997) indicated that many persons with illness or disability actively contribute to making decisions about their own care. Indeed, other research has

indicated that making decisions helps to preserve dignity. As stated previously in this review, Gallant et al. (2007) found that older adults perceived unwanted advice about their chronic disease management as threatening to independence.

Additionally, Brown (2007) found that having a low or high sense of control impacted care recipients' (N=127, ages 60-98) depression levels differently in different contexts. Specifically, Brown found that at low levels of control, elders with family caregivers experienced higher levels of depression than did elders with non-family caregivers. But, at high levels of control, elders receiving care from family members experienced lower levels of depression than persons receiving care from non-family.

On the other hand, Gallant et al. (2007) also found that some participants appreciated family members acting as collaborators in making health care decisions. This finding may reflect the aspect of protective care-receiving that involves working to receive the amount of desired care (Russell et al., 1997), in addition to cognitive research findings indicating that older adults generally seek less information when making decisions than do young adults, and also prefer to make fewer choices related to healthcare and everyday decisions (Reed, Mikels, & Simon, 2008). Thus, elders may frequently rely on caregivers to assist in decision-making in the form of reducing options to a more manageable number of choices. For example, Reed et al. (2008) concluded that the large number of choices for prescription drug plans under Medicare Part D is more than 10 times the number of choices preferred by elders and may thus impair enrollment rates and choice satisfaction.

In addition to considering how decisions are made by or about older adults, prior research has also explored how various factors influence decision making in later life or

regarding end-of-life care. For example, within a sample of 226 older adults with advanced cancer, congestive heart failure, or chronic obstructive pulmonary disease, reporting growing spiritually or growing closer to God during illness is associated with a greater willingness to undergo risky but potentially life-saving treatment (Van Ness, Towle, O’Leary, & Fried, 2008). This finding highlights the need to understand a broad range of factors that affect caregiving relationships, such as how religious or spiritual congruence between care recipients and their caregivers affects relationships and decision-making about care.

Not surprisingly, care recipients who have been more recently diagnosed with dementia as well as those whose dementia causes less impairment appear to be more involved in decision-making than persons with dementia that is more advanced or severe (Menne and Whitlatch, 2007). Prior research has also found that elders prefer that their family members, rather than medical professionals, will have the authority to make decisions about their care if they are to become incapacitated (Elliott, Gessert, & Peden-McAlpine, 2008).

Reciprocity

The third element of Shared Care, reciprocity, was reflected by the recognition and gratitude each member of the dyad expressed toward the other’s contribution to the shared care. Reciprocity may be defined as “the foundation and shared meaning of giving and receiving care, strengthening a person’s sense of common belonging and shared interdependence,” (Graham & Bassett, 2006, p. 336). While the terms caregiver and care receiver imply a dichotomized relationship in which one party gives and the other

receives, Russell et al's (1997) findings about protective care receiving, along with other literature discussed in this review, clearly demonstrate that reality is far more complex.

The experiences of feeling burdensome and feeling burdened appear to be an important element of reciprocity in care relationships. Sebern (1996) noted that the caregivers often expressed reciprocity in their comments about the care recipients contributing as much as they were able. Similarly, care recipients talked about wanting to do as much as possible in part to avoid being burdensome to their caregivers. Sebern's later (2005) expansion of Shared Care theory via a comprehensive literature review led to Sebern's assertion that, "Shared Care provides a structure to expand the view of family care to include both members of a care dyad and account for positive and negative aspects in the relationship (p. 178)."

Finch and Mason (1993) wrote about caregiving within the context of negotiating general family responsibilities, stating that receiving a gift creates the expectation that a counter-gift will be given later. Therefore assessing the experience of reciprocity involves discerning the presence of balance between older adults and their caregivers. For example, Wolff and Agree (2004) examined reciprocity by asking care recipients, "Does (your caregiver) ask you for advice or talk over (his/her) problems with you?" and considered "no" responses to reflect a lack of reciprocity. While this method of assessing reciprocity is fairly narrow, the finding that "yes" responses were associated with lower levels of depression among care recipients indicates that those whose caregivers rely on them for counsel, friendship, and/or support experience better mental health than those who do not interact in this way. Wolff and Agree also found that feeling respected and

valued by their caregivers is related to less incidence of depression, further supporting the notion that reciprocity plays an important role in caregiving relationships.

As with other aspects of care relationships, having dementia or other types of cognitive decline does not prohibit a person from contributing to others and to their relationships. After studying 88 dyads of persons with Alzheimer's disease and their caregivers through the ethnographic Atlantic Canada Alzheimer's Disease Investigation of Expectations (ACADIE) study, Graham and Bassett (2006) found that care recipients with dementia do contribute to their care relationships—whether or not their contributions are acknowledged or appreciated by their caregivers.

Graham and Basset (2006) identified themes that demonstrate reciprocity, as well as the importance of communication to reciprocity. The identified themes were dialectics of acceptance and resistance, cooperation and conflict, and togetherness and detachment. By examining these themes, Graham and Basset went beyond demonstrating the existence of reciprocity, and found that reciprocity within relationships could be generally positive or negative.

Positive reciprocity is exemplified in care relationships that Graham and Bassett (2006) described as, “cooperative and warm, with encouragement filtered through mutual respect, understanding, and trust” (p. 345). Negative reciprocity, in contrast, lacks trust and compassion. Graham and Bassett provided the example of caregivers who spoke about family care recipients in the third person, treating them like objects, even when in their presence. Despite the social dismissal and lack of respect afforded to the elders with Alzheimer's disease, Graham and Bassett noted that the elders would insert themselves into the conversation in an effort to contribute to the relationship.

The Impact of the Reciprocity Continuum on Care Recipient Well-Being

As demonstrated by much of the research discussed in this review (Purk & Richardson, 1994; Graham & Bassett, 2006; Russell et al, 1997; Tang et al, 2008; etc), older adults who require care due to illness or disability actively contribute to their caregiving situations and bear some responsibility for the quality of their relationships. Many researchers who have explored giving care, receiving care, or care relationships have indirectly addressed reciprocity without necessarily explicitly acknowledging this focus.

At a basic level, relationships involve being affected by others, and the caregiving literature is ripe with examples that illustrate the importance of studying individuals within caregiving systems. For example, the well-being of caregivers affects care recipients and vice versa among samples of terminally ill cancer patients (Tang et al., 2008; Fleming et al., 2006; McMillan & Mahon, 1994). Previous research has also found that depressed older persons are less likely to respond positively to antidepressant medication when their closest family members, often their caregivers, feel high levels of burden related to the older adult's depressive symptoms (Martire et al, 2008). Therefore, psychological and social well-being appear to be linked to psychological experiences such as dignity, sense of being burdensome and reciprocity, as well to mental and physical health indices.

Positively, this evidence of the influence of relationships on individual factors appears to be increased acknowledgement of the importance of how interpersonal factors within the caregiving relationship impact both the well-being of care recipients and their family caregivers. Unfortunately, previous literature that has examined the caregiving

relationship has often defined relationship quality according only to the perspective of one party in the relationship — the caregiver (e.g. Lawrence, Tennstedt, & Assmann, 1998; Schumacher, Stewart, & Archbold, 2007). While such studies provide valuable information about caregivers' perceptions of relationship quality with the elders for whom they care, defining the quality of a relationship between two parties based on the perspective of just one party is problematic.

Putting it all Together: Variables that Impact Psychological and Social Well-Being

This review describes the state of the family care literature, illustrates the lack of care recipients' perspectives within that literature, and integrates findings from prior studies to reveal a set of common themes that appear to be central to the experience of receiving care across types of disability or illness.

These findings include that:

(1) The extent to which illness or disability impacts a person's functioning may be more important than the type of illness or disability;

(2) Cognitive impairment has been used as a partial explanation for the lack of care recipient perspectives in the literature despite findings that persons with mild and moderate cognitive impairment are able to provide reliable information about their opinions and their care;

(3) Mental health, physical health/functional impairment, dignity, reciprocity, and the sense of being burdensome all appear to be linked in some way, and each of these variables appears to impact both the psychological and social well-being of persons who receive family care in later life; and

(4) Caregiving relationships also appear to be important to care recipient well-being, and thus relational aspects of receiving care such as reciprocity and self-perceived burden may have greater influence on the overall psychological and social well-being of care recipients than other factors.

This review of literature highlights the existence of a richer-than-meets-the-eye body of existing knowledge regarding the experience of receiving care from family members in later adulthood. That said, this body of knowledge is also limited in scope and depth, and many of the promising studies that have been conducted have yet to be replicated.

In addition to the conclusions listed above, this review also reveals methodological gaps that future studies should work to fill. These issues include:

- (1) The aforementioned lack of care recipients' voices, especially among persons who are homebound or have some cognitive impairment;
- (2) A need to collect data about the experience of receiving care in a confidential manner, in which participants will not be worried about whether their statements will hurt their caregivers' feelings; and
- (3) A lack of attention to diversity among older adults in terms of race, and ethnicity, sexual orientation, religion, and many other factors. This void may be masking important information about subgroups of elders.

The purpose of the present study is to extend the existing base of knowledge integrated into this review by further examining the impact of dignity, reciprocity, and self-perceived burden on the psychological and social well-being of elders who receive assistance with their care from at least one family member.

Additionally, given that care has traditionally been defined as assistance with functional impairment, ADL and IADL impairment were considered. The mental health variables of anxiety and depression, which have been used as variables in studies throughout this review, were also included in the present study. The inclusion of functional impairment, depression, and anxiety allowed for controlling for the effects of these variables, as well as consideration of whether and how much these variables matter to well-being in the first place.

Finally, the present study aimed to address some of the gaps in the existing literature by collecting data from participants without the presence of any family caregivers in order to promote validity and collecting data in participants' homes to make participation more accessible.

CHAPTER II

METHOD

Introduction

This study aimed to examine the impact of health and relationship variables on psychological and social well-being among adults ages 65 and older who receive assistance with their care from at least one family member or close friend. Regression techniques were used to examine the impact of functional impairment, depression, anxiety, self-perceived burden, dignity, and perceived reciprocity in the care relationship on psychological and social well-being in the population of interest.

This study addressed the following questions:

What are the effects of functional impairment, depression, anxiety, self-perceived burden, dignity, and perceived reciprocity on both psychological and social well-being among older adults who receive assistance with their care from at least one family member?

In particular, what are the individual and collective effects of self-perceived burden, dignity, and reciprocity on psychological and social well-being beyond the impact of functional impairment and mental illness?

The associated hypotheses for this study are:

H1: The overall regression(s) will be statistically significant when functional impairment, depression, anxiety, self-perceived burden, dignity, and perceived

reciprocity in the care relationship are collectively considered in relation to both psychological and social well-being.

H2: Higher levels of depression, anxiety, and functional impairment will collectively result in lower psychological and social well-being.

H3: The individual effects of higher levels of depression, anxiety, and functional impairment will each uniquely contribute negative effects to the variance of both psychological and social-well-being.

H4: Higher levels of self-perceived burden and lower levels of dignity and reciprocity will collectively result in lower psychological and social well-being beyond the impact of functional impairment and mental health indices.

H5: Higher levels of self-perceived burden and lower levels of dignity and reciprocity each uniquely contribute negatively to psychological and social well-being after controlling for functional impairment, anxiety, and depression in the regression model.

The remainder of the chapter is divided into the following sections: participants, procedures, instrumentation, data analysis and summary. The first section provides a description of the participant sample in this study. The procedure section describes the recruitment and data collection process. The instrumentation section lists, describes, and provides psychometric information for each of the measures used in this study. The final section of this chapter outlines the data analysis techniques that were implemented.

Participants

All participants (N=71) were community-dwelling or semi-independent-living English-speaking adults whose ages ranged from 68 to 97 (mean = 86.23, SD = 6.46). As

an inclusion criterion, all participants verbally reported having at least one person (spouse, unmarried partner, child, grandchild, sibling, cousin, close friend, etc.) as regularly providing help or assistance with care. Potential participants with severe cognitive impairment would have been excluded, however screening using the Mini-Mental State Exam (MMSE) indicated that all participants had adequate mentation to participate in the study.

The participant sample included 55 females (77.5%) and 16 males (22.5%). The majority of the sample identified as White, non-Hispanic (98.6%, N=70); one participant identified as Hispanic. A large majority (94.4%, n=67) of persons identified as heterosexual; the other four participants declined to indicate sexual orientation. Most of the sample (88.7%, N=63) identified as Christian, including a sizable portion (31.0%, N=22) who identified as Mennonite Christians. Most participants identified as “middle class” (N=47, 66.2%) or “upper middle class” (N=19, 26.8%). Regarding highest level of education completed, 4.2% had less than a high school education (N=3), 29.4% had completed high school, 23.9% had bachelor’s degrees (N=17), and 30.9% (N=22) had graduate or professional degrees.

MMSE scores for participants ranged from 21 to 30 with a mean score of 26.87 and a standard deviation of 2.50. The majority of participants (N=64, 90.2%) earned scores of 24 or higher; scores of 23 or lower are the standard cut-off for cognitive impairment, and 58.2% (N=42) earned scores of 27 or higher, a more conservative cut-off score that may be a more accurate indication of cognitive decline among highly-educated persons (Bryant et al, 2008). Additionally, 33.8% (N=24) of the participants were aged 68 through 84, while the vast majority of participants (66.2%, N= 47) were 85 or older,

representing an especially aged sample. Regarding disabilities and health status, 39.4% (N=28) reported a physical disability, 18.3% (N=13) reported blindness, 26.8% (N=19) reported some level of deafness, and 8.5% (N=6) reported having had a stroke. The majority of participants (N=62, 87.3%) lived in independent housing without home health aide visits at the time of data collection; the remainder of the sample (N=9) lived independently but received some type of care from home health aides. Regarding the number of persons who provide regular help or assistance to participants, 17 participants cited one person who helps (23.9%), 17 cited two persons (23.9%), seven cited three persons (9.9%), and 18 cited four or more persons (25.3%). Interestingly, 12 participants declined to specify a precise number of “friends or family who regularly assist you with day-to-day activities” in the background questionnaire despite having verbally acknowledged receiving regular help or assistance from family or friends when enrolling in the study.

Procedure

All procedures were approved by the Human Subjects Institutional Review Board; see Appendix A. Participants were recruited through three waves due to difficulty in recruiting and retaining participants. Wave 1 participants were recruited from July through September 2010 at a graduated care facility with 1200+ residents in a small town in northern Indiana that has a large Amish and Mennonite population. The site identified 675 households as having at least one resident eligible to receive a letter about the study; and distributed letters to these persons (Appendix B; persons unable to legally consent for themselves were not sent letters). Fliers (Appendix C) were also posted on communal bulletin boards throughout the campus and a brief informational item (Appendix D) about

the study was posted twice in a campus newsletter distributed to all residents. This strategy yielded contact from 48 potential participants, 24 of whom ultimately elected to schedule a data collection meeting in their homes with the student investigator or a research assistant. In most cases, persons who elected not to participate cited not receiving assistance with their care as the reason. Of the 48 potential participants who contacted the student investigator after receiving letters, 35 used the telephone, 12 sent an email, and one person sent a letter in the US mail. Potential participants at this site were also recruited through in-person presentation at three different resident meetings, which yielded six more participants. This resulted in a total of 30 full participants in Wave 1.

Wave 2 participants were recruited through five departments at a medical hospital in the same area of northern Indiana. In the department that provides hospice and homecare services, fliers (Appendix E) were to be distributed to patients directly by nurses, a social worker, and chaplains. Approximately 100 fliers were provided to this department (June 2011) as the patient census was estimated to be around 90 persons at that time. None of these patients attempted to enroll in the study. Fliers were also placed in the waiting rooms of four other departments and were displayed for four to six months: a cancer center, a women's health center, an outpatient rehabilitation center, and a wound care practice. This strategy yielded phone calls from four potential participants, only one of whom became a full participant.

The final wave of recruitment was expanded to a medium-sized urban area in Southwest Michigan where five residential communities initially agreed to allow residents to be contacted via letters in resident mailboxes. A revised version of the letter used at the northern Indiana site (Appendix F) was used at these sites, along with the flier

created during Wave 2. One site dropped out before data was collected and a second site yielded 0 new participants after 40 households received invitation letters. The three remaining Southwest Michigan-area communities collectively yielded a total of 41 new participants. At these three communities, 385 households with potential participants received invitation letters. At two sites, participants were also able to enroll in-person after presentations at resident meetings. Of 51 persons who expressed interest in the study at these three sites, 16 enrolled at resident meetings, 15 contacted the researcher via phone, and six contacted the researcher via e-mail.

Therefore, of 103 persons who initially indicated interest in the study, 72 (69.9%) became full participants. One Wave 1 participant was omitted from data analyses due to being conceptually different from the other participants due to residing in a nursing home whereas the remainder of the participants lived independently. Originally, the desired sample size for this study was at least 97 persons, a number that was determined using an online statistics calculator based on the number of predictor variables, an alpha level of 0.05, an anticipated effect size of 0.15 (medium), and desired statistical power level of 0.85 (Soper, 2009).

The data collection meetings took place in participants' homes. Participants were given the option to meet at a neutral site, but all participants elected to meet in their homes. Each meeting began with brief introductions, followed by provision of the Informed Consent Document (Appendix G). After obtaining Informed Consent, measures that assessed cognitive and functional levels were orally administered, followed by either oral or written item-by-item administration of the six remaining measures that assessed depression, anxiety, dignity, reciprocity, and self-perceived, along with the background

information form. Most participants completed measures independently whereas 15 participants required oral administration and/or other assistance in completing measures (e.g. unable to write due to tremor, etc). As incentive and appreciation for participating, participants were invited to enter a drawing for one of six \$50 Walgreens gift cards.

The variables of interest and the measures used to assess them are each outlined below.

Instruments

Mini-Mental State Examination

Participants' cognitive status was assessed with the Mini-Mental State Examination (MMSE), a brief questionnaire that contains 30 one-point items and is typically administered within 5-10 minutes. The MMSE items assessed participants' cognitive functioning in regards to orientation, attention, immediate and delayed recall tasks, language, and command. For example, to assess short-term and delayed recall, participants are ask to repeat three items immediately and again after completing another item. Higher scores on the MMSE indicate an absence of cognitive impairment; scores below 24 reflect possible cognitive impairment in the general population. Participants with scores of 14 or lower would have been excluded from full participation. This cut-off value was chosen in an attempt to allow persons with a range of cognitive impairment to participate in this study.

Internal consistency for the MMSE has been reported at .62 for persons without cognitive impairment and .81 for persons with an Alzheimer's disease diagnosis (Tombaugh, McDowell, Kristjansson, & Hubley, 1996). Among long-term care residents, Pangman, Sloan, and Guse (2000) reported internal consistency above .80 and one week

test-retest reliability at .90-.97. Tombaugh and McIntyre (1992) found evidence of construct validity, with better levels of sensitivity for persons with severe impairment than those with mild impairment. Folstein et al. (1975) reported convergent validity with the WAIS Verbal IQ and Performance IQ at .78 and .66. Additionally, Pangman et al. found that the MMSE and a more complex version that takes longer to administer, the Standardized MMSE, are so similar psychometrically that they could be used interchangeably. In the present study, the MMSE was chosen due to its parsimoniousness.

Functional Impairment

A singular functional impairment variable was created by combining scores from The Barthel Index (Mahoney & Barthel, 1965) and the Instrumental Activities of Daily Living scale (Lawton & Brody, 1969). The scores from each instrument were converted to a 200-point scale and then added together to create a combined Functional Impairment score that could range from 0 to 400. Each of these instruments is described below.

The Barthel Index

The Barthel Index (Mahoney & Barthel, 1965) is a 10-item instrument that was used to assess difficulty with Activities of Daily Living in the domains of feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair and back), mobility, and stairs. An example of an item from the BI is, “Dressing. 0 = dependent, 5 = needs help but can do about half unaided, 10 = independent (including buttons, zips, laces, etc.)”. The data collector interviewed participants about these domains in order to assess the best answer per each domain. Participants received a total score that ranged from 0 (total dependence) to 100 (total independence).

This index was chosen over other measures of ADL functioning because of its established validity over time as well as that it can be used to collect self-reported information (Hartigan, 2007). This measure is the most frequently used ADL scale in the stroke rehabilitation literature, which reflects widespread use in a population with high rates of dependency on caregivers (Sangha et al, 2005). On all items a score of 0 indicates dependence on others to assist with a domain or in the case of bladder/bowels, incontinence. Independence is reflected by a score of 15 on 2 items, 10 on 6 items, and 5 on 2 items. On eight items, participants can receive an intermediary score of 5 and/or 10 to reflect partial independence.

Gosman-Hedstrom and Svensson (2000) reported strong correlations between the Barthel Index and the Functional Impairment Index (another IADL measure), in addition to strong face validity. Internal consistency was reported at 0.92 among persons recovering from hip injury (Van Balen et al, 2003), 0.92 among persons with brain cancer (Aaronson et al, 1995) and 0.95 among Chinese stroke patients (Tang & Chen, 2002).

In the present study, Cronbach's alpha was .51; this low value is probably a result of the small range of scores obtained in the present study.

Instrumental Activities of Daily Living Scale

The Instrumental Activities of Daily Living scale (Lawton & Brody, 1969) was used to assess participants' ability to perform activities along eight dimensions: ability to use the telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medication, and ability to handle finances. Total scale scores range from 0 to 8, with a score of 0 indicating dependence on others for all activities and a score of 8 indicating complete independence. Each individual item is

scored 0 (needs help) or 1 (independent). For example, a respondent receives 1 point for “food preparation” if the respondent endorses that he or she “plans, prepares, and serves adequate meals independently”; all other answers to this item result in a score of 0. As stated above, the total score was combined with the total Barthel Index score for analysis purposes to create a more comprehensive functional impairment variable.

Graf (2007) reported that few studies have been performed to test the psychometric properties of this scale despite common use in both clinical practice and research. Internal consistency reliability has been reported at 0.85 (Graf, 2007). Edwards (1990) reports test-retest reliability at .93 among hospitalized persons aged 80 and older. A validity study among rural elders in the Midwestern US indicated that the measure is a “moderately strong” predictor of functioning in the population of interest (Vittengl, White, McGovern, & Morton, 2006). Additionally, that study found that seven different scoring methods had fairly equal predictive validity, and thus the simplest scoring method, a dichotomous Guttman scale, is considered as useful as the more complex methods that have been devised and was employed in this study. Cronbach’s alpha in the present study was .60, which is likely a result of a limited range of scores obtained from the present sample.

The Patient Dignity Inventory (PDI)

The PDI (Chochinov et al., 2008) is a 25-item measure that was used to assess participants’ thoughts and feelings regarding their maintenance of dignity in the face of decline that requires assistance with care. Items on the PDI include, “Feeling worthwhile or valued,” “Not being able to accept the way things are,” and, “Experiencing physically distressing symptoms.” Participants were instructed to “indicate how much of a problem

or concern these have been for you within the last few days.” For each item, participants indicated whether the issue is not a problem (score = 0), a slight problem, a problem, a major problem, or an overwhelming problem (score = 5). Items are combined to yield a total score (possible range = 25 to 125) with higher scores indicating lower levels of dignity.

The PDI is a new measure that lacks psychometric data aside from the scale development article summarized here. Use of this face-valid measure in a study with older adults in a palliative care setting yielded an overall Cronbach’s alpha of .93, an indication of high internal reliability; test-retest reliability was also strong, reported at 0.85 (Chochinov et al., 2008). A factor analysis of the original proposed Patient Dignity Measure revealed a five-factor scale. These factors were symptom distress, existential distress, dependency, peace of mind, and social support. Reliability and validity were reported for each factor as follows.

Items within the symptom distress domain (six items) had factor loadings that ranged from .57 to .71, with internal consistency reported at .80. Concurrent validity was established by examining how the symptom distress items correlated with other measures of symptom distress: currently reported will to live ($r=0.17$, $p<0.012$), the Edmonton Symptom Assessment Scale (ESAS, $r=.26-.56$, $p<.001$), the Beck Depression Inventory (BDI, $r=0.36$, $p<.001$), the National Center for Health Statistics General Well-Being scale ($r=.68$, $p<.001$), and a single-item measure of suffering ($r=0.43$, $p<.001$).

Factor loadings on the existential distress scale (six items) ranged from .57 to .74, with internal consistency reported at .83. These items correlated with measures of suffering ($r=.016$, $p<.012$), well-being (ESAS, $r=.018$, $p<.005$), depression (ESAS,

$r=0.30$, $p<.001$; BDI, 0.38 , $p<.001$), anxiety ($r=.017$, $p<.001$), quality of life rating ($r=0.20$, $p<.003$) and satisfaction with quality of life ($r=0.21$, $p<.002$).

Dependency factor loadings (three items) ranged from .55 to .80, with internal consistency reported at 0.77. These items correlated with measures of activity ($r=-0.35$, $p<.001$), ability to work ($r=0.22$, $p<.001$), quality of life rating ($r=-.36$, $p<.001$), satisfaction with quality of life ($r=-0.28$, $p<.001$), and sense of dignity ($r=0.40$; $p<.001$).

Peace of mind (three items) factor loadings ranged from 0.56 to 0.82, with internal consistency reported at 0.63. Chochinov et al. (2008) noted that anticipated correlations between this factor and measures of psychosocial well-being were not revealed, and component factor analysis of this factor indicated that the peace of mind components correlated with the Inner Peace scale on the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being ($r=-.026-0.28$, $p<0.001$). These components were feelings of not making a meaningful contribution, feelings of unfinished business, and concerns regarding spiritual life.

Social support (three items) had factor loadings that ranged from 0.70 to 0.81, with internal consistency reported at 0.70. These items correlated with composite measures of the availability of ($r=-0.26$, $p<-0.006$) of and satisfaction with support ($r=-0.36$, $p<0.001$) from friends, family, and health care providers.

Cronbach's alpha of the PDI in the present study was .87.

Interpersonal Relationship Inventory

Experienced reciprocity in the care relationship was assessed using the reciprocity subscale of the Interpersonal Relationship Inventory that has been utilized in numerous studies of older adult participants (Tilden, Nelson, & May, 1990). The entire 39-item

IPRI was administered so that participants answered items in the order in which psychometric properties were established. The IPRI yields three scores: one for reciprocity, one for social support, and one for conflict. Scale scores are derived from simple summation of items. Items are scored from 1 (Strongly Disagree or Never) to 5 points (Strongly Agree or Very Often). The items on the measure are all worded in present tense. The reciprocity scale is comprised of 13 items, such as these: “When I need help, I get it from my friends, and when they need help, I give it back,” and “I’m satisfied with the give and take between me and people I care about.” Total scores on the reciprocity scale can range from 13 to 65 with higher scores indicating higher levels of reciprocity.

Exploratory factor analysis among samples of students, patients, and women’s shelter residents responses to the IPRI indicated that 5 of the initial 13 items on the reciprocity scale, all related to balance, loaded onto the social support scale as well as the reciprocity scale. Thus, the reciprocity subscale reflects both balance as a part of support as well as giving and receiving (Tilden et al., 1990).

Previous studies that have utilized the reciprocity subscale of this measure reported findings that are consistent with the social exchange and equity theories that form the basis of the definition of this construct, and three prior studies demonstrated evidence of construct validity using theory testing, contrasted groups, and factor analysis (Tilden, Hirsch & Nelson, 1994). Prior studies reported alpha of this subscale to be .80-.88 in community-based adults (Tilden et al., 1994). Internal consistency of the entire IPRI was reported at .88 among 151 patients with either arthritis or a pain disorder, and in

214 cardiac patients (Tilden et al, 1994). Test-retest validity has not been reported for this scale. Cronbach's alpha for the reciprocity scale in the present study was .82.

Geriatric Depression Scale-Short Form

The Geriatric Depression Scale-Short Form (GDS-15; Yesavage et al, 1983) was used to measure depression in the present study. The GDS-15 is a widely-used, dichotomously scored (yes/no) 15-item scale designed to assess the presence of depressive symptoms in older adults. Reverse scoring of five positively framed items is required. Scores range from 1 to 15, with higher scores indicative of more depressive symptoms. Sample items include, "Are you basically satisfied with your life?," and, "Do you feel that your situation is hopeless?"

This instrument is a shorter version of a 30-item measure that has been subjected to more psychometric rigor; a validation study of 35 persons found a correlation of .84 between the 30-item version and the one used in the present study (Sheikh & Yesavage, 1986). For the original 30-item scale, concurrent validity was established with the Hamilton Depression Rating Scale and the Zung Depression Rating Scale (Yesavage et al., 1983). A recent examination of the psychometric properties of the GDS-15 in a sample of 960 functionally-impaired, cognitively intact, community-dwelling primary care patients 65 and older in 19 counties in New York, West Virginia, and Ohio provided evidence of strong validity and reliability of this measure (Friedman, Heisel, & Delavan, 2005). More specifically, internal consistency was reported at 0.75 and, exploratory factor analysis supported the instrument's intended structure, with factors of depression and positive affect accounting for 33% of the variance of the scale. Construct validity was demonstrated with correlation between the GDS-15 score and the presence of major

depression. Criterion validity was further demonstrated with the same sample using ROC analyses showing that the GDS-15 successfully differentiated between depressed and non-depressed persons. An important finding in relation to this study was that internal consistency reliability and construct validity did not differ significantly between persons with low and high levels of functional impairment, as indicated by number of ADLs and IADLs.

Arthur et al. (1999) also used ROC curves to establish that the GDS-15 shows agreement with depression and depressive symptoms, and found strong specificity and sensitivity of the instrument as a screening tool with adults 75 and older in a general practice population in the United Kingdom. Furthermore, the GDS-15 has additionally been found to have suitable specificity and sensitivity with adults ages 85 and older in a US sample (de Craen, Heeren, & Gusseloo, 2003). Test-retest reliability has not been reported for this scale. Cronbach's alpha in the present study was .52, which is likely a result of the limited range of scores on this measure.

Hospital Anxiety and Depression Scale

The Anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A) was used to detect symptoms of anxiety. This 7-item scale includes items framed both positively and negatively. Per item scores range from 0 to 3, resulting in a possible high score of 21. A sample item is, "I feel tense or wound up" with possible answers being "Most of the time," "A lot of the time," "From time to time, occasionally," and, "Not at all."

The HADS-A appears to have psychometric strength in regard to screening for anxiety among older adults in US samples. In a sample of 31 primary care patients aged

60 and older, the HADS-A significantly correlated with the Brief Symptom Inventory-18 Anxiety scale ($\alpha = .54$, $p < .01$), and was determined to have better divergent and discriminant validity than this instrument as well (Wetherell, Birchler, Ramsdell, & Unutzer, 2006). ROC curve analysis of the HADS-A resulted in a sensitivity of 0.97 and a specificity of 0.67 for detecting Generalized Anxiety Disorder (GAD) against a structured diagnostic interview. Internal consistency was reported at 0.73 in the primary care sample. A literature review of 747 research articles that utilized the HADS found that Cronbach's alpha for the HADS-A varied from .68 to .93 with a mean of .83, and that sensitivity and specificity was approximately .80 (Bjelland, Dahl, Haug, & Neckellman, 2002). Test-retest reliability has been reported at .90 in a general hospital sample in Greece and at .36 among patients with cardiomyopathy (Michopoulos et al., 2008; Poole & Morgan, 2006; both in McPherson & Martin, 2009). Cronbach's alpha in the present study was .77.

Self-perceived Burden Scale

The Self-perceived Burden Scale (SPBS) was used to consider a care recipient's perceptions of feeling burdensome to others. Using this scale, burden is conceptualized as a single construct that has physical, emotional, and financial components (Cousineau, McDowell, Hotz, & Hebert, 2003). The SPBS is 10-item self-report measure that uses a 5-point Likert scale to indicate the degree of experienced self-perceived burden (1= "none of the time," 5= "all of the time"). Sample questions included, "I feel guilty about the demands that I make on my caregiver," and, "I am concerned that because of my illness, my caregiver is trying to do too many things at once." Respondents are instructed to think about their family members and friends who regularly assist them with

medication or medical care management, transportation, shopping, preparing meals, etc. Per standard instructions, participants received explicit instruction to only think of persons who are not paid.

Validity for this instrument was examined with 100 participants with end-stage renal disease in which the average age was 64.7, 55% were male, and 70% had at least one co-morbid illness with cardiovascular diseases or diabetes being most common. In terms of caregiver support, participants indicated needing the IADL activities of help preparing meals (70%), cleaning the house (67%), doing laundry (42%), driving (41%), and shopping (34%). The majority (61%) reported that a spouse provided most of the help, and many cited adult children as providing additional help. Just 6% of participants reported sons as primary caregivers, and 16% reported daughters serving in this capacity. Initial psychometric analyses of a 25-item version of the measure revealed high internal consistency ($\alpha=0.93$) but also revealed frequent cross-loadings in a three-factor model. Thus, the instrument developers opted to simplify the model to a 10-item version to avoid redundancy and preserve good enough internal consistency ($\alpha=0.85$).

The final 10-item version correlated at 0.95 with the original 25-item version. Discriminant validity coefficients indicated that burden scores were independent of age, education, pain level, length of time on hemodialysis, and the nature of any co-morbid conditions. Cousineau et al. did, however, find that the number of co-morbid conditions correlated positively with burden levels ($r=0.22$ and 0.21 in the 25- and 10-item versions of the scale, $p<0.05$), indicating that disease severity impacts level of burden. Test-retest reliability is not available for this instrument. Cronbach's alpha in the present study was .71.

Sense of Well-being Inventory

Participants' well-being was assessed using two subscales of the Sense of Well-Being Inventory (SWBI, Chapin et al, 2004): the psychological well-being subscale, and the family and social well-being subscale. This measure was developed specifically to assess well-being among persons with disabilities. Each item utilizes a 4-point Likert type rating scale (1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree). The negative items on both scales are reverse scored. Higher scores reflect higher well-being, whereas lower scores reflect lower well-being.

This instrument lacks extensive psychometric data aside from what is reported here; however it was chosen for this study given that it the only identified well-being measure developed specifically for use among persons with disabilities and thus represented a better option than measures developed for the general population. The psychological well-being scale has seven items with an internal consistency coefficient that has been reported as ranging from .79 to .89 (Chapin et al., 2004; deRoos-Cassini et al, 2009). Five of the items are worded so as to represent distress (I get frustrated about my disability, I feel people view me differently because of my disability, I frequently feel down, I frequently feel nervous, and I feel lonely). The other two items are worded positively to represent adjustment (I feel good about myself, and I am satisfied with my physical appearance). This subscale correlated highly (.75) with the psychological subscale of the World Health Organization Quality of Life questionnaire (WHOQOL-BREF), an internationally used generic QOL measure (Chapin et al., 2004).

The family and social well-being scale has 6 items with internal consistency reported at .84 and .79 (Chapin et al, 2004). The items are about family (I am an

important member of my family and I receive emotional support from my family) and social support (I have someone I can talk to about my problems, I have friends who care about me, People like being with me, and People take advantage of me). This subscale correlated at .45 with the social relationships subscale on the WHOQOL-BREF (Chapin et al, 2004).

Cronbach's alpha was .73 for the family and social well-being scale and .63 for the psychological well being scale in the present study.

Background Information Form

The background information form used in this study (Appendix H) was a modified version of one created by Munley, Thiagarajan, Carney, Preacco, & Lidderdale (2007). Demographic items were based upon the Dimensions of Personal Identity Model (Arredondo & Glauner, 1992) in an effort to gather information according to the multiple and overlapping dimensions of identity by which persons may experience privilege or oppression. Within this model, dimensions are separated into three groups. The "A" group includes age, culture, ethnicity, gender, language, race, sexual orientation, and social class. The "A" group also includes "physical/mental well-being." On this background information form, this category was expanded to include different types of disabilities (e.g. blindness, deafness, cognitive, etc). The "B" dimensions on the form include education, religion, military experience, relationship status, and work experience. The "C" dimensions include eras/events and personal/family; on this form these questions were about how many persons regularly assist them with their care, how many hours per week care is provided, and the relationships of persons who provide care to them (i.e. spouse, child, friend, etc).

Data Analysis

This section describes data analyses for the present study in the following order: preliminary analyses, descriptive statistics, and hypothesis testing. First, preliminary analyses on all data were conducted to check for outliers and assess for normality. These analyses also involved determining whether the assumptions for regression—linearity, homoscedasticity, and collinearity—had been met. Descriptive statistics, including frequencies, means, standard deviations, and correlations among the variables were also conducted. Finally, the main statistical analyses for each of the research questions are presented. Predictor variables included anxiety, depression, functional impairment (ADLs and IADLs), dignity, reciprocity, and self-perceived burden. The two separate criterion variables were psychological well-being and social well-being. Hierarchical regression analysis was used to test hypotheses. Due to the smaller than anticipated sample size and associated decreased power, the significance value of .10 was used to include discussion of those variables that were approaching significance.

To test H1, two separate hierarchical analyses were performed, one for each of the criterion variables, to determine the collective effects of anxiety, depression, functional impairment, dignity, reciprocity, and self-perceived burden. To test H2, two separate analyses were performed, one for each criterion variable, to measure the collective effects of the Block 1 variables of anxiety, depression, and functional impairment. To test H3, the unique individual effects of depression, anxiety, and functional impairment on each of the criterion variables using the beta values of standardized coefficients.

To test H4, two separate hierarchical analyses were performed, one for each of the criterion variables, to determine the collective effects of dignity, reciprocity, and self-

perceived burden. Finally, H5 was tested by examining the magnitude of the unique individual effects of dignity, reciprocity, and self-perceived burden on each of the criterion variables using the beta values of standardized coefficients.

CHAPTER III

RESULTS

Introduction

The research findings of this study are presented in this chapter. First, preliminary analyses to check for outliers, and assess for normality and the assumptions for regression are described. Next, descriptive statistics, including correlations among the variables, are reported. Correlations, means, standard deviations, skewness, and kurtosis for each of the variables are presented in Table 1. Finally, the main statistical analyses for each of the research questions are presented.

Preliminary Analyses

Prior to the main analyses, all variables were examined to check for univariate and multivariate outliers and to assess for normality of distributions. Standardized residual scatterplots and collinearity diagnostics were also examined for indications of violations of assumptions inherent to multiple regression.

Regarding outliers, one participant — a nursing home resident, was excluded prior to data transformations and hypothesis testing due to being conceptually different from the remainder of the sample who resided independently. Box plots of the remaining sample distributions showed that one of the remaining participants was an extreme outlier, defined as extending more than 3 box-lengths from the edge of the box, on two variables: anxiety and dignity. Dignity also had an additional extreme outlier. These two participants also represented extreme multivariate outliers per the Mahalanobis Distance participants' entire data sets indicated that these participants would likely not represent

Table 1

Descriptive Statistics for Predictor and Criterion Variables.

	FI	Dep.	Anx.	Dig.	SPB	Rec.	PWB	SWB
Functional Impairment	1							
Depression	-.30*	1						
Anxiety	-.08	.31**	1					
Dignity	-.29*	.43**	.71**	1				
Self-Perceived Burden	-.34**	.25*	.31**	.40**	1			
Reciprocity	.35**	-.40*	-.12	-.31*	-.30*	1		
Psych. Well-Being	.17	-.41**	-.45**	-.49**	-.28*	.34**	1	
Social Well-Being	-.05	-.42**	-.33**	-.31**	-.11	.41**	.45**	1
Mean (SD)	347.25 (48.75)	1.97 (1.64)	3.19 (2.87)	32.90 (8.51)	15.23 (4.32)	50.85 (5.45)	20.93 (3.01)	19.86 (2.16)
Skewness	-1.10	1.07	1.49	2.71	.76	.32	.27	.37
Kurtosis	.95	.84	3.14	9.88	-.30	-.23	-.30	-.68

Notes: 1) Abbreviations of variables in row correspond to full variable names in column. 2) All measures except Dignity reflect more of the construct being measured. High scores on Dignity in contrast reflect lower levels of dignity. Thus, for example, the positive correlation between Burden and Dignity means that participants who experience themselves as a burden to others report lower levels of personal dignity. * $p < .05$. ** $p < .01$.

test conducted as a part of the regression analysis. However, close inspection of these outliers had a larger sample been achieved. These participants' scores would likely not have been considered extreme were the ranges of scores not restricted, which is elaborated on below. Therefore, these participants were retained in the dataset given that they likely represent a legitimate subsection of the population of interest to this study.

Regarding normality, the skewness and kurtosis of the measured variables of Self-Perceived Burden, Reciprocity, Social Well-Being and Psychological Well-Being were less than or equal to 1. For the variables of Functional Impairment and Depression, kurtosis was less than 1 and skewness was greater than 1 but less than 2. However, the variables of Dignity and Anxiety had more extreme values for skewness and/or kurtosis. Furthermore, the Kolmogorov-Smirnov and Shapiro-Wilk significance tests used to assess the normality of distributions indicated statistically significant deviation from normality for the variables of Functional Impairment, Depression, Self-Perceived Burden, and Social Well-Being, as well as Anxiety and Dignity. Therefore, transformations of all variables except Reciprocity and Psychological Well-Being were conducted in an attempt to achieve normality or near-normality on each variable. Then, the regression analyses used in this study were run with three different sets of variables: the original variables; a set of variables using transformations on Functional Impairment, Depression, Anxiety, Dignity, Self-Perceived Burden, and Social Well-Being that achieved the most significant normality per the Kolmogorov-Smirnov and Shapiro-Wilk tests, and a set of variables that included transformations on just Anxiety and Dignity, the two variables with large skewness and kurtosis problems. The transformations conducted are detailed below.

The measured variables that revealed the largest problems with skewness and kurtosis were Anxiety and Dignity. Anxiety, as measured by the anxiety subscale of the Hospital Anxiety and Depression scale, showed abnormal kurtosis. A square root transformation produced a more nearly normal distribution (skewness = $-.09$, kurtosis = $-.11$), although normality was still not achieved per the Kolmogorov-Smirnov and Shapiro-Wilk tests. Dignity, as measured by the Patient Dignity Inventory, initially had large values for both skewness and kurtosis. Two logarithm transformations of the variable reduced these impacts (skewness = 1.43 , kurtosis = 3.05), but the distribution remained abnormal per the Kolmogorov-Smirnov and Shapiro-Wilk tests.

On the remaining variables that were not considered normal per the initial Kolmogorov-Smirnov and Shapiro-Wilk tests, transformations were conducted in an attempt to achieve the most normal distributions possible by attaining non-significance and/or further reducing skewness and kurtosis. No transformations were successful in improving the normality of functional impairment as measured by combining scores from the Barthel Index and Lawton Brody Instrumental Activities of Daily Living scale. Depression, as measured by the Geriatric Depression Scale, was unable to be transformed in such a way as to achieve normality via either the Kolmogorov-Smirnov or Shapiro-Wilk tests but a square root transformation did reduce skewness from 1.07 to $-.33$ and kurtosis from $.84$ to $-.19$. Two logarithm transformations on Self-Perceived Burden, as measured by the Self-Perceived Burden Scale, improved normality by increasing the Kolmogorov-Smirov value from $.000$ to $.024$ and changing skewness from $.76$ to $.12$, although kurtosis increased from $-.30$ to $-.84$. Finally the criterion variable of Social Well-Being, as measured by the Sense of Well-Being Inventory, was made more normal

with two logarithm transformations increasing the Shapiro-Wilk value from .003 to .013 and decreasing skewness from .37 to .11 while kurtosis remained stable at .68.

Once variables were transformed to be nearer to normality, regression analyses were conducted on the original data set, the data set with just two (Dignity and Anxiety) transformed variables, and the data set with all non-normal (Dignity, Anxiety, Functional Impairment, Depression, Self-Perceived Burden, and Social Well-Being) variables transformed. The results of the regression analyses were not substantially different from the original data when utilizing all of the transformed variables or by utilizing just the transformed Anxiety and Dignity values. Furthermore, both of the analyses utilizing data sets with transformed variables led to violations of the absence of multicollinearity assumption. Therefore, hypothesis testing hierarchical regressions utilized the data in its original form.

Before interpreting the results of the hierarchical regressions, the data were examined to determine whether assumptions of multiple regression had been met. More specifically data were examined for evidence of linearity of relationships, homoscedasticity, and absence of multicollinearity among the predictor variables. First, violations to linearity and homoscedasticity were assessed by examining the standardized residual scatter plots. These scatter plots provided evidence that the assumptions were not violated as the majority of data points were concentrated in the center in a roughly rectangular shape (Pallant, 2005). Second, the tolerance and VIF values were examined in order to assess for multicollinearity of the independent variables. Data for all variables were within expected ranges (tolerance ≥ 1 ; VIF < 10 ; Mertler & Vannata, 2005).

Descriptive Analyses

The means, standard deviations, and other relevant information from each measure are described below. Pearson *r* correlations among each of the variables, along with the other descriptive statistics, are presented in Table 1. Descriptions of key bivariate correlations are also described below.

Combined Functional Impairment scores ranged from 160 to 400 with a mean of 347.25 (SD = 48.75, N = 71). This score was created by combining scores from the Barthel Index and the Lawton-Brody Instrumental Activities of Daily Living scales. On each scale, scores could range from 0 to 200. Scores on the Barthel Index ranged from 110 to 200, with a mean of 179.30 (SD = 21.34). The sample as a whole indicated one or two areas of impairment, with an item-level mean score of 17.93. The most commonly reported area of impairment on the Barthel Index was partial or complete bladder incontinence (N=31), although all participants (N=71) denied needing assistance using the toilet. Other areas of reported impairment were feeding (N=5), bathing (N=1), grooming (N=1), bowel incontinence (N=13), transferring from chair to bed (N=6), mobility (N=13), and stairs (N=27). Adjusted scores on the IADL measure ranged from 50 to 200 with a mean of 167.96 (SD = 35.92). The sample as a whole indicated between one and two areas of impairment, with an item-level mean score of 20.99. Areas of reported impairment on the IADL measure were shopping (N=28), food (N=16), housekeeping (N=3), laundry (N=9), transportation (N=19), medications (N=9), and finances (N=7).

Geriatric Depression Scale scores ranged from 0 to 7, with a mean of 1.97 (SD = 1.64, N=71). The maximum score for the measure is 15. A small number (N=6) of

participants endorsed enough items (>5) to earn scores suggestive of need for further assessment in a clinical setting. A mean score of 1.97 indicates that, on average, participants endorsed approximately only two out of 15 symptoms associated with depression indicating that as a whole the sample was not depressed.

Scores on the Anxiety Scale of the Hospital Anxiety and Depression Scale ranged from 0 to 15, with a mean of 3.19 ($SD = 2.87$, $N=71$). The maximum score for this measure is 21. Just five participants endorsed high enough levels of anxiety (>8) to warrant further assessment in a clinical setting. With an item-level mean score of .46, the sample as a whole was not very anxious (1 = “From time to time, occasionally,”; 0 = “Not at all”).

Patient Dignity Inventory scores ranged from 25 to 74 with a mean score of 33 ($SD = 8.51$, $N = 69$). Higher scores reflect less dignity. Scores of 25, the lowest possible score, indicate that a participant denied experiencing any of the threats to dignity described on the measure. The highest possible score on this measure was 125. The sample as a whole indicated minimal concerns with dignity, given an item-level mean score of 1.36.

Self-Perceived Burden Scale scores ranged from 10 to 25 with a mean of 15.23 ($SD = 4.32$, $N = 71$). Scores of 10 ($N=12$) indicated that participants endorsed never feeling like a burden. The maximum possible score was 50. The sample as a whole indicated feeling like a burden between never and a little of the time, with an item-level mean score of 1.52.

Reciprocity scores ranged from 38 to 65 with a mean of 50.85 ($SD = 5.45$, $N = 70$). With a minimum possible score of 13 and a maximum possible score of 65,

participants in the sample reported levels of reciprocity from across the range. An item level mean score of 3.9 reflects scores that mostly “agree” with the statements on the measure.

For the criterion variables derived from the Sense of Well-Being Inventory, Psychological Well-Being scores ranged from 15 to 28 with a mean of 20.93 (SD = 3.01, N = 70). The lowest possible score was 7 and the maximum possible score was 28. An item-level mean score of 2.99 indicates that the sample as a whole usually “agreed” with the statements about psychological well-being. Family and Social Well-Being scores ranged from 16 to 24 with a mean of 19.86 (SD = 2.16, N = 71). The lowest possible score was 6 and the maximum possible score was 24. With an item-level mean score of 3.31, the sample as a whole generally “agreed” with the statements about social well-being. Higher scores reflect higher levels of well-being.

Bivariate Correlations

Most of the predictor variables significantly correlated with both of the criterion variables. Many of the predictor variables also correlated with one another, suggesting relationships between the variables of interest in the present study. All correlations are presented in Table 1, and notable correlations are described below.

In regard to psychological well-being, statistically significant bivariate correlations were found between this variable and each of depression, anxiety, dignity, reciprocity, and self-perceived burden. Additional statistically significant bivariate correlations related to psychological health were found between each of: anxiety and dignity, anxiety and self-perceived burden, depression and dignity, depression and reciprocity, and depression and self-perceived burden.

Psychological well-being and functional impairment did not have a statistically significant bivariate relationship, although functional impairment and depression had a modestly statistically significant correlation. Functional impairment also had statistically significant bivariate relationships with reciprocity, self-perceived burden, and dignity. Dignity also showed statistically significant correlations (listed in order of strength) with anxiety, psychological well-being, depression, social well-being, self-perceived burden. In regard to social well-being, statistically significant relationships were found between this variable and each of depression, anxiety, dignity, and reciprocity. Self-perceived burden yielded a statistically non-significant correlation with social well-being.

Hypothesis Testing

Hypotheses associated with the present study were tested with two separate hierarchical regression models that examined the effects of functional impairment, depression, anxiety, dignity, reciprocity, and self-perceived burden on each of two criterion variables—psychological well-being and social well-being. In each of these analyses, the first block of variables entered into the regression model included functional impairment, anxiety, and depression. The second block of variables entered into each regression model included dignity, reciprocity, and self-perceived burden. Results for regression analysis for Psychological Well-Being are presented in Table 2. Results for regression analysis for Social Well-Being are presented in Table 3.

The overall regression equation was statistically significant in regard to psychological well-being ($F(6, 60) = 5.14, p \leq .001$). Step 1 yielded statistically significant results, indicating that the first block of variables that included functional impairment, anxiety, and depression accounts for 28.4% of the variance on psychological

well-being ($F_{\text{Change}}(3, 63) = 8.34; p = \leq .001$). Within Step 1, anxiety ($\beta = -.36, p = .002$) and depression ($\beta = -.28, p = .019$) each uniquely contributed to the variance. Step 2 did not yield statistically significant results, indicating that the addition of dignity, reciprocity, and self-perceived burden did not predict additional variance in the model.

Table 2
Hierarchical Regression Analyses Examining Effects of Variables on Psychological Well-being.

Variable	<i>B</i>	<i>SE B</i>	β	R^2	ΔR^2
Step 1					
Functional Impairment	.00	.01	.053		
Depression	-.51	.21	-.28**		
Anxiety	-.37	.12	-.36***	.284***	.284***
Step 2					
Functional Impairment	-.00	.01	-.04		
Depression	-.33	.22	-.18		
Anxiety	-.23	.16	-.22		
Dignity	-.07	.06	-.20		
Self-perceived burden	-.03	.08	-.05		
Reciprocity	.10	.07	.18	.339***	.055

Note. * $p < .10$, ** $p < .05$, *** $p < .01$.

Table 3
Hierarchical Regression Analyses Examining Effects of Variables on Social Well-being.

Variable	<i>B</i>	<i>SE B</i>	β	R^2	ΔR^2
Step 1					
Functional Impairment	-.01	.01	-.19*		
Depression	-.55	.16	-.41**		
Anxiety	-.16	.09	-.22*	.256***	.256***
Step 2					
Functional Impairment	-.01	.01	-.27**		
Depression	-.39	.16	-.30**		
Anxiety	-.17	.11	-.23		
Dignity	-.00	.04	-.01		
Self-perceived burden	.03	.06	.06		
Reciprocity	.15	.05	.37***	.361***	.104**

Note. * $p < .10$, ** $p < .05$, *** $p < .01$.

In the social well-being model, the overall regression equation was statistically significant ($F(6, 61) = 5.73; p = \leq .001$). In addition, each of the subsequent Steps within the regression yielded statistically significant changes in R-square. In Step 1, anxiety, depression, and functional impairment accounted for 25.6% of the variance ($F_{\text{Change}}(3, 64) = 7.35; p = \leq .001$). Within Step 1, depression ($\beta = -.41, p = .001$), anxiety ($\beta = -.22, p = .060$), and functional impairment ($\beta = -.19, p = .091$) each uniquely contributed to the variance, with depression contributing the largest effects.

In Step 2, the combined influence of all six variables accounted for 36.1 % of the variance on social well being. The addition of dignity, reciprocity, and self-perceived burden accounted for an additional 10.4% of the variance after controlling for the effects of anxiety, depression, and functional impairment. Within Step 2, reciprocity ($\beta = .37, p = .003$), depression ($\beta = -.30, p = .017$), and functional impairment ($\beta = -.27, p = .023$), each uniquely contributed to the variance with reciprocity showing the largest effects. Dignity ($\beta = -.01, p = .950$) and self-perceived burden ($\beta = .06, p = .618$) were not unique statistically significant predictors of social well-being in this model.

Hypothesis 1

H1: The overall regression(s) will be statistically significant when functional impairment, depression, anxiety, self-perceived burden, dignity, and perceived reciprocity in the care relationship are collectively considered in relation to both psychological and social well-being.

This hypothesis was tested by examining the collective effects of depression, anxiety, functional impairment, dignity, reciprocity, and self-perceived burden in regards to each of the criterion variables, psychological and social well-being. In both the

psychological well-being and social well-being models, the overall regression equations were statistically significant. Thus, this hypothesis was supported by the analyses.

Hypothesis 2

H2: Higher levels of depression, anxiety, and functional impairment will collectively result in lower psychological and social well-being.

This hypothesis was tested by examining the collective effects of the variables in Block 1 in regard to each criterion variable. In both the psychological well-being and social well-being regression equations, this step in the model was statistically significant when depression, anxiety, and functional impairment were considered. Thus, this hypothesis was supported by the analyses.

Hypothesis 3

H3: The individual effects of higher levels of depression, anxiety, and functional impairment will each uniquely contribute negative effects to the variance of both psychological and social-well-being.

This hypothesis was tested by examining the individual effects when only the first block of variables was entered into each regression equation. This hypothesis was partially supported in the psychological well-being model as depression and anxiety contributed unique effects, but functional impairment did not. This hypothesis was fully supported in the social well-being model.

Hypothesis 4

H4: Higher levels of self-perceived burden and lower levels of dignity and reciprocity will collectively result in lower psychological and social well-being beyond the impact of functional impairment and mental health indices.

This hypothesis was tested by examining how much variance the second block of variables added to the regression model after controlling for the effects of functional impairment, anxiety, and depression. In the psychological well-being model, this hypothesis failed to be supported as the addition of dignity, reciprocity, and self-perceived burden did not account for additional statistically significant variance. This hypothesis was supported in the social well-being model.

Hypothesis 5

H5: Higher levels of self-perceived burden and lower levels of dignity and reciprocity each uniquely contribute negatively to psychological and social well-being after controlling for functional impairment, anxiety, and depression in the regression model.

This hypothesis was tested by examining the unique effects of dignity, reciprocity, and self-perceived burden after entering all variables into the model (i.e. Step 2). This hypothesis was not supported for psychological well-being. This hypothesis was partially supported in the social well-being model with reciprocity uniquely contributing to the variance.

Summary

In summary, the effects of functional impairment, depression, anxiety, dignity, reciprocity, and self-perceived burden were examined in regards to two criterion variables, psychological well-being and social well-being.

In the psychological well-being regression equation, the overall model was statistically significant. When the variables in Block 1—anxiety, depression, and functional impairment—were considered, both anxiety and depression were found to be

strongly predictive of psychological well-being. The addition of dignity, reciprocity, and self-perceived burden in Step 2 did not produce statistically significant results, after controlling for the effects of the Block 1 variables.

In the social well-being regression equation, the overall model did show strong statistical significance. Furthermore, the addition of dignity, reciprocity, and self-perceived burden predicted an additional portion of the variance even after controlling for the effects of depression, anxiety, and functional impairment. When examining the unique individual effects of each variable, depression, functional impairment, and reciprocity all made statistically significant unique contributions of at least moderate size with the largest effects seen from reciprocity.

CHAPTER IV

DISCUSSION

Introduction

This chapter is a discussion of the findings and implications from the present study. Following the introduction to this chapter is a discussion of key findings. The remaining sections are implications, including directions for research and practice; limitations; and a conclusion section.

The purpose of this study was to examine the impact of health and relationship variables on psychological and social well-being among adults ages 65 and older who receive assistance from at least one family member or close friend. While there has been a paucity of research in this area, previous studies have been successful in identifying a number of variables of interest within this population that may impact well-being or quality of life. These variables included those examined in this study: functional impairment, depression, anxiety, self-perceived burden, dignity, and reciprocity. Given the sparseness of the literature, no previous studies have examined these variables in connection with one another among adults 65 and older who receive family care. Therefore, a key objective of the research questions and associated hypotheses was to gain insight into which of these variables may be most salient. This knowledge extends the existing body of knowledge about receiving care in later life and provides further rationale for continued research regarding variables that improve well-being among older adults who receive family care.

The results of the present study reflect a gross understanding that the variables considered—reciprocity, dignity, self-perceived burden, functional impairment, depression, and anxiety—impact well-being among older adults who receive family care. While the limitations addressed below reflect that precise conclusions cannot be drawn about the variables of interest in the present study, the results have provided important broader knowledge that supports ongoing inquiry and have implications for enhanced practice with older adults.

Key Findings

This section includes a summary of remarkable characteristics of the participant sample, followed by discussions about each of the criterion variables of psychological and social well-being. Within the discussions about psychological and social well-being, exploration of the magnitude and meaning of statistically significant regression results is followed by exploration of statistically non-significant results through examination of the bivariate correlations between each criterion variable and the relevant predictor variables. Examining psychological and social well-being separately allowed for consideration of the idea that one may experience high levels of well-being in one domain while struggling with the other. This is important given that a goal of this study was to identify ways in which one's psychological or social well-being may be high in spite of functional decline associated with aging. The idea is that individuals can compensate for losses in one area with gains in another.

Sample Characteristics

The participant sample consists mostly of persons 85 and older, a subgroup of older adults that is especially underrepresented in the literature. Of particular interest

given the advanced age of the sample is that all participants lived independently, and the sample as a whole had relatively few problems with ADLs and IADLs. In spite of the low levels of reported functional impairments, the participants also acknowledged receiving assistance or help from family members. Community samples of older adults are rare in the literature about care receiving, as are samples not bound by a specific type of disability or illness (i.e. cancer, stroke, etc.) Therefore, the findings of this study provide important information about independently-dwelling, relatively healthy older adults in senior living communities who receive some assistance with their care from family and friends.

Psychological Well-being

The overall regression model examining the collective effects of the health (anxiety, depression, functional impairment) and relationship (dignity, reciprocity, and perceived burden) variables on psychological well-being was statistically significant with a large effect size. This finding reflects the importance of these constructs to psychological well-being among older adults who receive assistance with their care from family members. The remainder of this discussion focuses on exploring unexpected statistically non-significant relationships.

Dignity, reciprocity, and self-perceived burden did not significantly contribute to the regression model after controlling for functional impairment and the mental health variables of anxiety and depression. However, examination of bivariate correlations among the variables reflects statistically significant relationships for psychological well-being with dignity, reciprocity, and self-perceived burden, with dignity having the strongest correlation. Additionally, bivariate correlations between anxiety and dignity,

anxiety and self-perceived burden, depression and dignity, depression and reciprocity, and depression and self-perceived burden were each statistically significant, providing further indication that these constructs do impact psychological health and well-being.

The lower than expected correlation between psychological well-being and depression does not raise construct validity concerns in this study, given the small size of the participant sample with a small, but not abnormal, prevalence of anxious and depressive symptoms. This applies to correlations between anxiety and the other variables as well. Additionally, this explanation also addresses why the significant unique effects of anxiety and depression on psychological well-being were less strong than anticipated when only the psychological health variables and functional impairment were considered in the regression model.

Although restricted ranges on the anxiety and depression measures impacted the magnitude of obtained internal consistency estimates and bivariate correlations, the levels of depression and anxiety reported on these measures by the present sample population are consistent with estimated prevalence rates in the general U.S. population of older adults. In the present study, 7.0% of participants endorsed clinically significant anxiety symptoms, while 5.0% endorsed clinically significant depression symptoms. Recent epidemiologic data from The National Comorbidity Study-Replication estimates anxiety rates among community-dwelling adults 65 and older at 7.0% and 2.6% for depressive disorders (Gum, King-Kallimanis, & Kohn, 2009). Therefore, a larger sample, a sample consisting of persons with anxious or depressive disorders, or a sample of persons with more physical health problems who receive care from family members is needed to

further examine the effects of each of anxiety and depression on well-being in this population.

This is illustrated by the contrast between the findings regarding the small bivariate correlation between self-perceived burden and depression in the present study and a much stronger correlation between these constructs in a larger study ($N=105$, $r=.63$, $p < .001$) of primary care patients 60 and older (Cukrowicz et al., 2011). The discrepancy may be due Cukrowicz et al.'s use of a larger sample drawn from a primary care setting, where participants likely had more health problems, including depressive symptoms, than persons recruited in the general population. The discrepancy may also be related to the larger sample size in Cukrowicz et al.'s study or the use of different measurement tools. While Cukrowicz and colleagues were examining the impact of self-perceived burden on suicidal ideation after controlling for depression, hopelessness, and functional impairment, their results are also relevant to the present study in that they obtained these statistically significant, robust results in a second study after failing to do so with a smaller sample not recruited in a medical setting.

Finally, functional impairment not only failed to predict psychological well-being in the regression model, but was also not statistically significantly correlated with this criterion variable. This finding is inconsistent with Purk and Richardson's (1994) finding of a positive relationship between low or absent functional impairment and higher levels of morale, a construct closely related to psychological well-being. This discrepancy may be explained by the restricted range of functional impairment scores in the present study. Or, given the high number of persons 85 and older in this study, it may be related to increasing acceptance of functional impairment with age given that gradually decreased

ability is associated with normal aging. Therefore, continued exploration of functional impairment and other variables not found statistically significant in the regression models is warranted in both larger and demographically different samples (e.g. persons who are dependent in most ADLs, etc.). The relationship between age and acceptance of functional impairment also calls for closer examination.

Social Well-being

The overall regression model examining the collective effects of the health (anxiety, depression, functional impairment) and relationship (dignity, reciprocity, and perceived burden) variables on social well-being was also statistically significant with a large effect size, further supporting the importance of these constructs to well-being among older adults who receive assistance with their care from family members.

Furthermore, the addition of the relationship variables to the model after controlling for the effects of the health variables predicted a moderately large amount of additional variance. This finding provides further evidence that dignity, reciprocity, and self-perceived burden are collectively important among older adults who receive family care. Finally, when the unique individual effects of variables on social well-being were examined, reciprocity was found to contribute the largest effects, followed by depression and functional impairment. The remainder of this discussion focuses on the individual impacts of the relationship variables.

Reciprocity, simply defined as experiencing a balance of giving and receiving, had the strongest unique effects on social well-being among the older adults in the present study. Interestingly, reciprocity is the least-studied and discussed construct of the relationship variables in the family care literature, despite being the most salient to the

participants in the present study. The significance of reciprocity in the present study also provides support for Sebern's (2005, 1996) Shared Care Theory which puts forth the notion that care relationships are not dichotomous dyads in which an active caregiver provides for a passive care receiver, but are dynamic relationships in which both parties actively participate. An individual who perceives adequate reciprocity likely values his or her contributions to others, and, in the face of a disabling condition, values being able to contribute to his or her own care.

Dignity and self-perceived burden did not yield statistically significant relationships with social well-being when all predictors were considered together. However, as is illustrated by examining bivariate correlations among the variables and previous findings regarding these variables, dignity and self-perceived burden should not be dismissed as unimportant to receiving family care. The limitations section will also address this issue.

Examination of bivariate correlations did reveal a statistically significant relationship between dignity and social well-being, but not between self-perceived burden and social well-being. The correlations between dignity and social well-being, dignity and reciprocity, and dignity and self-perceived burden in the present study particularly highlight the importance of needing to better understand the role of dignity among persons who receive family care. For example, Webster and Bryan (2009) found that needing more assistance with ADLs was associated with experiencing less dignity, a finding supported by the correlation, albeit small, between dignity and functional impairment in the present study. The participant sample in the present study had limited

difficulty with ADLs. Theoretically, the relationship between dignity and ADLs would be stronger in a population with higher levels of functional impairment.

While self-perceived burden failed to contribute to statistically significant unique effects in the social well-being model and also did not have a statistically significant bivariate correlation with social well-being, characteristics of the sample in the present study may have accounted for the lack of such relationships in the present study. For example, the limited difficulty with ADLs in the present study may have also reduced a sense of burdensomeness given the relationship Newsom and Schulz (1998) found between greater physical impairment and the degree of self-reported mental or emotional strain in response to receiving help from one's spouse. Previous findings related to caregiver burden may also be relevant to the consideration of self-perceived burden. Hughes and colleagues (1991) found that lower levels of education were associated with higher levels of caregiver burden and vice versa. Likewise, Gottlieb, Kelloway, and Fraboni (1994) reported a relationship between higher levels of caregiver burden and lower incomes. Therefore, socioeconomic variables may have also influenced the low levels of self-perceived burden among this highly educated and financially stable participant sample.

The lack of reported difficulty with burdensomeness and dignity in the present study may have also been influenced by recruitment in residential communities designed with built-in accommodations for disabilities, such as a lack of stairs and trip hazards. Such accommodations likely promote dignity by allowing residents to be more independent (Webster & Bryan, 2009). In turn, independence may reduce feeling burdensome to others because less help is needed. Therefore, dignity and self-perceived

burden may be more salient among persons who reside in housing not designed for aging or disabled adults, or persons who lack the educational, intellectual, or financial resources that were common in the participant sample. Similarly, persons with greater financial resources may perceive themselves as less burdensome to their family caregivers. For example, care recipients with the financial resources to utilize paid caregivers in addition to family caregivers may feel less burdensome to their families than persons who lack this choice. Many persons in this study also cited multiple family members as contributing to their care, and therefore diffusing helping responsibilities among multiple persons may prevent or inhibit one's perception of self as burdensome. Furthermore, the act of delegating help to various family members, which may be based on those family members strengths or preferences, may in turn promote a sense of reciprocity. Likewise, choosing or declining offered help may increase an older adult's sense of control or independence, which would promote dignity.

Implications

Prior to conducting this study, the effects of anxiety, depression, functional impairment, reciprocity, dignity, and self-perceived burden had not been studied collectively among older adults who receive family care. Additionally, these variables had not all been studied specifically in relation to well-being in this population. Therefore, the statistically significant and moderately sized, collective effects of the variables obtained in regard to both the social well-being and psychological well-being models adds considerably to the limited knowledge base regarding family care. Furthermore, bivariate correlations for the relationship variables with both psychological and social well-being provide support for additional exploration of these variables among

persons who receive assistance with their care from family members. Of note, the correlations between dignity and anxiety, dignity and psychological well-being, and dignity and social well-being are indicative of a relationship between dignity and psychosocial health. Finally, the significant and strong unique effects of reciprocity on social well-being underscores the need for a better understanding of this construct among older adults, especially among independently-dwelling persons 85 and older who are in relatively good health but also receive care from family members.

The findings of this study certainly support ongoing scholarly inquiry into how reciprocity, dignity, and self-perceived burden each play a role in the well-being of older adults who require help or assistance from family members. Due to the small sample size, replication of this study with a larger sample is called for to confirm these findings. Due to impact of generation-specific experiences (i.e. the “cohort effect”), this study should also be replicated with future generations. A cohort effect related to about one-third of the sample representing Mennonite heritage may have also influenced these findings as this sub-group of participants may have shared values or experiences that impact their experience of receiving care differently than their non-Mennonite peers. Therefore, replication of this study and other further inquiry about how reciprocity, dignity, and self-perceived burden impact well-being needs to include a more diverse sample such as persons who live with their caregivers, persons with lower socioeconomic status, non-White persons, and persons with specific types of disability or disease.

Directions for further research as indicated by the results of this study are numerous. These include exploration of whether and how the impact of reciprocity on well-being changes after one begins receiving family care, or develops functional

impairment or disability. More examination of the relationships between dignity and functional impairment, and dignity and mental health are also warranted. Testing the effects of interventions that promote dignity and/or reciprocity among older adults who receive family care could strengthen the association of these constructs with psychosocial health. Likewise, exploration of how living environment (i.e. with or without accommodations) impacts dignity levels among older adults would have important implications for the necessity of accommodations, and also help to answer the question of how living environment impacted the range of dignity scores obtained in the present study.

Future studies may also consider controlling for variables other than anxiety, depression, and functional impairment when examining reciprocity, dignity, and/or self-perceived burden among older adults who receive family care. Those variables could include gender, age, type of disability, number of disabilities, relationship to primary caregiver (i.e. spouse, parent, etc.), number of caregivers, type of housing, and whether one lives independently or with their caregiver(s).

For practitioners who work with older adults and their families, these results indicate that the promotion of both reciprocity and dignity can contribute to higher levels of well-being. For example, given Webster and Bryan's (2009) finding regarding the relationship between dignity and privacy, medical professionals may be able to reduce anxious symptoms by promoting dignity through providing more privacy and facilitating as much independence as is possible, safe, and comfortable for a given individual. Among persons who receive family care, this might include encouraging family caregivers to divert their gaze when assisting with grooming or toileting, or providing

feasible options rather than making executive decisions. The latter may also promote a sense of reciprocity, as encouraging persons who are receiving increasing levels of help and assistance from family members to be as active as possible in decision-making and other aspects of their care may lead to enhanced social well-being.

Additionally, practitioners could encourage family caregivers to utilize times when help with ADLs or IADLs is being given as opportunities for reciprocal interaction. For example, the caregiving family member could ask the care recipient for advice or emotional support while providing transportation to the grocery store or a medical appointment. Given the correlation in the present study between depression and social well-being, such simple steps may reduce symptoms with a lower side effect profile and costs than are associated with antidepressant medications or talk therapy. Further research regarding such interventions is certainly warranted by the results of the present study.

Limitations

Discussion of limitations in this chapter can be broadly understood within the categories of sample characteristics, measurement issues, and other design issues. The challenges associated with each, and the associated implications are discussed below.

Target vs. Obtained Sample

The obtained sample differed from the target sample in many ways, all of which fall under the two larger but connected categories of being too small and too homogenous. This study aimed to better understand dignity, reciprocity, and self-perceived burden along with the effects of functional impairment and mental health among a diverse cohort of older adults (e.g., racially, socioeconomically, etc.) who receive family caregiving to assist with varying levels of disability (e.g., disability/health

status ranging from low to high levels of impairment, hospice/palliative care patients, etc.) and living environments (e.g., completely independent, assisted living, skilled nursing care). Ideally the sample size would have included about 100 persons.

In contrast, the obtained research sample was homogenous and consisted of persons who were well-educated, White, middle to upper class, and, aside from those who receive help from their spouses, living independently of their family caregivers. Perhaps most importantly, the obtained sample did not include many persons with severe levels of disability who require extensive assistance. Therefore, the generalizability of the findings in the present study is limited to persons like those in the sample.

Recruitment issues and stigma of participation may have served to limit the sample. Substantial efforts were made to recruit participants from places other than graduated care communities such as nursing homes, hospitals, a low-income community clinic, and churches. The hospital system that allowed recruitment through placement of fliers in waiting rooms resulted in very low interest. There were significant obstacles to recruitment in these other settings, some of which may have been related to concerns about protecting vulnerable persons. For example, at the low-income community clinic, a representative stated that since their clients are already among the most vulnerable members of the community, they could not risk exploitation or the perception of exploitation. One graduated care community that was similar to the recruitment sites utilized in the present study originally agreed to allow recruitment via letters in all eligible residents' mailboxes but later withdrew this permission due to staff members' concerns about vulnerable residents' participation in research. Finally, staff at one assisted-living facility reported that permission to recruit residents would have to be

obtained from a corporate office in another state; phone calls to that corporate office were not returned.

The reading level of the recruitment materials may have affected recruitment by excluding older adults with literacy problems or limited educational opportunity. The socio-cultural make-up of the obtained sample corresponds with the make-up of those people more likely to have had access to educational systems that taught them adequate reading and vocabulary skills to feel comfortable with the terms used in recruitment materials. The words “research,” “dissertation,” and “university,” along with others, may be foreign or intimidating to persons who lack familiarity with higher education.

One of the biggest limitations of examining family care among persons who live in graduated care or other senior living communities is the fine line between family care and the care that would be needed if the participants did not have access to a community with built-in accommodations for physical disabilities (e.g. no stairs), a dining area where some or all meals were available, a shuttle to shopping centers, etc. Participants in the present study endorsed shopping, transportation, and food as the top three IADLs in which help is needed and stairs and mobility as the most common ADL impairments. The built-in accommodations in the communities where participants were recruited may promote dignity and reciprocity and reduce feeling like a burden, anxiety or depression. This phenomenon may help to explain the abnormal distributions of obtained scores in regard to all of these variables except reciprocity. A person older than 65 with mobility problems who lives in housing with stairs may require more help and thus be more likely to feel burdensome than a similar person who does not have to encounter stairs on a day-to-day basis. A study comparing burden levels among older adults who live in residential

communities designed for seniors versus those who do not would help to answer this question.

Another recruitment issue may relate to one of the variables of interest in the present study—dignity. Some people who received recruitment letters contacted the Investigator and left voice messages stating that they would like to help, but they are “too independent.” Webster and Bryan’s (2009) phenomenological research had found that the maintenance of independence was closely associated with dignity among hospitalized British older adults. Similarly, Gallant et al. (2007) had identified independence and the fear of losing it as a common experience among older adult participants in their study about how family and friends assist with disease self-management. Even when the student investigator clarified the range of activities that qualify as help or assistance with care to residents at community meetings, at least one person reported having heard through the community grapevine that the study was for people who were “not independent.” Therefore the impact of stigma associated with participation in the present study on recruitment is unknown.

In addition to stigma, older adults, especially those from historically disadvantaged groups, may associate disclosure of vulnerability with risk. Given the concerns about independence voiced by participants and potential participants, the fact that sometimes asking for help results in the reduction of privileges (e.g. driving) may have also discouraged persons from participation in a study about needing help. Furthermore, persons who participated may have been less than completely forthcoming about the range of help actually needed as a result of this concern.

Related to potential stigma, there were a number of participants who articulated receiving the type of help or assistance of interest to this study (e.g. relying on an adult child for grocery shopping, relying on a spouse to assist with medication management, etc), but also verbally denied that they received help with their “care.” Given that caregiving relationships are a natural evolution of existing family relationships in which the amount of care provided increases over time (Radina, 2007), participants may not acknowledge the ways in which their family members attend to their care by making accommodations for their increasing functional impairment. Therefore the language used on various measures may have impacted participants’ answers in such a way as to minimize experiences associated with receiving family care. Problem terminology may have included the words, “care,” “caregiver,” “disability,” etc. This hypothesis may also help to explain the phenomenon of persons who agreed to participate in the study with the understanding that inclusion was contingent upon having “at least one friend or family member who provides regular help or assistance” but then neglected to fill out "care information" about such people on the background information form. Had a high enough sample size been achieved, omission of these participants would have been considered. The anecdotal evidence from potential participants during Wave 1 of the study (i.e. persons reporting they were too independent, or got help but not help with their “care,”) led to omission of the word “care” from all recruitment materials during Waves 2 and 3. This evolution of recruitment materials may have contributed to the higher response rate at Wave 3 recruitment sites.

Geron et al. (2000) suggested that persons who receive family care are often homebound, and thus more difficult to access. The present study attempted to address this

concern by collecting data in participants' homes, which also allowed for assessment of cognitive impairment. However, the intimacy of data collection in their homes may have dissuaded persons with higher rates of impairment or mental health symptoms who may have been willing to share information more anonymously (e.g. via mail-in surveys). Another aspect of the recruitment strategy that may have served to keep persons with more impairment out of the sample was the inclusion requirement that participants provide data without their caregivers in the same room. Several spousal caregivers contacted the researcher to learn more about the study on behalf of their spouses before withdrawing interest on the grounds that their spouse was currently too ill to participate.

Future research with older adult participants, particularly those who belong to historically vulnerable groups, may be enhanced through relationship building in the community of interest prior to active participant recruitment. Such an investment may result in greater comfort with the researcher and/or participation in research.

Additionally, strategic marketing to potential participants may better help them to understand the value of their participation to themselves and their communities. Given the importance of reciprocity to the obtained sample in the present study, a firm sense of *quid pro quo* may be important to older adults regarding their participation in research.

Both of these strategies may serve to boost and diversify the obtained sample.

Measurement Issues

Limitations associated with the measures used in the present study include floor or ceiling effects associated with limited ranges, low obtained internal consistency values for several measures, and several new instruments lacking previous evidence of psychometric rigor. These issues served to decrease the power of this study to observe

relationships that may exist between variables, and thus potentially increased Type II errors.

The reciprocity measure was one of two measures in this study that had a normal distribution of scores. This may be a reflection of reciprocity being measured from a positive, rather than negative, perspective that allows for a broader range of scores in the general population. On the other hand, the dignity measure, for example, assesses only the degree of problems with dignity. Therefore, persons with the lowest scores on the dignity measure may have had little to no problems with dignity, but the measure fails to capture how much dignity a person has in a positive sense. The reciprocity measure, however, captures persons with both high and low levels on a continuum where persons with scores in the midrange have neither high nor low levels of reciprocity.

The small and homogenous sample likely impacted the ranges of scores obtained on measures in the present study, which resulted in floor or ceiling effects that impacted the normality of distributions. While the anxiety and depression measures yielded scores expected in the general population as discussed above, such scores do not represent a normal distribution. Previous studies using these measures and cited in the Method chapter, have provided ongoing evidence of the utility and psychometric strength of these measures. In addition to the anxiety and depression scales showing floor effects, scores on every measure used in the study hit either the floor or the ceiling of possible scores. The restricted ranges likely contributed to the low Cronbach's alpha values ($<.70$) obtained for the Barthel Index, the Lawton Brody Instrumental Activities of Daily Living scale, the Geriatric Depression Scale-Short Form, and the Psychological Well-Being Inventory. Internal consistency estimates are frequently inaccurate in cases of "overly

restricted score ranges” (Maberly, 1967). The Patient Dignity Inventory and the Self-Perceived Burden Scale are recently created measures, and thus have not been subjected to extensive psychometric study. The results of this study do call into question the utility of using these measures among care recipients who receive relatively less assistance, While internal consistency estimates for these measures were considered acceptable, the range of obtained scores was also restricted in such a way that few participants endorsed high levels of self-perceived burden or low levels of dignity.

The Sense of Well-Being Inventory (Chapin et al, 2004) was chosen for the present study instead of other measures that consider similar constructs, such as quality of life, because it was developed specifically for use among persons with disabilities rather than for use in a general population. The language on this instrument referring to disabilities may have rendered this measure less reliable among the participants who did not endorse having a disability (N=20, 28.2%). But, it also resulted in a normal distribution of scores within the sample and thus displayed much variation among persons who are relatively healthy. None of the items on the social well-being subscale specifically reference having a disability whereas two items on the psychological well-being scale do.

Terminology may have also impacted responses on The Self Perceived Burden Scale in which the term “caregiver” is used in most items. This term may not resonate with persons who are proactive in leading their own care with help or assistance from family members despite that they do receive help with ADLs or IADLs. For example, focus groups in a previous study with older adults identified a range of ways that help is received in regard to medication management from having another person be entirely

responsible for all medications to occasional reminders to take a medication (Gallant et al., 2007). Such help on the less severe end of the spectrum may not feel like assistance with care, and thus the participants in this sample may not even realize the extent to which their family members help. Additionally, participants in this sample chose to live in environments in which their limitations are less likely to interfere with day-to-day life and there is less of a need to request or require help, which in turn likely results in lower levels of feeling like a burden and higher levels of well-being. The consideration of terminology will be important in future research about self-perceived burden among care recipients. In addition to the need to be mindful of the impact of terminology in research, the implication is the same for practice. Practitioners who work with older adults may want to frame questions about receiving care as questions about help or assistance in an effort to affirm and encourage an older adult's active role in maintaining his or her own health in addition to collecting more accurate information.

Other Study Design Issues

Analysis of the data derived in the present study also revealed design issues that may have influenced the results. Consideration of both the type (i.e. spouse, parent-child, sibling, etc) and quality of relationships between older adults and the family members who help them may impact multiple aspects of the help being given. These aspects may include type of help, amount of help, quality of help, congruence between type of help offered/given and type of help needed/desired, caregiver burden level, and self-perceived burden level.

Regarding both type of help and nature of the relationship between care recipient and care giver, the level of intimacy associated with the help may directly influence how

one feels about that help. No participants in this study received assistance with toileting and one participant received assistance with bathing, which is likely at least partially a byproduct of recruitment setting. Receiving assistance with these activities theoretically poses more risk to one's dignity than does receiving rides to the grocery store. Similarly, relationship nature may play a role. For example, an older woman may experience different levels of self-perceived burden or dignity when receiving assistance with bathing from her husband than she would from an adult daughter. A future mixed-methods study may be useful in gleaning further insight into these issues.

Conclusion

In conclusion, the present study supports the notion that reciprocity, dignity, self-perceived burden, functional impairment, depression, and anxiety collectively impact both psychological and social well-being among older adults who receive family care. Additionally, the collective effects of reciprocity, dignity, and self-perceived burden impact social well-being above and beyond the effects of anxiety, depression, and functional impairment. Reciprocity showed the largest unique effects on social well-being, indicating that how one experiences a balance of giving and receiving is important to older adults who receive assistance with their care from family members. In addition, the strong correlations between dignity and the mental health-related variables support ongoing inquiry into these relationships. From a practical standpoint, this study provides adequate evidence that practitioners who work with older adults may enhance well-being among community-dwelling older adults who receive family care through the promotion of reciprocity and dignity.

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Appendix A

Human Subjects Institutional Review Board Approval Letter

WESTERN MICHIGAN UNIVERSITY



Human Subjects Institutional Review Board

Date: May 17, 2010

To: Mary Z. Anderson, Principal Investigator
Alyssa Ford, Student Investigator for dissertation

From: Amy Naugle, Ph.D., Chair

Re: HSIRB Project Number: 10-04-06

This letter will serve as confirmation that your research project titled "Variables Impacting Psychological and Social Well-being among Adults 65 and Older Receiving Family Care" has been **approved** under the **full** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: April 21, 2011

Webwood Hall, Kalamazoo, MI 49008-5435
PHONE: (269) 387-8293 FAX: (269) 387-8276

Appendix B

Wave 1 Recruitment Letter



You are invited to participate in a research study that is examining things that have an impact on well-being. If you choose to participate, the information that you provide may help healthcare providers and researchers better understand how certain factors work together to impact health among persons 65 and older.

This study will help me to complete the requirements for my dissertation at Western Michigan University. As a token of my appreciation, persons who participate in this study may enter a drawing to win one of (6) \$50 giftcards to Walgreen's.

The purpose of this study is to understand how certain factors impact well-being among persons 65 years of age and older who regularly receive help or assistance with their care from family members. You are eligible for this study if you are a) 65 or older, b) have at least one friend or family member who regularly helps you or provides assistance with your care, and c) are able to provide information without any of your family or friends present.

Your participation would involve one or two meetings with myself or one of my assistants. We can meet in your home, or in a meeting room on the (name of location removed) campus.

The first meeting will last for at least 10 minutes, and if you are invited to continue to participate, would last for between 45 and 75 more minutes. It may be necessary to schedule a second meeting that would probably last for an additional 30-60 minutes.

If you are interested in learning more about or participating in this study, please call me toll-free at 1-866-254-0152 or send me an email at alyssa.c.ford@wmich.edu.

Thank you for your consideration,

Alyssa Ford
Doctoral Student

Appendix C

Wave 1 Recruitment Flier

Participants needed for Well-Being Research

Persons living at or receiving services through (location name omitted) are invited to provide information for a study that is examining factors that impact psychological and social well-being in persons who receive assistance with their care or other help from friends or family members. This study is being conducted by Alyssa Ford as part of her requirements for a doctorate at Western Michigan University, under the supervision of Dr. Mary Z. Anderson, PhD.

Should you choose to participate, any information that you provide will be confidential. Your participation is optional, and there is no penalty for not participating. None of the information you provide will be shared with anyone without your written permission, unless you reveal information indicating that you or another person is in danger.

Participants who complete the data collection process will be eligible to enter a drawing to win one of six \$50 Walgreens gift cards.

In order to participate in this study, you must be:

- 65 years of age or older;
- Able to identify family members or friends who regularly help you or assist you with your care;
- Willing to provide information about your health; and
- Willing to provide information about the friends and family who help you and the type of help they provide;
- Able and willing to provide information without any of your family or friends present.

Please call toll-free at 1-866-254-0152 or send an email to alyssa.c.ford@wmich.edu for more information.

Appendix D

Wave 1 Newsletter Item

Persons who live at or receive services at (name of location removed) are invited to participate in a research study about well-being. The study is being conducted through Western Michigan University.

Persons who participate are eligible to win one of 6 \$50 giftcards to Walgreen's pharmacy. In order to participate, a person must be 65 or older, have at least 1 friend or family member who regularly provides help or assistance, be willing to provide information about their health and well-being, be able to legally consent for one's self, and be willing to provide information without any family or friends present.

If you are interested in participating, please leave a message for Alyssa Ford at 1-866-254-0152 that includes your name and phone number.

Appendix E

Wave 2 and 3 Recruitment Flier

Participants needed for Well-Being Research

Adults ages 65 and older are needed for a study that is examining things that impact social and psychological well-being among persons who receive regular help from friends or family. All participants will be eligible to enter a drawing to win one of six \$50 Walgreens gift cards.

Should you choose to participate, any information that you provide will be confidential. Participation is optional, and there is no penalty for not participating. None of the information you provide will be shared with anyone without your written permission, unless you reveal information indicating that you or another person is in danger.

Persons who participate must be:

- **65 years of age or older;**
- **Able to identify family members or friends who regularly provide help, assistance, or care;**
- **Willing to provide information about one's health;**
- **Willing to provide information about the friends and family who provide help and the type of help they provide;**
- **Able to legally consent for one's self; and**
- **Able and willing to provide information without any family or friends present.**

Please call toll-free at 1-866-254-0152 or send an email to alyssa.c.ford@wmich.edu for more information. This study is being conducted by Alyssa Ford as part of her requirements for a doctorate at Western Michigan University, under the supervision of Dr. Mary Z. Anderson, PhD.

Appendix F

Wave 3 Recruitment Letter



Greetings,

You previously received an invitation to participate in a research study about well-being through your residence. Participants are still needed.

If you choose to participate, the information that you provide may help healthcare providers and researchers better understand how certain factors work together to impact health among persons 65 and older.

This study will help me to complete the requirements for my dissertation at Western Michigan University. As a token of my appreciation, persons who participate in this study may enter a drawing to win one of (6) \$50 giftcards to Walgreen's.

The purpose of this study is to understand how certain factors impact well-being among persons 65 years of age and older who receive some type of help from their spouses, family members, or friends.

Married couples who regularly help one another may qualify for this study.

Single, widowed, or divorced persons who receive help from their siblings, adult children, or other family members or friends may qualify.

You are eligible for this study if you are a) 65 or older, b) have at least one friend or family member who helps you or provides assistance with your care, and c) are able to provide information without any of your family or friends present.

Help or assistance means many different things. Please contact me if you have any questions about what is meant by help, as you may be eligible even if the type of help you receive seems minimal.

Your participation would involve just one or two meetings with me or one of my assistants. We can meet in your home, or in a neutral space.

The first meeting will last for at least 10 minutes, and if you are invited to continue to participate, would last for between 45 and 75 more minutes. It may be necessary to schedule a second meeting that would probably last for an additional 30-60 minutes.

During the meeting, you will answer the first few questions out loud. You may choose to answer the rest of the survey questions out loud, or by filling out the answers yourself.

If you are interested in learning more about or participating in this study, please call me toll-free at 1-866-254-0152 or send me an email at alyssa.c.ford@wmich.edu.

Thank you for your consideration,

Alyssa Ford
Doctoral Student

Appendix G

Informed Consent Document

**Western Michigan University
Counselor Education and Counseling Psychology**

Principal Investigator: Mary Z. Anderson, PhD
Student Investigator: Alyssa C. Ford, MS
Title of Study: Variables impacting psychological and social well-being among adults 65 and older receiving family care

You have been invited to participate in a research project titled "*Variables impacting psychological and social well-being among adults 65 and older receiving family care.*" This project will serve as Alyssa C. Ford's dissertation for the requirements of a doctoral degree in Counseling Psychology. This consent document will explain the purpose of this research project and will go over all of the time commitments, the procedures used in the study, and the risks and benefits of participating in this research project. Please read this consent form carefully and completely and please ask any questions if you need more clarification.

What are we trying to find out in this study?

The purpose of this study is to understand how certain things impact well-being among persons who regularly receive help or assistance with their care from family members. Previous studies have indicated that things such as the type of tasks you need help and your general health status may affect well-being. However, all of these things have not been studied together. In an effort to obtain information that is common across various situations and types of health issues, we aim to collect information from a broad range of persons for this study.

Who can participate in this study?

You are eligible for this study if you are a) 65 or older, b) have at least one friend or family member who regularly helps you or provides assistance with your care, c) are able to provide information without any of your family or friends present, and d) are able to provide legal consent for yourself.

Where will this study take place?

Participants for this study are being recruited in Elkhart County, Indiana; Kalamazoo, Michigan; and the greater Kalamazoo area. If you decide to participate, the student investigator or a trained assistant will meet you in your home. If you don't want a meeting in your home, we can meet in a private room at your church, the public library, or a similar public place.

What is the time commitment for participating in this study?

All persons who participate in this study will spend 10-15 minutes answering questions for the first part of the study. Depending upon what we learn from this

first set of questions, you also may be invited to participate in the rest of the study. This part will probably take about 45-90 minutes more of your time. We can start the remainder of the study after the 10-minute first part. A second session may be scheduled.

What will you be asked to do if you choose to participate in this study?

All persons who participate in this study will answer a series of questions out loud to help us learn more about your thinking. This will take about 10-minutes, and will help determine whether we need more information from you.

If you are invited to provide more information, your continued participation will involve answering some questions about activities you may need help with. This will involve completing 7 questionnaires. You may answer them in writing or verbally.

What information is being measured during the study?

This section will describe the questions you will be asked in the study. All participants will answer questions that will provide information about your thinking. If you are asked to participate in the rest of the study you will also be asked to provide demographic information and to answer other questions. These other questions will be about your abilities to care for yourself, your current mental and physical health, your feelings about receiving help or assistance with your care from others, your relationships with persons who help you, and your overall well-being.

What are the risks of participating in this study and how will these risks be minimized?

As in all research, there may be unforeseen risks to the participant. If accidental injury occurs, appropriate emergency measures will be taken; however no compensation or treatment will be made available other than what is specified in this consent form. Possible risks of participation in this study include mild stress or emotional discomfort in sharing information about physical health, mental health, relationships, and other factors that may be impacting your well-being. If you appear to be upset by the study, the researcher will provide immediate assistance and contact your care manager. You may also be provided with a referral list to providers who can provide counseling.

What are the benefits of participating in this study?

One benefit of participation is the opportunity to consider and reflect on your well-being. You may also benefit from knowing that you are contributing to a study that has the potential to help inform health care providers and others about well-being in your age group.

Are there any costs associated with participating in this study?

There is no expense for participating in this study if you choose to have the researcher or a research assistant come to your home to meet with you. However, you may be responsible for transportation to meetings not at your home.

Is there any compensation for participating in this study?

If you participate in this study, you will be eligible to enter a drawing to win one of (6) \$50 gift cards to Walgreen's. An entry form that will only be used for the purpose of determining the winners of the drawing will be provided to you. On this card, you will be asked to provide your name, telephone number, and mailing address.

Who will have access to the information collected during this study?

Any information that you provide is confidential, except for that which reveals abuse or neglect to children younger than 18, or any vulnerable adult (as is required by law).

Your name will not appear on any papers on which information from you is recorded. A code list will be stored in a different location from the data to keep track of participants. Data will remain stored in a locked file for a minimum of three years following completion of the study. Data will only be accessed by the student and principal investigators, or the HSIRB in emergency circumstances. The results of this study may be published in academic journals or at professional conferences; neither your name nor any identifying information would be included in such publications.

What if you want to stop participating in this study?

You can choose to stop participating in the study at anytime for any reason. You will not suffer any prejudice or penalty by your decision to stop your participation. You will experience NO consequences if you choose to withdraw from this study. The investigator can also decide to stop your participation in the study without your consent.

Should you have any questions prior to or during the study, you can contact the student investigator, Alyssa C. Ford at 866-254-0152 or alyssa.c.ford@wmich.edu, or the principal investigator, Dr. Mary Z. Anderson, Ph.D., at 269-387-5113 or mary.anderson@wmich.edu. You may also contact the Chair, of the Western Michigan University Human Subjects Institutional Review Board at 269-387-8293 or the Vice President for Research at Western Michigan University at 269-387-8298 if questions arise during the course of the study.

This consent document has been approved for use for one year by the Western Michigan University Human Subjects Institutional Review Board (HSIRB) as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate in this study if the stamped date is older than one year. I have read this informed consent document. The risks and benefits have been explained to me. I agree to take part in this study.

Printed Name

Participant signature

Date

Appendix H

Background Information Form

Background Information Form

Please answer all of the following questions by filling in the blank or circling the choice that best describes you.

A. Current Age: _____

B. Career/ Occupation (current or former; you may list more than one)

C. Citizenship

US Citizen _____yes _____no

If not US Citizen, what country are you a citizen of?

D. Disability (Please circle)

1. None – No Disability
2. Physical/Orthopedic Disability
 - 2a. Amputation
3. Blind/Visually Impaired
3. Deaf/Hard of Hearing
4. Learning/Cognitive Disability
 - 4a. Related to stroke
 - 4b. Diagnosis of Alzheimer's disease or dementia
5. Developmental Disability
6. Serious Mental Illness
7. Other – Please Specify: _____

E. Education: Please enter the number of years of schooling completed _____.

Please circle highest education level completed:

- | | |
|------------------------------|---|
| 1. elementary school | 8. third year undergraduate |
| 2. junior high school | 9. fourth year undergraduate |
| 3. some high school | 10. fifth year undergraduate |
| 4. completed high school | 11. bachelor's degree |
| 5. technical school | 12. master's degree |
| 6. first year undergraduate | 13. Ph.D. degree |
| 7. second year undergraduate | 14. professional degree -please specify _____ |

F. Gender

1. male
2. female
3. transgender

G. Current Marital/Relationship Status (Please circle the one that best describes you.)

1. Divorced
2. Married
3. Partnered
4. Married/Separated
5. Partnered/Separated
6. Single
7. Widowed
8. Other – Specify _____

H. Language

1. English primary/first language
2. English second language - please specify primary/first language

I. Military Experience

1. US Military Veteran
2. Veteran of another nation's military - please specify _____
3. Not a veteran of the military

J. Race/Ethnicity (Please circle number and specify ethnicity as appropriate)

1. American Indian or Alaskan Native

(A person having origins in any of the original peoples of North America, and who maintains cultural identification through community recognition or tribal affiliation)

Specify tribal affiliation: _____

2. Asian or Pacific Islander

(A person having origins in any of the original peoples of the Far East, South Asia, the Indian subcontinent, or the Pacific islands. This area includes, for example, China, India, Japan, Korea, the Philippine Islands, and Samoa.)

Specify ethnicity: _____

3. African-American/Black - not of Hispanic origin

(A person having origins in any of the black racial groups of Africa. Does not include persons of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish cultures or origins – see Hispanic).

Specify ethnicity: _____

4. Hispanic

(A person of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish cultures or origins.)

Specify ethnicity: _____

5. White, not of Hispanic origin

(A person having origins in any of the original peoples of Europe, North Africa, or the Middle East. Does not include persons of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish cultures or origins)

Specify ethnicity: _____

6. Bi-racial/ Multi-racial

Specify ethnicity: _____

K. Religious Affiliation (Please circle)

- | | |
|----------------------------|----------------------------|
| 1. Agnosticism | 6. Hinduism |
| 2. Atheism | 7. Islam |
| 3. Buddhism | 8. Judaism |
| 4. Christianity, Mennonite | 9. Sikhism |
| 5. Christianity, Other | 10. Other (specify: _____) |

L. Sexual Orientation (Please circle)

1. heterosexual
2. gay male
3. lesbian
4. bisexual

M. Social Class (Please circle)

1. lower class
2. lower middle class
3. middle class
4. upper middle class
5. upper class

Health and Care Questions

N. Number of family members or friends who regularly assist you with day-to-day activities, such as medication or medical care management, transportation, shopping, preparing meals, or other tasks:

O. Estimated number of hours per week you spend with persons cited in question N:

P. Relationships to you of all persons cited in question N (i.e. wife, husband, daughter, sister, friend, etc.). Please indicate whether any of these persons live with you most of the time by circling yes or no after each name. Also circle which activities each person helps you with.

	1. _____	Yes	No
taking medication	medical care management transportation		shopping
preparing meals	household maintenance financial management		
	2. _____	Yes	No
taking medication	medical care management transportation		shopping
preparing meals	household maintenance financial management		
	3. _____	Yes	No
taking medication	medical care management transportation		shopping
preparing meals	household maintenance financial management		
	4. _____	Yes	No
taking medication	medical care management transportation		shopping
preparing meals	household maintenance financial management		
	5. _____	Yes	No
taking medication	medical care management transportation		shopping
preparing meals	household maintenance financial management		
	6. _____	Yes	No
taking medication	medical care management transportation		shopping
preparing meals	household maintenance financial management		other (list)

Q. Do any or all of the persons cited above ask you for advice or talk over their problems with you? (Please circle)

1. All

2. Any (please list)

1. _____
- 2.
- 3.
- 4.
- 5.
- 6.

R. Please indicate which type of housing you live you in:

1. Completely independent without any ongoing home health aide visits
2. Completely independent with home health aide visits
3. Semi-independent/ Assisted Living
4. Nursing Facility
5. Indicate whether people live alone or not