Making Hard Choices: Respecting Both Voices

Final Report

Submitted to
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Independent Choices Initiative

By

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May 2000

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FAMILY CAREGIVER ALLIANCE®

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EXECUTIVE SUMMARY

Families play a central role in both the decision making and delivery of long-term care to adults with cognitive impairment (e.g., Alzheimer's disease, stroke, Parkinson's disease, traumatic brain injury). Losses of cognitive and functional abilities affect the individual and his or her family in profound ways. One of the most difficult problems a family caregiver faces is making decisions in "everyday" long-term care at home for a loved one whose capacity for planning and judgment may be impaired. Often conflicting factors must be weighed: "What is my wife's potential risk or harm to herself or others?" "How do I weigh *her* wish not to let anyone in the house to help out, with *my* need for help because of my increasing exhaustion?" Deciding when to bathe, what to wear, whether to purchase and use support services (e.g., adult day services), or when to accept care from family members are examples of everyday care situations. In practice, it is oftentimes difficult to separate the needs, preferences and best interests of the person with dementia from the needs, preferences and best interests of the family.

This research explored choice and decision making in everyday care for persons with cognitive impairment and their family caregivers. This study differs from previous research on decision making by its focus on: 1) a community-dwelling, cognitively impaired population; 2) the dyad, i.e., the person with cognitive impairment and the family caregiver; and 3) the exploration of values, preferences and decision making for daily care. Given the aging of the population, the concomitant increase in the number of persons with cognitive impairment, the high costs of care, and the trend towards earlier diagnosis and new treatments to delay decline of dementing illnesses, understanding *both voices* – the person with cognitive impairment and the family caregiver – will advance the state-of-the-art in practice, research and public policy.

Method:

Respondents were 51 persons with cognitive impairment and 51 family caregivers. The respondent pairs or dyads (i.e., adult with cognitive impairment and the family caregiver) were recruited from Family Caregiver Alliance's (FCA) client lists in the San Francisco Bay Area and outreach to local agencies. To be eligible, family caregivers had to be: 1) the spouse or adult child of the person with cognitive impairment; and 2) the primary caregiver. The person with cognitive impairment (i.e., the care receiver) had to meet the following inclusion criteria: 1) have a confirmed diagnosis from a physician of an adult-onset brain disease/disorder; 2) be living at home (i.e., living in the community rather than an institutional setting); and 3) be mildly to moderately cognitively impaired with scores between 13 to 26 as measured by the Folstein Mini-Mental State Exam (MMSE).

Three in-depth, in-person interviews were conducted per dyad. Experienced and trained research staff interviewed the caregiver and care receiver separately. The interviewing sequence and process was as follows: the person with cognitive impairment was interviewed first. Within one week, the family caregiver was interviewed and the person with cognitive impairment was interviewed a second time. Data collection began in July, 1998 for 10 months through April, 1999 to achieve a final sample of 51 dyads (3 interviews per dyad or 153 total completed interviews).

Sample:

Caregivers (n = 51) were predominantly wives (56.9%) and daughters or daughters in-law (21.5%), followed by husbands (11.8%) and sons (9.8%). Thus, more than two-thirds (68.7%) were spouses and one-third (31.3%) were adult children caring for a parent or parent-in-law. Caregivers were on average 63.5 years (*SD* = 14.6, range 30-90 years) although over half (51%) were at least 65 years of age or older, and most likely to be female (78.4%). Most caregivers were white (78.4%), married (80.4%) and about one-third were in the labor force employed either full-time (17.6%) or part-time (15.7%). Overall, the educational level of the family caregivers was high, with the large majority having at least some college education (84.3%). Most caregivers (23.5%) reported annual family income between $40,000 and $49,000 a year (1997 dollars). On average caregivers had been caring for their relatives for 3.1 years (*SD* = 3.4, range 1-23 years) and provided 80 hours of care per week (*SD* = 50.8, range 7-168 hours).

Care receivers (n = 51) were most typically husbands (58.8%), followed by mothers or mothers-in-law (21.5%), fathers (9.8%) and wives (9.8%). The average age of the care receivers was 75.6 years (*SD* = 10.0, range 39-89 years) although nearly nine out of ten (88%) were at least 65 years of age. The majority of care receivers were male (68.7%) and married (78.4%). The most commonly diagnosed brain disease/disorder was Alzheimer's disease (51%) followed by other dementias such as Frontal Lobe, Lewy Body or Vascular dementia (13.7%), stroke (11.8%), non-specific dementia (9.8%), Parkinson's disease (7.8%), non-degenerative brain disorders such as Anoxia (3.9%) and traumatic brain injury (2%). The average MMSE score of care receivers was 20.8 (*SD* = 4.06, range 13-26), with two-thirds (67%) considered mildly cognitively impaired (MMSE scores 20-26) and one-third (33%) moderately cognitively impaired (MMSE scores 13-19). Care receivers also had a high educational level with most (68.6%) having at least some college education.

Key Findings:

Are persons with cognitive impairment able to communicate their preferences for the care they are currently receiving or will need in the future?

- Persons with cognitive impairment were able to answer questions about demographics, general preferences, and involvement in everyday care with a high degree of reliability (i.e., at two points in time) and validity (i.e., accuracy).
- Similar results were found when care receivers were split into three groups based on high, medium and low MMSE scores with very few exceptions.

What is the decision-making process between adults with cognitive impairment and their family caregivers?

- Care receivers were able to choose a person, most commonly the family caregiver, to make a variety of decisions for them should they no longer be able to make decisions for themselves in six areas: health care, finances, personal care, social activities, living arrangements, and the possibility of living in a nursing home.

- Care receivers reported discussing their daily care wishes more than their nursing home wishes with their family caregivers, yet also felt their caregivers knew their wishes for daily and nursing home care equally well.

- Caregivers felt they had discussed the care receiver's wishes equally for both daily and nursing home care, yet also felt they knew the care receiver's wishes for daily care better.

How does the availability and use of information and services, as well as the quality and cost of care, facilitate and/or impede family decision making related to the cognitively impaired adults' everyday care?

- The majority of the caregivers (84.3%) reported having used some type of paid service provider since the care receiver had been diagnosed with memory problems.

- The three services most utilized by caregivers were information about the care receiver's illness (65%), caregiver support groups (55%), and help with housework, shopping, laundry or cooking (53%). The three least utilized services were the Internet (14%), education classes for the caregiver (20%), and help with managing financial or legal matters (22%).

- Service availability, affordability, and satisfaction were unrelated to the amount of discussion between the caregiver and care receiver about daily care wishes. However, the more satisfied a caregiver was with formal service usage, the less likely s/he was to have discussed nursing home care with care receiver.

- Overall, family caregivers reported low levels of financial strain and believed they had enough money at the present time to cover the costs of care. However, more than one-third (38%) of the caregivers either said they had "just enough" or "not enough" money to make ends meet at the end of the month.

- Care receivers with family caregivers who had higher financial strain reported feeling that their caregivers did not know their wishes for daily care.

- The care receivers' five top ranked values and preferences in aspects of daily life were related to the environment/safety and family caregiver issues: "Have a comfortable place to live" (Environment/Safety), "Have caregiver be the one to help out" (Family Caregiver issues), "Live in own home" (Environment/Safety), "Feel safe in home, even if it restricts activities" (Environment/Safety), and "Caregiver not put life on hold" (Family Caregiver Issues).

- The majority of the persons with cognitive impairment said that it was very important to them to remain at home (78%) and not to live in a nursing home (73%).

- Caregivers were fairly inaccurate in their perceptions of the importance of the care receiver's values and preferences. Significant differences were found for 20 of the 36 values and preferences. Typically when there were significant differences, the care receiver placed greater importance on the item than the caregiver thought they did. For example, persons with cognitive impairment felt that "feel safe in home, even if it restricts activities" was significantly more important than caregivers felt it was to the care receiver.

- The highest ranked values and preferences subscale for both the care receiver and the caregiver was Family Caregiver Issues, followed by Environment/Safety.

- Care receivers and caregivers were congruent in their responses that the domain of Environment/Social Interactions (e.g., have a comfortable place to live, be with family or friends) was most important and significantly more important than the domain of Autonomy/Self Identity (e.g., do things for self, maintain dignity).

Is there congruence between the preferences of the adult with cognitive impairment and the needs and practices of the caregiver?

- Care receivers were asked who they would like to help them (i.e.,family/friends, service providers, no preference) with specific tasks (i.e., shopping and cooking, laundry and housecleaning, getting up and dressing, bathing and toilet care). For all tasks, the care receivers preferred help from family/friends to paid services.

- Caregivers were asked whether or not they were using paid help for the specific tasks (i.e., shopping and cooking). For each task, the majority of the caregivers' needs and practices were congruent with the care receivers' preferences. Caregivers had not used services when the care receiver preferred help from family/friends. Similarly, the caregivers had used services available in the community when the care receivers preferred help from service providers.

- There was no association between how much the dyad had discussed the care receiver's wishes for daily care and the level of congruence between the care receiver's preferences and the caregiver's needs and practices.

When there is a lack of congruence, whose wishes prevail and how does this influence service use patterns?

- Care receivers and caregivers were asked to rate the importance of their own and their relative's best interests when thinking about making daily care decisions in the future. Both the person with cognitive impairment and the family caregiver felt it was more important to consider the best interests of the other member of the dyad above their own best interests.

- When all the questions about "best interests" were combined, however, the best interests of the person with cognitive impairment was considered more important than the best interests of the family caregiver.

- The more important the care receiver considered his/her own best interests, the better the caregiver knew his/her wishes for daily care. This was particularly apparent in dyads with adult child caregivers. For these dyads, the more importance the care receiver placed on his/her own best interests, the more the adult child knew about their parent's wishes for daily care.

- The more a dyad disagreed on whether or not to use support services, the fewer services the caregiver actually used.

Discussion:

The most salient findings of this study indicate that persons with mild to moderate cognitive impairment are able to: 1) state consistent preferences and choices; 2) provide valid responses to questions about demographics and their own involvement in everyday care; 3) participate in care decisions; and 4) express life long values and wishes regarding care they are currently receiving or will need in the future.

Many of the questions asked of the persons with cognitive impairment requested that they provide the name of the specific person(s) they would like to make decisions for them if they were no longer able in the areas of health care, finances, personal care, social activities, living arrangements, and the possibility of living in a nursing home. The care receivers overwhelmingly preferred to pass decision-making responsibilities on to family members. In almost all cases (93%), the identified person was the family caregiver or another family member.

Results suggest that caregivers and care receivers are discussing the care receiver's wishes for both daily and nursing home care. However, there are more discussions about daily care, likely because these families are dealing with the day-to-day challenges of caring for a person with mild to moderate cognitive impairment. But as our findings indicate, more frequent discussions do not necessarily translate into a better understanding of or agreement with the care receiver's preferences for all types of everyday care.

Service availability, affordability and satisfaction with service use were found to be unrelated to the amount of discussion between the caregiver and care receiver about daily care wishes. However, the more satisfied a caregiver was with home and community-based services, the less likely s/he was to have discussed nursing home care with the care receiver. Conversely, if caregivers were unsatisfied with services, they appeared more likely to move to discussions about nursing home placement. Thus, our findings support the importance of an accessible, affordable and quality home and community-based system to meet the long-term care needs of people with chronic degenerative diseases.

Study results reveal the potentially negative effects of financial strain on the dyad's level of congruence on both knowledge of and agreement with the care receiver's daily care wishes. Although caregivers reported low levels of financial strain overall and believed they had enough money currently to cover the cost of care, those who experienced higher financial strain were less likely to know the care receiver's wishes for daily care. Families experiencing the multiple and long-term stressors of caregiving may find that discussions about the care receiver's daily care wishes are not a priority. Instead, they are worrying about how they are going to get through each day. Care receivers who feel their caregiver is experiencing financial strain may not want to "make matters worse" or more stressful for the caregiver so they do not make their preferences known. Unfortunately, if these issues are not discussed then the dyad will not be able to do advance planning, which, in the long run, could cause increased strain and impoverishment for the family.

Lastly, in this study the MMSE was not found to be a sensitive measure of competency relating to decision making. While the MMSE is widely used to screen for cognitive function, it does not determine decisional capacity. In discussing the interviewing experience with the research interviewers, they felt that some of the care receivers who screened out on the MMSE because of low scores would have been able to participate in this study and express valid and consistent preferences.

Practice Implications:

The study results suggest that persons with early to moderate cognitive impairment may well possess the capacity to express daily preferences for care, and should be encouraged to discuss their values and preferences with their family caregiver. In turn, this would assist family members by helping them to better understand the wishes and preferences of their loved ones earlier in the disease process before they, the family caregivers, inevitably must make difficult and often agonizing day-to-day long-term care decisions.

The findings suggest the need for incorporating a values assessment as part of interventions to improve education and enhance communication between the care receiver and the family caregiver around the issues of daily care preferences at home, as well as residential and nursing home settings. Caregivers do not fully understand the care preferences of their relative and often have inaccurate perceptions of the care receiver's preferences and choices for everyday care. Thus, it may be helpful in counseling sessions, for example, to enhance the family's decision-making skills by identifying and encouraging early conversations about the care receivers' values and preferences for current and future daily living which are mutually acceptable to the family caregiver.

Our findings on values and preferences suggest that the primacy of personal autonomy may not be of critical importance to the person with cognitive impairment. Rather, the reciprocal nature of daily care decisions fosters interdependence within the family. This view of autonomy acknowledges a consumer-directed focus whereby the care receiver decides who they want to make and carry out activities in their place.

The assessment of values and care preferences and discussions about decision making are, practically speaking, difficult and challenging for families to undertake. Yet, ignoring the decision-making process between the caregiver and care receiver, and postponing discussions about the values and preferences of the person with cognitive impairment could have negative consequences for both members of the dyad over time. For many family members, knowing their loved ones' wishes for daily care could reduce the strain in developing and implementing a plan for future long-term care services.

Policy Implications:

The findings of this study support the policy direction of utilizing a family systems approach whereby the person with cognitive impairment and the family caregiver are considered legitimate "consumers" of long-term care. A family systems approach would expand current practice by assessing: 1) the care receiver's values and preferences for everyday care, rather than relying solely on information from the "proxy" or "surrogate," who typically, is the family caregiver; and 2) the family caregiver's situation, well-being, and need for targeted support services (e.g., respite, counseling).

Long-term care systems development, therefore, should incorporate the concept of family caregiving, rather than focusing exclusively on the care receiver when cognitive impairment is an issue. Few programs adequately address this critical policy area of supporting family caregivers to maintain their own quality of life.

Lastly, in this study, the person with cognitive impairment or "consumer" was able to answer questions that reflected an ability to delegate responsibility for directing aspects of care when he or she is no longer able to do so. In other words, the care receiver was able to make a consumer-directed choice to have a family member acting as a "consumer" on his or her behalf. This is particularly important in home and community-based programs where the goal of practitioners, for example, may be to maintain the well-being of the family caregiver so that they can continue to provide care to the person with cognitive impairment and honor the care receiver's preferences to live in their own home.

Conclusion:

This study aimed to recognize the roles of both persons with cognitive impairment and their family caregivers with regard to everyday care preferences and decisions. Our research adds to the growing body of evidence that persons with early to moderate cognitive impairment are able to articulate values, preferences and choices for themselves, and be valid and reliable in their responses.

The challenge is to educate policymakers, practitioners and researchers to take into account the views and preferences of the person with cognitive impairment and the needs and situation of the family caregiver. How to balance divergent perspectives will continue to be a challenge for those who work with persons with cognitive impairment and their family caregivers. By recognizing and respecting both voices – the care receiver and caregiver – we can enhance future research and practice, foster the development of consumer direction in long-term care and advance public policy to support caregiving families.

Increased understanding of the preferences of the person with cognitive impairment will improve the decision-making process, lead to more informed decisions, and reduce the strain on family caregivers and associated health costs. It is, after all, family caregivers, who are today and will continue to be in the foreseeable future, the major providers of long-term care and who will, ultimately, be left with the experience of implementing these challenging and difficult everyday care decisions.

CHAPTER ONE

INTRODUCTION[1]

> *"Caring and caregiving, after all, are not only about meeting an individual's needs or making him comfortable; they are about the recognition of the person of the other, the one being cared for, and they are about the recognition of the caregiver's own personhood therein also."* (Jennings, 1999, p. 103)

Families and informal caregivers play a central role in both the decision making and delivery of long-term care to the estimated 13 to 15 million Americans with adult-onset cognitive impairment (e.g., Alzheimer's disease, stroke, Parkinson's disease, traumatic brain injury) (Family Caregiver Alliance, 1999). The economic costs of these brain disorders are conservatively estimated at more than $130 billion annually (Dana Alliance for Brain Initiatives, 1995). The economic *value of care* provided by families, however, is even more staggering. At an estimated value of $196 billion nationally (1997 dollars), informal caregiving eclipses home health care ($32 billion) and nursing home care ($83 billion) (Arno, Levine & Memmott, 1999). This trend is likely to continue in the decades ahead with family members taking on even greater caregiving demands (Cohen, 1999).

Despite the magnitude of the number of persons affected by cognitive impairment and the costs of care, we know very little about how families make choices and everyday care decisions. According to a recent AARP survey (1999) of *cognitively intact* older persons, more than two in

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[1] In this report, we use the term "family caregiver" interchangeably with "informal caregiver." The family or informal caregiver is defined broadly as one who provides care without pay and whose relationship to the person with cognitive impairment (i.e., the care receiver) is due to personal ties rather than to the service system. While various terms are used in the literature to describe individuals with cognitive impairment (e.g., patient), throughout this report we use the terms "person with cognitive impairment," "adult with cognitive impairment" or "care receiver" to refer to the individual with an adult-onset brain disease/disorder, such as Alzheimer's disease, Parkinson's disease, stroke.

three (67%) said they had <u>not</u> talked with their baby boomer-aged children about independent living issues although they thought it would be easy (24%) or very easy (56%) to do so.

Decisions are generally made in a social context. According to Kane (1995) "In long-term care, both the older person who perceives a need for help and family members who may decide to provide care have decisions to make. One decides whether to accept care, the other whether to give it. Each is influenced by the other, sometimes by explicit advice and sometimes by influences about what is important to the other" (p. 89). There is very little research about the interaction between the family caregiver and care receiver in general, and virtually no studies exist which examine the decision-making process for daily care when cognitive impairment is present.

Loss of cognitive and functional abilities affect the individual and his or her family in profound ways. For example, balancing the needs and preferences of a person with cognitive impairment with the needs and preferences of the family caregiver can be exceedingly complex. Often at great personal sacrifice, families strive to keep a loved one at home, avoiding more costly institutional care. One of the most difficult problems a family caregiver faces is making decisions for a loved one whose capacity for planning and judgment may be impaired. Often, conflicting factors must be weighed: "What is my wife's potential risk or harm to herself or others? How do I weigh *her* wish not to let anyone in the house to help out, with *my* need for help with her care because of my increasing exhaustion?" *There are no simple answers to these questions.* In practice, it is oftentimes difficult to separate the needs, preferences and best interests of the person with dementia from the needs, preferences and best interests of the family.

The original idea for this study arose during a "brainstorming session" at the Family Caregiver Alliance (FCA) in late 1996 to identify emerging issues in working with family caregivers of cognitively impaired adults. Since 1977, FCA's mission has been to support and assist caregivers of cognitively impaired adults through education, services, research and advocacy. FCA's social workers underscored the fact that families ask for guidance on when and how to include the care receiver in everyday care decisions. Social workers also noted that due to earlier diagnosis and increased public awareness, family caregivers are seeking help from service agencies earlier in the disease process. Since practitioners are working with families in earlier stages of the disease/disorder, when the care receiver can still participate in family decisions, it is critical to identify practice guidelines and methods for improved communication in working with the family caregiver and the person with cognitive impairment. In addition, better understanding of the preferences of persons with cognitive impairment regarding practical, everyday care is essential to enhance the autonomy of the population and improve their quality of life.

While more and more families are being affected by the economic and emotional costs of providing long-term care, at the same time, people with cognitive and physical disabilities are making strides toward greater autonomy through consumer-directed care. The concept of consumer direction in home and community care is based on the key elements of choice and control, and the philosophy that informed consumers make choices about the services they receive (National Council on the Aging, 1996). While the consumer should be presumed competent to make choices, "the presumption of competence also means that a consumer's decision to delegate responsibility for directing certain aspects of service provision to other persons can be a consumer-directed choice, under the right circumstances: for example, where a person with cognitive impairment has a family member acting as a consumer on his or her behalf"(National Council on the Aging, 1996, p. 7). Thus the notion of who is the "consumer" in long-term care is an important policy and practice issue for those designing and testing long-term care service delivery systems and interventions for persons with cognitive impairment and their family and informal caregivers.

Given the trend toward earlier diagnosis and greater public awareness of dementing illnesses, the focus in both dementia care and research is shifting to include the person with dementia in decision making (Woods, 1999). Maintaining independence and control in decision making are issues of utmost concern to persons with disabilities and frail elders today. Preparing and supporting people with chronic illness to maintain control in the face of declining physical and cognitive abilities and increasing constraints in public sector financing for care will become even more important to society as the baby boomers reach old age in the 21st century.

Moreover, exploration of the decision making process from the perspective of both the "care receiver" and the "family caregiver" is a necessary component in long-term care research and practice. Understanding the dynamic interaction of the decision-making process in everyday care, and identifying the preferences, choices and strengths of the person with cognitive impairment are critical factors in developing strategies in consumer direction.

This study explored choice and decision making in everyday care for community-dwelling persons with cognitive impairment *and* their family caregivers, with a focus on their perceptions, values, preferences and practices in home and community-based care. Given the aging of the population, the concomitant increase in the number of persons with cognitive impairment, the high costs of care, and the trend towards earlier diagnosis and new treatments to delay decline of dementing illnesses, understanding *both voices* – the person with cognitive impairment and the family caregiver – will advance the state-of-the-art in practice, research and public policy in long-term care.

Research Questions

This study addressed five research questions:

1. *Are persons with cognitive impairment able to communicate their preferences for the care they are currently receiving or will need in the future?*

2. *What is the decision-making process between the care receiver and their family caregiver?*

3. *How does the availability and use of information and services, as well as the quality and cost of care, facilitate and/or impede family decision making related to the care receiver's everyday care?*

4. *Is there congruence between the care receiver's preferences and the needs and practices of the caregiver?*

5. *When there is a lack of congruence, whose wishes prevail, and how does this influence service use patterns?*

The balance of this report includes five chapters. Chapter two provides the background and review of the literature; chapter three describes the study methods; chapter four covers the study's quantitative results; and chapter five summarizes the qualitative findings. Chapter six offers a discussion of the findings and implications of this research study.

CHAPTER TWO

BACKGROUND

> *"When I was 5 years old I remember my mother said that she never wanted to go to a nursing home. So coming to some understanding of what is in the best interest of my mother, is the hardest part."* (48 year-old adult daughter caring for her mother who has Alzheimer's disease)

> *"Your [questions] helped me a lot. I haven't thought about myself in awhile. I thought I had lost it."* (55 year-old man diagnosed with vascular dementia)

In recent years, there has been a growing body of research on health care preferences and decision making. The research, however, has largely focused on consumer direction regarding "end-of-life" medical care in acute settings. Preferences for and decisions about "do not resuscitate" (DNR) orders or naming a health care proxy make up the majority of this research. In contrast, few studies have examined day-to-day care preferences and decision making. Yet some of the most difficult decisions and conflicts for persons with cognitive impairment and their families arise in "everyday" long-term care at home and in community-based settings. For example, tremendous conflict arises related to changing abilities in carrying out such daily activities as managing money, driving, or cooking. Deciding when to bathe, what to wear, whether to purchase and use support services (e.g., in-home care or adult day services), or when to accept care from family members are other examples of everyday care situations. For persons with cognitive impairment, decisions and preferences about everyday care become increasingly difficult to communicate as their disease progresses and their cognitive and functional abilities deteriorate.

To date, the studies of decision making and consumer choice have focused on: 1) patient autonomy within a medical model of health care decision making (e.g., advance directives, "do not resuscitate orders") (Gerety et al., 1993; High, 1988; Sansone et al.,1996; Wetle,1988); 2) case examples or dyads of family caregivers and older persons with physical, rather than cognitive, disorders (Pratt, Jones, Shin, & Walker, 1989; Walker & Allen, 1991; Zweibel & Lydens, 1990); 3) younger persons with physical disabilities (Litvak & Kennedy, 1991; Nosek, 1991); and 4) interviews with family caregivers only (Feinberg & Whitlatch, 1996; Morycz, 1985). No previous study has examined the process of decision making in everyday care situations with both the family caregiver and the person with cognitive impairment, including their degree of congruence on preferences for home and community-based care.

It is widely accepted that families provide the majority of hands on care to their cognitively impaired loved ones. Yet, such caregiving often exacts a heavy emotional, physical and financial toll. Family caregivers are more depressed than age-matched controls in the general population (Haley, Levine, Brown, Berry, & Hughes, 1987), and report more emotional strain in terms of higher levels of depression, anger, and anxiety (Anthony-Bergstone, Zarit, & Gatz, 1988; Friss & Whitlatch, 1991; Gallagher, Rose, Lovett, & Thompson, 1989). Compared to family members not giving care, family caregivers report feeling more depressed (Dura, Haywood-Niler, & Kiecolt-Glaser, 1990; Dura, Stukenberg, & Kiecolt-Glaser, 1991; Pruchno and Potashnick, 1989; Tennstedt, Cafferta, & Sullivan, 1992) and in worse physical health (Stone, Cafferata, & Sangl, 1987); and those who feel strained with caregiving are more likely to die (Schulz & Beach, 1999). Moreover, caregiving has financial costs, including lost income from quitting a job to give care (Petty & Friss, 1987; Scharlach, 1989; Wagner & Neal, 1994).

Questions about the family's role in home and community-based care are complex when the person being cared for has cognitive impairment because, frequently, the family becomes both the “decision maker” and “service provider.” According to Kapp (1996), empowering the person with cognitive impairment often means empowering his or her family support system. Past research suggests that most -- but not all -- adults want a family member to make health care decisions for them if they are not able to make decisions themselves (Louis Harris and Associates, 1982; High, 1988). Some care receivers, however, have no family, while others have families who are unable or unwilling to assume the decision-making role (Feinberg & Whitlatch, 1996). Nevertheless, few individuals make decisions entirely on their own. The role of families and other informal caregivers in the decision-making process when a family member is cognitively impaired is important to understand (Feasley, 1996).

Although researchers have examined at length caregiving practices and consequences for families, little is known about the potentially stressful nature of making care-related decisions and the context in which these decisions are made (Smerglia & Deimling, 1997). Smerglia and Deimling (1997) suggest that in the case of spouse caregivers, decisions may be “merely an extension of lifelong marital processes” (p.659). For adult children, however, decision making about care for a parent may represent a “reversal of lifelong patterns of responsibility, a change that can produce tension and conflict” (p.659).

Very little research attention has been paid to the experience of persons with dementia, let alone the caregiver’s perceptions of the care receiver’s everyday values and preferences. The absence of the care receiver’s perspective has led to a lack of representation of their needs in the selection of care strategies (Cohen, 1991). One reason for this oversight is that researchers have only recently begun to include persons with cognitive impairment in studies as “legitimate contributors” to the research process (Cotrell & Schulz, 1993). As Woods (1999) has noted, “there has been the assumption that people with dementia are unable to communicate in a meaningful way, invalidating their participation in decision making about their own situation as well as rendering their lived experience and their perspective as being impossible to research" (p.36). According to Stewart, Sherbourne and Brod (1996), subjective assessment in cognitively impaired populations has been ignored due to the presumed logistical and methodological issues, specifically regarding comprehension and reliability. Sadly, as a result, researchers and practitioners often wrongly assume that persons with cognitive impairment are unable to make care decisions for themselves.

Recently, however, in both research and practice, there has been a move to better understand the preferences and experiences of persons with dementia (Kitwood & Benson, 1995; Downs, 1997; Woods, 1999). To date, the majority of the literature on the emergence of the person in dementia research has been qualitative in design. Downs (1997) outlines three areas which have been studied: 1) the individual's sense of self; 2) perspectives of persons with dementia; and 3) a person's rights. In terms of sense of self, a growing body of research suggests that people with dementia retain a sense of self, despite cognitive impairment, into the late stages of the illness (Downs, 1997; Kitwood, 1997; Woods, 1999). Further evidence that persons with dementia are able to report on their situation comes from the growing number of support groups and other services developed specifically for persons with early stage dementia (Brod et al., 1999; Yale, 1999). Downs (1997) notes that while more attention has recently been paid to the perspectives of persons with dementia, there is a "clear bias towards eliciting views from people in the early stages" (p. 605). Lastly, there is a growing trend acknowledging the rights of people with dementia (Downs, 1997). A gap still exists, however, in exploring the person's values, preferences, and decision making for daily care situations.

Even with the recent increasing interest in studying persons with dementia, the caregiving literature has generally emphasized either the family caregiver or the cognitively intact care receiver. Studies that examine both the family caregiver and the care receiver, with or without cognitive impairment, are rare (Young, 1994). A gap also exists with regard to dyadic research, particularly in terms of involving persons with cognitive impairment. This body of research, which comes from work in marriage and family, typically examines the marital or parent-child dyad, with little or no attention paid to persons with cognitive impairment. The research on congruence between family members and older persons is also a relatively new area of study (Horowitz, 1998), and even more recent with the cognitively impaired population.

Given the advances in diagnostic testing and the trend toward earlier diagnosis (Cotrell & Schulz, 1993), more and more families are entering the long-term care system earlier in the disease process. These advances have created an opportunity for earlier and more consistent involvement of both the person with cognitive impairment and the family caregiver in everyday care decisions. According to Kapp (1992), "the process of sharing power through frank and concrete discussions between an older person and the family, which take place while the individual is still decisionally capable, should lead to better, more accurate surrogate decision making if it subsequently becomes necessary as a result of the individual's mental decline. Shared decision making affords a chance for continued dialogue that informs future proxies more fully about the individual's values and preferences concerning later decisions" (p.785). Etzioni (1988) contends, "most choices are made on the basis of emotional involvement and value commitments" (p. 125). These factors are critical in examining decision making. As well, some researchers suggest that family surrogate decision making when properly used, can function as an extension of an older person's autonomy in that "individual autonomy, fully understood, is interdependent with family autonomy" (High, 1988, p. 50).

Unfortunately, other than the emerging models for early-stage support groups (Yale, 1999), information and interventions for those in the early-stage dementia population have not kept pace with the growing demand and numbers of persons in need of services and assistance.

Rather than focusing on behavior management approaches to be used later in the progression of the illness, treatment with psychosocial interventions and knowledge of the care receiver's preferences and desires early in the dementing process could yield a better understanding of the individual (Cotrell & Schulz, 1993). Related research and service interventions have lagged far behind the trend towards earlier diagnosis of persons with dementing illnesses.

While the onset of cognitive impairment weakens a person's intellectual functioning, judgment or the ability to make decisions about his/her care are not uniformly impaired (Post & Whitehouse, 1995; Rabins & Mace, 1985; Sansone, Schmitt & Nichols, 1996). Since the cognitive abilities of a person with dementia typically varies from day to day, and even in the course of the same day, the person's decision-making capacity may be greater at some times than others. Many persons with Alzheimer's disease, for example, function at their highest level in the mornings and deteriorate as the day progresses (Brechling & Schneider, 1993).

According to Wetle (1995) "determining the capacity to make decisions is an inexact science" (p.67). Most ethicists, clinicians and researchers prefer the concept of "decisional capacity," recognizing that persons with cognitive impairment may be capable of making some decisions but not others (Kapp, 1990; Sabatino, 1996). Moreover, assessment of decision-making capacity should incorporate the individual's comprehension (i.e., ability to understand and assimilate relevant information) and reasoning (i.e., ability to evaluate and integrate information) (Kapp, 1990; Salthouse, 1996). Thus, depending on the situation, persons with cognitive deficits may have varying abilities in matters of decision making. To date, no valid, standardized method exists to determine decisional capacity (Gerety et al., 1993; Kapp & Mossman, 1996). In home and community-based care, capacity is oftentimes best assessed on a decision-specific basis, where some persons with cognitive impairment may have decisional capacity in some respects but lack capacity in others. For example, Mrs. M. may be able to decide who should make health care decisions for her if she is no longer able, but not competent enough to shop for groceries. Due to the intellectual impairment that characterizes most dementing illnesses, the capacity to make decisions about daily activities is often compromised (Zarit & Goodman, 1990). When cognitive impairment is mild, questions may arise about the care receiver's ability to perform certain activities (e.g., to continue working or handle financial affairs). If cognitive functioning further deteriorates, care receivers are faced with decisions about daily life activities which may jeopardize the safety of both the person with cognitive impairment and others, e.g., driving and cooking (Zarit & Goodman, 1990). In the advanced stage of dementia, language deficits limit the individual's ability to communicate. Unless the care receiver had previously expressed preferences for everyday care, it is nearly impossible to know what the individual wants and needs (Cotrell & Schulz, 1993).

Following diagnosis, mildly to moderately impaired persons and their families often begin planning for and adapting to the disease/disorder. Family members gather information about the disease process, talk with others who have had similar experiences, or determine potential service options. During this early stage it has become increasingly common for family members to discuss the care options available to them. Persons with cognitive impairment may verbalize to family and friends their preferences for care, although this is not always the case. A person in the early stage of dementia who is confused and disoriented to time and place may still be capable of making choices and expressing preferences about many aspects of his or her care (Brechling & Schneider, 1993). However, findings from decision making research suggests that people often find it difficult to anticipate their own needs or plan for long-term care. Often, one's assessment of needs changes according to the circumstances, and it is difficult to anticipate preferences and options in those changed circumstances (Hibbard, Slovic & Jewett, 1997).

With the disease progression, it becomes nearly impossible for the care receiver to voice preferences for care. During the later stages, the family caregiver faces the critical task of determining what services are available to keep their loved one at home, or whether another living arrangement is called for, e.g., a move to a nursing home. Even when a caregiver makes decisions that reflect the care receiver's clearly stated choices, the family may experience considerable anguish and conflict. The lack of guidelines to help with identifying values and care preferences integral to the decision- making process, as well as the high costs of care, can amplify the family's distress.

Case studies (Cohen & Eisdorfer, 1986) and more recent research (McHorney, 1996; Parmelee, Lawton, & Katz, 1989) suggest that individuals who are mildly to moderately cognitively impaired are able to articulate their feelings, concerns and preferences, and provide self-assessments of their health status and quality of life. Direct assessment of the quality of life of mildly to moderately cognitively impaired persons has been found to be reliable and valid (Brod et al.,1999; Logsdon & Teri, 1996). For example, all 36 subjects who scored below 23 on the Mini Mental Status Exam (MMSE) were as able as cognitively intact older respondents to provide reliable, valid self-report information about their health status on the Medical Outcomes Study SF-36 Health Survey (McHorney, 1996). Similarly, persons with Alzheimer's disease scoring between 10-28 on the MMSE were able to complete a brief quality of life measure (Logsdon & Teri, 1996). This measure was found have good psychometric properties and is available in a form for use with family caregivers as well. Although Logsdon and Teri found that persons with cognitive impairment were able to provide a valid and reliable assessment of their own quality of life, they also found that the care receiver's and caregiver's reports were related, but not identical. Brod et al. (1999) developed a 29-item instrument assessing quality of life and tested it with 99 persons with mild to moderate dementia (MMSE scores of 13 – 23).

They found the instrument to be reliable with evidence of validity; nearly all (96%) were able to respond to questions appropriately. While these few studies suggest that persons with mild to moderate cognitive impairment can often respond to carefully designed instruments, it remains unclear when, in the course of dementing illness, individuals are no longer able to provide reliable reports (Logsdon & Albert, 1999).

Increasingly, most researchers studying quality of life support the notion that assessment of quality of life can and should only be made "by persons for themselves, about themselves" (Jennings, 1999, p. 97). In a study of medical decision making with 52 nursing home residents with mild to moderate dementia and their proxy, the respondents were able to clearly communicate their desires, and demonstrated decision making consistency; only 13 percent of the subjects made inconsistent decisions (Gerety et al., 1993). Further, research suggests that about 30 percent of institutionalized adults with dementia can consistently make decisions about their health care, including, but not limited to, "do not resuscitate orders" and durable powers of attorney (Sansone et al., 1996). Lastly, a qualitative study of five persons with dementia (MMSE mean score of 19) found that people with early Alzheimer's disease are able to participate actively in interviews up to one hour in length (Phinney, 1998).

A final issue for persons with cognitive impairment and their families relates to the costs of home and community-based care. Research has shown that cost plays a central role in determining access to care, and the type and duration of care received (Advisory Panel on Alzheimer's disease, 1992; Wilson, 1995). But how do costs influence family caregiver and care receiver preferences for and decisions about the use of home and community-based care? Results from our recent research on consumer choice and in-home respite care indicate that the "direct pay" (i.e., independent provider) mode of in-home respite was the preferred mode of respite service delivery, and it was also more cost effective than the use of agency-based respite care (Feinberg & Whitlatch, 1996). Specifically, our results indicate that caregivers who used the direct pay mode received more hours of respite care than caregivers who used agency-based respite. In addition, compared to agency-based respite, the direct pay mode was shown to be significantly less costly per hour of service. On the other hand, our study results also suggest that caregivers in both groups (i.e., direct pay and agency-based users) valued safety concerns, and good, reliable, and trustworthy help over cost issues and amount of care. More research is needed to examine whether meaningful choices can be made by family caregivers and persons with cognitive impairment within current financing and service delivery systems (Kapp, 1996).

Building upon this past body of work, the present study was designed to advance knowledge on consumer direction for persons with cognitive impairment and their families. Specifically, this research addresses gaps in the literature related to: (1) the decision-making capacity and process of persons with cognitive impairment with respect to their everyday care preferences and needs; (2) the information needed by persons with cognitive impairment and their families to help them make informed choices about care; (3) the tradeoff for families and care receivers with respect to safety and autonomy; and (4) related issues on the availability, use, quality and costs of care.

CHAPTER THREE

METHODS

Procedures

Sample recruitment and screening: Recruitment efforts yielded a total of 233 family caregivers of persons with cognitive impairment who were contacted by mail or referred directly to FCA for the purpose of participating in the study. The respondent pairs or dyads (i.e., person with cognitive impairment and the family caregiver) were recruited from Family Caregiver Alliance's (FCA) client lists in the San Francisco Bay Area (n = 200, 86%), client referrals from an Alzheimer's research center (n = 6, 3 %) and requests for subjects through local agency newsletters (e.g., Alzheimer's Association) or community presentations (n = 27, 11%). These prospective subjects were sent a letter describing the study and asking for their participation. Dyads were then screened by telephone to determine preliminary eligibility.

In accordance with the consent procedures approved by the Institutional Review Board, the research coordinator first contacted the caregiver by phone to determine willingness and availability to participate in the study and whether the dyad met the study's eligibility requirements. To be eligible, family caregivers had to be: a) the spouse or adult child of the person with cognitive impairment; and b) the primary caregiver.[2] The person with cognitive impairment (i.e., the care receiver) had to meet the following inclusion criteria: a) have a

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[2] Primary caregiver was operationalized as follows: a) spouses were automatically considered a primary caregiver, unless they had a significant mental and/or physical disability that left them largely unable to provide assistance; b) adult children were automatically considered primary caregivers if they shared a household with the care receiver (unless the care receiver had a non-disabled spouse living in the household; c) if adult children lived in a separate household from their parent, they had to have the primary responsibility for organizing, managing and supervising care, and assist with activities of daily living on a regular basis.

confirmed diagnosis from a physician of an adult-onset brain disease/disorder; b) be living at home (i.e., living in the community rather than an institutional setting); and c) be mildly to moderately cognitively impaired (scores between 13-26, as measured by the Folstein Mini-Mental State Exam).

If the caregiver agreed to participate, the research coordinator then telephoned the person with cognitive impairment to determine their willingness and availability to participate. Both the caregiver and care receiver had to give verbal consent over the telephone to be scheduled for the interviews, and had to give written consent at the time of the first interview to participate in the research. Final eligibility was determined during the care receiver's Part 1 interview once the MMSE was scored, thus determining the individual's level of cognitive impairment.

Of the 233 families identified, 21 (9%) could not be reached by phone to conduct the preliminary screening. The research coordinator made every effort to contact all caregivers, telephoning up to three times, either leaving a message with another person or on the telephone answering machine. Another 58 (25%) were found to be ineligible. The most frequent reasons for ineligibility were: caregivers not meeting the initial inclusion criteria (31%); care receivers being too impaired to be interviewed based on caregiver reports (28%); placement of the care receiver in a skilled nursing facility or residential care (16%); caregiver moving out of the area (15%); or the death of the care receiver (10%).

Forty-five percent (n = 69) of the remaining 154 caregivers refused to participate for a variety of reasons, yielding a 55 percent acceptance rate. The most frequent reasons cited by the caregiver for choosing not to participate included the following: unwilling to participate in the research study or not giving an explanation for refusal (42%); the care receiver was too impaired to participate (based on caregiver reports) (19%); the care receiver either did not or was unable to participate after the caregiver discussed the study with their relative (17%); the caregiver was too busy (9%); or other reasons (13%). Of the 85 eligible dyads, two were used for interviewer "practice," yielding a final preliminary sample of 83 caregiver/care receiver dyads.

At the outset of the study, the inclusion criteria required that the care receiver score between 16 and 23 and on the MMSE. However, a high number of persons with cognitive impairment screened out because they either scored too high or too low on the initial inclusion criteria of MMSE scores between 16-23. Therefore two months after we began interviews, and after consultation with the national advisory committee, we modified the screening criteria by expanding the cut-off in both directions to include persons with cognitive impairment with MMSE scores between 13 to 26, enabling us to include in the study a wider range of persons with cognitive impairment and their family caregivers.

About one-third (n = 27 or 32%) of 83 eligible care receivers screened out at the Part 1 interview with 12 (44%) scoring less than 13 on the MMSE and 15 (56%) scoring above 26 on the MMSE. In addition, three (4%) care receivers were unable to complete the written consent process at the Part 1 interview; one (1%) care receiver declined to continue after the first interview; and one (1%) caregiver declined to participate at the scheduled time of the caregiver interview. The final sample for the study includes 51 adults with cognitive impairment and 51 family caregivers.

Interviewing: Following the telephone screening, the research coordinator scheduled the in-person interviews. Experienced and trained interviewers interviewed the caregiver and care receiver separately.[3] Every effort was made to ensure that the same

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[3] A comprehensive one-day interviewer training was conducted by the PI and Co-PI on the actual in-person dyad interviews, roles and responsibilities, written consent procedures, interviewing techniques, thorough review of the interview schedules and training manual, and other related issues. Each interviewer completed one "practice" set of interviews with a dyad prior to the start of actual data collection. The research team met regularly during the interviewing phase of the study to ensure reliability and consistency in data collection and to provide solution-oriented support to the interviewers related to the interview process.

interviewer was assigned to interview each member of the dyad. For the most part, interviews were conducted with the dyads in their own homes. In some cases, the caregiver was interviewed at his or her place of employment, or in a restaurant; for the care receiver, several interviews were held either at an adult day care center or senior center, always in a location that protected privacy and ensured confidentiality during the interview.

For this study, three interviews were conducted per dyad. The interviewing sequence and process was as follows: the person with cognitive impairment was interviewed first. Within one week, the family caregiver was interviewed and the person with cognitive impairment was interviewed a second time. We chose this sequence and timing of interviews for two reasons: 1) to limit the potential for respondent attrition; and 2) because we recognized that the questions regarding daily living preferences and care decisions could generate discussion between the family caregiver and care receiver between interviews which could affect their responses. Interviewers contacted the family caregiver the day before or the day of the interview to confirm date, time and location. For the person with cognitive impairment, the interviewers generally contacted them the day of the interview to make certain they were able and willing to participate.

The interview process for the person with cognitive impairment was as follows:

1. The care receiver was interviewed first (Part 1) to determine final eligibility with the MMSE score. The trained interviewer met in the home with the care receiver alone in a private area. The interviewer briefly explained the study, described the consent process, and asked the respondent to sign the appropriate consent form.

2. The interviewer asked preliminary demographic questions and then administered the MMSE to screen for level of cognitive functioning. If the respondent did not meet the final inclusion criteria (MMSE scores between 13-26), he or she was excluded from the study and the interview was ended with an appreciation of thanks for the respondent's time. Within 48 hours, the research staff telephoned the caregiver to communicate the outcome of the screening, inform him or her that they were ineligible to participate in the study, and to thank him or her as well.

3. If the care receiver met the final criteria, the interviewer proceeded to complete the Part 1 interview.

4. Within one week a second in-person interview (Part 2) was conducted by an interviewer to insure the reliability and stability of their responses (Sansone et al., 1996) and to ask additional questions.

If at any point during the interview process the family caregiver or person with cognitive impairment became upset or agitated, they were to be referred to an FCA social worker for support and intervention. All respondent pairs received a thank you letter and check for their time and participation in the study ($30 for care receiver and $25 for caregiver).

On average, the Part 1 interview with the person with cognitive impairment lasted 42 minutes (range: 24 to 103 minutes) and the Part 2 interviews, conducted one week later, took 50 minutes to complete (range 25 to 100 minutes). The interviews with the caregivers lasted longer, averaging 107 minutes (range: 27 to 193 minutes).

Under the supervision of the principal investigator, data collection began in Year 2 of the study[4], commencing July, 1998 and continuing for 10 months through April, 1999 to achieve a final sample of 51 dyads (3 interviews per dyad or 153 total completed interviews). In our initial proposal we had estimated six months for data collection with a final sample of 60 dyads. Recruitment and screening, however, took longer than anticipated for several reasons: 1) research staff were all part-time with only 15 to 25 percent time per week devoted to the study resulting in a lower number of interviews scheduled on a weekly basis than had been originally anticipated; 2) a high refusal rate by caregivers who said, from their perspective, that their family member was too impaired to participate or simply didn't want to be involved in a dyad study on decision making; and 3) a higher than expected number of persons

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[4] The study instruments were developed, pre-tested and refined in Year 1 of the study. Data collection took place during most of Year 2, and data cleaning, analysis and report writing occurred in Year 3 of the study.

with cognitive impairment who screened out early on because they either scored too high or too low on the MMSE, the most commonly used measure to screen for level of cognitive impairment.

We do not believe that our final sample of 51 dyads compromises the power of this exploratory study or our ability detect meaningful effects for three reasons: 1) the research hypotheses and questions do not require large numbers of independent variables; 2) data reduction techniques utilized ensure that summary scales are used in analyses; and 3) data analysis techniques used to test the dyad's level of agreement/disagreement reflect global constructs (e.g., personal care) in addition to individual items (e.g., bathing).

Measures

The three instruments to examine choice and decision making in everyday care were developed by research staff with input from the national advisory committee drawing upon measures used previously or adapting existing measures. The instruments were pretested with a sample of six dyads between February – March, 1998 to determine ease of comprehension, interview length, and appropriateness of vocabulary and content areas. Based on the results of the pretest, the research instruments were revised and clarified.

The final instrument for the person with cognitive impairment (Part 1) includes the following measures: 1) Mini-Mental State Examination (MMSE) to screen for cognitive impairment; 2) sociodemographic items; 3) Correct Scale to assess ability to answer correctly to general demographic questions; 4) Preference Scale to assess the ability to choose or state a preference; 5) Decision Control Inventory to assess personal control over dimensions of daily life; and 6) questions to assess decision making for daily living, personal care and advance directives. At the second interview (Part 2), one week later, the instrument includes three repeated measures: Correct Scale, Preference Scale and decision making (for daily living only); and additional measures assessing: 1) values and preferences for everyday care; 2) dyadic and family relationship strain; 3) quality of the caregiver-care recipient relationship; 4) quality of life; and 5) attitudes towards receiving informal/formal assistance. An open-ended question at the end of the Part 1 interview asked about how the person with cognitive impairment likes to spend the day, and at the end of Part 2, the interviewer asked the respondent if there was anything else that they wanted to share about their situation that was not covered.

The final instrument for the caregiver includes most all of the measures asked of the person with cognitive impairment, with the exception of the MMSE and the Preference Scale. Additional measures include: 1) Revised Memory and Behavior Problems Checklist (RMBPC); 2) income and financial strain; 3) information needs; and 4) questions regarding formal support services and influences on service use in the future. Lastly, five open-ended questions were included in the instrument.

Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975) is an 11-item, widely used measure to assess seven dimensions of cognitive functioning on a 0 to 30 point scale: orientation and time (5 points), orientation to place (5 points), registration (3 points), attention and calculation (5 points), recall (3 points), language (8 points), and visual construction (1 point). Lower scores indicate greater cognitive impairment. For purposes of this study, the care receivers were categorized into three groups based on their MMSE score in the following way: *low* scores between 13-15 (n = 8) indicating greater cognitive impairment; *medium* scores between 16-23 (n = 27); and *high* scores between 24 –26 (n = 16) indicating mild cognitive impairment.

The Correct Scale, adapted from the work of Sansone et al. (1996), assesses the care receiver's ability to respond accurately to eight questions about specific factual information (i.e., day, month, and year of birth, number of children and siblings, education level, marital status, and age). In the original study using this measure, with a sample of nursing home residents who suffered dementia, respondent answers were verified by the nursing home's social service files. For the present study, we asked caregivers the same set of questions with the thought that the caregivers would be able to verify the care receiver's responses. With a few exceptions, caregivers were able to confirm the care receiver's responses. For example, often a caregiver and care receiver would disagree about the care receiver's level of education. In one dyad, the caregiving wife did not mention her husband had attended college level courses, while the husband made a point to mention the coursework. For these and other questions, we relied on the comments of the interviewers to help determine if the caregiver and care receiver responded consistently. In addition, we found that care receivers often had difficulty answering the question about their date of birth. In Sansone et al.'s (1996) original study, care receivers had to state her/his birth day, birth month, and birth year correctly in order to be scored as correct for date of birth. We decided to use each piece of information separately, thus our version of the Correct Scale has three items rather than one for birth date and eight rather than six items in total. This revised scoring of date of birth provides a more accurate picture of the care receiver's ability to answer questions correctly.

Demographic questions (e.g., age, educational level, ethnicity, religiosity) were asked of both the care receiver and the caregiver. Additional questions asked of the caregiver only related to employment status, living arrangement, and the number of hours a week providing care. As noted above, the care receiver was asked eight demographic questions (adapted from the Sansone et al., Correct Scale) at both the Part 1 and Part 2 interviews to assess correctness (i.e., validity) and consistency of responses at two time points. In addition to obtaining the caregiver's demographics, the caregiver was also asked to confirm their relative's responses to the demographic questions.

The Preference Scale (Sansone et al., 1996) assesses the care receivers' ability to choose or state a preference consistently over a one week period. Respondents were asked four questions about things they might like or not like: 1) "Do you like to watch television (yes/no)?"; 2) "Do you prefer winter or summer?" (winter or summer); 3) "Which of these colors do you like the best?" (yellow, green or red); and 4) "Which of these three ways do you prefer to have your eggs cooked?" (scrambled, fried, boiled, or don't eat eggs). A score of one point was assigned for each choice given for a range of one to four. Those who made no choices (n = 0) were identified as "unable to state a preference," those who made one or two choices (Part 1, n = 4; Part 2, n = 3) had a "low ability to state a preference," and those who made three of four choices (Part 1, n = 47; Part 2, n = 48) were rated as having a "high ability to state a preference" respectively, for Parts 1 and Parts 2.

Decision Control Inventory (DCI) assesses 15 dimensions of the care receiver's day-to-day decision making. Questions assess the care receiver's level of involvement in a variety of daily decisions (e.g., what to do with money, when to get up). The DCI is adapted from the Independent Evaluation of the Monadnock Self-Determination Project with persons with developmental disabilities (Conroy and Yskauskas, 1996) and has been revised for use with adults with cognitive impairment and their family caregivers as part of the present study. For each item, the care receivers are asked to describe their involvement in decision making on a four point scale: 0 = not at all involved; 1 = a little involved; 2 = fairly involved; 3 = very involved. The family caregiver was also given the DCI asking how involved their relative is with the 15 decision areas of daily living. The summary scales are composed by combining the

15 items separately for the care receiver and the caregiver (ranging from 13 - 42 for the care receiver, and 5 - 41 for the caregivers). Internal consistency as measured by Cronbach's Alpha was .79 for the care receiver, and .86 for the family caregiver.

Decision Making for Daily Living was adapted from measures used in previous studies (Cicerelli, 1992; High & Rowles, 1995; Pratt et al., 1989; and Wetle et al., 1988) to assess preferences for decision making about routine daily living, including three questions: 1) "Who is the person most involved in making decisions about how you spend your day?" (care receiver, caregiver, other relative, friend/neighbor, paid helper, other); 2) "How much are you involved in making decisions about how you spend your day?" ("not at all involved" to "very involved"); and 3) "How do you feel about your involvement in making decisions about how you spend your day?" ("not enough involvement to "too much involvement"). Higher scores reflect greater levels of involvement by the care receiver.

Decision Making for Personal Care was adapted from previous studies (Cicerelli, 1992; High, 1988) with additional items developed for this study. These questions were administered to both the care receiver (one time only) and the caregiver to identify who the care receiver would want to make decisions for them in a range of areas in the event they could not. Items assessed the dynamics of decision making for daily care as well as potential nursing home care.

The first question asked, "If there comes a time when you are no longer able to make decisions for yourself about your health care, finances, etc., who would you want to make these decision for you?" For each decision area (health care, finances, personal care, social activities, living arrangement, possibility of living in a nursing home) the care receiver was asked to identify the individual and his/her relationship to the identified individual.

Next, three questions assessed how well the respondent pairs know the care receivers' wishes for daily care: 1) "Have you and your [family caregiver] ever discussed your wishes for daily care?" (four point scale from "never discussed," to "have talked about it a lot"); 2) "How well do you feel that your [family caregiver] knows your wishes for daily care?" (four point scale from "very well" to "not at all"); and 3) "How much does your [family caregiver] currently agree with your wishes for your daily care?" (four point scale from "agrees a great deal" to "disagrees a great deal"). Last, a similar set of questions assessed how well the respondent pairs know the care receivers' wishes should he/she ever need nursing home care. One additional question asked the respondent pairs about the care receivers' actual preferences should he/she ever need nursing home care (to remain at home cared for by family, to remain at home with the assistance of paid home care, to move to an apartment that provides meals, to move to a nursing home if need be).

Decision Making: Advance Directives was adapted from previous work (High, 1988, Lambert, Gibson & Nathanson, 1990) to assess decision making regarding durable powers of attorney for health care and finances. The respondent pairs were asked whether or not the care receiver had a durable power of attorney (yes/no), had appointed someone (and if so, whom), talked to anyone about it (yes/no) or considered putting in writing instructions or preferences (yes/no) for health care and finances.

Values and Preferences Scale was adapted from previous work with cognitively intact samples (Degenholtz, Kane & Kivnick, 1997; Kane & Degenholtz, 1997; McCullough et al., 1993). Following the work of Ogletree (1995), Degenholtz et al. (1997) define *values* as "broad beliefs about features in the everyday world to which people attach importance, and *preferences* as more specific choices that flow from values" (p. 768). The measure rates 36 values and preferences in everyday care that the care receiver felt were "very important," "somewhat important," or "not at all important" in seven domains: safety/environment (e.g., have personal privacy), seven items, alpha = .75; social interactions (e.g., do things with other people), five items, alpha = .78; autonomy (e.g., do things for her/himself), five items, alpha = .74; self-identity (e.g., feel useful), five items, alpha = .73; helping out/care (e.g., have reliable help), six items, alpha = .58; family caregiver issues (e.g., avoid being a physical burden), four items, alpha = .78; and finances (e.g., have some money to leave her/his family), four items, alpha = .75. At the end of each domain, we also asked the respondent pairs to identify the most important item per domain. The three larger domains combined the seven subscales to include environment/social interactions (alpha = .81), autonomy/self-identity (alpha = .81), and helping out/caregiving/finances (alpha = .86). Results of factor analyses indicated seven rather than eight subscales that were collapsed into three larger domains.

Dyadic and Family Relationship Strain was measured using two instruments developed by Bass et al.(1988). These nine and five item scales assess the strain with the dyad (i.e., between the caregiver and care receiver) and within the larger family unit as perceived by the care receiver (alphas = .58 and .47 respectively) and the caregiver (alphas = .81 and .65 respectively). Questions assess how strongly the respondent agrees or disagrees with each statement. For dyadic strain, questions include “learning good things about my relative,” “feeling angry towards my relative,” “feeling resentful towards my relative,” “learning nice things about myself,” etc. For family relationship strain, questions include “feeling closer to my other family members,” “relying more on other family members for support,” “relationship with other family members have become strained,” etc. All response categories were on a four point scale from “strongly agree” to “strongly disagree”.

Quality of Caregiver-Care Recipient Relationship was measured by four items from a longitudinal study of families (Mangen, Bengston & Laundry, 1988) subsequently utilized to measure current relationship quality (Lawrence, Tennstedt & Assmann, 1998). The items assess the respondent’s perception about the closeness of the relationship, the level of communication, similarity of life views, and how well the two "get along together." The response categories, on a four point scale ranged from "not at all close/good/similar/well" to "very close/good/similar/well". Cronbach's alphas for this scale were .78 for the care receivers and .77 for the caregivers. Scores ranged from six to 16 with observed means of 13.4 for the care recipients (*SD* = 2.27) and 12.1 for the caregivers (*SD* = 2.65).

Attitudes Towards Receiving Informal/Formal Assistance was developed for the present study with input from the national advisory committee. The five-item scale measures the care receiver's preference and the caregiver's perception of the care receiver's preference for receiving specific types of assistance (i.e., shopping and cooking, laundry and housecleaning, getting up and dressing, bathing and toilet care, and taking medications) from either family/friends or paid helpers.

Quality of Life was measured by the quality of life-Alzheimer's Disease (QOL-AD) instrument developed by Logsdon et al. (1999) to assess physical, emotional, interpersonal, and environmental domains of the quality of life of persons with cognitive impairment from the perspective of both the care receiver and the family caregiver. Although used primarily in Alzheimer's samples, the QOL-AD measure has broad application to other cognitively impaired populations, and consists of 13 items (e.g., physical health, mood, self as a whole, etc.), rated on a four point scale (1 = poor to 4 = excellent). Total scores range from 13 to 52. The two versions of the scale (one for the care receiver and one for the caregiver) have been found to have adequate reliability (.88 and .87 respectively) and validity (Logsdon et al., 1999). In our study, three versions of the measure were used: for the care receiver to rate his/her quality of life (alpha = .82); for the caregiver to rate the care receiver's quality of life (alpha = .82), and for the caregiver to rate his/her own quality of life (alpha = .84). The mean scores were 2.8 for the care receiver, 2.4 for the caregiver's rating of the care receiver, and 2.8 for the caregiver's quality of life.

The caregiver instrument included several additional measures:

Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al., 1992) was used to assess the memory and behavior problems of the persons with cognitive impairment. The family caregivers were asked to rate the frequency of occurrence of 24 common, dementia-related behaviors (e.g., forgetfulness, aggressive behavior, irritability). Caregivers rated the frequency of each behavior problem during the past week on a scale of 0 (never occurred) to 4 (occurred daily or more often). Caregivers were also asked to rate their reaction to each behavior, that is, whether the behavior bothered them "a little" to "extremely." In addition, eight items from the original MBPC (alpha = .82) was asked of the caregivers to assess the care receiver's ability to perform ADLs (e.g., dressing, bathing) and IADLs (e.g., household chores). Both the original and revised MBPC have been used widely in numerous caregiving studies and have been found to have good reliability and validity (Zarit, Rever & Bach-Peterson, 1980; J. Zarit, 1982). Factor analyses confirmed the presence of three factors: depression (9 items, alpha = .77), disruption (8 items, alpha = .79) and memory problems (7 items, alpha = .69).

Income and financial strain measures were adapted from previous studies (Aneshensel et al., 1995; Bass, 1992; Lambert, Gibson & Nathanson, 1990; National Alliance for Caregiving and AARP, 1997; and Pearlin, 1990). Questions assessed the total amount of income for the family and the care receiver (1997 dollars); out-of-pocket spending per month for caregiving; and how helping the care receiver has affected the caregiver's finances during the past month (i.e., "some money left over," "enough to make ends meet," or "not enough to make ends meet"). Caregiver financial strain (Aneshensel et al., 1995) was assessed by a ten-item scale (alpha = .89) that included questions such as "we dipped into our savings," "had enough money for basic needs," and "had enough money for little extras." Response categories ranged from "strongly agree" = 3 to "strongly disagree" = 0.

Information needs were measured by a nine-item scale adapted from Fortinsky and Hathaway (1990). Eight items developed by the PI and Co-PI were added to assess the types of information the caregiver felt would help him or her make informed decisions about care of the person with cognitive impairment now and in the future (alpha = .84). For each of 17 information needs (e.g., cost of services, Internet, management of medications, etc.) the caregiver was asked to rate how helpful information on the subject would be on a three point scale from 2 = "very helpful" to 0 = "not at all helpful."

Formal support was measured using three scales developed for the present study with input from the national advisory committee. These scales assess current publicly-funded or privately financed service usage and satisfaction with 14 services (e.g., caregiver support group, respite care); how helpful or unhelpful formal services would be to the caregiver in the future, and the knowledge of whether the 14 services were available in the community (Yes, No, Don't Know) and affordable to the caregiver (Yes/No, Don't Know). Caregivers were asked affordability questions only if they reported that the specific service was available.

The final measure, *Influences on Service Use,* was adapted from work by Pearlin and colleagues (Aneshensel et al., 1995; Zarit & Whitlatch, 1992) and recent work by the PI and Co-PI (Whitlatch, Feinberg & Harrison-Jay, 1995). This 12-item scale (alpha = .81) assesses how strongly caregivers agree or disagree on what factors influence their use of paid services (e.g., caregiver's own physical health, caregiver's exhaustion, care receiver's inability to feed him/her self) (4 = strongly agree to 1 = strongly disagree).

Definition of Congruence

During the development of this study, the PI and Co-PI began to conceptualize the construct of "congruence". Although the main focus of the study has been to develop and test measures that examine choice and decision making in everyday care for persons with cognitive impairment and their family caregivers, we also have had a secondary goal; that is, to begin to explore whether the dyads had discussed the care receiver's preferences for daily care and if the caregivers had accurate perceptions of the care receiver's preferences. Originally, we expected that a congruent dyad was one where the caregiver knew the care receiver's preferences for care (e.g., the caregiver knows that the care receiver wants to live at home). But as we became more involved in data analysis, we came to realize that congruence is neither so simply defined nor so unidimensional.

A strict definition of congruence requires that both members of the dyad respond to a question or series of questions absolutely the same. Lack of congruence occurs when a caregiver responds "somewhat important" and the care receiver responds "very important" to a question about the importance of being with family or avoiding family conflict. But this dyad is more congruent than the dyad that responds "not at all important" and "very important". Thus, the definition of congruence must allow for variation in the degree of congruence across the dyad.

There are different types of congruence (Whitlatch, 2000). Our experience from this exploratory study and related presentations has led to a definition of three different types of congruence: 1) *knowledge congruence*, where the caregiver has accurate knowledge of the care receiver's preferences; 2) *agreement congruence*, where the caregiver agrees with the preferences of the care receiver; and 3) *behavior congruence*, where the behavior of the caregiver conforms to the preference's of the care receiver. These three dimensions are conceptually and temporally linked, yet not completely dependent. For example, take the case of a caregiving daughter who correctly perceives that her father wishes never to be placed in a nursing home (knowledge congruence), agrees with his preference (agreement congruence), and helps her father to remain living at home (behavior congruence). On the other hand, the daughter can have an accurate sense of her father's care preferences (knowledge congruence), yet disagree with them (agreement congruence), and still she helps him to remain at home (behavior congruence). If she does not know her father's preferences (knowledge congruence), she could still feel that he should not be placed in a nursing home (agreement congruence), and help him to remain at home (behavior congruence). Hence, agreement, knowledge and behavior congruence can be independent of each other. The three dimensions of congruence are linked but not totally dependent.

There are varying degrees of *knowledge, agreement* and *behavior congruence* that can occur between a care receiver and family caregiver. These varying degrees comprise the continuum that goes from complete congruence to complete lack of congruence, also referred to as *incongruence.* For example, complete congruence occurs when a caregiver knows (knowledge congruence), agrees with (agreement congruence), and conforms to the wishes (behavior congruence) of the care receiver. There is lack of <u>knowledge</u> congruence, or incongruence, when a caregiver has no sense or an inaccurate sense of the care receiver's preferences. There is lack of <u>agreement</u> congruence when a caregiver holds a divergent opinion from that of the care receiver regardless of whether or not either member of the dyad is aware of it. There is lack of <u>behavior</u> congruence when the caregiver's actions diverge from the preferences of the care receiver, regardless of whether or not the caregiver is aware of the care receiver's preferences. These examples demonstrate the complex and multidimensional nature of congruence within the context of the family caregiver and care receiver dyad.

Finally, the difference between congruence and validity requires brief discussion. A fundamental question for this study has been whether persons with cognitive impairment are able to answer questions reliably and accurately (i.e., validity). Research question 1 and related hypotheses speak to this central issue. However, it is important to note that validity for these questions (e.g., age, date of birth, etc.) is different from congruence because the former is based on factual information. Congruence, on the other hand, is based on perceptions, knowledge and behavior. We use similar analytic techniques to determine whether care receivers are providing valid information and whether the dyads agree on certain questions. Though there may be no differences in analyzing validity and congruence, the two constructs are distinct.

For the purposes of this study, and specifically for research questions 4 and 5 and related hypotheses, we have incorporated these definitions of congruence into our analyses, results and discussion. Throughout the results chapter we refer to the analytic procedures used (e.g., kappa statistic for testing significant agreement between the caregiver and care receiver since it takes into account chance agreement) to determine if congruence exists across the dyad.

CHAPTER FOUR

RESULTS

What are the characteristics of the sample?

Characteristics of Caregivers

As shown in Table 1, caregivers were predominately wives (56.9%) and daughters or daughter-in-laws (21.5%). Husbands (11.8%) including one gay male couple and sons (9.8%) comprised the remaining caregivers. Thus, more than two-thirds (68.7%) were spouses and one-third (31.3%) adult children caring for a parent or parent-in-law. Caregivers were on average 63.5 years of age (*SD* = 14.6, range 30-90 years) although over half (51%) were at least 65 years of age or older, and most likely to be female (78.4%). Most caregivers were married (80.4%), although a few were never married (11.8%), divorced/separated (5.9%), or widowed (2%).

Overall, the educational level of the caregivers was high, with everyone in the sample being a high school graduate, and the large majority having at least some college education (84.3%). Almost half were retired (49%), while about one-third were in the labor force employed either full-time (17.6%) or part-time (15.7%). The remaining were keeping house full time (9.8%), unemployed (5.9%), or taking a leave of absence (2%). Most caregivers (23.5%) reported an annual family income between $40,000 and $49,000 a year (1997 dollars), with nearly two-thirds (62.6%) reporting annual family incomes of over $30,000. Caregivers were most likely to be white (78.4%), followed by African American (11.8%), Asian (5.9%), American Indian or Alaskan native (2%), and Hispanic or Latino (2%). Protestant (35.3%), Catholic (17.6%), Jewish (11.8%), and others such as Jehovah's Witness and Buddhist (5.9%)

made up most caregivers' responses to religious affiliation, although some were unaffiliated (29.4%).

On average, caregivers had been caring for their relatives for 3.1 years (*SD* = 3.4, range 1-23 years), and provided 80 hours of care per week (*SD* = 50.8, range 7-168 hours).

Characteristics of Care Receivers

Most care receivers were husbands (58.8%) including one gay male couple, followed by mothers or mothers-in-law (21.5%), fathers (9.8%), and wives (9.8%). The average age of the care receivers was 75.6 years (*SD* = 10.0, range 39-89) although nearly nine out of ten (88%) were at least 65 years of age. The majority of care receivers were male (68.7%) and married (78.4%). The remaining were widowed (15.7%) or divorced/separated (5.9%). Almost all care receivers were living at home with their caregivers (94.1%), although a few were living at home alone (3.9%) or at home with other family (2%).

Care receivers also had a high educational level with most (68.6%) having at least some college education. The remaining 16 persons were either high school graduates (20%) or had less than or some high school education (12%). Most care receivers with adult children as caregivers (N = 14) were divorced (21%) or widowed (50%) and had annual incomes between $8,000 and $29,999 (range less than $8,000 to $50,000). Care receivers with spouse caregivers had median incomes between $40,000 - $50,000 (range $8,000 - $60,000+). Religious affiliations were similar to those of the caregivers; Protestant (33.3%), Catholic (27.5%), Jewish (13.7%), other (2.0%), and unaffiliated (23.5%).

All care receivers had memory problems that had been diagnosed by a physician, with the most commonly diagnosed brain disease/disorder being Alzheimer's disease (51%) followed by other dementias such as Frontal Lobe, Lewy Body or Vascular dementia (13.7%), Stroke

(11.8%), non-specific dementia (9.8%), Parkinson's disease (7.8%), non-degenerative brain disorders such as Anoxia (3.9%), and Traumatic Brain Injury (2%). The majority (56.9%) were not taking medication specifically for memory problems. The average MMSE score of care receivers was 20.8 (*SD* = 4.06, range 13-26), with two-thirds (67%) considered mildly cognitively impaired (MMSE scores between 20-26), and one third (33%) considered moderately cognitively impaired (MMSE scores between 13-19).

Summary

The sample for this study represents a group of predominately female caregivers, comprised mainly of wives caring for their husbands, and daughters or daughters-in-law caring for their mothers or mothers-in-law with dementia. These caregivers and care receivers are highly educated, white, and in their early 60's or mid 70's, respectively, with moderately high incomes.

Table 1
Caregiver and Care Receiver Demographics

DEMOGRAPHICS	CAREGIVERS		CARE RECEIVERS	
	N	%	N	%
Total	51		51	
Relationship				
Mother/Mother-in-law	—	—	11	21
Father	—	—	5	10
Wife	29	57	5	10
Husband	6	12	30	59
Daughter/Dghtr-in-law	11	22	—	—
Son	5	10	—	—
Age				
Mean	63.5		75.6	
SD	14.6		10.0	
Range	30-90		39-89	
Gender				
Female	40	78	16	31
Marital Status				
Married	41	78	50	79
Divorced/Separated	3	6	3	6
Widowed	1	2	8	16
Never Married	6	12	0	0
Living Situation				
At home w/ CG	—	—	48	94
At home alone	—	—	2	4
At home w/ other family	—	—	1	2
Education				
Less than H.S.	—	—	3	6
Some H.S.	—	—	3	6
High School Graduate	8	16	10	20
Some College	20	39	16	31
College Graduate	9	18	12	24
Post Grad Degree	14	28	7	14
Employment				
Work Full Time	9	18	—	—
Work Part Time	8	16	—	—
Leave of Absence	1	2	—	—
Keep House Full Time	5	10	—	—
Retired	25	49	—	—
Unemployed	3	6	—	—

DEMOGRAPHICS	CAREGIVERS		CARE RECEIVERS	
	N	%	N	%
Income[a]				
Less than $15,999/yr	6	12	6	12
$16,000 to 29,999	9	18	5	10
$30,000 to 39,999	4	8	2	4
$40,000 to 49,999	12	24	1	2
$50,000 to 59,999	9	18	—	—
$60,000 or more	7	14	—	—
Race				
Am. Indian/Alaskan Native	1	2	1	2
Asian	3	6	3	6
Black/African Am.	6	12	6	12
Hispanic/Latino	1	2	1	2
White	40	78	38	75
Other	—	—	—	—
Religion				
Protestant	18	35	17	33
Catholic	9	18	14	28
Jewish	6	12	7	14
Other	3	6	1	2
Unaffiliated	15	29	12	24
Years of Caregiving				
Mean	3.1			
SD	3.4			
Range	1-23			
Diagnosis				
Alzheimer's Disease			26	51
Other Dementia			7	14
Stroke			6	12
Parkinson's Disease			4	8
Traumatic Brain Injury			1	2
Non-specific dementia			5	10
Non-degenerative disorders			2	4
MMSE				
Mean			20.76	
SD			4.06	
Range			13-26	

[a] N = 14 for care receivers who were cared for by adult children and had separate incomes.

*Percentages totaling less than 100 are due to missing information.

1. *Are adults with cognitive impairment able to communicate their preferences for the care they are currently receiving or will need in the future?*

Hypothesis 1a: Adults with mild to moderate cognitive impairment are able to provide a reliable and valid report of their current and future preferences for care at two points in time over a one week period.

Reliability

Care receivers were asked demographic questions (birthday, age, marital status, etc.) as well as questions from the Preferences Scale (Sansone et al., 1996, favorite color, favorite season, etc.) and their own involvement in everyday care at two points in time a week apart. The care receivers' Part 1 and Part 2 responses were then compared to determine whether adults with mild to moderate memory problems were able to provide reliable answers over time. Further, to determine if level of impairment was related to reliability of responses, care receivers were divided into three groups depending on their MMSE score (i.e., low MMSE: 13-15 (N = 8); medium 16-23 (N = 27); high 24-26 (N= 16)).

The Kappa statistic, a coefficient for nominally scaled data, was used to determine if there was significant agreement between the responses given at Part 1 and Part 2. The advantage of the kappa coefficient over percentage agreement is that it takes into account chance agreement. Occasionally, due to different response categories at Part 1 and Part 2, kappa could not be computed. In these cases, Chi-square was used to test for significant differences between the care receiver's answers. Responses with interval data were similarly tested using paired t-tests.

As seen in Table 2, results revealed that for the sample as a whole care receivers were able to provide answers with significant levels of agreement to nearly every question. In fact, of the 17 questions asked of care receivers, only one (the care receiver's age) yielded responses that were significantly different from Part 1 to Part 2 ($t = 2.11$, $p = .042$). Even among those care receivers whose MMSE scores were lowest (MMSE 13-15, N=8), significant levels of agreement were obtained for all but two questions: favorite season and favorite color. For these two questions, 17 percent and 40 percent of care receivers were found to have unreliable answers ($K = .571$, $p = .121$; $K = .063$, p = .848). On the other hand, in this same subset, perfect agreement was obtained for marital status ($K = 1.00$, $p = .000$), whether the care receiver has children ($K = 1.00$, $p = .005$), and the care receiver's feelings about their level of involvement in care ($K = 1.00$, $p = .014$).

Care receivers with medium MMSE scores (16-23, N = 27) answered reliably to all questions but favorite season ($K = .327$, $p = .116$) where 13 percent of care receivers answered unreliably. Those with the highest MMSE scores (24-26, N = 16) answered only two questions unreliably: "Do you like to watch TV?" ($K = -.071$, $p = .782$), and "How do you feel about your level of involvement in your care?" ($K = .026$, $p = .891$). For these two questions, 13 percent and 33 percent of care receivers answered unreliably. Perfect agreement, with all care receivers providing the same answer at both the Part 1 and Part 2 interview, was reached by this high MMSE group for six questions: day ($K = 1.000$ $p = .000$), month ($K = 1.000$ $p = .000$), and year ($K = 1.000$ $p = .000$) of birth, marital status ($K = 1.000$ $p = .000$), children ($K = 1.000$ $p = .000$), and siblings ($K = 1.000$ $p = .000$).

Table 2
Reliability of care receivers' answers from Part 1 to Part 2.

Item	All Cases	Low	Med	High
	N=51	N=8	N=27	N=16
Birth Day	X	X	X	X
Birth Month	X	X	X	X
Birth Year	X	X	X	X
Age	—	X	—	X
Marital Status	X	X	X	X
Children (y/n)	X	X	X	X
No. of Children	X	X	X	X
Education	X	X	X	X
Religion	X	X	X	X
Siblings	X	X	X	X
TV	X	X	X	—
Season	X	—	—	X
Color	X	—	X	X
Eggs	X	X	X	X

Note: X = Reliable answer, — = Unreliable answer

Validity

In addition to answering reliably to basic questions such as birthday, age, and marital status, it was also important that care receivers were able to answer questions with a high degree of accuracy (i.e., validity). To determine validity, kappa, chi-square, and t-test statistics were again computed, this time comparing care receivers' responses to the Correct Scale (Sansone et al., 1996) to those of their caregivers. Responses were analyzed twice, first comparing caregiver's answers with the care receiver's at Part 1, then at Part 2. The average number of correct responses for The Correct Scale was 6.61 (*SD* = 1.4) for the Part 1 interview and 6.49 (*SD* = 1.35) for the Part 2 interview (range from 2 – 8 correct responses for both Parts 1 and 2).

Over three-fourths of the care receivers were able to answer at least six of ten questions accurately during Part 1 (82.4%) and Part 2 (78.4%).

In general (see Table 3), the results indicate that care receivers were able to answer questions with a high degree of accuracy. Significant levels of agreement between care receivers at the Part 1 interview and their caregivers were found for all demographic questions with the exception of one: "Do you have any children?" ($K = .207, p = .137$). At the care receivers' Part 2 interview, there was significant agreement among care receivers' and caregivers' answers to all questions.

Similar results were found when analyses focused on level of cognitive impairment, that is, low, medium, and high MMSE scores. Specifically, those with the lowest MMSE scores responded accurately to all but two of ten questions at both Part 1 and Part 2. Those questions answered inaccurately at Part 1 were whether the care receiver has children ($K = -.143, p = .686$), and level of education ($K = .304, p = .128$). Those questions answered inaccurately at Part 2 were whether the care receiver has children ($K = -.143, p = .686$), and siblings ($K = .300, p = .427$). Care receivers with medium MMSE scores responded accurately to all questions at both Part 1 and Part 2. Care receivers with the highest MMSE scores were inaccurate when answering questions about the number of children at Part 1 ($t = -3.174, p = .006$) and Part 2 ($t = -2.784, p = .014$), and age ($t = -2.449, p = .028$) at Part 2.

Table 3
Validity of care receivers' responses to demographic questions at Part 1 & Part 2.

	Part 1				Part 2			
Item	All Cases N=51	Low N=8	Med N=27	High N=16	All Cases N=51	Low N=8	Med N=27	High N=16
Birth Day	X	X	X	X	X	X	X	X
Birth Month	X	X	X	X	X	X	X	X
Birth Year	X	X	X	X	X	X	X	X
Age	X	X	X	X	X	X	X	—
Marital Status	X	X	X	X	X	X	X	X
Children (y/n)	—	—	X	X	X	—	X	X
No. of Children	—	X	X	—	X	X	X	—
Education	X	—	X	X	X	X	X	X
Religion	X	X	X	X	X	X	X	X
Siblings	X	X	X	X	X	—	X	X

Note: X = Valid answer, — = Invalid answer

Summary

Using Kappa, chi-square, or t-test statistics as appropriate, results indicated that care receivers were able to answer questions about demographics, general preferences, and involvement in everyday care with a high degree of reliability and validity. Similar results were found when care receivers were split into three groups based in high, medium, and low MMSE scores with very few exceptions.

2. *What is the decision-making process between adults with cognitive impairment and their family caregivers?*

Hypothesis 2a: Adults with cognitive impairment are able to identify a person or persons whom they would like to have make their everyday care decisions for them if there comes a time when they can no longer make these decisions for themselves.

Care receivers were asked to name the person whom they would like to make their decisions if they were no longer able for each of six areas of care: health care, finances, personal care, social activities, living arrangements, and the possibility of living in a nursing home. For each of these areas of care, at least 90% of the care receivers were able to identify a person whom they would like to make their decisions for them. The greatest number of care receivers were able to name a person to make health care decisions (100%), followed by finances and personal care (98%), social activities (96%), living arrangements (92%), and the possibility of living in a nursing home (90%). The person most often chosen by care receivers to make these decisions was the family caregiver (74%), followed by another family member (19%), or a paid service provider (2%). The remaining care receivers did not name anyone (5%).

Hypothesis 2b: Adults with cognitive impairment are more likely to discuss with family or friends issues related to their everyday care needs and preferences than issues related to nursing home or other residential care placement.

Both care receivers and family caregivers were asked to what extent they had discussed with each other daily care and nursing home care wishes (never discussed wishes, tried but relative would not, talked about it a little, or talked about it a lot), and how well caregivers knew the care receiver's wishes for daily care and nursing home care (very well, adequately, not very well, not at all). The results of a paired t-test revealed that care receivers felt daily care wishes ($M = 2.91$, $SD = 1.05$) were discussed significantly more than nursing home care wishes ($M = 2.50$, $SD = 1.19$, $t = 3.08$, $p = .003$). Despite this, when care receivers were asked how well they felt their family caregivers knew their wishes for care, there were no differences between daily care (*M* = 3.35, *SD* = .71) and nursing home care (*M* = 3.46, *SD* = .75). In other words, although care receivers felt they had discussed their wishes for daily care more than their wishes for nursing home care, they also felt their caregivers knew their wishes for daily and nursing home care equally as well (i.e., adequately to very well).

On the other hand, the caregivers reported no significant differences in the amount of discussion of wishes for daily care (*M* = 2.73, *SD* = 1.17) and nursing home care (*M* = 2.61, *SD* = 1.17), but did feel that they knew significantly more about their relative's daily care wishes (*M* = 3.41, *SD* = .81) than nursing home care wishes (*M* = 3.10, *SD* = .98, *t* = 2.53, *p* = .015).

Although not a specific hypothesis, we next examined whether assignment of Durable Power of Attorney for Health Care (DPAHC) was related to whether the dyad had discussed the care receiver's wishes for daily care. When dyads who had assigned a DPAHC were compared to those who had not, results of t-tests showed no significant differences in the amount the caregiver reported having discussed the care receiver's wishes for daily care. As well, there were no significant correlations between the amount of discussion of daily care wishes and presence of a DPAHC. The only significant correlation indicated a positive association between caregivers and care receivers reporting that the care receiver had a durable power of attorney for health care (*r* = .58, *p* = .000).

Hypothesis 2c: Adults with cognitive impairment are more likely to discuss their everyday care preferences with spouse caregivers than care receivers with adult child caregivers.

When dyads with spouse caregivers (N = 35) were compared to those with adult child caregivers (N = 16), there were no differences in the care receivers' responses to questions regarding the discussion of daily or nursing home care wishes. The responses revealed a trend suggesting that care receivers with spouse caregivers ($M = 3.59$, $SD = .61$) felt their spouses knew significantly more about their preference for nursing home care than care receivers cared for by adult child caregivers ($M = 3.14$, $SD = .95$, $t = 1.93$, $p = .060$) where 3 = "adequately" and 4 = "very well".

When the spouse caregivers' responses were compared to the adult child caregivers' responses to these questions, another trend suggested that dyads with spouse caregivers ($M = 2.51$, $SD = 1.15$) had discussed wishes for daily care significantly more than dyads with adult child caregivers ($M = 3.19$, $SD = 1.11$, $t = 1.97$, $p = .06$) where 1 = "have never discussed wishes" and 2 = "tried to discuss wishes but relative would not".

Summary

Care receivers were able to choose a person, most commonly the family caregiver, to make a variety of decisions for them should they no longer be able to make decisions for themselves. Care receivers reported discussing their daily care wishes more than their nursing home wishes with their caregivers, yet also felt their caregivers knew their wishes for daily and nursing home care equally well (adequately to very well). Caregivers felt they knew the care receiver's wishes adequately for both daily and nursing home care, yet also felt they knew the care receiver's wishes for daily care better. Differences between spouse and adult child caregiver dyads suggested that compared to parent care receivers, spouse care receivers felt their caregivers knew more about their nursing home care preferences, and spouse caregivers reported discussing the care receiver's daily care wishes more than adult child caregivers.

3. *How does the availability and use of information and services, as well as the quality and cost of care, facilitate and/or impede family decision making related to the cognitively impaired adults' everyday care?*

Hypothesis 3a: Family caregivers who perceive that little information and few home and community-based services are available and affordable to them are less likely to have discussed with the care receiver preferences for care and care options.

The majority of the caregivers interviewed (84.3%) reported having used some type of paid service provider since the care receiver had been diagnosed with memory problems. Caregivers were asked about 14 services such as help with housework, home health care, support groups, and respite, and reported using an average of six services since their relative had been diagnosed with memory problems (*SD* = 2.7, range 1-13). The three most utilized services were information about the care receiver's illness (65%), caregiver support groups (55%), and help with housework, shopping, laundry, or cooking (53%). The three least utilized services were the Internet (14%), education classes regarding help for the caregiver (20%), and help with managing financial or legal matters (22%) (see Table 4).

Caregivers were also asked about the availability and affordability of various home and community-based services that might be helpful to them in the future. These responses were correlated with the amount of discussion that had taken place about wishes for daily care. No significant correlations were found between discussion of wishes and the degree to which caregivers perceived that services were affordable or available. Thus, whether or not a dyad had discussed the care receiver's daily care wishes was unassociated with the caregiver's perception that services were affordable or available.

Table 4
Formal Support: Caregiver Usage

Ranked by percentage of caregivers who had used the service since care receiver was diagnosed	
65%	Information about your relative's illness
55%	Caregiver support group
53%	Housework, maintenance, shopping, laundry, cooking, transportation
43%	Help in arranging services or benefits
37%	Respite care
35%	Individual or family counseling
29%	Family consultation
29%	Other
28%	Support group for caregivers of newly diagnosed or early stage person
26%	Eating, dressing, bathing, toileting, grooming
24%	Adult day care
24%	Education classes regarding the care of your relative
22%	Managing financial or legal matters
20%	Education classes regarding help for yourself
14%	The Internet to seek information on caregiving

Hypothesis 3b: Family caregivers who have discussed preferences for everyday care with the care receiver are more likely to report a high level of quality of care for the services they receive.

Caregivers reported being satisfied with the quality of specific services they had or were using ($M = 3.3$, $SD = .48$) and with the quality of services overall ($M = 3.3$, $SD = .59$). No correlation was found between the caregivers' overall satisfaction with the services they had received and the amount of discussion of daily care wishes the caregiver reported having with the care receiver. Thus, discussion of daily wishes was unrelated to a caregiver's satisfaction with services. Although it was not an a priori research question, we decided to broaden our perspective to examine the relationship between satisfaction with care and discussion of nursing home care wishes. Interestingly, we found a trend ($r = -.290$, $p = .059$) indicating that the more satisfied caregivers were with services, the less they had discussed nursing home care wishes with the care receivers. Another way to view this finding is that caregivers who are less satisfied with services are more likely to be discussing options for nursing home care.

Hypothesis 3c: Decision making is impeded for family caregivers who cannot afford to pay out-of-pocket for home and community-based services.

In order to determine the affordability of services, caregivers were asked to respond to questions about their current income and the financial strain associated with caregiving. Financial strain was measured by asking caregivers how strongly they agreed with statements about the cost of caring for their relative (e.g., "We dipped into our savings to pay for care", "We had enough money for basic needs", $\alpha = .89$). As well, caregivers were asked about their annual family income and monthly out-of-pocket caregiving expenses. Of the 25 caregivers who reported having out-of-pocket expenses in caring for their relative, the median amount spent in a typical month was \$200 (*SD* = \$350, range = \$0 – \$1500). Caregivers reported that compared to a year ago, their monthly expenses where somewhat less now (43%), about the same (39%), or more than a year ago (18%). When asked how their finances work out at the end of the month, the majority reported having some money left over (63%). The remaining said there was either "just enough to make ends meet" (26%) or "not enough to make ends meet" (12%).

Most caregivers disagreed (response category "1") or strongly disagreed (response category "0") with the statements, "I dipped into my savings to pay for care" (80%), "I had to spend more of my own money on my relative's care than I expected" (67%) and "I had to spend money on my relative's care that I would have liked to have spent on other things" (55%). Caregivers agreed (response category "2") or strongly agreed (response category "3") with the statement, "I had enough money to cover the costs of caring for my relative" (88%). Overall, caregivers reported low levels of financial strain associated with caring for their relative (*M* = 1.01, *SD* = .52, range = 0 - 2.44).

Caregivers were also asked to respond to questions about the availability and affordability of 14 specific services including housework, support groups, and adult day care. On average, caregivers believed half (7.2) of 14 services were available in their community (SD = 3.52, range = 0 – 14) (See Table 5). In general, over half the caregivers reported that they could afford the services (64%), about one-fifth (22%) of caregivers didn't know if they could afford services, while the remaining (15%) reported they could not afford the services.

Table 5
Formal Support: Current Availability

Ranked by the percent of caregivers who said the service was available	
88%	Adult Day Care
75%	Respite
67%	Caregiver support group
67%	Eating, dressing, bathing, toileting, grooming
57%	Housework, maintenance, shopping, laundry, cooling, transportation
57%	Individual or family counseling
53%	The Internet
51%	Managing financial or legal matters
51%	Family consultation
49%	Support group for newly diagnosed or early stage persons
43%	Help in arranging services or benefits
29%	Education classes regarding help for you
26%	Education classes regarding the care of your relative

Next, measures of financial strain were compared to care receiver and caregiver responses about two domains of the decision-making process. The first decision-making domain addressed three issues: How much discussion had taken place between the care receiver and caregiver regarding daily care and nursing home care wishes, how much the caregiver knew the care receiver's wishes for daily and nursing home care, and how much the caregiver agreed with the care receiver's daily and nursing home care wishes. Decision making was thought to be impeded when there was little discussion, knowledge, and/or agreement between the caregiver and the care receiver.

Neither care receivers' nor caregivers' reports of the amount of discussion of daily care or nursing home care wishes were significantly correlated with financial strain. This would indicate that when decision making is measured in terms of discussion of wishes, it is not impeded by financial strain. The level of agreement between care receivers and caregivers about daily care wishes was also not significantly correlated with any measure of financial strain.

Significant correlations were found, however, between financial strain and the care receiver's responses to the question, "How well do you feel your caregiver knows your wishes for daily care"? For example, the more financial strain caregivers reported at the end of the month, the less the care receivers felt the caregivers knew their preferences for daily care (r = -.286, p = .046). Further, the lower the care receivers' (with adult child caregivers) income, the less the care receivers felt the caregivers knew their wishes for daily care (r = .663. p = .014). A similar correlation was found between the care receiver's (with adult child caregivers) income and how much the care receiver felt the caregiver knew their nursing home care preferences. As income decreased, there was a decrease in how well the care receivers felt caregivers knew their preferences (r = .734, p = .004). A final correlation indicated that higher out-of-pocket monthly caregiving expenses for adult child caregivers, were associated with caregivers who knew more about the care receiver's preferences for nursing home care (r = .553, p = .033).

Correlations were also used to test the relationship between financial strain and decision-making difference scores. The difference scores were computed by subtracting the care receiver's response to preferences for care questions, from the caregiver's response to the same question. For example, if a caregiver believed s/he knew her/his relative's wishes for daily care very well (response = 4), and the care receiver believed the caregiver did not know his wishes at all (response = 1), the difference score would be high (4 – 1 = 3), and the dyad was considered incongruent. Decision making was believed to be impeded when dyads were incongruent and difference scores were high.

Difference scores from the question "How well does the caregiver know the care receiver's wishes for daily care?" were significantly correlated with two of the financial strain variables ("Compared to a year ago, are your monthly expenses more or less?", $r = .381$, $p = .007$, and a summary score of financial strain, $r = .329$, $p = .021$). Both relationships were positive, indicating that as financial strain increased the dyad's responses became less congruent, that is, they agreed less about how well the caregiver knew the care receiver's wishes for daily care.

The second domain of decision making to be compared with measures of financial strain assessed the importance of the care receivers' values and preferences for everyday care and the caregivers' perceptions of the care receivers' preferences. As described in Chapter Three (Methods), the Values and Preferences Scale contained 36 items which fell into one of seven subscales: Environment (7 items), Social Interactions (5 items), Autonomy (5 items) , Self Identity (5 items), Helping Out (6 items), Family Caregiver Issues (4 items), and Finances/Cost of Care (4 items). These subscales covered three broad areas including environment/social interaction (12 items, $\alpha = .81$), autonomy/self identity (10 items, $\alpha = .81$), and caregiver issues/finances (14 items, $\alpha = .86$). Questions were worded so that the respondent could answer "very important" (3), "somewhat important" (2), or "not at all important" (1). Before describing the analyses comparing financial strain and values and preferences, we turn to a discussion of the descriptive results of the larger Values and Preferences scale.

Table 6 lists the seven most important values and preferences in daily living for the care receivers as well as the caregivers' top ratings of the care receivers' preferences. For care receivers, the top seven items were "Have a comfortable place to live" (2.82), "Have caregiver be the one to help out" (2.78), "Live in own home" and "Feel safe in home, even if it restricts activities" (both 2.76), "Caregiver not put life on hold" (2.71), "Avoid being a physical burden on family" (2.70), "Do things for self" (2.69), and "Avoid being a financial burden on family" (2.68). For caregivers, the top seven items were, "Have caregiver be the one to help out" (2.84), "Have a comfortable place to live" (2.82), "Live in own home" (2.78), "Maintain dignity" (2.75), "Be with family or friends" (2.55), "Be safe from crime" (2.57), and "Avoid being a physical burden on family" (2.53). Although the top three responses were similar across care receivers and caregivers, differences were found in how important each group rated the remaining top responses.

Table 6
Top Seven Values and Preferences Scale Items for Care Receivers and Caregivers

Care Receiver	Subscale	Mean
1 Have a comfortable place to live	Environ./Safety	2.82
2 Have caregiver be the one to help out	Family Caregiver	2.78
3 Live in own home	Environ./Safety	2.76
3 Feel safe in home, even if it restricts activities	Environ./Safety	2.76
4 Caregiver not put life on hold	Family Caregiver	2.71
5 Avoid being a physical burden on family	Family Caregiver	2.70
6 Do things for self	Autonomy	2.69
7 Avoid being a financial burden on family	Finances	2.68

Caregiver		Mean
1 Have caregiver be the one to help out	Family Caregiver	2.84
2 Have a comfortable place to live	Environ./Safety	2.82
3 Live in own home	Environ./Safety	2.78
4 Maintain dignity	Self Identity	2.75
5 Be safe from crime	Environ./Safety	2.57
6 Be with family or friends	Social Interaction	2.55
7 Avoid being a physical burden on family	Family Caregiver	2.53

For each subscale, analyses revealed that the value or preference that care receivers rated most important was also the one that caregivers believed was most important to care receivers (Table 7). The top rated items by subscale were "Have a comfortable place to live" (Environment/Safety), "Be with family or friends" (Social Interactions), "Do things for self" (Autonomy), "Maintain dignity (Self Identity), "Have reliable help" (Helping out), "Have caregiver be the one to help out" (Family Caregiver Issues) and "Avoid being a financial burden" (Finances).

For the subscales of Social Interactions, Autonomy and Self Identity, caregivers were consistent with the care receivers in their ranking of values and preferences by importance to the care receiver. On the other hand, for the subscales of Environment/Safety, Helping Out, Family Caregiver Issues and Finances, caregivers were inconsistent with the care receivers in their importance rankings (Table 7).

Table 7
Values and Preferences Subscales with Items Ranked in Order of Importance to Care Receiver

Item	**Care Receiver Rank**	**Caregiver Rank**
Have comfortable place to live	1	1
Live in own home	2*	2
Feel safe in home, even if restricts activities	2*	5
Be in touch w/others in case of emergency	3	7
Be safe from crime	4	3
Accept restrictions in order to be safe	5	6
Have personal privacy	6	4
Environment/Safety Subscale		
Be with family or friends	1	1
Avoid family conflict	2	3
Be part of family celebrations	3	2
Keep in touch with family/friends at distance	4	4
Do things with other people	5	5
Social Interactions Subscale		
Do things for self	1	1
Come and go as please	2	2
Have time to self	3*	3
Spend money how wants	3*	4
Organize daily routines in own way	4	5
Autonomy Subscale		
Maintain dignity	1	1
Have something to do	2	4
Feel useful	3	2
Maintain continuity with past	4	3
Practice religious/spiritual beliefs	5	5
Self Identity Subscale		
Have reliable help	1	1
Choose family/friends to help	2	4
Use services only covered by insurance	3	6
Keep same doctors	4	3
Have families help own	5	2
Have say in excluding family from helping	6	5
Helping Out Subscale		
Have CG be one to help out	1	1
CG not put life on hold	2	4
Avoid being physical burden on family	3	2
Avoid being emotional burden on family	4	3
Family Caregiver Issues Subscale		
Avoid being financial burden	1	1
Make own financial decisions	2	3
Use services that can pay for by self	3	4
Have some money to leave family	4	2
Finances Subscale		

*Item has same mean as another item in the subscale.

Next, responses of care receivers were compared to the responses of caregivers on each of the 36 items in the Values and Preferences scale. These t-tests determined whether there was congruence or agreement between care receivers and caregivers. In other words, if there were significant differences in how important the caregivers thought the item was to the care receiver and how important the item actually was to the care receiver, the item was considered incongruent. Significant differences were found for 20 of the 36 items (see Table 8). Typically when there were significant differences, the care receiver placed greater importance on the item than the caregiver thought they did. For example, care receivers felt the item from the Environment subscale "Feel safe in home, even if it restricts activities, " was significantly more important than caregivers felt (2.76 vs. 2.31, $p < .01$).

In the Environment subscale, significant differences were found for three items "Accept restrictions in order to be safe", "Feel safe in home, even if it restricts activities", and "Be in touch with others in case of emergency". Only one item in the Social Interactions subscale revealed significant differences between caregiver and care receiver responses ("Do things with other people"), while all six items in the Autonomy subscale were significantly different ("Do things for self", "Come and go as please", "Organize daily routines in own way", "Have time to self", and "Spend money how s/he wants"). For all these items, caregivers significantly underestimated the importance to the care receiver.

Table 8 Values and Preferences Means and Care Receiver vs. Caregiver t-values

Item	Care receiver mean	Caregiver mean	t-value
Have comfortable place to live	2.82	2.82	0.00
Live in own home	2.76	2.78	0.57
Feel safe in home, even if restricts activities	2.76	2.31	-4.20***
Be in touch w/others in case of emergeney	2.65	2.14	-3.85***
Be safe from crime	2.63	2.57	-0.65
Accept restrictions in order to be safe	2.52	2.18	-3.01***
Have personal privacy	2.27	2.43	1.53
Environment/Safety Subscale	**2.63**	**2.46**	**-2.94*****
Be with family or friends	2.61	2.55	-0.62
Avoid family conflict	2.51	2.33	-1.46
Be part of family celebrations	2.41	2.49	0.68
Keep in touch with family/friends at distance	2.35	2.25	-0.68
Do things with other people	2.21	1.88	-2.77***
Social Interactions Subscale	**2.42**	**2.30**	**-2.94*****
Environment/Social Interactions Domain	**2.54**	**2.40**	**-2.66****
Do things for self	2.69	2.33	-2.99***
Come and go as please	2.59	2.25	-2.75***
Have time to self	2.35	2.12	-2.37**
Spend money how wants	2.35	2.04	-2.38**
Organize daily routines in own way	2.34	2.00	-3.08***
Autonomy Subscale	**2.46**	**2.15**	**-4.19*****
Maintain dignity	2.62	2.75	1.27
Have something to do	2.46	2.20	-1.76*
Feel useful	2.45	2.51	0.48
Maintain continuity with past	2.33	2.41	0.67
Practice religious/spiritual beliefs	2.27	1.78	-3.83***
Self Identity Subscale	**2.43**	**2.33**	**-1.23**
Autonomy/Self Identity Domain	**2.45**	**2.24**	**-3.07*****
Have reliable help	2.55	2.49	-0.60
Choose family/friends to help	2.49	2.18	-2.16**
Use services only covered by insurance	2.43	1.95	-4.14***
Keep same doctors	2.38	2.19	-1.50
Have families help own	2.33	2.24	-0.85
Have say in excluding family from helping	2.24	1.96	-1.81*
Helping Out Subscale	**2.40**	**2.17**	**-3.24*****
Have CG be one to help out	2.78	2.84	0.72
CG not put life on hold	2.71	2.11	-4.52***
Avoid being physical burden on family	2.70	2.53	-1.43
Avoid being emotional burden on family	2.62	2.47	-1.13
Family Caregiver Issues Subscale	**2.70**	**2.49**	**-2.65*****
Avoid being financial burden	2.68	2.26	-3.29***
Make own financial decisions	2.41	1.96	-3.32***
Use services that can pay for by self	2.31	1.76	-3.82***
Have some money to leave family	2.26	2.01	-1.92*
Finances Subscale	**2.42**	**2.00**	**-4.34*****
Helping Out/Family Cger/Finances Domain	**2.49**	**2.21**	**-4.44*****

Note: Scale 3=very important, 2=somewhat important, 1=not at all important

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

Significant differences were also found between “Practice religious/spiritual beliefs” in the Self Identity subscale in that care receivers felt practicing religious or spiritual beliefs was more important than the caregiver felt it would be to care receivers. “Choose family/friends to help” and ”Use services only covered by insurance” were significantly different in the Helping Out subscale. The only significantly different item in the Family Caregiver Issues subscale was “Caregiver not putting their life on hold”. All but one item in the Finances subscale were significantly different (“Avoid being financial burden”, “Make own financial decisions”, and “Use services that can pay for by her/himself”). Again, for each of these items, the caregiver significantly underestimated its importance to the care receiver.

Subscales were next ranked according to the importance the care receiver placed on each (see Table 9). For care receivers, the most important subscales were “Family Caregiver Issues” (2.70), “Environment/Safety” (2.63), and “Autonomy” (2.46). Caregivers correctly rated the “Family Caregiver Issues” (2.49) and “Environment/Safety” (2.46) subscales as the two most important to the care receivers, followed by “Self Identity” (2.33). Factor analysis revealed that the 36 Values and Preferences items fell into three broad domains which care receivers ranked in the following order of importance: “Environment/Social Interactions” (2.54), “Helping Out/Family Caregiver/Finances” (2.49) , and “Autonomy/Self Identity” (2.45). Caregivers ranked the “Environment/Social Interactions” (2.40) area as most important, followed by “Autonomy/Self Identity” (2.24), and “Helping Out/Family Caregiver/Finances” (2.21).

Table 9
Values and Preferences: Subscale Domain Means and Ranking[a]

Subscales	Care receiver		Caregiver		t values
	Mean	Rank	Mean	Rank	
Family Caregiver Issues	2.70	1	2.49	1	-2.65***
Environment	2.63	2	2.46	2	-2.61***
Autonomy	2.46	3	2.15	6	-4.19***
Self-Identity	2.43	4	2.33	3	-1.23
Finances/Cost of Care	2.42	5	2.00	7	-4.34***
Social Interactions	2.42	7	2.30	4	-0.6
Helping Out	2.40	6	2.17	5	-3.24***

Domains	Care receiver		Caregiver		t values
	Mean	Rank	Mean	Rank	
Environment/Social Interactions	2.54	1	2.40	1	-1.78*
Helping/Caregiver issues/Finances	2.49	2	2.21	3	-4.52***
Autonomy/Self Identity	2.45	3	2.24	2	-3.07***

[a]Scale: 3=very important, 2=somewhat important, 1=not at all important
***p < .01 **p < .05 *p < .10

Turning to the results of t-tests across the broader three domains, significant differences were found for care receivers between the Autonomy/Self Identity and Environment/Social Interactions domains (2.45 vs. 2.54, t = 2.91, p = .005). For caregivers, significant differences were found between the Environment/Social Interactions and Helping/Caregiver Issues/Finances domains (2.40 vs. 2.21, t = 3.26, p = .002) and between the Environment/Social Interactions and Autonomy/Self Identity domains (2.40 vs. 2.24, t = 2.63, p = .011). Thus, for care receivers the Environment/Social Interactions domain was ranked highest and was rated significantly higher than the Autonomy/Self Identity domain. For caregivers, the Environment/Social Interactions domain was also ranked highest and was rated significantly higher than the other two domains.

Comparisons between care receivers and caregivers across the three domains indicated significant differences between care receiver and caregiver responses in the domains of

Autonomy/Self Identity (*t* = -3.07, *p* = .004), and Helping/Caregiver Issues/Finances (*t* = -4.52, *p* = .000). A trend suggested significant differences between care receivers and caregiver on Environment/Social Interaction (*t* = -1.78, *p* = .081). In each area, the care receivers' mean score was higher than the caregivers', indicating that caregivers significantly underestimated how important the issues in each of these areas were to the care receiver. Care receiver and caregiver mean scores were as follows: Environment/Social Interaction: 2.50 vs. 2.40, Autonomy/Self Identity: 2.45 vs. 2.34, and Helping/Caregiver Issues/Finances: 2.48 vs. 2.21.

The sample was next divided by kin group (dyads with spouse caregivers, N=35 and dyads with adult child caregivers, N=16) and t-tests were again performed between caregiver and care receiver responses for each group. Dyads with spouse caregivers yielded significantly different care receiver/caregiver answers on 10 of the 36 items. The dyads with adult child caregivers answered significantly differently on 12 of the 36 items. As with the sample as a whole, when there were significant differences, the care receivers typically placed greater importance on the item than the caregivers thought they did. One exception to this trend appeared on one item in the dyads with spouse caregivers. Here, the spouse caregivers believed the care receivers placed more importance on "Maintain dignity" than the care receivers actually did.

Finally, adult child caregivers' responses were compared to spouse caregivers' responses for each item in the Values and Preferences scale. Significant differences between adult child caregivers and spouse caregivers were found for only four items, "Live in own home" (adult child mean = 2.50, spouse mean = 2.91, t = -2.69, p = .010), "Be in touch with others in case of emergency" (adult child mean = 1.81, spouse mean = 2.29, *t* = -2.17, p = .035), and "Have time to self" (adult child mean = 2.44, spouse mean = 1.97, *t* =2.49, p = .016), and "Have caregiver be the one to help out" (adult child mean = 2.63, spouse mean = 2.94, *t* = -2.67, p = .010). There were no significant differences between the responses of care receivers with adult child caregivers and care receivers with spouse caregivers.

We return to analyses comparing measures of financial strain with the three larger domains of the Values and Preferences scale. First we created difference scores for each domain by subtracting the caregivers' responses from the care receivers' responses and taking the absolute value of the difference. The higher the difference score for each domain, the less the caregiver knew how important the care receiver considered the items in that domain to be. These difference scores were then correlated with the measures of income and financial strain associated with caregiving. Of the four single items assessing income (i.e., household income, out-of-pocket expenses associated with caregiving, monthly expenses compared to a year ago, and how finances work out at the end of the month) and a separate measure of financial strain, the autonomy/self identity and environment/social interactions domains were correlated with one question, "How do your finances work out at the end of the month?" This positive correlation indicated that the less money the caregiver had at the end of the month, the less the caregiver knew the care receiver's values and preferences for autonomy/self identity (r = .265, p = .060) and environment/social interaction (r = .304, p = .030).

The caregiver issues/finances domain was significantly correlated with three of the finance questions. As the income of care receiver's with adult children as caregivers decreased, caregivers knew less about the importance of the caregiver issues/finances area to the care receiver (r = -.586, p = .028). Similarly, as the amount spent out-of-pocket on caregiving and the monthly expenses compared to a year ago increased, caregivers knew less about the importance of this area to the care receiver (r = 2.98, p = .049, and r = .292, p = .038).

Hypothesis 3d: A family caregiver's home and community-based service use and satisfaction with the quality of care is positively associated with the family's decision-making process. In other words, family caregivers who have discussed the care receivers' everyday care preferences use more services than family caregivers who have not discussed everyday care preferences with the care receiver.

Caregiver and care receiver responses to the amount of discussion regarding daily and nursing home care were correlated with the caregiver's responses to the number of, and satisfaction with, services used. No significant correlations were found for these analyses. In other words, neither the number of services caregivers have used nor the caregiver's satisfaction with services was related to the amount of discussion that had taken place within the dyad regarding daily care and nursing home care. As noted previously, (see Hypothesis 3b), one trend did appear indicating that as satisfaction with services decreased, caregivers reported more discussion about nursing home care ($r = -.290$, $p = .059$).

Summary

Caregivers had used a variety of services to help care for the care receiver but mainly services that provide information about the care receiver's illness, support groups, chore work (e.g., housework, maintenance, shopping etc.), help in arranging services, respite, and counseling. Service availability, affordability, and satisfaction were unrelated to the amount of discussion between the caregiver and care receiver about daily care wishes. However, the more satisfied a caregiver was with services, the less likely s/he was to have discussed nursing home care with the care receiver.

Caregivers reported low levels of financial strain, and believed they had enough money at the present time to cover the cost of the care receiver's care. However, more than one-third

(38%) of the caregivers either said they had "just enough" or "not enough" money to make ends meet at the end of the month.

Care receivers with caregivers who had higher financial strain reported feeling that their caregivers did not know their wishes for daily care. As well, increased caregiver financial strain was associated with the dyads not agreeing about how well the caregiver knew the care receiver's wishes for daily care.

Overall, the five top ranked values and preferences in aspects of daily life for the care receivers were "Have a comfortable place to live" (Environment/Safety), "Have caregivers be the one to help out" (Family Caregiver Issues), "Live in own home" (Environment/Safety), "Feel safe in home, even if it restricts activities" (Environment/Safety), "Caregiver not put life on hold" (Family Caregiver Issues). Caregivers, however, were fairly inaccurate in their perceptions of the importance of the care receivers' specific values and preferences. Although caregivers as a group were accurate in their perceptions of what care receivers felt were important relative to other values and preferences (i.e., ranked items), the caregivers frequently placed less importance on the items than the care receivers (i.e., t-tests of mean differences). One exception concerns the item related to "dignity" where caregivers felt maintaining the care receivers' dignity was of greater importance than the care receivers perceived it to be.

The highest ranked subscale for both the care receivers and the caregivers was Family Caregiver Issues, followed by Environment/Safety. On the subscale and domain level, again, caregivers generally placed less importance on the subscale or domain than care receivers. The exception was the self-identity subscale where mean differences were not significant. However, care receivers and caregivers were congruent in their responses that the Environment/Social

Interactions domain was most important and significantly more important than the domain of Autonomy/Self Identity.

4. *Is there congruence between the preferences of the adult with cognitive impairment and the needs and practices of the caregiver?*

> Hypothesis 4a: There is greater congruence between the care receiver's preferences and the needs and practices of the caregiver in families who have discussed the care receiver's preferences for everyday care.

To answer this question, dyads were first divided into two groups: those who had discussed the care receiver's wishes for daily care, and those who had not. Both the care receiver and the caregiver were asked to what extent they had discussed the relative's daily care wishes. The sample was first divided based on the care receiver's response to the question, "Have you and your caregiver ever discussed your wishes for daily care?". Responses, which fell into one of four categories, were combined to create a dichotomous scale. The responses "Have never discussed your wishes" and "Tried but your relative would not" were combined into the "Wishes not discussed" category (0), and "Have talked about it a little" and "Have talked about it a lot" were combined into the "Have discussed wishes" category (1). Dyads who had "discussed wishes" where then compared to dyads who had "not discussed wishes".

When comparing the care receivers' responses to the question "How much does your caregiver agree with your wishes for daily care?", t-tests revealed no significant differences between the two groups (dyads who had discussed daily care wishes and dyads who had not). In other words, the care receivers in dyads who had discussed daily care wishes were no more likely to think their caregiver agreed with their wishes for daily care, than the care receivers in dyads who had not discussed daily care wishes. Similarly, when the dyads were divided into groups based on the caregiver's responses to the question "Have you and your relative ever discussed his/her wishes for daily care?", there were no differences between the groups on how much the caregivers reported agreeing with what they thought were the care receiver's wishes. In other words, a caregiver's perception that s/he has discussed the care receiver's preferences for daily care has no bearing on whether s/he agreed with what s/he thought were the care receiver's preferences. The converse is also true; that is, how much a caregiver agrees or disagrees with the care receiver's wishes for care has no bearing on whether the dyad has discussed the care receiver's wishes for daily care.

In addition to relying solely on the respondents' reports of the congruence between care receiver's and caregiver's preferences for daily care (questions regarding the level of agreement on daily care wishes), we developed a measure of congruence that reflected the care receiver's preferences for care and the caregiver's use of services. Specifically, we compared the care receiver's report of who they would like to help them (friends/family, service providers, no preference) with specific tasks (shopping and cooking, laundry and house cleaning, getting up and dressing, bathing and toilet care), and whether their family caregiver was or was not using paid help for those tasks. Dyads were considered congruent when the care receiver preferred help from service providers on a certain task, and the caregiver had received help from service providers on that task, or when care receiver preferred help from family or friend and the caregiver had not received help from service providers. Conversely, dyads were thought to be incongruent when the care receiver preferred help from service providers and the caregiver had not received help from service providers or when care receivers preferred help from family or friends and the caregiver had received help from service providers. Care receivers who said they had no preference ("shopping and cooking" 8%, "laundry and house cleaning" 14%, "getting up and dressing" 18%, and "bathing and toilet care 18%) were considered congruent regardless of whether their caregiver had used services or not. Based on these criteria, dyads were labeled either congruent or incongruent for each of the four tasks (shopping and cooking, laundry and house cleaning, getting up and dressing, bathing and toilet care). Congruent dyads where then compared to incongruent dyads on the amount of discussion about daily care wishes (see Table 10).

Results of Chi-square tests revealed no significant differences between congruent and incongruent dyads for any of the four tasks regarding the amount of discussion either the care receiver or the caregiver reported about daily care wishes. There was, however, a trend suggesting that there may be differences in the level of congruence for shopping and cooking between dyads who had and had not discussed wishes for daily care ($X^2 = 3.617$, $p = .061$). Thus, for dyads who had discussed wishes for daily care, there was a slight trend that they are less congruent in knowing who the care receiver would prefer to do her/his shopping and cooking.

Table 10
Attitudes Towards Formal Assistance

Shopping and Cooking		Has caregiver used paid services?	
		No	Yes
Care receiver prefers help from	Family/Friends	**20 (41%)**	21 (43%)
	Paid Services	3 (6%)	**5 (10%)**

Laundry and House Cleaning		Has caregiver used paid services?	
		No	Yes
Care receiver prefers help from	Family/Friends	**17 (34%)**	9 (18%)
	Paid Services	6 (12%)	**18 (36%)**

Getting Up and Dressing		Has caregiver used paid services?	
		No	Yes
Care receiver prefers help from	Family/Friends	**29 (59%)**	8 (16%)
	Paid Services	7 (14%)	**5 (10%)**

Bathing and Toilet Care		Has caregiver used paid services?	
		No	Yes
Care receiver prefers help from	Family/Friends	**25 (51%)**	5 (10%)
	Paid Services	11 (22%)	**8 (16%)**

Note: Numbers in bold face reflect dyads who are congruent (e.g., care receiver prefers help from family and friends and caregiver has not used formal services).

No significant findings resulted when congruence scores were summed across all four tasks, ($M = 2.49$, $SD = 1.38$, range = 0-4) and correlated with the care receiver's and caregiver's responses to the amount of discussion of wishes. In general, dyads who had discussed the care receiver's wishes for daily care were no more likely to be congruent than dyads who had not discussed the care receiver's wishes.

Hypothesis 4b: There is greater congruence between the care receiver's preferences and caregiver's needs and practices for spouse caregivers as compared to adult child caregivers.

Of the 51 caregivers in the sample, 35 (68.2%) were spouses, and 16 (31.8%) were adult children. Dividing the sample into kin groups and comparing them on their level of congruence (care receiver's preferences for services, and caregiver's use of services) for each of the four tasks using the Chi-square statistic resulted in no significant differences between the two groups. Thus, there was no support for Hypothesis 4b; that is, spouse caregivers are no more likely than adult child caregivers to be congruent in terms of the care receiver's preferences for daily care and the caregiver's use of services.

Summary

Using a variety of measures we found that regardless of how much the dyad had discussed the care receiver's wishes for daily care, it did not affect the congruence between the care receiver's preferences and the caregiver's needs and practices. One trend did suggest that the more a dyad had discussed the care receiver's wishes for daily care, the more likely the caregiver knew who the care receiver would prefer to help with her/his shopping and cooking. No differences were found when analyses compared spouse to adult child caregivers.

5. When there is a lack of congruence, whose wishes prevail, and how does this influence service use patterns?

Hypothesis 5a: When the adult with cognitive impairment (i.e., care receiver) and the family caregiver disagree on preferences and needs related to the care receiver's everyday care, it is the care receiver's wishes that take precedence.

Both care receivers and caregivers were asked if it was "very important", "somewhat important", or "not at all important" to consider the best interests of themselves and the other half of the dyad when thinking about making daily care decisions. When care receivers were responding, a paired t-test showed significant differences between the importance of considering their caregiver's best interests (*M* = 2.80 *SD* = .40) and their own best interests (*M* = 2.42, *SD* = .57, *t* = -4.89, *p* = .000). Care receivers felt their family caregiver's bests interests were more important than their own. Like the care receiver's responses, caregiver's responses indicated that they believe it is more important to consider their relative's best interests (*M* = 2.94, *SD* = .24) than their own (*M* = 2.24, *SD* = .68, t = 5.99, *p* = .000).

There was also an overall difference between care receiver and caregiver best interests. When care receiver and caregiver responses to the question, "How important is it to consider the best interests of [the care receiver]?" were summed (*M* = 5.36, *SD* = .63) and compared to the sum of the care receiver and caregiver responses to the question "How important is it to consider the best interests of [the caregiver]?" (*M* = 5.02, *SD* = .74), there was a significant difference (*t* = -2.35, *p* = .023). This indicates that, on the whole, respondents believe it is more important to consider the best interests of the care receiver when thinking about making daily care decisions.

These "best interest" questions were also correlated with a variable which measured the extent to which caregivers knew their relative's preferences for care. This "preferences for care" variable was calculated by totaling the number of times the caregiver's responses regarding who the care receiver would like to help with five tasks (e.g., cooking and shopping) matched the care receiver's responses to these questions (see Table 11). If the dyad agreed on who the care receiver preferred for "shopping and cooking" and "taking medications", but disagreed on the remaining three tasks, they would receive a score of two for the "preferences for care" variable. If the dyad was congruent across all five categories, the dyad would score five on the "preferences for care" variable. The caregiver's score on this variable could range from 0 (caregiver's responses matched none of the care receiver's) to 5 (caregiver's responses matched all five of the care receiver's).

Table 11

Percent of Care Receivers and Caregivers who chose "Family/Friends", "Paid Helper", or "No Preference" to help with daily care tasks.

	Family/Friends		Paid Helper		No Preference		Total % in agreement per task
	Care Receiver	Caregiver	Care Receiver	Caregiver	Care Reeeiver	Caregiver	
Shopping and Cooking	77%	78%	14%	10%	8%	12%	20%
(% in agreement)	(12%)		(8%)		(0%)		
Laundry & House Cleaning	45%	61%	41%	26%	14%	12%	36%
(% in agreement)	(28%)		(8%)		(0%)		
Getting Up and Dressing	57%	75%	24%	14%	18%	8%	51%
(% in agreement)	(45%)		(4%)		(2%)		
Bathing and Toilet Care	47%	61%	33%	31%	18%	4%	41%
(% in agreement)	(31%)		(10%)		(0%)		
Taking Medications	69%	86%	2%	2%	12%	12%	63%
(% in agreement)	(61%)		(0%)		(2%)		
Average % in agreement per helper	(35%)		(6%)		(1%)		

Results of the correlation between the "preferences for care" variable and best interests revealed a significant association between the number of matching responses and how important the care receiver considered his own best interests ($r = .411$, $p = .006$). This positive correlation suggests that the more important the care receiver considers his own best interests, the more the caregiver knows his/her wishes for daily care.

The same correlation performed on the level of impairment subsamples (i.e., low MMSE: 13-15 ($N = 8$); medium 16-23 ($N = 27$); high 24-26 ($N = 16$)) resulted in significance only for the medium impairment group ($r = .434$, $p = .030$). This finding suggests that the significance found in the entire sample can be attributed to those dyads who fall into this medium impairment group. When dividing the sample by kin group (i.e., dyads with adult child caregivers vs. spouse caregivers), a significant correlation was found only for the adult child dyads between the agreement variable and the importance the care receiver placed on his own best interests ($r(14) = .662$, $p = .010$). In other words, adult child caregivers' knowledge of the care receiver's wishes for daily care increases as the importance the care receiver places on his own best interests increases. For spouse caregivers however, their knowledge of the care receiver's wishes for daily care is not related to the importance the care receiver places on his own best interests.

Hypothesis 5b: Home and community-based service use is associated with the level of congruence between the care receiver's preferences and the needs of the family caregiver.

To test Hypothesis 5b, the measure of congruence between the care receiver's wishes regarding services providers and the caregiver's use of service providers as explained in Hypothesis 4a, was used. Again, to calculate this measure of congruence, we compared the care receiver's report of who they would like to help them (friends/family, service providers, no preference) with specific tasks (shopping and cooking, laundry and house cleaning, getting up and dressing, bathing and toilet care), and whether their caregiver was or was not using paid help for those tasks. Dyads were considered congruent when the care receiver preferred help from service providers on a certain task, and the caregiver had received help from service providers on that task, or when care receiver preferred help from family or friend and the caregiver had not received help from service providers. Conversely, dyads were thought to be incongruent when the care receiver preferred help from service providers and the caregiver had not received help from service providers or when care receivers preferred help from family or friends and the caregiver had received help from service providers. Care receivers who said they had no preference were considered congruent regardless of whether their caregiver had used services or not. Based on these criteria, dyads were labeled either congruent or incongruent for each of the four tasks (shopping and cooking, laundry and house cleaning, getting up and dressing, bathing and toilet care) (see Table 11).

Here, the level of congruence was correlated with the total number of services used by the caregiver. A significant negative association was found ($r = -.302, p = .049$), indicating that as caregivers used more services, dyads became more congruent on the care receiver's preferences for daily care (i.e., using the scale "Attitudes towards receiving formal/informal assistance) and the caregiver's actual service use. This suggests that the more the dyad disagreed on whether or not to use formal or informal assistance, the fewer services the caregiver had used.

Summary

Caregivers and care receivers were asked to rate the importance of their own and their relative's best interests. Both caregivers and care receivers felt it was more important to consider the best interests of the other member of the dyad above their own best interests. Next, the answers about the care receiver's best interests were compared to the answers about the caregiver's best interests.

Overall, respondents believed it was more important to consider the best interests of the care receiver over the best interests of the caregiver. As well, the more important the care receiver considered her/his own best interests, the better the caregiver knew her/his wishes for daily care. Comparisons between spouse and adult child caregivers suggested that this finding was mostly apparent in dyads with adult child caregivers. For these dyads, the more importance the care receiver placed on her/his own best interests, the more the adult child knew about the care receiver's wishes for daily care. Finally, the more a dyad disagreed on whether or not to use services, the fewer services the caregiver used.

Additional Analyses

Durable Power of Attorney for Health Care

Care receivers and caregivers were asked to respond to questions concerning the care receiver's Durable Power of Attorney for Health Care (DPAHC). While less than half of care receivers (45%) reported having a DPAHC, most caregivers (77%) said that their relative did have a DPAHC (see Table 12). For those dyads where both the care receiver and caregiver reported having appointed someone DPAHC, there was a trend suggesting that the dyad also agreed on whether it was the caregiver or someone else who had been appointed ($\kappa = 1.85, p = .065$).

Table 12
Care Receiver and Caregiver Responses to the Question "Who has been appointed Durable Power of Attorney for Health Care and Finances"?

		Caregiver	Other Family	Service Provider	Nobody, but have considered	Nobody, have not considered	Missing
Health Care	Care Receiver	37.3%	5.9%	2.0%	11.8%	29.4%	13.7%
		45.2%			41.2%		13.7%
	Caregiver	68.6%	7.9%	0.0%	7.8%	13.7%	2.0%
		76.5%			21.5%		2.0%
Finances	Care Receiver	25.5%	9.9%	2.0%	9.8%	45.1%	7.8%
		37.4%			54.9%		7.8%
	Caregiver	60.8%	11.8%	0.0%	3.9%	23.5%	0.0%
		72.6%			27.4%		0.0%

Nursing Home Placement

In order to determine how well caregivers knew care receivers' preferences for nursing home care, care receivers' responses to two questions from the Values and Preferences scale regarding nursing home care ("How important is it for you to remain at home", and "How important is it for you not to live in a nursing home?") were compared with what the caregivers said they thought would be the care receivers' responses to these questions. A chi-square revealed that the two sets of answers were not significantly different. The majority of care receivers said that it was very important to remain at home and not to live in a nursing home (78% and 73%, respectively).

Another method of determining whether caregivers knew their care receiver's preferences for nursing home care was to compare caregiver and care receiver responses to the question "What are [your relative's] your preferences should [s/he] you ever need nursing home care?" Responses fell into one of four categories: "To remain at home cared for only by family", "To remain at home with the assistance of paid home care", "To move to an apartment that provides meals", and "To move to a nursing home if need be". Twenty-six percent of caregiver responses matched those of their care receiver. In each of these congruent dyads (N = 13) the caregiver also reported agreeing with the care receiver's preference for nursing home care. Interestingly, none of the congruent dyads chose "Move to a nursing home if need be" as their preference for nursing home care.

For those dyads where the caregiver did not know the care receiver's preference for nursing home care (N = 38), the majority (75%) disagreed with what they thought were the care receiver's preferences. Results of a Chi-square indicated that those caregivers who knew their care receiver's preferences for nursing home care were more likely to agree with the care receiver's preferences than those caregivers who did not know the care receiver's nursing home preferences (X^2 = .3.88, p = .058)

Quality of Life

Both care receivers and caregivers were asked to respond to questions pertaining to their quality of life. Caregivers were also asked to rate their relative's quality of life. When rating their own quality of life, there was not a significant difference between the responses from caregivers (*M* = 2.81) and care receivers (*M* = 2.79); that is, both rated their quality of life as fair to good. Significant differences did result, however, when the care receivers' ratings of their own quality of life were compared to the caregivers' ratings of the care receivers' quality of life

(*M* = 2.35, or fair; see Table 13). In other words, caregivers rated the care receivers' quality of life lower than the care receiver rated her/his own quality of life. Caregivers' ratings of the care receivers' quality of life were also significantly different than the caregivers' ratings of their own quality of life. Caregivers rated their own quality of life significantly higher than they rated their relative's.

Table 13
Caregivers' Quality of Life vs. Caregivers' of Care Receivers' Quality of Life vs. Care Receiver Quality of Life

	Dyads with Adult Child Caregivers		Dyads with Spouse Caregivers		Whole Sample	
	Means	t-values	Means	t-values	Means	t-values
CG QoL	2.69	2.26*	2.87	4.98***	2.81	5.32***
CG of CR QoL	2.28		2.39		2.35	
CG QoL	2.69	-0.48	2.87	0.85	2.81	0.26
CR QoL	2.78		2.80		2.79	
CG of CR QoL	2.28	-3.63**	2.39	-4.76***	2.35	-6.03***
CR QoL	2.78		2.80		2.79	

Note: CG=Caregiver, CR=Care Receiver, QoL=Quality of Life

Note: Scale 4=excellent, 3=good, 2=fair, 1=poor

***p < .001 **p < .01 *p < .05

These same comparisons were made after dividing the sample by caregiver kin group with similar results. In other words, there were no significant differences in levels of self-reported quality of life for adult child caregivers and their parents (2.69 vs. 2.78 respectively) or for spouse dyads (caregiver spouse QOL = 2.87 vs. care receiver QOL = 2.80).

Decision Control Inventory

Care receivers and caregivers provided significantly different responses to eight of 15 Decision Control Inventory items (see Table 14). For six of the eight items (what to spend money on, visiting with friends, what foods to buy, being physically active, choosing places to go, and getting medical care), care receivers reported being significantly more involved than their caregivers reported they were. Only two items (when to go to bed and having a pet) showed significant differences with the caregiver reporting the care receiver more involved than the care receiver reported her/himself. Overall, comparing the summed caregiver scale with the summed care receiver scale revealed that care receivers believe they are more involved in decision making than caregivers think they are ($M = 28.42$ vs. $M = 25.07$, $t = -2.76$, $p = < .01$).

Table 14
Decision Control Inventory: Item Means* and t-values

	Caregiver	Care receiver	t-value
What to spend money on	0.78	1.82	-6.10***
Visiting with friends	1.39	1.75	-1.84*
What foods to buy	0.90	1.62	-4.82***
Being physically active	1.73	2.20	-2.83***
Choosing places to go	1.20	1.84	-3.67***
Getting medical care	1.61	2.16	-2.94***
When to go to bed	2.49	2.18	2.31**
Having a pet	1.65	1.34	1.76*
Expressing affection	2.15	2.14	.06
What to eat at meals	1.51	1.73	-1.32
Participating in religious or spiritual activities	1.64	1.47	.84
What clothes to wear	2.00	2.12	-.78
Choosing where to live	1.90	1.86	.20
When to get up	2.20	2.24	-.35
What to do in her/his spare time	1.96	2.04	-.68
Sum score	25.07	28.42	-2.76***

*Scale: 0=not involved at all, 1=a little involved, 2=failry involved, 3=very involved
***$p < .01$, **$p < .05$, *$p < .10$

Table 15
Factors Influencing Caregivers' Service Use: Ranked by Number Who Responded "Strongly Agree"

71.4%	Mental health of other parent*
71.4%	Other parent's ability to mange care receiver's care*
60.0%	Ability to control problem behaviors
57.1%	Physical health of other parent*
56.0%	Wondering if [Relative] was in danger of falling and injuring her/himself
53.1%	Care receiver's control of bowel or bladder
48.0%	Caregiver's physical health
42.9%	Caregiver's exhaustion
42.0%	Caregiver's mental health
41.7%	Care receiver's aggressive behavior
36.0%	Care receiver's inability to feed self
34.0%	Caregiver's ability to pay for services
31.3%	Care receiver's inability to recognize family members
20.0%	Care receiver's ability to pay for services
17.1%	Caregiver's previous experience using paid services

*$N = 7$

Table 16
Factors Influencing Caregivers' Service Use: Ranked by Number Who Responded "Strongly Agree" or "Agree"

94.0%	Caregiver's ability to pay for services
92.0%	Ability to control problem behaviors
91.9%	Caregiver's exhaustion
88.0%	Caregiver's physical health
88.0%	Caregiver's mental health
88.0%	Wondering of care receiver was in danger of falling and injuring self
87.8%	Care receiver's control of bowel or bladder
87.8%	Caregiver's previous experience using paid services
85.7%	Mental health of other parent*
80.0%	Care receiver's ability to pay for services
78.0%	Care receiver's inability to feed self
77.1%	Care receiver's aggressive behavior
71.4%	Physical health of other parent*
71.4%	Other parent's ability to mange care receiver's care*
64.6%	Care receiver's inability to recognize family members

*$N = 7$

Table 17
Informed Decision Making: Information Needs
Ranked in order of percentage of caregivers who felt information on the topic would be very helpful

86%	Cost of services
78%	Availability of public benefits
78%	Home and community services for care receiver
75%	Home and community services for caregiver
73%	Potential living arrangements for care receiver
71%	Progression of dementia
65%	Managing problem behaviors
63%	Incontinence
63%	Legislative/public policy issues
49%	When to involve care receiver in care planning
47%	Management of medications
45%	How to involve rest of family in care planning
43%	Cost of private long-term care insurance
41%	How to involve care receiver in care planning
37%	The Internet
35%	Genetic information
14%	How to involve friends in care planning

Note: Total scores ranged from 9 to 34 (mean = 23.7, SD = 6.3) and mean scores ranged from .53 to 2.0 with a final mean = 1.40 (SD = .37). Thus, caregivers felt on average that these areas of information would be somewhat helpful to very helpful.

CHAPTER FIVE

QUALITATIVE FINDINGS

Method

The research instruments included several open-ended questions for both the family caregiver and the person with cognitive impairment. In this way we were able to capture themes and trends from the "voices" of the respondents themselves.

The open-ended questions with more than a 50 percent response rate were coded qualitatively, following an iterative process of developing categories, coding, refining, and finalizing categories. Rater bias was reduced by having a second rater review the coded responses. A summary and analysis of the salient responses are noted below.

Responses from the Family Caregiver

Caregivers were asked: ***For you, what are the three most difficult parts of providing care for your relative?*** Almost half (45%) of the 51 family caregivers noted that the **time they spent caregiving and/or the daily caregiving routine** was one of the most difficult parts of providing care for their relative. Their comments reveal multiple layers of burdens brought on by the caregiving situation. The respondents said the caregiving routine is taxing because of the duties and daily activities involved, as well as the psychological and emotional elements of giving care to a loved one with memory loss. They said caregiving involves additional, new and difficult tasks, some relating to the direct care of the person with cognitive impairment, like managing medications and incontinence, and some that arise where the caregiver must assume responsibility for the "everyday" things once done by the care receiver.

One 81 year-old wife who cares for her husband with Alzheimer's disease said, "*I have to learn to do things I never did before, like taking care of a car.*"

The increased workload demands a great deal of planning and several caregivers talked about the difficulty of daily planning and management. The work and the planning itself that the caregiving situation demands are also accompanied by intense psychological and emotional burdens, ranging from "*the sheer responsibility of having to do it all*" to the strains involved in everyday life: "*repeating questions*" and "*everyday irritations.*" What's more, these burdens can be relentless: many caregivers used words like "*constant*" and "*repetition*" in their responses, or cited "*the everydayness*" of caregiving when describing what about their caregiving routine was difficult for them.

Nineteen (38%) caregivers noted **feeling trapped/resentful/helpless** about their caregiving role. Some spoke about being literally trapped by their situations, saying for example, that they "*had no transportation.*" Many of these caregivers spoke about their constant need to control their feelings, citing "*intense frustration*" and "*impatience which I just can't seem to control.*" For some, the feelings of helplessness and being trapped seemed to stem from the powerlessness they felt about the degenerative brain diseases of their loved one. They mentioned the burdens of "*the lack of hope for anything in the future.*" One adult child commented about the helplessness she felt for her mother and the pain in "*seeing her groping for something, no place to go, nothing to do, no future.*" For others, feeling helpless was emotional (e.g., "*not being able to control my frustration*") or practical (e.g., "*worries about finances or handling emergencies*").

Thirteen (25%) caregivers noted the variety of difficulties pertaining to the **dynamics of the dyad relationship.** The caregivers portrayed a dynamic between themselves and their relative that is consuming, trying and hurtful – mostly around changes in communication with the person with cognitive impairment. Caregivers spoke about communication as "*tedious, frustrating and difficult.*" They also noted that communication is diminished. Indeed loss -- of communication, of support, of shared memories -- of a person -- was a seminal aspect of caregiving for a loved one with cognitive impairment.

Lack of time was a common theme about the difficult parts of providing care: The actual **time spent caregiving** as noted above (45%), **lack of personal time** (24%), and **lack of time for other responsibilities/family** (20%). Caregivers cited difficulties in getting to work on time or keeping appointments, and a sense that they were restricted in their ability to, as one caregiver said, "*to lead my life the way I want to.*" A number of caregivers conveyed a sense of loss, of diminished quality of life, and sometimes resignation about their lack of personal time. One caregiver said, "*I have no more goals. I lost myself.*"

Nine (18%) caregivers noted the **care receiver's problem behaviors** as being most difficult for them. These responses provide insight into what is involved in day-to-day care. Caregivers mentioned that their relatives demonstrated a "*lack of motivation, interest or cooperation*" as well as "*anger, distrust and agitation.*" Some caregivers expressed how difficult it is to cope with these behaviors, such as trying to find activities to keep their loved one "*interested in life,*" and the frustration of seeing the futility of such efforts.

Seven (14%) caregivers noted that **financial concerns** are a source of difficulty. Some noted that they could not afford the services they needed. One 53 year-old daughter caring for her 87 year-old father with Parkinson's disease said: "*The most difficult part is getting assistance that is affordable for middle income people. Poor people can get it through public benefits and rich people can afford it.*" A few mentioned their anxiety about money, citing "*financial stress*" and "*the worry of financial difficulties down the line.*" In terms of financial decision making, one adult son noted that he *"felt the weight of responsibility for decision making about finances, but no power to make decisions."*

Lastly, one adult daughter spoke of the difficult burden of decision making, not just in terms of finances, but in daily life in general. She said, *"Coming to some understanding of what IS in the best interest of my mother, is the hardest part."*

These qualitative findings parallel quantitative work suggesting that across samples and methodologies, caregivers are reporting similar stressors and reactions to the experience of caregiving. For example, the caregivers in this study report increased workload demands and a sense of being trapped in their caregiving role. These constructs have been reported by Pearlin and colleagues (Anshensel et al., 1995; Pearlin et al., 1990) who have used the terms "role overload" and "role captivity" to capture these experiences. Similar to Pearlin's work, we also find that these caregivers discuss feeling strain in family relationships and the loss of the person for whom they care. Our qualitative work provides evidence that in addition to more broadly defined family strain, there is stress associated with specific conflicting interactions between the two members of the dyad. Loss of the person with dementia also has the potential to cause caregivers distress and sadness as well as frustration.

Caregivers were also asked the following question: ***What might be helpful to you to lessen the difficulty in each of these areas?*** The vast majority of caregivers (76%) said that formal services would be helpful to them. In contrast, only five (10%) noted additional help from their own family and friends, and seven (14%) caregivers said that nothing could be done to lessen their difficulties.

Of the 39 caregivers who said that formal services would be helpful, the most common service types mentioned included: respite care (44%); behavior management advice (26%);

information and education (26%); counseling and/or support groups (18%); care management (8%); socialization for the care receiver (8%); and transportation (2%).

Most caregivers expressed the desire for respite care through assistance in the home or support to "*free up some time*" for themselves. A number of caregivers said it would be helpful if someone would spend time with their relative, pointing out that the care receiver would also benefit from time spent apart from the caregiver. One adult child said, "*A bath a week would be a gold mine.*"

Many caregivers expressed the need for information and education to lessen their difficulties; their responses revealed a sense of personal responsibility and a desire for empowerment. Some sought knowledge to gain a sense of control and comfort such as a wife caring for her husband, a stroke survivor, who said, "*getting more information is what I want – that lessens my worries.*" Several caregivers expressed a desire to obtain as much information as possible about the medical and scientific aspects of the disease/disorder affecting their relative, as well as the practical issues related to the care receiver's condition. Several other caregivers noted a desire for general information that would help them "*practically manage*" the care of their relative.

Three caregivers gave responses that suggested they would like assistance with care management, though none used these words to describe their needs. One caregiver said she would like help to get more organized, another said it would be helpful if he could figure out which services he and his father needed and would need, and another worried about the transition from having her mother living at home to living in a nursing home. As one of these caregivers said, "*I want someone to help straighten me out; to not have this situation just thrust upon me.*"

Of the five caregivers who cited the need for more help from their own family and friends, most said that it would be more appropriate to have help from a friend or family member rather than "*paid help*". One caregiver noted the limitations that could be provided by her own family: "*Friends and family can help, but at the end of the day, I still have to face it.*"

Lastly, caregivers were asked to respond to the following: ***How will you know when you have reached your limit in caring for your relative?*** Many of the caregivers interviewed expressed that this question, in particular, was difficult to answer. A number of them said they had not really thought about this issue before. In fact, 16 (31%) of the caregivers said they **didn't know** when they would reach their limit in caregiving. As one 90 year-old wife said, who cares for her husband with Alzheimer's disease, "*Don't know. Right now it is ok, but you never know.*" A 51 year-old wife caring for her husband who suffered a stroke said, "*I really don't know. Hard to know until you get there.*"

The rest of the caregivers cited a variety of factors including: their own deteriorating **physical health** (29%) or **mental health** (18%), **inability to manage** (10%), **danger to self and others** (4%), and **incontinence** (2%). Three caregivers said they **would never reach limit** (6%).

Of those who cited physical health reasons, the great majority focused their response on exhaustion. As one 77 year-old husband who cares for his wife with vascular dementia said, "*It is hard to tell. When I feel I can't do it anymore. I guess when I become plain exhausted.*" Another caregiver, a 79 year-old woman who cares for her husband with Alzheimer's disease said, "*Sometimes I think I've reached it already. I'm exhausted. I need to get some sleep but he keeps me up all the time.*"

Deteriorating mental health was also identified. A 78 year-old wife caring for her husband with Alzheimer's disease said, "*When the men in white coats come and take me away.*" Another said, "*When I've had a nervous breakdown. When I've tried everything else and I have nothing left to give, then I'll know it is time to get help.*"

Several caregivers felt they would never reach their limit in caring for their relative. One 46 year-old son caring for his mother who has Parkinson's disease said, "*I will never. I only have one mother.*" Lastly, another caregiver remarked, "*She cared for me. I will care for her.*"

These qualitative findings indicate that many caregivers have a sense of when they will have "reached their limit" in caring for their relative. Although nearly one-third did not know when they would reach that point, the remainder reported that deteriorating physical and/or mental health or exhaustion would be the more significant factor. These findings are similar to past work by the PI and Co-PI in their study of placement (Feinberg & Whitlatch, 1995). Caregivers who were considering placement for their cognitively impaired relatives and caregivers who had recently placed their relative were asked what factors would (or did) influence their decision to place. For caregivers who were considering placement, the top three anticipated influences were physical health, exhaustion, and not finding needing assistance. For caregivers who had already placed their relative the top four influences were emotional strain, physical health, exhaustion, and the care receiver's wandering behavior. Taking these findings together, it is possible that once the caregivers from the present study "reach their limit" they may be likely to begin the process of placing their loved one in a residential or nursing home setting.

Responses from the Person with Cognitive Impairment

At the end of the Part 1 interview, the persons with cognitive impairment were asked about how they like to spend their day. Specifically: ***What kinds of activities do you like to do now?*** Those who said they do not participate in activities made remarks such as, "*I really don't care to do much of anything anymore,*" or "*I can't do anything to speak of.*" Four gave nonsensical answers.

The great majority (86%), however, responded that they do participate in activities and enjoyed them. Several care receivers mentioned limitations they face, sometimes lamenting their attenuated activity level or ability, or noting that they felt restricted by physical circumstances or their dependence upon others. One care receiver said, "*I don't remember how to dance anymore. That was my favorite thing to do.*" Others did not name specific activities, often stating that they enjoy *"keeping busy"*. Another care receiver said, "*I like to keep busy…I do keep busy doing something. I'm having trouble remembering what kind of activities, though. I don't know what is wrong with me – I just can't think of anything right now.*"

One-third of the care receivers cited **exercise** as the most common activity. Another 28 percent said they enjoyed **hobbies** (or cited the hobbies they enjoy, e.g., working around the house, gardening, etc.); another 20 percent responded that they liked to watch **television** or listen to the **radio**, and 16 percent said they liked to **socialize outside the home.** Other activities mentioned by a few care receivers were going to the movies or religious activities.

These qualitative findings show that persons with cognitive impairment were able to respond to open-ended questions about their activities noting that they were active (e.g., exercise, hobbies, etc.) yet limited by their disease/disability. Very few directly discussed limitations stemming from cognitive decline. Clearly, persons with mild to moderate cognitive impairment are aware of their day-to-day activities and even the limitations to their daily routines.

At the end of the Part 2 interview, the person with cognitive impairment was asked if ***there is anything else that you want to share [with me] about your situation?*** Only 14 of the 51 care receivers (28%) responded to this last question. Because of the relatively few responses, we have chosen to highlight, verbatim, the compelling and rich comments which illuminate the "voices" of the persons with cognitive impairment:

- *"The whole thing has been hard to describe. It's amazing when I think about the many years with all the fun and games, all the wonderful experiences I've had, and I don't know how much is left." NO ONE talks about – what is in the future. I would like someone to tell me what's in store. The whole thing is fraught with fraughts."*
  (79 year-old man with Alzheimer's disease).

- *"Life doesn't seem to hold anything for me. I just walk around the block and come home. I found out today that my wife is leaving town for four days to go to an embroidery seminar. I'm sick of it. It's been that way for years. Sometimes I wish the grim reaper would come and take me away. It just doesn't seem worth it."*
  (68 year-old man with Alzheimer's disease).

- *"I don't tell the children how I live. I hide a lot of things from them."*
  (62 year-old woman with Parkinson's disease).

- *"Alzheimer's disease washes so much away. I have always been scared about loosing my mind. I want to know what I am thinking."*
  (72 year-old woman with Alzheimer's disease).

- *"No. I don't think we've covered everything. You haven't asked me anything about sex…sex isn't like it was early in our marriage. There's nothing written in any of the Alzheimer's literature about sex – I guess they think it doesn't happen.*
  (68 year-old woman with Alzheimer's disease).

Lastly, two comments from care receivers illustrate the value of including persons with cognitive impairment in research studies:

- *"I'm very positive. I live day by day. Nothing strange happens. I'm the oldest in the family. I'll probably live till I'm 100. I have a pretty good life and I try to make it better. Your questions let me know myself better."* (86 year-old man with unspecified dementia)

- *"You helped me a lot. I haven't thought about myself in awhile. I thought I had lost it."* (55 year-old man with vascular dementia).

In sum, these qualitative findings provide strong evidence that many quantitative constructs widely used in past research have merit within a qualitative context. Additional constructs that are not currently under investigation warrant more in-depth attention at both the qualitative and quantitative levels.

CHAPTER SIX

DISCUSSION

This 35-month exploratory study examined choice and decision making in everyday care for persons with cognitive impairment <u>and</u> their family caregivers. This study differs from previous research on decision making by its focus on: 1) a community-dwelling, cognitively impaired population; 2) the dyad, i.e., the person with cognitive impairment and the family caregiver; and 3) the exploration of values, preferences and decision making for daily care.

The most salient findings of this study indicate that persons with mild to moderate cognitive impairment are able to: 1) state consistent preferences and choices; 2) provide valid responses to questions about demographics and their own involvement in everyday care; 3) participate in care decisions; and 4) express life long values and wishes regarding care they are currently receiving or will need in the future. These data support previous research that persons with dementia possess sufficient capacity to state specific preferences and make care-related decisions (Gerety et al., 1993; Sansone et al., 1996).

Many of the questions asked of the persons with cognitive impairment (i.e., care receivers) requested that they provide the name of the specific person(s) they would like to make decisions for them if they were no longer able. At least 90% of the care receivers were able to identify a person whom they would like to make their everyday care decisions in the areas of health care, finances, personal care, social activities, living arrangements, and the possibility of living in a nursing home. In almost all cases (93%), the identified person was the family caregiver or another family member. This finding supports prior research suggesting that older persons who have families prefer to pass decision- making responsibilities on to family members (High, 1988).

Results indicate that persons with cognitive impairment discuss their wishes for daily care with their families more than they discuss their preferences for nursing home care, although both topics are discussed within the dyad. Yet, care receivers also felt that their caregivers knew their wishes for daily and nursing home care equally well. Care receivers who were spouses felt their caregivers knew more about their nursing home care preferences than did care receivers who were cared for by adult children. Similarly, caregivers felt they knew the care receiver's wishes adequately for both daily care and nursing home care, yet also felt they knew the care receiver's wishes for daily care better. This was especially true for spouse caregivers who reported discussing the person with cognitive impairment's daily care wishes more often than adult child caregivers.

These results suggest that caregivers and care receivers are discussing the care receiver's wishes for daily and nursing home care. There are more discussions about daily care, likely because these families are dealing with the day-to-day challenges of caring for a person with mild to moderate cognitive impairment. Nursing home issues are neither immediate nor paramount because the care receivers are still fairly high functioning. Moreover, families often avoid talking about difficult and unpleasant matters, such as out-of-home placement. In this study, the vast majority (73%) of care receivers said it was very important to them <u>not</u> to live in a nursing home. But, as our findings indicate, more frequent discussions do not necessarily translate into a better understanding of or agreement with the care receiver's preferences for all types of everyday care. In only one situation (i.e., caregiver knowing who the care receiver would like to have help her/him with shopping and cooking), more discussion was linked to a better understanding of the care receiver's preferences. It might be that more focused discussions between the caregiver and care receiver, preferably facilitated by a trained clinician, could lead to a better understanding of the care receiver's preferences.

Turning to caregiver service use, we found that caregivers had used a variety of support services, typically programs and services that provided information about the care receiver's illness or direct assistance such as support groups, chore work (e.g., housework, maintenance, shopping etc.), help in arranging services, respite, and counseling. Service availability, affordability, and satisfaction were unrelated to the amount of discussion between the caregiver and care receiver about daily care wishes. However, the more satisfied a caregiver was with home and community-based services, the less likely s/he was to have discussed nursing home care with the care receiver. Conversely, if caregivers were unsatisfied with services, they appeared more likely to move to discussions about nursing home placement. Thus, our findings support the importance of an accessible, affordable and quality home and community-based service system to meet the needs of people with chronic degenerative diseases.

Our findings reveal the potentially negative effects of financial strain on the dyads' level of congruence on both knowledge of and agreement with the care receiver's daily care wishes. Specifically, although caregivers reported low levels of financial strain and believed they had enough money currently to cover the cost of care, the care receivers with caregivers who had higher financial strain reported feeling that their caregivers did not know their wishes for daily care. Increased caregiver financial strain was also associated with the dyads not agreeing about how well the caregiver knew the care receiver's wishes for daily care. These findings illustrate the adverse effects that financial strain can have on the decision-making process and the perception of agreement within dyads. Families experiencing the multiple and long-term stressors that accompany caregiving may find that discussions about the care receiver's daily care wishes are not a priority. Instead, they are worrying about how they are going to get through each day. Care receivers who feel their caregiver is experiencing financial strain may not want to "make matters worse" or more stressful for the caregiver so they do not make their preferences known. Unfortunately, if the dyad does not discuss these issues then they will not be able to do advance planning, which in turn, could cause increased strain and impoverishment in the long term. It would appear that structured discussions between the caregiver and care receiver, facilitated by a trained clinician, may help counter the potentially negative effects of lack of communication about the care receiver's preferences.

Another potential stressor for families is trying to determine whose "best interests" are most important to consider as important care decisions are made over the course of the care receiver's illness. Our findings suggest that family caregivers believed the care receiver's best interests are most important and that care receivers felt the caregiver's best interests are most important. When all the questions about best interests were combined, however, we found that both members of the dyad believed it was more important to consider the best interests of the person with cognitive impairment over the best interests of the caregiver. While these results seem contradictory, they clearly reflect the importance of asking multiple questions in order to understand issues concerning choice and decision making. Had we relied on a single "best interests" question, we would be left with an incomplete picture of the opinions within the dyad.

We also learned that the more important the care receiver considered her/his own best interests, the better the caregiver knew her/his relative's wishes for daily care. In other words, the more importance one places on a value or preference, the more likely one is to articulate what is wanted. Comparisons between spouse and adult child caregivers suggested that this finding was mostly apparent in dyads with adult child caregivers. For these dyads, the more importance the care receivers placed on their own best interests, the more their adult child knew about the care receivers' wishes for daily care.

Our results suggest that caregivers in general have a fairly inaccurate perception of the importance of the care receivers' values and preferences in aspects of daily life. Caregivers, as a group, were accurate in what values and preferences they thought the care receivers' felt were important compared to other specific items, but oftentimes caregivers placed less importance on the values than the care receivers. Interestingly, on the subscale level, both care receivers and caregivers ranked family caregiver issues the highest (e.g., have caregiver be the one to help out, caregiver not put life on hold). For the domains, we found that persons with cognitive impairment placed most importance on values and preferences related to their environment/safety and social interactions (e.g., comfortable place to live, live in own home, be with family and friends) as compared to their autonomy and self identity (e.g., have time to self, organize daily routines in own way, feel useful). These findings reflect the complexities involved in studying the perceptions of everyday values and preferences across a family dyad. Caregivers may perceive what is important to the person with cognitive impairment but be unaware of just <u>how</u> important certain everyday values and preferences may be to their relative.

The findings from the qualitative data point to new areas for study within the caregiving stress literature. In the present research, the caregivers reported that the time constraints and new responsibilities that are required of them are the most difficult and burdensome aspects of their role. These time requirements and new responsibilities are multifaceted and include tasks that are emotional, psychological, physical and/or practical. Caregivers must learn to do things they have never done before, and with these added responsibilities, come added stress. However, it is possible that some caregivers gain a sense of competency and personal worth as they adapt to these new responsibilities. Future research might examine the characteristics of family caregivers who meet the challenges of their new and changing role without becoming stressed or who experience positive outcomes (e.g., improved self-worth). Understanding the mechanisms underlying a more adaptive or positive response to caregiving may result in the development of interventions that address adaptive coping skills.

Lastly, in this study as well as others (Ashford, 1992; Willis et al., 1998), the MMSE was not found to be a sensitive measure of competency relating to decision making. While the MMSE, a measure of global cognitive impairment, has been widely used to screen for cognitive function, no valid, standardized, straightforward method exists to determine decisional capacity (Gerety et al., 1993; Kapp & Mossman, 1996). Due to the numbers of care receivers screening out because of our initial eligibility criteria (MMSE scores between 16-23), we felt it necessary to modify our screening criteria and expand the range of MMSE eligibility (to 13 to 26). Unfortunately, we have no way to determine how many of the care receivers who were initially screened out because of scores below 16 would have been capable of participating in the research. In discussing the interviewing experience with the research interviewers, they felt that some of the care receivers who screened out on the MMSE because of low scores would have been able to participate in the study and express valid and consistent preferences.

Practice Implications

Many health care and social service practitioners have regarded cognitive impairment as a potential barrier to informed decision making and the ability to state wishes, values and preferences. The results of this study suggest that persons with early to moderate cognitive impairment may well possess the capacity to express daily preferences for care, and should be encouraged to discuss their values and preferences with their family caregiver. In turn, this would assist family members by helping them to better understand the wishes and preferences of their loved ones earlier in the disease process and before they, the family caregivers, inevitably must make difficult and often agonizing day-to-day long-term care decisions.

These data support previous research (McCullough et al., 1993) suggesting that the decision-making process for family caregivers is more complex and potentially more stressful than for the care receivers. As a caregiver, the family member takes on multiple and changing roles. The caregiver must provide hands-on care and supervision, make decisions about care, try to determine what the care receiver prefers, and then balance these new roles and situations with other work and family responsibilities. In contrast, the person with cognitive impairment seems more focused on "maintaining personal continuity in the midst of change" (McCullough et al., 1993, p. 330), and not being a burden to the family caregiver. It may be helpful in counseling sessions, for example, to identify or encourage early conversations about the care receivers' values and preferences for current and future daily living which are mutually acceptable to the family caregiver. These structured sessions may, in turn, help to ameliorate the caregiver's feelings of overload and role captivity (Pearlin et al., 1990).

Our findings on values and preferences suggest that, relative to other domains (e.g., environment/safety and social interactions), the primacy of personal autonomy may not be of critical importance to the person with cognitive impairment. Rather, the reciprocal nature of daily care decisions fosters interdependence and the concept of "delegated autonomy" (Collopy, 1988). This view of autonomy acknowledges a consumer-directed focus whereby the care receiver decides who they want to make and carry out activities in their place. Families might benefit from working out how they can share decision making, familial responsibilities and strengths in spite of loss.

The assessment of values and care preferences and discussions about decision making are, practically speaking, difficult and challenging for families to undertake. Yet, the findings suggest that ignoring the decision-making process between the caregiver and care receiver, and postponing discussions about the values and preferences of the person with cognitive impairment could have negative consequences for both members of the dyad over time. For many family members, knowing their loved ones' wishes for daily care could reduce the strain in developing and implementing a plan of care for future long-term services. Everyday care that embraces the cognitively impaired individuals' own values and preferences is likely to provide caregivers with greater satisfaction while simultaneously easing their burden and strain, goals that are consistent with the movement toward consumer-directed care (Kane & Degenholz, 1997). For those who work with persons with cognitive impairment and their caregivers, enhancing the family's decision-making skills and improving caregiver well-being would be beneficial.

Similar to past work (Cicirelli, 1992), this study found that caregivers do not fully understand the care preferences of their relative and often have inaccurate perceptions of the care receiver's preferences and choices for everyday care. The findings suggest the need for more focused interventions to improve education and enhance communication between the person with cognitive impairment and the family caregiver around the issues of care preferences in home and community-based care, as well as residential and nursing home care.

These data support previous research (Degenholtz et al., 1997; Kane & Degenholtz, 1997; McCullough et al., 1993) suggesting that practitioners should incorporate values assessments in their work, and also focus on functional problems of the care receiver and the well-being of the caregiver. Families (i.e., the care receiver and caregiver) need a method that frames these issues by first helping them to identify and articulate their values and preferences regarding everyday care (components of decision-making skills). Further development of the values and preferences questionnaire used in this study for the cognitive impaired population could prove useful for practitioners to stimulate discussion of care preferences and decision making.

It was the interviewers' experience that the majority of the participants – both the care receiver and the caregiver – appreciated the opportunity to discuss issues related to preferences, values and daily care decisions. When asked if they would like to participate in follow-up studies, virtually all (over 90%) dyads said they would be interested in participating in follow-up research. Several caregivers said that the questions asked during the interviews motivated them to seek additional support and assistance for themselves and the person with cognitive impairment.

Policy Implications

Our findings support the policy direction of utilizing a family systems approach whereby the person with cognitive impairment and the family caregiver are considered legitimate "consumers" of long-term care. A family systems approach would expand current practice by assessing: 1) the person with cognitive impairment's values and preferences for everyday care, rather than relying solely on information from the "proxy," or "surrogate," who, typically, is the family caregiver; and 2) the family caregiver's situation, well-being, and need for targeted caregiver support services (e.g., respite care, counseling).

In this cognitively impaired sample, the care receiver or "consumer" was able to answer questions that reflected an ability to delegate responsibility for directing aspects of care when he or she is no longer able to do so. In other words, the care receiver was able to make a consumer-directed choice to have a family member acting as a "consumer" on his or her behalf. This is particularly important in home and community-based care programs where the goal of practitioners, for example, may be to maintain the well-being of the family caregiver so that they can continue to provide care to their relative and honor the cognitively impaired person's preferences to live in their own home. However, it is not enough to talk about consumer direction in home and community-based care. Not only should the person with cognitive impairment and the family caregiver be considered "consumers" with appropriate support services to address their respective needs and preference, in a family systems approach they would also have meaningful and affordable choices as they move through the continuum of long-term care (Sabatino, 1990).

Long-term care systems development, therefore, should incorporate the concept of family caregiving, rather than focusing exclusively on the care receiver when cognitive impairment is an issue. Few programs adequately address this critical policy area of supporting family caregivers or assessing the family's needs for support services to maintain their own quality of life (Feinberg & Pilisuk, 1999; Hooyman & Kiyak, 1996).

Limitations of the Study

This study was limited by its relatively small, nonrandom sample and its cross-sectional design. It is important to recall that the sample in this study represented a group of predominately female caregivers, comprised mainly of wives caring for their husbands, and daughters or daughters-in-law caring for their mothers or mothers-in-law with dementia. The caregivers and care receivers in our sample were highly educated, white, and in their early 60's or mid 70's, respectively, with moderately high incomes. This sample, which is not unlike many in the caregiving literature, may not be representative of most caregiver-care receiver dyads. This group, however, does reflect other caregiving samples (Aneshensel et al., 1995; Feinberg & Whitlatch, 1996).

Because of the exploratory nature of this research we did not use a theoretical model. Instead we relied on descriptive statistics and congruence analyses (i.e., Kappa statistic, etc.). Now that this has been accomplished, follow-up studies with a theoretical framework and more sophisticated analytic approaches can be developed to include the experience of both the person with cognitive impairment and their family caregiver in future caregiving research. In fact, the results from this study are currently being used to add dimensions of congruence to a more theoretically driven study of family decision making (Whitlatch, 2000).

Despite these limitations, this study has identified directions for the methodology, sample, and content of future research on consumer direction and decision making. The next step for researchers is to examine the stability over time of the measures employed in this study, and to explore the longer-term effects of decision making in everyday care for persons with cognitive impairment and their family caregivers (e.g., well being, service use).

Conclusions

This study aimed to recognize the roles of both persons with cognitive impairment and their family caregivers with regard to everyday care preferences and decisions. Our research adds to the growing body of evidence that persons with early to moderate cognitive impairment are able to articulate values, preferences and choices for themselves, and be valid and reliable in their responses. The challenge is to educate practitioners, policymakers and researchers to take into account the views and preferences of the person with cognitive impairment and the needs and situation of the family caregiver. How to balance divergent perspectives and preferences will continue to be a challenge for policymakers and for practitioners who work with persons with cognitive impairment and their family caregivers. By recognizing and respecting both voices – the care receiver and caregiver – we can enhance future research and practice, foster the development of consumer direction in long-term care and advance public policy to support caregiving families.

This study provides important preliminary evidence that persons with cognitive impairment can state a consistent choice and preference for care, and can respond meaningfully to questions about their values and wishes in important, domains of everyday care. Including the perspective of the person with cognitive impairment – in both research and practice – is essential to empower this population, enhance their autonomy, and improve their quality of life.

Increased understanding of the preferences of the person with cognitive impairment will improve the decision-making process, lead to more informed decisions, and reduce the strain on family caregivers and associated health costs. It is, after all, family caregivers, who are today and will continue to be in the foreseeable future, the major providers of long-term care and who will, ultimately, be left with the experience of implementing these challenging and difficult everyday care decisions.

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