

Are Persons With Cognitive Impairment Able to State Consistent Choices?

Lynn Friss Feinberg, MSW,¹ and Carol J. Whitlatch, PhD²

Purpose: This study examined the decision-making capacity of persons with cognitive impairment with respect to their everyday care preferences and choices. This is the first in a series of articles to report on findings from a larger study that examines choice, decision making, values, preferences, and practices in everyday care for community-dwelling persons with cognitive impairment and their family caregivers. **Design and Methods:** Fifty-one respondent pairs, or dyads, were interviewed, that is, persons with cognitive impairment ($n = 51$) and their family caregivers ($n = 51$). All persons with cognitive impairment were interviewed twice within a week using a parallel interview to determine stability and accuracy of responses. The family caregiver was interviewed once. **Results:** Persons with mild to moderate cognitive impairment (i.e., Mini-Mental State Exam scores 13–26) are able to respond consistently to questions about preferences, choices, and their own involvement in decisions about daily living, and to provide accurate and reliable responses to questions about demographics. **Implications:** Including the perspective of persons with cognitive impairment in both research and practice has the potential to enhance their autonomy and improve their quality of life.

Key Words: Dementia, Decision making, Everyday care, Preferences

Maintaining independence and control in decision making are issues of utmost concern to frail elders and persons with disabilities. Preparing and supporting people with chronic illness to maintain control in the face of declining physical and cognitive abilities will become even more important to society as the

baby boomers reach old age in the 21st century and constraints on public financing for long-term care continue to mount.

Despite the trend toward earlier diagnosis and greater public awareness of dementing illnesses, very little research has focused on the experience of persons with cognitive impairment (i.e., care receivers). The absence of the perspective of care receivers 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 included 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). The major objective of the present study is to reduce this gap in the existing literature by examining the decision-making capacity of persons with cognitive impairment with respect to their everyday care preferences and needs.

According to Stewart, Sherbourne, and Brod (1996), subjective assessment in cognitively impaired populations has been ignored because of the presumed logistical and methodological issues, specifically regarding comprehension and reliability. 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 understand better the preferences and experiences of persons with dementia (Downs, 1997; Kitwood & Benson, 1995; Woods, 1999). To date, the majority of the research on the emergence of the person in dementia has been qualitative. Downs (1997) outlines three areas that have been studied: (1) the individual’s sense of self; (2) perspectives of persons with dementia; and (3) a person’s rights. First, 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).

This study was supported by a grant from The Robert Wood Johnson Foundation under its national initiative, *Independent Choices: Enhancing Consumer Direction for People With Disabilities*. The assistance of Shandra Tucke in data analysis is gratefully acknowledged. We thank the anonymous reviewers for their helpful and constructive suggestions on an earlier version of this article.

Address correspondence to Lynn Friss Feinberg, MSW, Family Caregiver Alliance, 690 Market Street, Suite 600, San Francisco, CA 94104. E-mail: lfeinberg@caregiver.org

¹Family Caregiver Alliance, San Francisco, CA.

²The Benjamin Rose Institute, Cleveland, OH.

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, Stewart, Sands, & Walton, 1999; Yale, 1999). Lastly, there is a growing trend toward acknowledging the rights of people with dementia (Downs, 1997). A gap still exists, however, in exploring those individuals' values, preferences, and decision making for daily care situations.

Even with the emerging 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 when persons with cognitive impairment are involved. This body of research, which draws upon the 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), especially within the cognitively impaired population.

The advances in diagnostic testing and the trend toward earlier diagnosis have created an opportunity for earlier and more consistent involvement in everyday care decisions for both the person with cognitive impairment and the family caregiver. Although the onset of cognitive impairment adversely affects a person's intellectual functioning, judgment or the ability to make decisions about his or her care are not uniformly impaired (Post & Whitehouse, 1995; Rabins & Mace, 1985; Sansone, Schmitt, & Nichols, 1996).

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). Thus, depending on the situation, persons with cognitive deficits may have varying abilities in matters of decision making. For example, Mrs. M. may be able to decide who should make health care decisions for her even if she is no longer competent to shop for groceries. To date, no valid, standardized method exists to determine decisional capacity (Gerety et al., 1993; Kapp & Mossman, 1996).

Following diagnosis, mildly to moderately impaired persons and their families often begin planning for and adapting to the disease or disorder. Family members gather information about the disease process, talk with others who have had similar experiences, or determine potential service options. 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 disori-

ented 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).

As the disease progresses, 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, such as a move to a nursing home. 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). 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, McHorney (1996) reports that all 36 subjects who scored below 23 on the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) 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. Similarly, persons with Alzheimer's disease scoring from 10–28 on the MMSE were able to complete a brief quality-of-life measure (Logsdon & Teri, 1996). 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 receivers' and caregivers' reports were related, but not identical. Brod and colleagues (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. Although 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 resident respondents with mild to moderate dementia and their proxies, the respondents were able to clearly communicate their desires and demonstrated decision-making consistency; only 13% of the respondents made inconsistent decisions (Gerety et al., 1993). Further, research suggests that about 30% 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).

Purpose of the Study

Building on this past body of work, the present study is one of the first to examine choice and decision making in everyday care for community-dwelling persons with cognitive impairment and their family caregivers, with a focus on perceptions, values, preferences, and practices in home- and community-based care. This article is the first in a series to report on findings from this study. We address the following research question: Are persons with cognitive impairment able to answer questions about their demographics, preferences, and choices, and their own involvement in decisions about daily living? Specifically, we report on the reliability and/or accuracy of the responses given by individuals with cognitive impairment. Determining a person with cognitive impairment’s level of reliability and accuracy, and ability to state consistent preferences and choices is a necessary first step before exploring the decision-making process within the dyad (i.e., the care receiver and their family caregiver) and the congruence between the care receiver’s preferences and the needs and practices of the caregiver.

Methods

Participants

The sample consisted of 51 respondent pairs or dyads. Individuals with cognitive impairment ($n = 51$) and their family caregivers ($n = 51$) were recruited from Family Caregiver Alliance’s (FCA) client lists in the San Francisco Bay Area and community outreach. FCA supports and assists families and caregivers of adults with cognitive impairment through education, advocacy, services, and research.

The majority of care receivers were men (68.7%), White (74.5%), married (78.4%), and averaged 75.6 years of age ($SD = 10.0$, range 39–89). Most (68.6%) had at least some college education. The care receivers with adult children as caregivers ($n = 16$) had annual incomes between \$8,000 and \$29,000; those care receivers with spouse caregivers ($n = 35$) had median incomes between \$40,000 and \$50,000 a year. 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 (51.0%), followed by other dementias such as frontal lobe, lewy body or vascular dementia (13.7%), stroke (11.8%), nonspecific demen-

tia (9.8%), Parkinson’s disease (7.8%), and other disorders (5.9%). 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 and 26) and one third (33%) considered moderately cognitively impaired (MMSE scores between 13 and 19).

The family caregivers were most likely women (78.4%), White (78.4%), married (80.4%), and were on average 64.5 years of age ($SD = 14.6$, range 30–90 years), although over half (51%) were at least 65 years of age or older. More than two thirds (68.7%) were spouses and one third (31.3%) were adult children caring for a parent or parent-in-law. The majority (84.3%) had at least some college education. 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 over \$30,000. Almost half were retired (49.0%), and one third (33.3%) were in the labor force. 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).

Procedure

Prospective participants were sent a letter describing the study and asking for their participation. Dyads were then screened by telephone to determine preliminary eligibility. 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. The person with cognitive impairment had to: (a) have a confirmed physician’s diagnosis 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 MMSE).

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 the 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 Time 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 and 83 (36%) were found to be ineligible. The most frequent reasons for ineligibility were: care receivers being too impaired to be interviewed based on caregiver reports (45%); caregivers not meeting the initial inclusion criteria (18%); the care receiver being unable to participate (15%); placement of the care receiver in a skilled nursing facility or residential care (8%); caregiver moving out of the area (8%); or the death of the care receiver (6%).

Thirty-four percent ($n = 44$) of the remaining 129 caregivers refused to participate for a variety of reasons, yielding a 66% acceptance rate. The most frequent reasons cited by the caregiver for choosing not to participate included the following: unwilling to participate or not giving an explanation for refusal (66%); the caregiver was too busy (14%); or other reasons (20%). Of the 85 eligible dyads, two were used for interviewer practice, yielding a final preliminary sample of 83 caregiver/care receiver dyads.

About one third ($n = 27$ or 32%) of 83 eligible care receivers were screened out at the Time 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 Time 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.

Following the telephone screening, the research coordinator scheduled the in-person interviews. Experienced and trained individuals interviewed the caregiver and care receiver separately. For the most part, interviews were conducted with the dyads in their own homes. Every effort was made to ensure that the same interviewer was assigned to interview each member of the dyad.

For this study, three interviews were conducted per dyad. The interviewing sequence and process required that the person with cognitive impairment be interviewed first to determine final eligibility with the MMSE score. Within one week, the family caregiver was interviewed and the person with cognitive impairment was interviewed a second time to investigate the reliability and stability of their responses (Sansone et al., 1996) and to ask additional questions. 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 the care receiver between interviews that 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.

Data collection began in July 1998 and continued for 10 months through April 1999 to achieve a final sample of 51 dyads (3 interviews per dyad or 153 total completed interviews). On average, the Time 1 interview with the person with cognitive impairment lasted 42 minutes (range: 24–103 minutes), and the Time 2 interviews, conducted one week later, took 50 minutes to complete (range 25–100 minutes). The interviews with the caregivers lasted longer, averaging 107 minutes (range: 27–193 minutes).

Measures

All measures for the larger study were pretested with a sample of six dyads to determine ease of com-

prehension, interview length, and appropriateness of vocabulary and content areas and revised as appropriate. For the present study, we report results based on five measures drawn from the larger study.

The Mini-Mental State Examination (MMSE).—The MMSE 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 the present 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 and colleagues (1996), the Correct Scale assesses the care receiver's ability to respond accurately to 10 questions about specific factual information (i.e., day, month, and year of birth; number of children and siblings; education level; marital status; religious affiliation; and age). In Sansone and associates' (1996) original study, a care receiver 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 so that our version of the Correct Scale has three items rather than one for birth date. This revised scoring of date of birth more accurately represents the care receiver's ability to answer questions correctly. Also, Sansone and colleagues used this measure with a sample of nursing home residents with dementia, and 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.

Demographic Questions.—Questions regarding educational level, ethnicity, religiosity, and such were asked of both the care receiver and the caregiver. Additional questions asked only of the caregiver related to their own employment status, living arrangement, and the number of hours a week providing care. As noted above, the care receiver was asked 10 demographic questions adapted from the Correct Scale at both the Time 1 and Time 2 interviews to assess accuracy and consistency of responses at two time points. In addition to obtaining the caregiver's demographics, the caregiver was also asked to confirm their relatives' responses to the demographic questions.

The Preference Scale.—Again, drawing upon the work of Sansone and colleagues (1996), the Preference Scale assesses the care receivers' ability to choose or state a preference consistently over a one-

week period. Respondents were asked four questions: “Do you like to watch television?” (yes/no); “Do you prefer winter or summer?” (winter or summer); “Which of these colors do you like the best?” (yellow, green or red); and “Which of these three ways do you prefer to have your eggs cooked?” (scrambled, fried, boiled, or don’t eat eggs). Items were scored so that the respondents’ ability to give a response was coded as 1; thus, responses could range from 0 to 4, with higher scores indicating greater ability to state a preference.

Involvement in Everyday Living.—These items were adapted from measures used in previous studies (Cicerelli, 1992; High & Rowles, 1995; Pratt, Jones, Shin, & Walter, 1989; and Wetle, Levkoff, Cwikel, & Rosen, 1988) to assess preferences for decision making about routine daily living. Participants were asked three questions: “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); “How much are you involved in making decisions about how you spend your day?” (not at all involved, a little involved, fairly involved, very involved); and “How do you feel about your involvement in making decisions about how you spend your day?” (not enough involvement, the right amount of involvement, too much involvement). Higher scores reflect greater levels of involvement by the care receiver.

Data Analysis

Care receivers were asked 17 questions to determine the test–retest reliability of their responses for the Time 1 and Time 2 interviews: 10 demographic questions (birthday, age, marital status, etc.), 4 questions from the Preferences Scale (favorite color, favorite season, etc.) and 3 questions about their own involvement in everyday living. 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 (Roberto, 1999), was used to determine if there was significant agreement between the responses given at Time 1 and Time 2. The advantage of the Kappa coefficient over percentage agreement is that it takes into account chance agreement (Coriell & Cohen, 1995; Pett, 1997). Thus, regardless of the number of nominal level responses possible, Kappa is based on exact agreement rather than nearness of response. Kappa values that approach 1.00 reflect that there is perfect agreement, whereas values that approach 0.00 reflect responses that would be expected by chance. For these analyses, we considered p values less than .05 as sufficient indicators of test–retest reliability. When Kappa could not be computed for nominal level data due to empty cells, chi-square statistics were used instead. Responses

with interval data (i.e., age and number of children) were similarly tested using paired t tests.

To determine accuracy, Kappa, chi-square, or t -test statistics were again computed, this time comparing care receivers’ responses to the 10-item Correct Scale (Sansone et al., 1996) to those of their caregivers. Caregivers’ responses were compared against the care receivers’ responses at both Time 1 and Time 2. For analyses of test–retest reliability and response accuracy, we deleted cases when either respondent answered a question, “I don’t know.”

Results

Test–Retest Reliability

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 (see Table 1). In fact, of the 17 questions asked of care receivers, only one (the care receiver’s age) yielded responses that were significantly different from Time 1 to Time 2. 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% and 40% of care receivers, respectively, were found to have unreliable answers. On the other hand, in this same subset, perfect agreement was obtained for marital status, whether the care receiver has children, and the question about how the care receiver feels about his/her level of involvement in daily living.

Care receivers with medium MMSE scores (16–23, $n = 27$) answered reliably to all questions but favorite season and how involved the care receiver is in making decisions about how to spend his/her day. For these two questions, 19% and 52% of care receivers, respectively, were found to have unreliable answers. Perfect agreement was found for three questions: marital status, religion, and watching TV. Those with the highest MMSE scores (24–26, $n = 16$) answered only two questions unreliably: “Do you like to watch TV?” and “How do you feel about your level of involvement in your care?” For these two questions, 13% and 33% of care receivers, respectively, answered unreliably. Perfect agreement, with all care receivers providing the same answer at both the Time 1 and Time 2 interviews, was reached by this high MMSE group for six questions: day, month, and year of birth; marital status; children; and siblings.

Accuracy

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). Accuracy was measured by the extent of agreement between the care receiver and the caregiver. Responses from the 10-item Correct Scale were analyzed twice, first comparing the caregiver’s

Table 1. Test-Retest Reliability of Care Receivers' (CRs') Responses

Item	All Cases N = 51	Low MMSE n = 8	Med MMSE n = 27	High MMSE n = 16
Demographics				
Birth day	6.533 ^c	2.533 ^c	0.000 ^c	1.000 ^a
Birth month	0.954 ^a	0.855 ^a	0.955 ^a	1.000 ^a
Birth year	2.677 ^c	1.200 ^c	0.000 ^c	1.000 ^a
Age	—	1.000 ^d	2.000 ^d	-1.000 ^d
Marital status	1.000 ^a	1.000 ^a	1.000 ^a	1.000 ^a
Children (yes/no)	0.912 ^a	1.000 ^a	0.835 ^a	1.000 ^a
No. of children	-0.423 ^d	constant ^c	0.000 ^d	-1.000 ^d
Education	0.874 ^a	1.111 ^c	0.855 ^a	0.922 ^a
Religion	0.910 ^a	0.788 ^a	1.000 ^a	0.033 ^c
Siblings	0.746 ^a	0.696 ^a	0.620 ^a	1.000 ^a
Preferences				
TV	0.728 ^a	constant ^c	1.000 ^a	—
Season	0.547 ^a	—	—	0.755 ^a
Color	0.695 ^a	—	0.700 ^a	0.896 ^a
Eggs	0.706 ^a	0.810 ^a	0.621 ^a	0.778 ^a
CR's Involvement In Everyday Living				
Who most involved?	0.383 ^a	1.250 ^c	0.000 ^c	0.500 ^b
How involved is CR?	0.357 ^a	3.833 ^c	—	0.605 ^a
How does CR feel about involvement?	0.436 ^a	1.000 ^a	0.675 ^c	—

Note: MMSE = Mini-Mental State Examination; — indicates unreliable test-retest responses.

^aThese values represent Kappas where $p < .01$.

^bThis value represents a Kappa with $p < .05$.

^cChi-square values were used when Kappa could not be computed due to empty cells. Nonsignificant values (i.e., $p > .05$) indicate no significant differences in responses (i.e., caregiver receiver responses do not significantly vary from Time 1 to Time 2).

^dT values were used for interval data. Nonsignificant values (i.e., $p > .05$) indicate no significant differences in responses (i.e., care receiver responses do not significantly vary from Time 1 to Time 2).

^eT value (number of children) or chi-square value (TV) could not be computed because the distributions were exactly the same, indicating perfect agreement.

answers with the care receiver's at Time 1, then at Time 2. The average number of correct responses for the Correct Scale was 6.61 ($SD = 1.4$) for the Time 1 interview and 6.49 ($SD = 1.35$) for the Time 2 interview (range 2–8 correct responses for both Time 1 and 2). More than three fourths of the care receivers

were able to answer at least 7 of 10 questions accurately during Time 1 (84.3%) and Time 2 (82.3%).

In general (see Table 2), the results indicate that care receivers were able to answer questions with a high degree of accuracy. Across the entire sample, significant levels of agreement between care receivers

Table 2. Agreement Between Care Receiver and Caregiver Responses on Demographic Items

Demographic Items	Time 1				Time 2			
	All Cases N = 51	Low MMSE n = 8	Med MMSE n = 27	High MMSE n = 16	All Cases N = 51	Low MMSE n = 8	Med MMSE n = 27	High MMSE n = 16
Birth day	5.448 ^c	0.846 ^a	0.969 ^c	1.000 ^a	4.305 ^c	0.855 ^a	0.956 ^a	1.000 ^a
Birth month	0.955 ^a	0.667 ^c	0.969 ^c	1.515 ^c	0.978 ^a	1.000 ^a	0.957 ^a	1.000 ^a
Birth year	3.723 ^c	2.143 ^c	0.969 ^c	1.000 ^a	2.244 ^c	0.938 ^c	0.969 ^c	2.182 ^c
Age	0.968 ^d	1.266 ^d	-0.462 ^d	0.000 ^d	1.981 ^d	1.034 ^d	2.001 ^d	—
Marital status	1.679 ^c	0.711 ^a	0.000 ^c	1.000 ^a	1.679 ^c	0.771 ^a	0.000 ^c	1.000 ^a
Children (yes/no)	—	—	—	0.133 ^c	0.382 ^a	—	0.598 ^a	0.092 ^c
No. of children	-1.787 ^d	0.607 ^d	-0.225 ^d	—	-1.278 ^d	0.607 ^d	0.214 ^d	—
Education	0.624 ^a	—	0.758 ^a	0.725 ^c	0.572 ^a	2.952 ^c	0.662 ^a	0.349 ^c
Religion	0.942 ^a	0.788 ^a	0.945 ^a	1.000 ^a	0.913 ^a	1.000 ^a	0.943 ^a	0.123 ^c
Siblings	0.864 ^a	0.714 ^b	0.830 ^a	1.000 ^a	0.702 ^a	—	0.620 ^a	1.000 ^a

Note: MMSE = Mini-Mental State Examination; — indicates responses that are inaccurate.

^aThese values represent Kappas where $p < .01$.

^bThis value represents a Kappa with $p < .05$.

^cChi-square values were used when Kappa could not be computed due to empty cells. Nonsignificant values (i.e., $p > .05$) indicate no significant differences in responses (i.e., caregiver and care receiver do not significantly disagree).

^dT values were used for interval data. Nonsignificant values (i.e., $p > .05$) indicate no significant differences in responses (i.e., caregiver and care receiver do not significantly disagree).

at the Time 1 interview and their caregivers were found for all demographic questions with one exception: “Do you have any children?” At the care receivers’ Time 2 interview, there was significant agreement among care receivers’ and caregivers’ answers to all demographic 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 nearly all questions at both Time 1 and Time 2. One question was answered inaccurately at Time 1 and Time 2 (whether the care receiver has children), whereas level of education was answered inaccurately at Time 1 and whether the care receiver has siblings was answered inaccurately at Time 2. Care receivers with medium MMSE scores responded accurately to all but one question at Time 1 (whether the care receiver has children) and reported accurately to all questions at Time 2. Care receivers with the highest MMSE scores were inaccurate when answering questions about the number of children at Time 1 and Time 2, and age at Time 2.

Discussion

The results of this study indicate that persons with mild to moderate cognitive impairment (i.e., MMSE from 13–26) are able to respond consistently to questions about preferences, choices, and their own involvement in decisions about daily living, and provide accurate and reliable responses to questions about their own demographics. These data support previous research findings that persons with dementia possess sufficient capacity to state specific preferences and make care-related decisions (Gerety et al., 1993; Sansone et al., 1996).

It could be argued that the promising results related to test–retest reliability could be a result of memory effects that would have inflated our reliability estimates. However, given the small total sample size in this exploratory study, the even smaller sample sizes when the analyses compared low, medium, and high MMSE groups, and our conservative *p* values, we found that the number or proportion of dyads that were required to be congruent in order to demonstrate statistically significant levels was quite high. In the low MMSE group, for example, seven out of eight dyads had to be reliable in order to reach statistical significance. In addition, the cognitively impaired subsamples varied only slightly in the number of questions that were not reliable. If our results had been influenced by memory effects, we would have expected an increased number of reliable responses as level of impairment decreased (i.e., higher MMSE scores).

With few exceptions (e.g., education, questions about children), family caregivers were able to confirm the care receivers’ responses. For example, caregivers and care receivers did not always agree about the care receiver’s level of education. In one dyad, the caregiving wife did not mention that her husband

had attended college level courses, whereas 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 the care receiver were congruent in their responses. Similarly, in the total sample, dyads were found to be inaccurate or incongruent when responding to the question, “Does the care receiver have children?”

This finding in the larger sample most likely reflects the results of the inaccurate responses of the low and medium MMSE groups. In other words, rather than indicating that persons with cognitive impairment uniformly respond inaccurately to a question about whether they have children, the results suggest this is true for persons who are more cognitively impaired. It could also be that persons who are more cognitively impaired misunderstood the question as asking, “Have you ever had children?” rather than “Do you have children who are currently alive?” This question may require higher cognitive functioning than other questions. In addition, it is puzzling why dyads with higher functioning care receivers were incongruent in answering questions about the number of children. These results reveal gaps in our understanding of “knowledge congruence” (Whitlatch, 2001). Few studies have examined the level of agreement between family caregivers and cognitively impaired care receivers about subjective information (e.g., care preferences) or objective information (e.g., demographics). It will be interesting to see if our findings change as we examine these dyads over time.

These findings suggest that family caregivers should not be assumed to be the “gold standard” for determining whether persons with cognitive impairment are able to accurately answer questions that relate to specific demographics. The findings also suggest that the level of “agreement congruence” (Whitlatch, 2001) within a dyad (i.e., how much two persons within a dyad agree on certain issues or questions) may be influenced as much by the person’s cognitive impairment as by the caregiver’s lack of knowledge.

In this study as well as others (Ashford et al., 1992; Willis et al., 1998), the MMSE was not found to be a sensitive measure of competency relating to capacity to state preferences and make daily care decisions. Although 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). In discussing the interviewing experience, the research interviewers in this study stated 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.

It was also 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.

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 everyday care wishes 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.

The findings of this study are especially important when considered within the context of our larger study. The aim of our work in the larger study is to examine 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 this broader context, our next task is to move beyond the Correct Scale and General Preference Scale (Sansone et al., 1996) developed to assess the reliability of specific factual information (e.g., current marital status) and general preferences (e.g., favorite season, like to watch TV), to answer more specific questions about the actual everyday values and preferences of persons with cognitive impairment (e.g., live in own home, be safe from crime, do things for self, feel useful, be part of family celebrations) and the caregivers' perceptions of these values. Understanding the importance of the care receiver's values and preferences that are more salient to day-to-day caregiving will be particularly useful for researchers and practitioners.

Because of the exploratory nature of this research we did not use a theoretical model. Instead we relied on descriptive statistics and analyses for reliability and accuracy (e.g., Kappa statistics). Given our preliminary yet encouraging findings that persons with mild to moderate cognitive impairment are reliable and accurate respondents, we can move toward development of a theoretical framework and use more sophisticated analytic approaches that include the experience of people with cognitive impairment and their family caregiver. Caregiving research, in particular, lags in its efforts to incorporate the perspective of the person with cognitive impairment into theories

of caregiving and related stress. 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, 2001).

A final limitation of this study was its relatively small, nonrandom sample and its cross-sectional design. It is important to recall that the study sample represented a group of predominately female caregivers, composed 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 60s or mid 70s, respectively, with moderate incomes. This sample, which is not unlike many in the caregiving literature, may not be representative of caregiver-care receiver dyads who do not seek or use formal services. This group, however, does reflect other caregiving samples (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Feinberg & Whitlatch, 1996).

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 and service use).

This study provides important preliminary evidence that persons with early to moderate cognitive impairment are able to articulate certain preferences and choices for themselves, and to be accurate and reliable in their responses. 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.

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Received July 5, 2000

Accepted January 15, 2001

Decision Editor: Laurence G. Branch, PhD