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Three Methods of Assessing Values for Advance Care Planning:

Comparing Persons With and Without Dementia

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Abstract

Advance care planning ideally includes communication about values between patients, family members, and care providers. This study examined the utility of health care values assessment tools for older adults with and without dementia. Adults aged 60 and older, with and without dementia, completed three values assessment tools—open-ended, forced-choice, and rating scale questions—and named a preferred surrogate decision maker. Responses to forced-choice items were examined at 9-month retest. Adults with and without dementia appeared equally able to respond meaningfully to questions about values regarding quality of life and health care decisions. People with dementia were generally as able as controls to respond consistently after 9 months. Although values assessment methods show promise, further item and scale development work is needed. Older adults with dementia should be included in clarifying values for advance care planning to the extent that they desire and are able.

Keywords

advance care planning; values; dementia

Older adults at risk for dementia or with early dementia may be particularly interested to engage in advance care planning. Broadly speaking, advance care planning entails communicating with loved ones, health care providers, or other relevant parties to prepare for decisions that may need to be made during a time of future decisional incapacity. For older adults at risk for dementia, such planning might entail preparing for financial, residential, and/or health care eventualities. Within the health care realm, advance care planning has primarily focused on the completion of advance directives that allow individuals to designate surrogate decision makers (i.e., durable power of attorney for health care) or to document particular health care instructions (i.e., living will). However, research and clinical evidence suggests that completing advance directives—in the absence of communication about an individual’s and his or her family’s values, fears, and preferences—may not ultimately help to facilitate good decisions on behalf of individuals with dementia or other incapacitating illnesses (Covinsky et al., 2000; Miles, Koepp, & Weber, 1996; Teno et al., 1997).

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A process of values clarification in advance care planning recognizes both that individuals differ in health-care related beliefs and preferences and that medical decisions are made within a social context. With regard to individual differences, cultural (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Ersek, Kagawa-Singer, Barnes, Blackhall, & Koenig, 1998; Hornung et al., 1998), religious (Cohen-Mansfield, Droge, & Billig, 1992), socioeconomic (Cicirelli, 1997), personality (Lockhart et al., 2001), or life experience (Allen-Burge & Haley, 1997; Coppola, Danks, Ditto, & Smucker, 1998) factors may influence values related to medical decision making. These values include preferences for autonomous versus shared decision making (Blackhall et al., 1995), concern for individual versus family or community interests (Klessig, 1992), beliefs in sanctity of life or possibility of miracles (Klessig, 1992), and personal ideas about what makes life worth living versus intolerable (Ditto, Druley, Moore, Danks, & Smucker, 1996). Although there is evidence that values-related variables do correspond to decision outcomes (Fischer, Alpert, Stoeckle, & Emanuel, 1997; Schonwetter, Walker, Solomon, Indurkhya, & Robinson, 1996), there is mixed evidence regarding the stability of and relationship between values and treatment preferences through time (Ditto et al., 2003; Emanuel, Emanuel, Stoeckle, Hummel, & Barry, 1994; Lockhart, Ditto, Danks, Coppola, & Smucker, 2001).

The social context of medical decision making also calls for a process of values clarification and communication. Families often face heart-wrenching decisions for which their loved one’s advance directive, if one exists, does not provide clear direction. The autonomy-based model wherein surrogate decision makers provide a “substituted judgment” of an incapacitated individual’s treatment preferences is increasingly viewed as an ethical ideal rather than a social reality. Multiple studies have demonstrated that family member proxies are rarely able to predict patients’ treatment preferences beyond chance (Hare, Pratt, & Nelson, 1992; Seckler, Meier, Mulvihill, & Cammer Paris, 1991; Suhl, Simons, Reedy, & Garrick, 1994). Furthermore, many patients want designated proxies to do what they think is best at the time rather than simply to represent what they think the patient would have wanted (Ditto et al., 2001; Puchalski et al., 2000; Singer et al., 1998; Terry et al., 1999). Proxies also report wanting to consider multiple factors, including the doctor’s input and what is best for everyone involved (Mezey, Kluger, Maislin, & Mittelman, 1996). Despite their emotionally difficult and weighty roles, designated proxy decision makers have been largely absent from the process of completing advance directives (Lane & Dubler, 1997; Zeleznik et al., 1999).

Many experts recommend bringing family members or other loved ones into the process of advance care planning to give patients and families an opportunity to discuss future care decisions and, hopefully, to provide family members more comfort in the potential role of surrogate decision maker. One of the most well-known and effective advance care planning programs was a community education and facilitated discussion intervention in La Crosse, Wisconsin (Schwartz et al., 2002). In the facilitated discussion, a nurse, social worker, or other nonphysician health care worker guided patients and their health care proxies through discussions of the patients’ values and preferences related to various end-of-life treatment options. The intervention led to increased completion of advance directives and, ultimately, care that was consistent with patients’wishes at the end of life. Furthermore, other research suggests that discussions focused on values clarification may provide comfort and reassurance to families (Ditto et al., 2001; Karel, Powell, & Cantor, 2004; Singer et al., 1998).

Various tools exist to help patients clarify and communicate their values and goals relevant to medical care decisions (Karel, 2000). Some of these “values history” tools are designed as open-ended questions or interviews (Gibson, 1990; Hammes & Rooney, 1998; Karel et al., 2004; Schwartz et al., 2003), whereas others include specific rating scales or questions about treatment preferences (Doukas & McCullough, 1991; Gillick, Berkman, & Cullen, 1999; Pearlman, Starks, Cain, Rosengreen, & Patrick, 1998). Some instruments were designed primarily for research purposes (Ditto et al., 1996; Karel & Gatz, 1996; Lawton et al., 1999; Schonwetter et al., 1996).

Although values clarification instruments may be promising for patients and families to use in advance care planning, little empirical research exists to support the use of these tools in either clinical or research settings. The aim of this research was to examine three methods for asking older adults with and without dementia to communicate values and preferences related to potentially serious future medical care decisions. Older adults who participated in a study of medical decision-making capacity responded to (a) two open-ended questions regarding what makes life meaningful or good and whether there is a point at which life would not be worth living, (b) a series of forced-choice questions with large print material to follow along, and (c) a 3-point rating scale of extent to which various concerns would influence a decision about medical treatment. In addition, participants were asked to name a person they would trust as a surrogate decision maker. The goals were to explore potential benefits and pitfalls of these approaches for values assessment in advance care planning and to identify approaches worthy of future instrument development.

This study was guided by three primary research questions:

1. How do people with and without dementia respond to questions about health care values and preferences, in terms of individual differences elicited by the items and their apparent ease, or lack thereof, of response to different questioning formats?
2. Is there evidence of stability of response to values items during a 9-month period of time, and is there any difference in response stability, including in the naming of a surrogate, when comparing older adults with and without dementia?
3. Are individual differences in response to health care values items related to demographic or health status variables (e.g., gender, age, education, religious background, health status, and dementia status)?

Method

Medical Decision-Making Study

This research was part of a larger study of medical decision-making capacity in older adults with and without dementia (Moye, Karel, Azar, & Gurrera, 2004). In addition to completing neuropsychological and decision-making capacity assessment instruments, the participants responded to questions about health care values in both open-ended and forced-choice formats. Participants were invited to participate in 9-month follow-up interviews. A subsample of participants, who had expressed interest in participating in other projects, were mailed a survey about their experiences with illness and disability, difficult medical decisions, spiritual coping, use of alternative medical approaches, and ratings of health care values.

Sample Recruitment and Screening

Two groups were recruited: a group of older adults with mild/early dementia and a matched group of healthy controls free of health conditions that could lead to cognitive impairment. Participants were self-referred or referred by a caregiver or clinician via fliers circulated in hospital waiting rooms, senior centers, and senior housing as well as advertisements placed in community newspapers, council of aging newsletters, and an Alzheimer Association newsletter. Efforts were made to recruit participants of color through fliers and advertisements posted at senior housing and media outlets serving communities of color.

Potential participants completed a range of medical, cognitive, and psychiatric screening tools in order to determine dementia versus control group status and to exclude individuals with serious health or psychiatric conditions. Screens included a modified version of the Telephone Interview for Cognitive Status (Brandt, Spencer, & Folstein, 1988), the Geriatric Depression Scale short form (Sheikh & Yesavage, 1986), and the Brief Symptom Inventory (Derogatis, 1993) for all participants; the Dementia Diagnostic Screening Questionnaire (Rogers & Meyer, 1988) for potential dementia participants; and the Health Screening Questionnaire (Christensen, Moye, Armson, & Kern, 1992) for potential control group participants. Potential dementia group participants also provided medical records including blood work, neurological examinations, and computed tomographic or magnetic resonance image of the head. Clinical diagnoses of dementia were based on Diagnostic and Statistical Manual of Mental Disorders-IV (American Psychiatric Association, 1994) criteria, with consensus review of all screening scores and medical record data by a geropsychiatrist and geropsychologist. Dementia diagnoses could be attributable to Alzheimer’s, vascular, or Parkinson’s disease and/or alcohol-induced persisting types; this study did not attempt to specify or track dementia subtype. Further details about sample recruitment can be found in Moye et al. (2004).

Informed Consent

All participants provided written informed consent as approved by hospital and medical school institutional review boards and human subjects committees. Details about informed consent procedures can be found in Moye et al. (2004).

Participants

In the first wave of data collection, 88 men and 88 women older than age 60 years participated in the longitudinal medical decision-making study. Half of the sample, 44 men and 44 women, were clinically assessed to have dementia. Of the 176 participants, 165 had complete data on the forced-choice Health Care Values Survey described below and comprise the Time 1 sample for this report. Of these 165 participants, 81 had dementia and 84 were controls. The dementia and control groups did not differ by sex, race, marital status, or years of education, but those with dementia were significantly older ($M = 75.42$ and $SD = 6.42$ vs. $M = 72.08$ and $SD = 6.31$, $t = 3.36$, $p < .001$; see Table 1).

Longitudinal analyses of the forced-choice Health Care Values Survey included participants who completed this measure at both the initial time of measurement and 9 months later. Of the 165 who had complete values data at Time 1, 114 participated at Time 2 (69.1%), but only 112 of them (67.9%) completed the values questions. This rate is consistent with the 73.3% retention through Time 2 for the entire study (129/176 participants returned for the 9-month follow-up). The longitudinal sample with values data included 49 people with dementia (60.5% retention) and 63 controls (75% retention). Not surprisingly, participants with dementia were less likely to follow up at Time 2.

Ninety-seven participants (48 men and 49 women; 44 with dementia and 53 controls) completed an additional mail-out survey. This survey included the Health Care Values rating scale items.

Measures

Health Care Values—

This study examined three measures of health care values and one of preferred surrogate decision makers.

Health Care Values Survey, open-ended questions: After completing the decision-making capacity and neuropsychological assessment measures, which required approximately 2 hr of testing, participants were introduced to a series of questions about their health care values. The introduction to these questions was both read by and read aloud to participants as follows:

> Sometimes people face serious medical decisions, such as whether they would like to be resuscitated if their heart stopped beating or if they would like to be kept alive by a machine if they could no longer breathe. People have different opinions when making these serious health care decisions. We want to ask you some questions about what is important to you in making those decisions. There are no right or wrong answers.

Participants were then asked the following two open-ended questions: “In general, what makes life meaningful or good for you now? What are you thankful for?” and “On the other hand, is there a point for you where life would not be worth living? Can you imagine any circumstance in which you would prefer to die rather than remain alive?” The evaluator wrote down verbatim the participants’ responses. Participants responded to these questions at both the initial time of measurement and 9-month follow-up. This open-ended approach to eliciting patient values and preferences has been used in qualitative studies regarding end-of-life and long-term care (McCullough, Wilson, Teasdale, Kolpakchi, & Skelly, 1993; Singer, Martin, & Kelner, 1999; Vig, Davenport, & Pearlman, 2002). In this study, however, there was no attempt to flesh out participant responses through in-depth interview; we simply recorded responses to the two open-ended questions.

Health Care Values Survey, forced-choice format: This measure included 14 items in which participants chose the responses that most closely matched their preferences or beliefs regarding quality of life, where and from whom to receive care, who should make decisions, religious and interpersonal concerns, and preferences if they could no longer swallow food. Item content and format were developed based on a review of the literature, data from a pilot study of a larger pool of items (Karel, 2000), and data from a pilot study using a similar forced-choice format in a nursing home sample (Karel, Moye, & Oville, 1996). The nursing home pilot study showed evidence of 2-week test–retest stability in forced-choice items, although some items were more stable than others (Karel et al., 1996). We examined the forced-choice approach both as a potential method to clarify preferences that can be more difficult to detect on a normative rating scale and to offer a simple and visual method for individuals with cognitive impairment.

The research evaluator read aloud the following introduction to these items, while participants read along:

> Next are questions about what is important to you if you had to make serious, or even life and death, medical decisions. I will give you 2 choices on each topic, and you choose the answer that is the best one for you. You can also say both are true, or that you don't know, but in most cases, do try to choose one answer that is best for you. If you got very sick and had to make medical decisions, which would you choose?

The research evaluator then read aloud the theme of each item and the two choices, while the participant read along. For example, regarding the theme of who makes decisions, participants could choose "It is alright if my family or doctor makes medical decisions for me" or "If I am able, I want to make medical decisions for myself." They could also choose the options "some of both" or "I don't know." For analytic purposes, these uncertain responses were collapsed into one category of uncertainty.

Of note, after the first 52 participants were interviewed, we changed one item that asked about preference for tube feeding if no longer able to swallow food. In the initial item, no context about health or prognosis was given, and most participants responded, "it depends." Thus, we created two new items that asked participants if they would want to be fed through a tube in the stomach in the condition (a) "if I was aware, not terminally ill," or (b) "if I was very impaired, terminally ill."

Participants completed the forced-choice items at both the initial time of measurement and 9-month follow-up. At both times, after completion of these items participants were also asked, "We are interested in your feedback on these questions. What was it like to answer these questions?"

Health Care Values rating scale format: Using most but not all of the same themes covered in the forced-choice items, participants were asked to rate the extent to which 13 different issues would influence their decisions about medical treatment. Instructions read, "How much would each of these concerns influence your decision about a medical treatment? For example, whether or not to start a potentially life saving but difficult treatment?" Each item was rated on a 3-point scale, where 1 = *influence not at all*, 2 = *influence a little*, and 3 = *influence a lot*. Prior research found evidence of individual variability when asking people to rate the importance of various factors that might influence medical decisions or end-of-life care, as well as evidence of underlying constructs that such items tap (Doukas & Gorenflo, 1993; Karel, 2000; Karel & Gatz, 1996; Schonwetter et al., 1996; Steinhauser et al., 2000).

Trusted and nontrusted surrogate decision makers: After completing the interview-based forced-choice Health Care Values Survey items, participants were asked to name individuals they would or would not want to make decisions for them if they were not able to speak for themselves. The questions were as follows:

> If somebody else had to make a medical decision for you (that is, if you were unable to speak for yourself), who would you want that to be? Why? (Instruction to interviewer: Prompt for first name and relationship; if more than one person named, circle the most preferred surrogate.)
>
> Is there somebody that you do NOT want to make decisions for you? Why not? (Instruction to interviewer: If needed, explain that some people may have a particular family member or friend they would not trust to be involved in making decisions for them.)

Participants completed this item at the initial time of measurement and 9-month follow-up.

Demographic Variables—The Medical Decision-Making study included measures of sex, years of education, marital status, race, and religion.

Health and Life Experience Variables—The additional mail survey included questions about health, functioning, experience with serious illness, and experience making life-sustaining treatment decisions for oneself or others.

Data Analysis

Data analysis included qualitative thematic analysis of the open-ended questions, descriptive statistics (frequency distributions) on the forced-choice and rating scale values items, group difference analyses using chi-square and ANOVA statistics, and correlational analyses. Factor analysis was used to reduce the rating scale items to underlying thematic variables. In addition, longitudinal comparison of participant responses to forced-choice values items included calculation of Cohen's κ as an indicator of test–retest reliability (with Time 1 and Time 2 measures viewed as separate raters).

Results

Open-Ended Questions

Qualitative Analysis—Participant responses were quite brief, ranging from a few words to one or two sentences. Responses to each question, by both dementia and control participants and at the initial time of measurement and 9-month follow-up, were typed verbatim into a separate MS Word document for each question. The primary investigator (PI) listed each discrete response on an index card. For example, many participants stated that having "good health" is what makes life meaningful or good; thus, *good health* would be written once on an index card. Specific variations would each be listed on an index card (e.g., being able to walk). No two index cards said exactly the same thing. The PI and two geropsychology postdoctoral fellows then independently sorted the cards into piles in an effort to break down the large number of responses into thematic categories. There was good consensus on the major categories elicited for each question. Sorters determined different numbers of categories, but in each case, the categories could be collapsed into the major categories described below (e.g., categories of health and self-sufficiency combined into the broader category of health and autonomous functioning).

Regarding what makes life meaningful or good for you now, major domains were (a) simply to be alive, life itself; (b) interpersonal relations (e.g., family, friends); (c) health and autonomous functioning (e.g., self-sufficiency, mobility, mental clarity); (d) specific enjoyed activities, including feelings of being involved and productive; (e) spiritual/metaphysical feelings (e.g., faith, peace, beauty, nature, happiness); and (f) practical comforts (e.g., being in one’s home, financial stability). Regarding a point when life might not be worth living, major domains were (a) illness and functional incapacity; (b) mental incapacity; (c) interpersonal concerns (e.g., being isolated or a burden to others); (d) dependency, loss of control; (e) impaired quality of life, loss of enjoyed activities; and (f) life is always worth living.

Experiences Administering and Pros/Cons of This Format—Participants did not appear to have difficulty answering these open-ended questions. Without follow-up prompting, few participants provided detailed or in-depth responses but may have voiced their most salient reactions. The research evaluator was not trained nor asked to elicit more detailed elaboration from participants. This type of open-ended question may offer a good starting point for a discussion about advance care planning to help patients and families identify major themes that patients may be thinking or worried about. More detailed follow-up questions and/or the assistance of a professional facilitator would help patients and families to elaborate on beliefs about what makes life worth or not worth living (Karel et al., 2004).

Health Care Values Survey: Forced-Choice Items

Frequency Distributions—Some forced-choice items elicited strong consensus among participants, whereas other items elicited a wider range of opinion (see Table 2). At least 70% of the participants (both those with and without dementia) chose the same response to five of the items, as follows. More than 70% of participants stated that quality of life is more important than length of life, they can accept help for personal needs, they are not afraid to die, they prefer to make medical decisions for themselves, and they are concerned about being a burden to others. Items with greater variability in opinion included whether life-sustaining medical treatments should be used if they become no longer able to think clearly, whether religious beliefs will influence medical decisions, whether to receive care in a hospital or nursing home versus at home when very sick or dying, and whether to choose tube feeding if they become no longer able to swallow food.

Items also differed in the extent to which participants were able to make a clear choice of the two options offered versus choosing either *some of both* or *I don't know*. Items that elicited the greatest degree of uncertainty, with 15% or more of participants choosing *some of both* or *I don't know* (due either to poor item clarity or relative complexity of the issue), were preference to live or not if they were no longer able to enjoy simple pleasures, whether to take pain medicine for severe pain if it causes sleepiness or confusion, whether to receive care in a hospital or nursing home versus at home when very sick or dying, preference to receive personal care from family members or professionals, whether decisions are based on what is best for the participant versus best for family or friends, and whether to take tube feeding if they are still aware and not terminally ill.

Group Comparisons—Group differences in dementia status, age, education, marital status, and religion were examined by comparing frequency distributions through chi-square analyses. Only participants who responded with one of the two choices offered were included in these analyses; those who responded *some of both* or *I don't know* were excluded because those cell sizes were too small for chi-square analyses.

People with and without dementia did not differ significantly in their responses to these items. Several age group differences were present. When comparing adults 75 or older to those younger than 75, the younger group was significantly more likely to choose "It is important to me to make medical decisions based on what is best for me" (86.5% of the younger group vs. 60.0% of the older group) versus "It is important for me to make medical decisions based on what is best for my family and friends" (13.5% of the younger group vs. 40% of the older group; $\chi^2(1, n = 139) = 12.65$, $p < .001$). Also, although the large majority of all participants stated that they preferred to make medical decisions themselves rather than have decisions made by family or doctors and that they were concerned about being a burden to others, there was a trend for the older group to be more likely to be all right with decisions made by family or doctors (19.2% of the older group vs. 7.5% of the younger group; $\chi^2(1, n = 158) = 4.72$, $p < .05$) and to express concern about being a burden (97.3% of the older group vs. 87.3% of the younger group; $\chi^2(1, n = 154) = 5.35$, $p < .05$).

Those not married (combining single, divorced, and widowed) were more likely to prefer personal care from professionals versus family (89.5% of unmarried vs. 68.9% of married participants preferred professional help for personal care; $\chi^2(1, n = 131) = 7.89$, $p < .01$). Married participants were more likely to want to receive care at home versus a nursing home or hospital when very sick or dying (58.4% of married vs. 40.7% unmarried participants; $\chi^2(1, n = 136) = 4.22$, $p < .05$). And, married participants were more likely to express being afraid to die (19.8% of married vs. 6.6% of unmarried participants, $\chi^2(1, n = 142) = 5.01$, $p < .05$).

In terms of religious group differences, Catholics were more likely to state that they would follow religious beliefs when making medical decisions compared to Protestants or other groups (including Jewish and Others; 39.0% vs. 16.7% vs. 15.6%, respectively; $\chi^2(2, n = 145) = 9.25$, $p < .01$). There were no other religious group differences.

There were no differences in item response when comparing those with and without a high school education.

Stability Through Time—Participant responses on each item were compared between Time 1 and the 9-month follow-up. Table 3 shows the κ statistic for each item, broken down by dementia versus control group. Cohen's κ is typically an indicator of interrater reliability for categorical variables, which takes into account item variance and the probability of reaching the same rating by chance. In this case, participant ratings at Time 1 and Time 2 were compared to determine the extent to which individual ratings through time showed stability beyond chance levels. A κ value greater than 0.70 typically indicates agreement beyond chance. Note that in this analysis, κ was calculated on each item only for the subset of participants who chose either Choice 1 or Choice 2 at both times of measurement (excluding participants who chose *some of both* or *I don't know*). Therefore, the percentage of participants included in κ calculations for each item varied depending on the degree of certain versus uncertain response elicited by each item, as discussed above.

Review of these data shows that items with the greatest stability through time are ratings of quality versus length of life, desire for pain medication, accepting help for personal needs (control group), feelings about dying, and from whom to receive personal care (control group). Items with lower stability ratings may be less reliable (due to poor clarity or relevance of the item) or more likely to capture changes in perspective through time. Without short-term test–retest analysis, it is impossible to sort this out. Of note, stability coefficients were often similar between control and dementia participants. It did not appear that people with dementia responded less consistently on average than control participants.

Participant Response to What It Was Like to Answer Questions—After answering the open-ended and forced-choice questions (and naming a surrogate, below), participants were asked, “We are interested in your feedback on these questions. What was it like for you to answer these questions?” and 131 participants responded to this query. Responses fell into five major categories: Participants responded that answering the questions was (a) fine, no problem ($n = 75$, 57.3%); (b) a positive experience, enjoyable, interesting, fun ($n = 8$, 6.1%); (c) difficult because the questions were hard to understand or answer in some way ($n = 15$, 11.5%); (d) difficult because the questions were emotionally challenging in some way ($n = 17$, 13.0%); and (e) thought-provoking, something viewed as important but not labeled as positive or negative ($n = 16$, 12.2%).

Experiences Administering and Pros/Cons of This Format—Participants both with and without dementia appeared able to respond to these forced-choice questions without difficulty. They appeared able to understand the task, to find it relevant to their participation in a study on medical decision making, and to respond with confidence to the items. Although this type of structured format may help individuals to review particular values-related topics in a systematic way, it does not provide a context for individuals to explain or qualify their responses. Pros and cons of forced-choice versus other response formats for values assessment will be considered in the discussion.

Health Care Values Rating Scale Items

Frequency Distributions—Table 4 shows frequency distributions for these items, which asked respondents to a mail-out survey “How much would each of these concerns influence your decision about a medical treatment?” Number of respondents for each item ranged from 91 to 97. Items most likely to be rated as influencing a decision *a lot* were the ability to still make decisions for oneself (rated as influencing *a lot* by 80.4% of participants); the ability to still communicate with others (77.1%); the emotional impact on one’s family (70.3%); and one’s quality of life at the time (62.5%). Items least likely to be rated as influencing *a lot* were religious beliefs about the situation (34.7%); feelings and beliefs (e.g., fears) about dying (35.8%); and the level of physical pain involved in the treatment (37.2%).

Interitem Correlations and Factor Analysis—To determine if several underlying themes or factors might account for item responses, a correlation matrix was examined and principal component factor analysis conducted. Inspection of the correlation matrix clearly showed that subsets of items had moderate to strong correlations with each other and fairly low correlations with other items. A factor analysis found a four-factor model accounted fairly well for these observed interitem relationships. These four components accounted for 69.8% of the item variance. A varimax rotation of the first four principal components found items to have primary loadings on one of the four factors, as shown in Table 4. New variables for each factor were calculated by taking the mean score of the items loading on that factor. These new variables were used to examine group differences.

As shown in Table 4, the first factor appears to account for a common variable that might be labeled Extent of Concern for Maintaining Self-Sufficiency. The mean score on this new variable (on a 1–3 scale) was 2.57 ($SD = 0.57$). The second factor might be labeled Extent of Concern About Pain and Quality of Life. The mean score on this new variable was 2.27 ($SD = 0.63$). The third factor might be labeled Extent of Concern About Preserving Life. The mean score on this new variable was 2.01 ($SD = 0.66$). The fourth factor might be labeled Extent of Concern About Impact of Decisions on the Family. The mean score on this new variable was 2.46 ($SD = 0.71$).

Group Differences—Group comparisons were examined for dementia status, gender, age group (older vs. younger than 75), marital status, education (more than high school vs. high school or less), and religion, using mean score (t test or ANOVA) comparisons on the four factor scores. There were no differences between dementia and control participants, nor between older and younger participants, in ratings for these items. Nor were there differences based on gender, marital status, or education. There were no significant differences between religious groups, but there was a trend for Catholics to have a higher mean score on the factor Extent of Concern About Preserving Life, $F(2, 88) = 2.91$, $p = .06$.

In addition, the mailed questionnaire that included the Values Rating Scale had several items regarding past experiences with serious illness or medical treatment decisions. There were no differences in responses to these values items for people who had versus had not been in the hospital in the prior 12 months, nor for people who did or did not report a history of life-threatening illness in themselves. However, there appeared to be differences between people who had or had not ever made a life-sustaining treatment decision for another person. Of the 97 respondents to this questionnaire, 24 reported they had either made a decision not to start a potentially lifesaving treatment (e.g., dialysis, cardiopulmonary resuscitation, or treatment for cancer) or a decision to stop a lifesaving treatment (e.g., taking someone off breathing machine or stopping dialysis) for a loved one. Those who had made previous life-sustaining treatment decisions had higher mean scores on both the factor Extent of Concern for Maintaining Self-Sufficiency, $t(94) = -2.68$, $p < .01$, and Extent of Concern About Pain and Quality of Life, $t(94) = -3.73$, $p < .001$.

Apparent Pros and Cons of This Format—Because these items were administered through a mailed survey, we did not have access to information about the process of responding. Nor did we ask participants in the mailed survey to tell us what it was like to answer the questions. Given the fairly complete data returned on these items, it did not appear that participants had particular difficulty or confusion in responding. However, a rating scale format can make it difficult to infer the relative importance of values or concerns to individuals, and in some cases, it may not be clear just how the issue would be a consideration (e.g., who would provide care, family or professionals; in this format, we do not know which the person would prefer). The rating scale, while offering a structured method to review issues, may offer fairly abstract information, at least on this particular scale.

Naming a Surrogate Decision Maker

Participants were asked to provide the name and relationship of the person they would want to make medical decisions for them if they could not speak for themselves. In some cases, participants responded with a relation (e.g., wife, son), but not a name. If a participant named the same relation at both points in time (e.g., son), that was assumed to be the same person (although there could be two sons and he or she might have been thinking of a different son each time). In a few cases, a specific person was not named (e.g., children), and those cases were excluded. Of note, very few participants responded with the name or relation of someone they would *not* trust to speak for them.

Of the 57 participants in the control group who named a preferred surrogate at both Time 1 and Time 2 (9 months later), 45 of them (78.9%) named the same person or relation at both times whereas 12 (21.1%) named a different person or relation. Of the 45 participants with dementia who named a surrogate at both times, 38 (84.4%) named the same person or relation whereas 7 (15.6%) named a different person or relation. Therefore, people with dementia and controls showed similar stability in preference for a surrogate decision maker after 9 months. Of note is that approximately 1 in 5 participants changed their stated preferred surrogate during this time.

Discussion

Although most experts agree it is a worthy goal to help patients, families, and care providers clarify and communicate values and preferences related to medical care decision making, just how to do that and what tools might help (and which tools, for whom, when, and for what exact purpose) remain unclear. This study examined three methods for eliciting health care values from a sample of older adults, half of whom carried a diagnosis of dementia. Given the importance of including adults with early dementia in advance care planning, it is necessary to determine if people with dementia can participate meaningfully in these values assessments. This study illustrates some of the benefits but also challenges of developing standardized values assessment tools for advance care planning.

The discussion comments are organized around the three primary research questions: First, how do older adults with and without dementia respond to different methods of assessing health care values and preferences? Second, is there evidence of stability in values choices and surrogate preferences after 9 months for adults with and without dementia? And third, are there socioeconomic or other variables that relate to individual differences in response to health care values items?

Comparing Values Assessment Methods in Older Adults With and Without Dementia

In this sample, older adults with mild to moderate dementia were as able as normal control participants to respond meaningfully to values assessment questions. Older adults with dementia were able to answer open-ended questions about quality of life, respond to forced-choice questions regarding health care values and preferences, name a preferred surrogate decision maker, and respond to a mailed survey values rating scale. On objective items, there were no differences between adults with and without dementia on response frequency distributions; that is, the content of values item responses did not appear to be related to whether one suffered from dementia. Therefore, comparison of the values assessment methods will be discussed without consideration of dementia status.

The three values assessment methods described in this article—open-ended, forced-choice, and rating scale formats—offered strengths and drawbacks as tools for assessing values for advance care planning. Open-ended questions offer a good way to open up a discussion and may be most useful in a clinical setting when a trained clinician can use such questions to facilitate a conversation between patients, family members, and/or care providers (Hammes & Rooney, 1998). In this study, we posed very general questions about quality of life and did not offer follow-up inquiry to help specify how very general concerns for quality of life might translate to more specific beliefs and preferences regarding medical treatment decisions.

The forced-choice method is intriguing as an objective method that can elicit particular values and preferences. However, it is also limiting in its black and white approach, without options for clarifying gray areas for respondents. To address this concern, we allowed uncertain categories of *some of both* or *I don't know*, but those categories create challenges for data analysis in a research context. Respondents appeared well able to provide their choices in response to these questions. Because prioritization of values is an important part of advance care planning (e.g., is it more important for you to control pain or remain alert and aware?), a values assessment method that allows comparisons or choices deserves further attention. Future research might examine other methods of asking people to compare values or situations, such as questioning which is most true or which situation would be worse.

The values rating scale items tapped underlying themes along which people did express differences in opinion. The underlying factors identified in this study—extent of concern for maintaining self-sufficiency, for pain and quality of life, for preserving life, and for impact of decisions on the family—are consistent with the underlying themes found in similar analyses (Doukas & Gorenflo, 1993; Karel, 2000; Karel & Gatz, 1996; Schonwetter et al., 1996). A drawback of any rating scale, wherein each potential value is rated independently, is that it becomes more difficult to contrast different issues; respondents could potentially rate that each value is of utmost importance. A useful rating scale approach used by Pearlman and colleagues (Pearlman et al., 1998) is to rate the extent to which living in a particular condition or situation (e.g., can no longer get outside, can no longer recognize family/friends) would make life difficult but acceptable, worth living but just barely, or not worth living; respondents are then given the opportunity to explain or clarify their answers.

In part, the utility of a values assessment method depends on the setting in which it might be used and what the tool is called on to do (e.g., to help communication, to document responses as part of an advance directive, or to collect information in a research study). In this study, the tools we examined were administered as part of a research project rather than in a clinical setting, were used regarding hypothetical future decisions rather than actual and/or personalized future medical decisions, and did not include potential health care proxies in the discussion. In addition, our observations about these tools are limited to this sample that was mostly White, with at least a high school education, and healthy enough to travel to a hospital clinic to participate in a research study. Other samples of older adults may have responded quite differently.

Stability of Values Through Time

An important question about assessing values for advance care planning is whether such values remain fairly stable, or not, through time. Are there core values and beliefs relevant for medical decision making that remain stable through time, and can we devise ways to measure these core values? And in circumstances where life experience really does lead someone to shift previously held values or assumptions (Sprangers & Schwartz, 1999), can values assessment measures tap changes that occur spanning longer periods of time?

We examined the stability of response to the forced-choice values items and looked at the stability of naming a preferred surrogate decision maker over a 9-month period of time. The major barrier to examining long-term stability or change in health care values and preferences with such assessment tools is that we do not yet have evidence of simple test–retest reliability. If people cannot provide consistent responses to items after a short time period such as 1 week (i.e., is the item measuring a true construct apart from random response?), then it is impossible to assess questions of longer term stability or change. (Of note, there is some evidence of 1-week test–retest stability for cognitively impaired older adults' responses to questions about preferences and choices for daily living; Feinberg & Whitlatch, 2001).

With this caveat in mind, we found evidence of greater stability in items assessing the importance of quality versus length of life, use of pain medication, preferences for where and from whom to receive care, and feelings about dying. Although in several cases adults without dementia appeared to have more stable responses through time, that was not a consistent finding, and in general, adults with dementia had similar κ coefficients to normal controls. Also, adults with and without dementia performed similarly in naming a consistent surrogate after a 9-month interval. In fact, both groups named the same person only approximately 80% of the time; unfortunately, we did not collect information about changes that could have occurred to influence change in surrogate choice (e.g., death of the previously named surrogate).

Previous research varies in the extent of stability found in patients' ability to express stable treatment preferences or quality of life judgments through time; stability is generally moderate and varies across illness scenarios and methods of questioning (Gready et al., 2000; Lockhart et al., 2001). In this study, stability of values responses was also moderate and varied across items. However, we have no evidence at this time to suggest that adults with mild to moderate dementia cannot express consistent values through time. Findings from this and other studies suggest that it remains important and valid to include adults with dementia in advance care planning discussions.

Predictors of Individual Differences

In general, we did not find strong predictors of responses to values items through socioeconomic or health-related variables. The lack of group differences may relate to poor reliability or validity of values items and/or the very individualized nature of these values and beliefs. However, when we did find demographic differences, they were consistent with prior research findings. For example, older adults are more likely to be concerned about being a burden and to be comfortable with others making decisions (High, 1988; Karel & Gatz, 1996). Other findings were sensible, including that married participants were more likely to state that they preferred to get care from family members and at home. Catholics were more likely to say that their religion would influence health care decisions (and to tend toward greater value of preservation of life).

One salient finding was that participants who had made a life-sustaining treatment decision for another person expressed a greater degree of concern for issues of self-sufficiency, pain, and quality of life compared to those who had not faced such a difficult decision. This finding is important because it highlights that people may not be able to anticipate how they would feel or react in circumstances of life-threatening illness and that people who have faced such issues with loved ones may experience meaningful shifts in values or beliefs regarding their own future medical care.

Conclusions and Future Research Directions

Various approaches to health care values assessment appear promising to help patients and families in the process of advance care planning. Older adults with and without dementia appear well able to respond to various formats of questions about health care values. We need further study to develop reliable and valid values assessment tools for both clinical and research purposes. Studies of test–retest reliability are needed. We need to study the use of these tools in more diverse groups, particularly regarding what types of tools may aid communication in various cultural groups as well as in particular patient populations.

Clinicians may ultimately target values assessments to the needs and types of decisions likely to be faced by certain groups (e.g., people with Alzheimer's disease vs. end-stage pulmonary or renal disease). We need further research on the utility of such tools to facilitate communication between patients, families, and care providers. Furthermore, tools should be understandable and usable by people with mild to moderate cognitive impairment because often these people face difficult health care decisions. In this research, people with mild to moderate dementia were well able to express their values and beliefs relevant to health care decisions. These individuals should be included in health care planning to the extent that they are able and wish to participate.

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Table 1

Sample Description

Demographic Variable	**Category**	**Control Group (n = 84) n (%)**	**Dementia Group (n = 81) n (%)**	**Total (N = 165) n (%)**
Sex	Female	41 (48.8%)	42 (51.9%)	83 (50.3%)
Race	African American	8 (9.5%)	3 (3.7%)	11 (6.7%)
	Caucasian	75 (89.3%)	77 (95.1%)	152 (92.1%)
	Other	1 (1.2%)	1 (1.2%)	2 (1.2%)
Marital status[a]	Married	48 (58.5%)	46 (56.8%)	94 (57.7%)
	Widowed	16 (19.0%)	23 (28.4%)	39 (23.6%)
	Divorced/separated	13 (15.5%)	12 (14.8%)	25 (15.1%)
	Never married/other	7 (8.4%)	0 (0%)	7 (4.2%)
Religion[b]	Catholic	44 (52.4%)	40 (49.4%)	84 (50.9%)
	Protestant	20 (23.8%)	17 (21.0%)	37 (22.4%)
	Jewish	12 (14.3%)	13 (16.0%)	25 (15.2%)
	Other	8 (9.5%)	11 (13.6%)	19 (11.6%)
Age group[c]	Age 75 or older	29 (34.5%)	51 (63.0%)	80 (48.5%)
Years of school	Beyond high school (> 12)	52 (61.9%)	46 (58.2%)	98 (60.1%)

Note: There were no significant differences between the control and dementia groups on these demographic variables, with the exception of age.

[a] These cells were collapsed into married versus unmarried to compute chi-square statistic.

[b] These cells were collapsed into Catholic, Protestant, and Other to compute chi-square statistic.

[c] Those in the dementia group are significantly more likely to be older than 75 years of age than those in the control group, $\chi^2(1, n = 165) = 13.353$, $p < .0001$.

Table 2

Health Care Values Survey, Forced-Choice Items: Frequency Distributions (*N* = 165)

Item Theme	Choice 1 (%)	Choice 2 (%)	Some of Both (%)	I Don't Know (%)
1. Enjoying simple pleasures (e.g., music, TV, even if sick)	Want to live no matter what 38.8	Would prefer not to live if could no longer enjoy simple pleasures 42.4	12.7	6.1
2. Ability to think clearly (If I can no longer think clearly …)	Do not want intensive medical treatments used to keep me alive 61.2	Do want intensive medical treatments to keep me alive 27.9	3.0	7.9
3. Quality versus length of life	Believe living as long as possible is more important 6.7	Believe quality of life is more important 84.8	3.6	4.8
4. Pain medicine	Prefer medicine, even if sleepy or confused 60.6	Prefer pain than medicine that makes me sleepy or confused 16.4	17.0	6.1
5. Accepting help (for personal needs)	Do not want to accept help 12.7	Can accept help 77.0	7.9	2.4
6. Religious beliefs (when making medical decisions)	Will follow my religious beliefs 25.5	Will not be influenced by religious beliefs 67.9	4.8	1.8
7. Where to receive care (when very sick or dying)	Prefer hospital or nursing home 40.6	Prefer to be at home 42.4	7.9	9.1
8. Feelings about dying	Am afraid to die 12.7	Am not afraid to die 74.5	9.1	3.6
9. Receiving personal care (such as bathing)	Prefer family members 18.2	Prefer professionals, such as nurses 61.8	17.6	2.4
10. Who makes medical decisions	OK with family or doctor making decisions for me 12.7	Want to make decisions for myself if able 83.0	4.2	0.0

Item Theme	Choice 1 (%)	Choice 2 (%)	Some of Both (%)	I Don’t Know (%)
11. Being a burden	Am not concerned 7.3	Am concerned 86.1	6.1	0.6
12. Who medical decisions are for	Make decisions based on what is best for me 62.4	Make decisions based on what is best for family or friends 21.8	14.5	1.2
13a. Ability to eat food if aware, not terminally ill ($n = 115$)	Feed through tube in stomach if can no longer swallow 49.6	Would prefer to die if could no longer swallow 29.6	5.2	15.7
13b. Ability to eat food if very impaired, terminally ill ($n = 115$)	Feed through tube 17.4	Prefer to die 75.7	0.9	6.1

Note: Complete item wording is not provided in this table. The table combines results for dementia versus control groups because no group differences were detected in item frequency distributions.

Table 3

Stability of Forced-Choice Item Response During a 9-Month Period, for Participants With and Without Dementia

	% of Longitudinal Sample Included in This Analysis		Cohen's κ	
Item	**Control**	**Dementia**	**Control**	**Dementia**
1. Enjoying simple pleasures	71.0	71.4	.318	.364
2. Ability to think clearly	75.8	83.7	.510	.168
3. Quality versus length of life	79.0	89.8	.728	−.048[a]
4. Pain medicine	58.1	64.6	.739	.716
5. Accepting help for personal needs	80.6	85.7	.730	.195
6. Religious beliefs	77.4	95.9	.520	.619
7. Where to receive care	69.4	85.7	.583	.665
8. Feelings about dying	77.4	81.6	.929	.895
9. From whom to receive personal care	71.0	75.5	.758	.466
10. Who makes decisions	91.9	93.9	.497	.311
11. Being a burden	88.7	89.8	.650	.616
12. Who decisions are for	74.2	71.4	.548	.190
13a. Feeding tube, if aware	64.5	72.1	.524	.472
13b. Feeding tube, if terminally ill	87.1	95.3	.234	.221

Note: This analysis includes only participants who chose one of the two forced choices at both times of measurement (excluding those who chose *some of both* or *I don't know*). The percentage column indicates the percentage of the entire longitudinal sample (63 control and 49 dementia participants) included in this analysis.

[a] This number is so low because there were no people with dementia who said, at both times of measurement, that length of life was more important.

Table 4

Heath Care Values Rating Scale: Frequency Distributions and Principal Component Factor Analysis

	How Much Influence? (%)			Principal Component			
Item	***A lot***	***A little***	***Not at all***	**1**	**2**	**3**	**4**
My level of physical pain at the moment	45.3	27.4	27.4	.153	.859	−.008	−.002
The level of physical pain involved in the treatment	37.2	40.4	22.3	.307	.762	.119	−.007
My quality of life at the time	62.5	22.9	14.6	.192	.806	.179	.247
Ability to enjoy simply pleasures (read, TV, radio) at the time	52.6	22.7	24.7	.007	.583	.363	.240
A desire to live as long as possible	47.4	22.1	30.5	−.003	.148	.769	.165
The extent to which I would depend on others for personal care	58.3	26.0	15.6	.711	.361	−.002	.300
Who (family members or professionals) would provide my personal care	58.9	28.4	12.6	.837	.145	.111	.175
The financial impact on my family	59.6	16.0	24.5	.212	.002	.256	.835
The emotional impact on my family	70.3	19.8	9.9	.274	.153	−.009	.835
My feelings and beliefs (e.g., fears) about dying	35.8	23.2	41.1	.263	.009	.711	−.007
My religious beliefs about the situation	34.7	17.9	47.4	.318	.002	.533	.106
Ability to still communicate with others	77.1	12.5	10.4	.807	.180	.327	.248
Ability to still make decisions for myself	80.4	11.3	8.2	.719	.244	.335	−.009
Percentage of total variance				40.53%	12.83%	8.89%	7.60%