Published in final edited form as:

J Aging Health. 2009 June ; 21(4): 627–650. doi:10.1177/0898264309333316.

Surrogate Decision-makers' Understanding of Dementia Patients' Prior Wishes for End-of-Life Care

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Abstract

Objectives—This study examines how surrogate decision-makers for dementia patients developed an understanding of patient preferences about end-of-life (EOL) care and patient wishes.

Methods—Semi-structured interviews were conducted with 34 surrogate decision-makers for hospice-eligible nursing home patients with dementia. The data were content analyzed.

Results—Most surrogates reported that patients had previously completed an advance directive (59%), discussed preferences for EOL care (56%), or done both (38%). Catalysts for and barriers to completing an advance directive or having EOL care discussions included factors that were both intrinsic and extrinsic to the patient. The most commonly reported wish for EOL care was to *not* be kept alive by “machines” or “extraordinary measures.”

Discussion—Health care providers may be able to assist patients and families by normalizing discussions of dying, encouraging advance care planning, helping them identify goals for EOL care, and providing information to support treatment decisions consistent with patients' wishes.

Keywords

advance care planning; advance directives; treatment preferences; nursing home patients; advanced dementia

Introduction

When seriously ill patients lack adequate capacity to make decisions about their own medical care, surrogate decision-makers, usually family members, must decide for them. In some cases, illness and incapacity are sudden and unexpected, leaving no opportunity for specific planning, but for individuals with dementia, the losses of cognitive function and decisional capacity usually develop gradually, progressively and often predictably in older age (Rabins, Lyketsos, & Steele, 2006). Individuals in the first stages of dementia may have the capacity to choose a

health care agent, express health care preferences or complete an advance directive (Mezey, Mitty, Bottrell, Ramsey, & Fisher, 2000; Rempusheski & Hurley, 2000). Thus, people who will become surrogate decision-makers for individuals with dementia often have an opportunity to develop an understanding of patients' wishes, fears and goals for end-of-life (EOL) care.

Two assumptions underlie surrogate decision-making in the current model of biomedical ethics in the United States. Both assumptions are intended to honor the autonomy of the patient by basing real-time decisions on preferences expressed previously, thus using the ethical and legal standard of substituted judgment (Beauchamp & Childress, 2008). The first assumption is that patients have, or are able to generate, well-formed and durable preferences about treatment in future hypothetical situations. Second, potential surrogates are assumed to be able to ascertain from patients what their goals for care and treatment preferences are. While these assumptions may be valid in many cases, studies examining advance care planning and surrogate decision-making often reveal other realities (Carrese, Faden & Finucane, 2002; Gamble, McDonald & Lichstein, 1991; Hines et al., 2001; Hopp, 2000).

One challenge to this model is empirical evidence suggesting that not all older adults wish to consider or express their preferences for how future treatment decisions should be made. For example, through in-depth interviews with a sample of community-residing older adults, High and Turner (1987) found in an early study that 52% had not discussed their preferences for care if they were too ill to participate in decision-making, 40% had not spoken to anyone about what medical care they would want should they become terminally ill, and few had documented their preferences in a living will (18%) or had designated a health care proxy (15%). Another qualitative study of chronically ill housebound older adults found that, while most of these individuals had made "final arrangements" for their death (e.g., a will, funeral plans) and some had completed an advance directive (e.g., living will, health care agent form), the majority were reluctant to think about, discuss, or plan for serious future illness (Carrese et al., 2002). In fact, many older adults either have not discussed their preferences for EOL care with the person they trust to make health care decisions for them or do not have an advance directive (Gamble et al., 1991; Hopp, 2000). Finally, survey data have shown that surrogates are significantly more likely than patients to believe that patients should express, both orally and in writing, their treatment preferences (Hines et al., 2001).

A related area of study has examined the accuracy with which potential surrogates predict patients' treatment preferences. A comprehensive literature review based on meta-analysis of data from 16 studies showed that surrogates predict patients' preferences with 68% accuracy when considering hypothetical scenarios (Shalowitz, Garrett-Mayer, & Wendler, 2006). Accuracy is highest when considering patients' current health status and lowest for scenarios involving stroke or dementia. Neither the designation of surrogates as the patients' decision-makers nor discussions of patients' treatment preferences improved surrogates' accuracy.

The usefulness of advance directives or prior discussions for guiding decision-making may be limited by their content. For example, a study on the use of advance directives found that many individuals prefer to express general preferences (e.g., values, goals for care) rather than document specific medical treatment preferences (Hawkins, Ditto, Danks, & Smucker, 2005). They also found that many patients prefer that surrogates have some leeway in following their advance directives. Other studies report that discussions regarding EOL care often do not include specific treatment preferences (Hines et al., 2001; McDonald et al., 2003) and may occur only in casual conversations (High & Turner, 1987).

Since the 1991 enactment of the Patient Self-Determination Act (PSDA), which requires health care institutions to inform patients of their right to prepare an advance directive, efforts to increase the use of advance directives have had mixed results. Teno et al. (1997) found that

the overall rates of advance directive use did not change either after the initiation of the PSDA or in the intervention group of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). The SUPPORT study also showed that most advance directives provide little specific direction to guide patients' treatments in hospital, since only 13% had instructions beyond naming a proxy decision-maker or stating preferences of a standard living will (Teno, Licks et al., 1997). Hammes and Rooney (1998) examined the use of advance directives to determine the effectiveness of a two-year advance directive education program in a defined geographic area of Wisconsin. Prior to the intervention, an estimated 15% of the population had an advance directive. Over an 11-month period following the intervention, 85% of all decedents had an advance directive, most of which were used to appoint a health care agent, with only 10% including health care instructions.

Interventions seeking to increase communication between patients and potential surrogates regarding EOL care wishes have also had mixed findings. For example, in a randomized trial to determine whether instructional directives improved the accuracy of surrogate decisions, Ditto et al. (2001) found that, while none of their interventions improved surrogates' accuracy, the discussion interventions improved perceived surrogate understanding and comfort in making medical decisions for those without an advance directive prior to the study. Conversely, in a randomized trial to examine the efficacy of an advance care planning intervention with geriatric patients, Schwartz (2002) found greater congruence between patients and their health care agents in the intervention group than in the controls in understanding patients' EOL care preferences. In another randomized trial, Gutheil and Heyman (2005) found that educational and support group sessions significantly improved communication between older adults and their health care agents but did not increase their comfort level with EOL care planning.

Few studies have examined the perspectives of surrogate decision-makers for individuals with dementia. Using focus group discussions with family members of nursing home patients with dementia, Gessert and colleagues found that, while most families had formal advance directives or informal knowledge of their relatives' wishes, these prior communications were only modestly helpful in EOL decision-making because they lacked the specificity needed to address clinical situations or families had difficulty interpreting and applying the sentiments expressed by the individuals (Gessert, Mosier, Brown, & Frey, 2000). A further analysis of the same study revealed that even when documents were available participants were not sure they would follow the directives closely (Forbes, Bern-Klug, & Gessert, 2000). At the same time, the values and goals participants identified were so broad that they provided little guidance for decision-making. More recently, investigators used semi-structured interviews with family members of patients with advanced dementia to identify the standards (i.e., substituted judgment, best interest) they used for decision-making (Hirschman, Kapo, & Karlawish, 2006). A small majority reported using only the best interest standard, most often because they had no knowledge of their relative's healthcare preferences. The most commonly reported reason for why they did not have prior discussions with relatives about their healthcare wishes was that it was "too late" because the patient was no longer capable of participating.

The purpose of the current study was to determine how surrogate decision-makers for nursing home patients with advanced dementia developed their understanding of patients' treatment preferences, what those preferences were, and how confidently the surrogates held their beliefs about patients' wishes for EOL care. This study also identifies surrogate-reported factors that either impeded or motivated individuals to express their treatment preferences and suggests opportunities for health care providers to encourage and support advance care planning.

Design and Methods

Since little is known about how surrogates engage in decision-making for dementia patients near the end of life, qualitative descriptive methods (Sandelowski, 2000) were used as part of a larger project—the Care of Nursing Home Residents with Advance Dementia (CareAD) study—involving patients at three Maryland nursing homes who met hospice criteria for dementia and their surrogate decision-makers. The CareAD study was designed to document, both quantitatively and qualitatively, the management of patients' chronic and acute health problems during their final months of life and the experiences of their surrogate decision-makers. A total of 125 patients and their surrogates were enrolled from December 2000 through August 2003 and followed while the patients lived at the nursing home or until the study ended in August 2004. The recruitment and enrollment process for the CareAD study is described in detail in an earlier report (Black et al., 2006).

Institutional review boards at the Johns Hopkins School of Medicine and the University of Maryland reviewed and approved all study procedures. Written informed consent was obtained from all surrogates who agreed to participate, and proxy consent was obtained from legally authorized representatives of all patients who assented or did not object to participation, except for one patient assessed as being capable of providing informed consent.

Sample Selection

A purposive sub-sample of surrogates enrolled in the CareAD study was recruited for the qualitative component of the project. Sample selection was based on an a priori decision to seek phenomenal variation (Sandelowski, 1995) that would provide coverage of factors likely to be important to the process of decision-making. Participants were selected to represent the three nursing homes, both sexes, a mix of whites and non-whites and different types of decisions-makers (i.e., spouses, adult children, other relatives, non-relatives). Once these characteristics were adequately accounted for during recruitment, the sub-sample was limited to a size that, from a practical perspective, could be followed over an extended period of time in order to ensure that the quantity of qualitative data was manageable yet the study questions were saturated (i.e., no new information was found by adding new cases) (Creswell, 1998). Of the 38 surrogates asked to participate in the qualitative component of the CareAD study, 35 agreed and signed an additional consent form.

Data Collection

Semi-structured field guides were used for interviewing surrogates at enrollment (i.e., baseline) and once every 3–5 months thereafter, including a final interview following the patient's death or at the end of the study if the patient was still living at the nursing home. The guides were developed with the overall goal of determining how surrogates make decisions for patients near the end of life. In baseline interviews, surrogates were asked to describe: (1) the patient's course of illness, (2) the process of any formal or informal advance care planning (including catalysts for and barriers to planning) for EOL care, (3) their knowledge of any advance directive documents, (4) their understanding of the patient's prior wishes for EOL care, (5) the patient's most recent health problems, and (6) how treatment decisions were made for those problems. Each follow-up interview focused on the patient's health since the previous interview and how any health care decisions had been made. In the final interview following the patient's death, surrogates were encouraged to describe the events leading up to the patient's death and how any final health care decisions were made. Over the course of the study, the interview guides were modified to address newly emerging issues, such as patients' quality of life and the role of religious or spiritual beliefs in surrogates' decision-making.

Patients' medical records were reviewed to identify whether any advance directives were present and, if so, what type of documents they were. In Maryland, advance directives can be: (1) a living will that addresses an individual's treatment preferences, (2) a durable power of attorney for health care that designates a health care agent, or (3) a document that both designates a health care agent and specifies treatment preferences. If a patient had completed any of these documents, they are included by policy in their medical chart. We have previously reported that 66% of all patients who participated in the CareAD study had an advance directive in their medical charts (Triplett et al., 2008).

Interviews were conducted at a time and place of the surrogate's choosing by one of three investigators (BSB, LAF, HP), each of whom followed 9–14 surrogates over the course of the study, completing a total of 140 in-depth interviews. While the content of each interview was determined primarily by the field guide, interviewers followed-up on issues discussed in previous interviews to verify their understanding of events, determine outcomes of prior decisions, and pursue newly emerging relevant issues raised by the surrogates. Interviews were audio taped and transcribed verbatim.

Data Analysis

Analysis was an iterative process in which the three investigators began by reading and verifying the transcripts of their own interviews. Interviewers created a summary of each case they followed to summarize information across interviews into one brief document, highlighting key quotes and noting similarities with other cases and unique contributions of each case. They read the transcripts and summaries of all cases and met regularly to discuss their findings. Based on their discussions, case summaries were revised and field guides were modified as needed to examine emerging issues. Over the course of the study, summaries were updated as follow-up and final interviews were completed.

Transcript data were coded and segmented with the aid of QSR NUD*IST, Version 4 (1997) qualitative data software. Codes were created initially to answer central study questions, a codebook was developed containing code definitions and examples from the transcripts, and additional codes were added as new themes were identified. Transcripts were coded independently by two coders and any discrepancies were resolved by consensus until acceptable inter-coder agreement was achieved (90% agreement).

Data for this report were derived primarily from baseline interviews. Because the tape of one surrogate's baseline interview was damaged, data from 34 cases were analyzed. The three investigators read all relevant coded text, noted and discussed relevant themes, identified quotes representing common or noteworthy responses, summarized themes emerging from the text, and then re-read the transcripts to verify that quotes were representative of the context. Tables that identified major themes and sub-themes related to the content of this report were used to document the analysis. The team met frequently to discuss their findings, verified their interpretations by re-immersion in the data and met with the other study investigators for peer-debriefing and to discuss implications of their findings. Consensus was reached regarding minor adjustments to the categorization of some data, and a model was created to describe how surrogates developed an understanding of patients' EOL care wishes.

Results

Participants' Characteristics

Of the 34 cases in this sample, most of the patients were white (79%) and half were female (50%). Patients' mean age was 81 (range, 68 to 95), and their symptoms of dementia had been present for an average of seven years (range, 1 to 27). The majority of their surrogate decision-

makers were female (79%) and white (76%). Surrogates' average age was 61 (range, 37 to 79), and they had completed an average of 15 years (range, 12 to 20) of education. Among the surrogates, 38% were patients' children, 35% were spouses and 27% had other relationships to the patients, including sister (1), sister-in-law (1), friend (3) and public guardian (3).

How Surrogates Developed an Understanding of Patients' EOL Care Wishes

The surrogate decision-makers in this study described multiple paths by which they developed their understanding of patients' prior wishes for EOL care. Figure 1 shows some of the common elements that determined *whether, how* and *what* surrogates knew about patients' preferences. This model includes: (1) factors that influenced whether an individual expressed their preferences for EOL care, (2) sources of information from which surrogates obtained their understanding of patients' wishes, and (3) what surrogates understood patients' wishes for EOL care to be. Each of these elements is described below.

Influencing Factors—While the majority of surrogates reported that the patient had either completed an advance care directive (59%), discussed their wishes for EOL care (56%), or done both (38%), other surrogates (24%) had neither of these sources on which to rely. Surrogate-reported factors that influenced whether patients had expressed their wishes for EOL care in some way included factors that were both intrinsic and extrinsic to the patient and often involved multiple factors. Surrogates described catalysts for and barriers to both creating advance directives and discussing EOL care preferences.

Catalysts for creating advance directives: Seventeen surrogates provided information about catalysts for executing an advance care directive (ACD). Patients often developed their ACD with others (frequently the surrogate), were encouraged by others to document their wishes formally, or were motivated by life events to do so. In some cases (n=6) the patients' failing health led to developing documents. For example, one surrogate described how the patient's progressively declining health eventually led to creating the document, but only when the surrogate was emotionally prepared.

Surrogate: Well, I knew I had to do it. I procrastinated for a couple of years about it, because I just couldn't, I couldn't deal with it, emotionally. It was something I knew we had to do, and I knew we had to do it before he got too sick, so that he could sign all the papers, and I just, I couldn't deal with it for a while. So, when I finally got it together, it was a good thing I did, because we were right on the verge there, of being at a point where that would have, a doctor might not have been comfortable signing the paper.

In other cases (n=6), the patient had been encouraged by others (e.g., health care provider, lawyer, accountant) to develop an ACD.

Surrogate: So Daddy talked to his doctor and told his doctor he did not want to be on life support. And his doctor told him it's very well to say that but it has to, we have to document it in case something happens. So it was documented with his doctor that he did not want to be on life support system.

Sometimes (n=5) the illness or death of others led patients or surrogates to initiate document preparation.

Surrogate: She did the living will all by herself, as I said, with some neighbors, two neighbors. They exchanged them. Basically, she did it for them and that was done before she ever got anything like symptoms for this. I think that was probably instigated by her brother's death.

One surrogate described how the patient's observation of the effect of end-of-life care on others led her to make her final wishes known and to create the document.

Interviewer: Can you tell me why she decided to make those? Was there some event or...?

Surrogate: I think, she has seen family members just suffer, friends, neighbors, and she just basically said, "I do not want to be kept alive artificially."

Sometimes documents were developed because it seemed like "the right time," or the patient valued planning. Many surrogates stated that documents were created to help others make difficult final decisions in accordance with patients' wishes.

Surrogate: Because we did it long ago, knowing that some day we were going to reach this stage, and that while we were the ones who were capable and able at the time, we should be the ones to make the decisions. Not wait until there was an emergency, or not wait until both of us were so senile, that we didn't know what in the heck was going on, so the decisions were made when he was still able.

Barriers to creating advance care directives: Based on responses of seven surrogates who had no formal documents on which to base medical decision-making, the reason some patients did not develop an ACD was because they were reluctant to discuss such matters and preferred to leave the decision to others.

Interviewer: Okay, I want to know if your father had any formal care plans, any arrangements...

Surrogate: No.

Interviewer: ...about things like advanced directives...

Surrogate: Nothing.

Interviewer: ...advanced care planning?

Surrogate: Nothing. Zero. There's no point going down the list. Nothing....every person we've ever encountered, every medical person says, "Oh, [Patient]." They might as well save their breath. He went to the lawyer, and the lawyer tried to get him to do all this. "No, let them figure it out." I think he can't face his own mortality, is what it is.

Others simply never thought about such matters or deferred to others.

Interviewer: Did your mom ever have any kind of formal arrangements made?

Surrogate: No, I think my mom really depended on my father to a large extent. And there weren't, there was nothing like that, there was nothing like that. It was sort of like, she just never thought in those terms, she never thought in those terms.

According to some surrogates, the patient did not view it as important or necessary to create formal EOL care planning documents.

Surrogate: No, my mother, before she became, before she regressed at that further she knew I would take care of it. So, it was like, it was never really a decision. I guess it was agreed upon, or not agreed upon, or, I forget the word one uses. There was already known I would take care of it. She knew I would do the right thing.

Catalysts for discussing EOL care wishes: Surrogates also described a variety of factors that led to discussions with patients about EOL care preferences. Several were quite similar to those factors that led to creating an ACD. In fact, developing a living will prompted these discussions for four patients. The illness or death of someone often prompted discussions about EOL care wishes (n=7), whereas one surrogate stated that the impetus for the discussion was the patient's wanting to ensure his wishes were known.

Several surrogates (n=7) reported that it was the willingness of the patient or surrogate that allowed such discussions to happen.

Surrogate: I probably come from one of the most realistic families and we were just...we always discuss these things. We've never been where it couldn't happen to you and I think that's what probably triggered it. And then seeing other loved ones get sick and pass away and he would make a comment, "Well this is what I want. Well don't do this to me," those type of things. And that's all that you have to base it on. He may have had something in writing...I'm not sure. [Sister #1] would have it. So I'm not going to say that there's no formal documentation but I know what his wishes were as far as conversation and she would know.

Two surrogates stated that the patient was encouraged by others (in one case the surrogate) to discuss these matters and that they would likely not have been discussed otherwise.

Barriers to having EOL care discussions: When surrogates described why patients did not have EOL care discussions, the reasons were similar to those that kept patients from creating an ACD; they reflected a complex interplay among the personalities, expectations, and inclinations of both the patient and surrogate. In three cases, the patient no longer had the capacity to participate in a discussion of EOL care by the time the surrogate could initiate such a conversation.

Often EOL care planning was not discussed because of a combination of the patient's or surrogate's reluctance to discuss an unpleasant topic, lack of an easy opportunity to begin such a discussion, or a belief on the part of the surrogate, patient or both that such a discussion was not necessary. Personality characteristics or a belief structure were common barriers to such discussions. For example, four surrogates stated that patients were unwilling to talk about EOL care plans, and one patient's fear of death made the topic taboo. One son described wanting to protect his mother from the discomfort of discussing the topic.

Interviewer: Did you ever have a discussion with your mom about what she wanted, just informal discussions?

Surrogate: No, not really, because I didn't want to scare her. One time when she went to [X] Nursing Home, they wanted her to sign a paper, some sort of paper dealing with if she was going to die, just shook her up. I said, "Mom, you're not going to die... I'll make the decisions here." So she pretty well left it in my hands. She has her fear of dying.

One patient tended not to plan ahead in general and depended upon her son's acting on her behalf, and therefore did not feel the need to think about it, much less discuss it.

Surrogate: We never had the conversation, as far as, 'cause my mother never planned other than tomorrow, meaning the next day, not five, ten years out. So we never had the discussion, nor do I think she ever thought about, what happens when she cannot leave her home? Her home was her home, and she basically thought that she'd die and be carried out of there.

While being the “right” person sometimes encouraged discussions, being the “wrong” person could also inhibit them. One surrogate described how her mother’s distrust of how her financial affairs would be handled made it hard to discuss such matters.

Interviewer: And so, tell me the kinds of, have you had informal discussions with your mom ever about the kinds of medical interventions she might want to have?

Surrogate: Unfortunately, no. I mean, it was hard, I would say hard, but not difficult because there were issues with us, just hard for us to even talk about the will and me doing the right thing by my sister.... But we never talked about physical things which, I wish I had thought of when she first got her hips done.

Sources of Information—As noted, surrogates’ primary sources for understanding patients’ prior wishes for EOL care were formal advance directives and informal discussions. In addition, surrogates also relied on other, more indirect ways of knowing what patients’ EOL care wishes were.

Surrogates’ reports of advance care directives: Twenty surrogates reported that patients had completed an ACD, 12 said patients had not, one was uncertain and one surrogate’s report was unclear. Of those reported to have an ACD, 12 had both a living will and a durable power of attorney for health care, three had only a living will, three were reported to have an ACD without the type specified, and two were said to have documents that included treatment preferences. There was wide variability in *when* and *how* these documents were prepared. According to the surrogates, many patients had thoroughly planned for their future medical care by preparing all the necessary documents to ensure their wishes would be known. For example, one surrogate said:

She even did have the foresight to do that ...she has a living will, power of attorney, medical power of attorney, last will and testament. In fact, she and her husband had also decided, again prior to my coming into the picture, to have their bodies donated to science.... So she did quite a bit of planning on her own and then I did a few more documents and planning with her.

For the majority of patients reported to have an ACD, it was clear that these documents had been drawn up while patients were fully capable of doing so. However, in four cases patients signed their ACD when cognitively impaired and decisional capacity, as judged by surrogates, was questionable.

Surrogate: The only thing he did was sign a living will. He also signed, and I think it was one of the last things he signed, a power of attorney. They were the last decisions he made. But, you know, when you can’t, he did write his name then, but right after that, he couldn’t write his name and, he’s just in another world.

In one additional case, when documents were finally drawn up, it was too late for the patient to sign his name.

Surrogate: We were doing the living will but we didn’t get the living will completed because by the time that we got to the lawyer to do the living will, we sat there in the lawyer’s office for about an hour and he explained everything to my husband. My husband said, “Yes.” But by the time he got that completed to get him to sign the papers my husband couldn’t even get his name written.

Advance care directives in medical records: When patients’ medical records were examined to determine if an ACD was available at the facility, we found a moderate degree of agreement

between surrogates' reports and the chart reviews. Documents were found in charts for 21 patients (see Table 1). Of these, surrogates were aware of 17. Three of the 20 documents reported by surrogates to exist were not found in the charts. However, three documents were found for patients whose surrogates said there was no document and for one case in which the surrogate's report was unclear. Nineteen of the 21 documents found in the charts included treatment preferences for EOL care.

Discussions of EOL care wishes: Nineteen surrogates reported having discussed EOL care plans with patients. In several cases (n=5) these discussions occurred frequently over years and led to a clarity and understanding of patients' wishes, as in the example below.

Surrogate: Well, she was never a person that wanted to, if it was her time, she wants to go. Like, "Don't keep me here. Don't hook me up, no feeding, tube feeding." She would always say this. Even when she was younger she'd say, "I don't know why people do that." So, it was, I know how she would want to go when the time comes and if it's her time, let her go. No, we always talked about different things like that.

In other cases, discussions happened once or twice and never again. For example, one patient's wife stated that the only time the topic was discussed was decades earlier when they were newlyweds. At that time her husband said,

"Don't ever hook me up, [Wife]." But it was just a figure of speech then. Whoever thought, he was only, I was eighteen. [Patient] was twenty when I got married, and who would have ever thought he would wind up like this.

Other ways of knowing EOL care wishes: Surrogates described using many sources upon which to base their impression of patients' wishes for EOL care. These included not only an ACD and informal discussions, but other ways of knowing patients' preferences, accumulated over time, including the values they expressed, the way they lived, and the decisions they made in other health-related contexts. In some cases these "other ways of knowing" were surrogates' only available sources for understanding patients' preferences.

Five surrogates, who had neither an ACD nor previous discussions on which to rely, reported having a clear understanding of what the patient would want based on their knowledge of that person from living with or knowing them over time. For example, one wife who never discussed these issues with her husband believed she understood his wishes.

Surrogate: After you're married so many years, you just know.

Interviewer: What is your understanding of what your husband wants now?

Surrogate: Exactly what I have decided...that he wants to be made comfortable and not to prolong this life, because it isn't much of a life.

One surrogate who never discussed these issues with her mother deduced her mother's values from observing her behaviors and planned to use that as a guide for making EOL care decisions for her.

Surrogate: Well, based on knowing her, I know, well, my mother had somewhat retired. She still was involved with the church. She would get involved with neighbors, if they needed rides to stores or take them to lunch, or, that was their way of paying her back sometime, by taking her to lunch, and other relatives have gone on and how my mother came to visit them and I suspect, what I gathered from that is that it was more the quality of life than the quantity.

Other surrogates used information gathered from friends who had had relevant conversations with the patient to inform their decisions.

Interviewer: What were his wishes in terms of how he wanted to be cared for, when he could no longer make those decisions?

Surrogate: He wanted somebody to shoot him.

Interviewer: Somebody to shoot him, was he quite serious?

Surrogate: He told friends that. He never said that to me, but he told family members and friends, “If I ever get like that, kill me. I don’t want to be there. I don’t want to do that.”

Finally, the daughter of one patient expressed the difficulty of making correct final decisions without an ACD or prior discussions but felt she could rely on her clear sense of who her mother was as a person.

Surrogate: At times it’s hard because you want to make sure you’re making the right decision. But, I feel like, if she trusted me with this, and I know the kind of person she is, then, I feel like, if I make a decision for her, I know what she wants in life, or in death, so, I feel like I’m just doing what she would want me to do for her because she can’t do it anymore for herself.

Understanding of Patients’ Prior Wishes—Surrogates’ understanding of patients’ prior wishes ranged from being very specific to vague or, in a few cases, they had no knowledge at all of the patient’s preferences. The most common wish reported by surrogates was that the patient did *not* want to be kept alive by “machines” or “extraordinary measures.” Of the 23 surrogates providing a description of preferences, 15 described this wish in a variety of ways (see Table 2). The common sentiment of these statements is the desire to avoid life-sustaining interventions that do not provide restorative benefits.

Specificity of wishes: Surrogates described what they believed to be patients’ wishes for EOL care with a wide range of clarity and specificity. Nine surrogates reported what we categorized as *very specific* instructions, such as the following: no respirator, do-not-resuscitate, no CPR (cardiopulmonary resuscitation), no feeding tube, no intravenous food or water, provide nourishment or liquids, and provide oxygen for comfort. Fourteen additional surrogates provided *non-specific* descriptions of patients’ wishes, using phrases such as no extraordinary measures, no machines or equipment, not left on a machine, no artificial heroics, or no vegetable state. The remaining 11 surrogates provided no information, were uncertain, or had no knowledge of patients’ wishes. The following quotes from three surrogates illustrate the range of surrogates’ understanding of patients’ wishes, from very specific in the first statement to having no idea of the patient’s wishes, as the last brief quote illustrates.

1. **Surrogate:** He did not want to be resuscitated once a single system failed, and any regulatory, systemic failure that he had, that was the end, because his quality of life now is zero.
2. **Interviewer:** So he never, ever mentioned what kinds of medical procedures he would want if he became very ill?

Surrogate: Well, once-in-a-while he would say something. He’s not consistent. Sometimes he says, “Yeah, I want them to do everything.” And then, if he sees something on TV, he’ll say, “I don’t want that.” And then he’ll go back, “Yeah, they should try to save you.” So, they just put the whole burden on us to figure it out.

Interviewer: Okay, so there was no informal planning or formal planning at all.

Surrogate: Uh-uh [negative].

Interviewer: And what is your understanding of what your father wants? How did you come to some understanding that helped you decide his view?

Surrogate: Well, I'm still in a quandary over that, to tell you the truth.

3. **Surrogate:** I haven't a clue.

Table 3 shows the relationship between the sources of information available to surrogates in developing an understanding of patients' wishes and the specificity with which surrogates reported those wishes. While our numbers are small, it is worth noting that surrogates who reported having both an ACD and discussions about EOL care tended to be more specific in their description of patients' final wishes.

Surrogates' confidence in knowing patients' prior wishes: The majority of surrogates (n=24), regardless of the source of their information, conveyed a sense of confidence in knowing patients' wishes for EOL care. Whether their knowledge about what patients wanted was very specific or more general, surrogates often expressed their understanding emphatically. In many cases, patients' most strongly held wishes, as expressed by the surrogate, centered on not wanting to be kept alive only by machines.

Surrogate: He never wanted, I mean, anything that would put him in a vegetable state, he's never wanted that. That has never been his desire, but he's always, like I said before, he didn't want to be put on a machine just to stay alive.

Some surrogates also expressed with certainty patients' preferences regarding the use of feeding tubes. Most of those who discussed this issue reported that the patient would not wish to have this intervention. "No, he wants none of that; none, absolutely no extra activities to keep him alive. If he can't eat, he doesn't want to be stomach fed or anything like this, no heroics, nothing."

For some, surrogates' confidence in knowing patients' wishes for EOL care was based in part or entirely on having shared values over years of married life together.

Surrogate: Yes, that was discussed and I believe that is actually written in our medical power of attorney stuff, that neither one of the two of us wanted that. And we did not want to be resuscitated, nor did we want to be held for five years on artificial nourishments and things like that. That well, we both felt that someday you're going to die, so why not go gracefully?

Discussion

This study of a small sample of surrogate decision-makers for nursing home patients with advanced dementia identified multiple paths by which surrogates develop an understanding of patients' prior wishes for EOL care. Both intrinsic and extrinsic factors influence *whether* individuals express their preferences for how EOL care decisions should be made, and often multiple factors influence *when* and *how* individuals convey their preferences.

Intrinsic catalysts to expressing EOL care wishes include individuals' inclination to discuss these issues and plan ahead, the wish to provide direction for surrogates and health care providers, and the desire to shield surrogates from some of the burdens of difficult decisions. *When* preferences are expressed is often influenced by extrinsic factors including significant events, such as the patient's declining health, the death of a relative or acquaintance, or by the encouragement of others. For some, catalysts do not occur until the person with dementia is unable or minimally able to express or document their preferences. These findings and those

of Hirschman et al. (2006) highlight the importance of finding opportune moments to raise these issues with older adults early on when they have the cognitive capacity to engage meaningfully in informal or formal advance care planning. Individuals who can serve to motivate older adults to address EOL care issues include family members, friends, health care providers, attorneys and other professionals.

In this study, patients' preferences regarding EOL care were commonly expressed in both formal advance directives and informal discussions. Sometimes, one of these approaches (i.e., creating documents or having discussions) led to the other, and this combined approach often provided greater specificity of the patient's preferences. This suggests that a combination of approaches, either separately or in tandem is most helpful to many surrogates' understanding of patients' desires. Thus, future efforts to improve the rates of expressing wishes for EOL care might first examine the patient's preferences for *how* they would like to communicate them, that is, through a formal document, through conversation or both.

While surrogates' understanding of patients' wishes for EOL care ranged from very specific treatment preferences to having no knowledge of what the individual wanted, most surrogates who had some idea of patients' preferences expressed confidence in understanding the individual's wishes. However, many surrogates (41%) in this study reported only non-specific patient wishes, a finding supported by Hawkins et al. (2005) who found that many older adults do not wish to "micromanage" EOL treatment decision-making, preferring instead to express general preferences (e.g., values, goals of care) and to allow surrogates leeway in decision-making. In the total CareAD study sample, with the exception of requests for comfort care and pain treatment, advance directives primarily restricted, not requested, many forms of care at the end of life (Triplett et al., 2008). In this sub-sample, the most commonly understood preference for EOL care was the desire *not* to be kept alive by "machines" or "extraordinary measures." If that is a strongly held value, patients should be encouraged to document their preferences to avoid undesired treatments.

Few patients in this sample engaged in several widely advocated approaches to advance care planning (ACP). Advocates of ACP describe it as a process that is part of preventive health care (Bomba, 2005; Emanuel, Danis, Pearlman, & Singer, 1995). For example, Bomba (2005) outlines five components of ACP, including: (1) becoming educated about the topic, including the documents, the process and its benefits, (2) exploring, clarifying and documenting the individual's values, beliefs, goals of care and expectations, (3) understanding how to choose a substitute decision-maker and discussing preferences with that individual and others (e.g., family, physician, attorney, spiritual advisor) as needed, (4) understanding various life-sustaining treatments beyond CPR, and (5) maintaining document accessibility and periodically reviewing and updating the documents.

Our results suggest that Bomba's approach is more comprehensive than was used by CareAD study participants. Whether that is because it was not available or not acceptable to the study participants cannot be ascertained, but these results suggest that such approaches may be too high a standard for some individuals. Nonetheless, studies have demonstrated that educational interventions can significantly increase discussions of EOL care wishes (Gutheil & Heyman, 2005) and increase use of advance directives (Hammes & Rooney, 1998). Programs to increase ACP have also proven effective in nursing homes (Caplan, Meller, Squires, Chan, & Willett, 2006; Molloy et al., 2000). We believe that interventions tailored to the desires of individuals may be more successful than a single approach applied to all individuals. Health care providers can facilitate and encourage ACP with dementia patients and those who will become their surrogate decision-makers. Providers who initiate such conversations may be able to help "normalize" discussions of dying to aid in overcoming emotional barriers to ACP, assist

individuals in clarifying goals for EOL care, and provide information to support treatment decisions (Gessert, Forbes, & Bern-Klug, 2001).

Some individuals, however, appear to have no desire to consider or discuss the eventualities of their death or to provide guidance for surrogates. These individuals may have a history of relying on others for decision-making, trust the judgments of those likely to be their surrogates, or assume their wishes for EOL care are known to those who will decide for them. In qualitative interviews, Rodriquez and Young (2006) found that older adults who they described as having an internal locus of control were more likely to have completed an ACD than those with a more external locus of control. They suggested that individuals who held both internal and external control beliefs were more likely to engage in ACP than those with only beliefs in external controls. Since patients do not value autonomy equally (Winzelberg, Hanson, & Tulskey, 2005), respect for the person in some cases may involve respecting an individual's preference not to choose how their EOL care decisions will be made.

One limitation of this study is that those with dementia who participated in the CareAD study were too cognitively impaired to be interviewed to determine whether surrogates' reports accurately reflect the patients' wishes for EOL care. Since surrogate decision-makers are sometimes inaccurate in predicting patients' treatment preferences (Shalowitz et al., 2006), some CareAD surrogates may have been mistaken in their understanding of patients' wishes. Surrogate judgments can be biased by their own treatment preferences and projections may be more likely to occur when surrogates are predicting for loved ones in long-term, close relationships (Fagerlin, Ditto, Danks, Houts, & Smucker, 2001).

Prospective data from the CareAD study will be examined in future reports to determine how surrogates use their understanding of patients' wishes for EOL care when actual treatment choices are made and what role advance directives play in their decision-making. While advance care planning cannot relieve all burdens that surrogates bear when making EOL care decisions, it may provide some comfort if their decisions are in keeping with the patients' prior wishes (Chambers-Evans & Carnevale, 2005). The method of learning patients' preferences also has to be in keeping with the individual's culture, nature and ability to engage in a process of advance care planning.

Acknowledgments

The National Institute of Neurological Disorders and Stroke, grant #NS39810, funded this study. Drs. Black, Finucane, Blass and Rabins are also affiliated with the Johns Hopkins Berman Institute of Bioethics. The authors wish to thank Kathryn Hicks for her assistance with this project. They are especially grateful to the study participants, the participating nursing homes and their staff who made this study possible.

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Figure 1.

A Model of How Surrogate Decision-Makers Develop an Understanding of Dementia Patients' End-of-life Care Wishes

^a DPA – Durable power of attorney

^b CPR – Cardiopulmonary resuscitation

Table 1

Correspondence Between Advance Directive Documents Reported by Surrogates and Advance Directive Documents Found in Medical Records

Advance Directive Documents Reported by Surrogates	Advance Directive Documents Found in Medical Records		
	Yes	No	Total
Yes	17	3	20
No	3	9	12
Uncertain/Unclear	1	1	2
Total	21	13	34

Table 2

Surrogates' Reports of Patients' Most Common Wish to Not Be Kept Alive by "Machines" or "Extraordinary Measures"

-
- Not on a machine just to stay alive
 - No life suspension
 - No keeping alive with machines
 - Not prolong this life
 - If we ever got terminal, don't hook us up to anything
 - We don't want life extended by artificial means
 - No advance life support
 - "I wouldn't want to be kept alive by a machine"
 - Not on any type of machinery to keep her alive; "I don't want to be kept alive artificially"
 - She wouldn't want to be hooked up to any system to keep her
 - Absolutely no extra activities to keep him alive
 - No life support
 - If it's her time she wants to go. "Don't keep me here. Don't hook me up."
 - Didn't want to be on no support thing, like something to keep her living
 - Didn't want to be held for 5 years on artificial nourishment
-

Table 3

Specificity of Patients' Wishes by Source of Information

Source of Information	Specificity of Patients' Wishes Based on Surrogates' Understanding			Total
	Very Specific	Not Specific	Unclear / Unknown	
Document and Discussion	7	5	1	13
Discussion Only	2	3	1	6
Document Only	0	3	4	7
No Document or Discussion	0	3	5	8
Total	9	14	11	34