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Identifying the Factors That Facilitate or Hinder Advance Planning by Persons With Dementia

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Abstract

We performed semistructured interviews with 30 family members of patients with advanced dementia to identify the factors that facilitate or hinder advance planning by persons with dementia. All interviews were analyzed using qualitative data analysis techniques. The majority (77%) of family members reported that their relative had some form of written advance directive, and at least half reported previous discussions about health care preferences (57%), living situation or placement issues (50%), and finances or estate planning (60%) with the patient. Family members reported some themes that prompted planning and others that were barriers to planning. Events that most often triggered planning were medical, living situation, or financial issues associated with a friend or family member of the patient (57%). Barriers to planning included both passive and active avoidance. The most common form of passive avoidance was not realizing the importance of planning until it was too late to have the discussion (63%). The most common form of active avoidance was avoiding the discussion (53%). These data suggest potentially remediable strategies to address barriers to advance planning discussions.

Keywords

advance care planning; Alzheimer disease; decision making; advance directives

In the United States, policy makers, health professionals, and patient advocacy groups have promoted the process of advance care planning, that is, planning for future medical care in the event that a person is unable to make his or her own decisions at the end of life. Advance care planning allows persons with chronic and ultimately fatal illnesses to convey preferences to guide decisions when they cannot speak for themselves.^{1,2} However, many people do not

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engage in advance care planning discussions, which results in documents such as a living will. A common reason for this is that they do not perceive advance care planning as sufficiently urgent.^{1,3-6}

But advance care planning has a plausible value for at least 1 group of persons. Unlike persons suffering from other chronic diseases of adulthood, patients with dementia experience a period during which they can participate in decisions followed by several years when they cannot make decisions,⁷ requiring others, often family members, to make decisions for them.^{8,9} These decisions include difficult end-of-life choices,^{10,11} but for several years before death they will also include day-to-day decisions about their care and daily living.¹²

One way to achieve patient-centered care and maintain patient autonomy for patients with dementia is to elicit their health care values and preferences before they lose their ability to state those preferences. In the early stage of dementia, the patient has a plausible window of time to talk with family about what goals and values should inform a range of future decisions. Without these discussions, families are left struggling to make decisions about nursing home placement^{13,14} and end-of-life care^{2,15-17} without the guidance of the patients' preferences.¹⁸ The prevalence of this problem is likely to increase by the year 2050 when the number of persons with dementia in the United States is estimated to reach 11 to 16 million.¹⁹

Although, advance care planning is appealing for dementia patients and their family members, little is known about the strategies that can facilitate advance care planning discussions or about the reasons why people do not have these discussions. Understanding these strategies and reasons is crucial to fostering advance care planning. Therefore, the goals for this study were to explore what types of planning dementia patients and their family members do to identify ways to help patients and themselves plan for the future.

Methods

Design

We used a semistructured interview format with the family members of patients in the advanced stages of dementia to examine in depth their experiences in planning for the future with their relative.

Participants

To study the families of patients with dementia with a range of experiences and knowledge about Alzheimer disease and other dementias, we used purposive sampling to recruit subjects from 2 locations. The first group was recruited from the Alzheimer's Disease Center (ADC) at the University of Pennsylvania where family members of patients with dementia have exposure to up-to-date knowledge about dementia as a result of participating in the ADC's PENN Memory Center. The second group comprised family members of residents at a suburban long-term care facility that had no previous experience with an ADC subspecialty clinic.

Family members were eligible to participate if their relative had advanced dementia (Mini Mental State Examination score < 12, which is the standard cut point for severe dementia) and either a diagnosis of Alzheimer disease²⁰ or dementia (as defined by DRG code 290.0). In addition, the family members had to self-identify as the primary contact, responsible party, and/or caregiver for the patient to be eligible. Finally, all family members needed to indicate that they made final medical care decisions for the patient to be considered the patient's surrogate decision maker.

All family members were recruited by letter by the principal investigator (K.B.H.) or the social worker at the long-term care facility. Details on the recruitment process are published

elsewhere.¹⁸ The overall response rate on the basis of those family members who were reached over the phone was 88%. One investigator (K.B.H.) conducted the interview either in the family member's home or over the phone on the basis of the preference of the family member. Participants were compensated \$15 in the form of cash or a gift certificate.

Data Collection

The interview guide included open-ended questions about difficult decisions made in the past 6 months: whether the participant used substituted judgment to make medical decisions for the patient¹⁸; past advance planning discussions (including health care, living situation, and financial planning); and written advance directives. Only data on past advance planning discussions and written advance directives are discussed here.¹⁸

Advance Planning Discussions

Family members were asked to describe any discussions they had had with the patient about health care preferences, living situation preferences, and financial planning preferences [eg, Did you ever discuss with your relative (his/her) preferences or values or plans about the kinds of *health care* (he/she) would want if (he/she) became unable to make (his/her) own health care decisions?] Family members were also offered the opportunity to talk about other types of discussions that they recalled and that did not fit into the above 3 categories. Family members who reported prior discussions about preferences were asked to describe what prompted the discussion, the content of what was discussed, who was involved in the discussion, barriers to having the discussion, and whether they would do anything differently if they could go back and do it again. Family members who did not have these discussions were asked why they thought the discussion did not occur before the progression of their relative's dementia, what barriers they perceived to having the discussions, and what they thought they could have done differently.

Written Directives

Family members were asked to report if their relatives had any written advance planning documents, such as a living will or a durable power of attorney (POA). Definitions of these documents were provided and probe questions were used to explore the process that took place to complete these documents (eg, when?, why?, what prompted the signing of these documents?) or why a document or documents were not created. Family members were also asked to report if any written directives regarding finances or other property, such as a will, or a financial POA, had been put together by the patient.

Patient and Caregiver Demographics

The family member provided information on his or her own and the patient's age, education, race, and relationship to patient and caregiver employment status and finances. These data are presented primarily as descriptive information about the sample.

Interviews took approximately 45 minutes. Data collection and analyses were conducted using the technique of theoretical saturation, meaning that interviews were conducted until no new categories or themes were uncovered in the data.²¹ Interviews were first completed with the ADC subjects, and theoretical saturation was reached within 10 subjects. Five additional subjects were added from the ADC group to confirm saturation. The same procedure and outcome was reached with the nursing home family members. All interviews were audio taped and transcribed verbatim for analysis while data were being collected.

Data Analyses

Qualitative and quantitative methods were used to analyze these data. Data were coded by an interdisciplinary team of one social worker (K.B.H.) and 2 physicians (J.M.K. and J.H.K.) with expertise in geriatrics and ethics. Detailed coding procedures are presented at length.¹⁸ On the basis of techniques developed by Strauss and Corbin,²² a multistep procedure of breaking down, examining, comparing, and conceptualizing the data was used, and a final set of codes was developed on the basis of the themes and categories that emerged (Fig. 1). Finally, all transcripts were reviewed again using the final set of codes. Agreement on codes ranged from 87% to 100% with κ ranging from 0.71 to 1.00. The panel of coders resolved all disagreements through consensus agreement. Percentages do not add up to 100% because themes could emerge in multiple areas of the interview and were coded accordingly. QSR*NUDIST, a qualitative data analysis package, which allows for handling data that are relatively unstructured, was used to organize the data analyses (N6. Melbourne, Australia: QSR International Proprietary Ltd).

Demographic data collected from the interviews were entered into Stata, a statistical software package (Intercooled Stata 8.0 for Windows. College Station, TX: College Station). Data on advance directives and other formal documents were coded as yes, had a document (= 1) and no or unsure if patient has document (= 0). We used Fisher exact and Wilcoxon rank-sum tests to determine associations between variables. Frequency counts and distributions for all data are presented.

Human Subjects' Protections

Family members provided verbal informed consent to participate in this research, which was approved by the University of Pennsylvania Institutional Review Board.

Results

Family Member and Patient Characteristics

Fifteen family members from each site participated in this study ($n = 30$). Family members were on average 64.3 years old, female (16/30; 53%), had a college degree or higher (17/30; 56%), white (27/30; 90%), and were predominantly spouses or adult children of the patient (13/30; 43%, each) (Table 1). Patients were older than family members (mean = 80.2 y), female (25/30; 83%), and predominantly white (27/30; 90%). Only 27% (8/30) of patients had a college degree or higher. Among the 15 patients from the ADC, 7 of 15 resided in a long-term care facility or assisted living and 8 of 15 lived at home with either a spouse or adult child as their primary caregiver. Family members of patients from the ADC were almost entirely spouses (12/15) as compared with those from the suburban long-term care facility (1/15) (Fisher exact test, $P < 0.001$). Patients in the suburban long-term care facility were older (median age: 88 y) than patients seen at the ADC (median age: 73 y) (Wilcoxon rank-sum test, $P < 0.001$). Patients and family members did not differ on any other demographics or characteristics.

Do Dementia Patients Have Discussions About Their Preferences?

Family members discussed both informal conversations and formal documentation as forms of planning for the future. At least half of the family members reported previous discussions with the patient about health care preferences (57%, 17/30), living situation or nursing home placement (50%, 15/30), and finances or estate planning (60%, 18/30). Eighty-three percent (25/30) of family members report having at least 1 of these discussions, but less than one third had all 3 discussions (8/30). Fifteen family members reported that the patient had a living will and a durable POA for health care, 6 reported having just the latter, 5 reported having only a

living will, and 4 reported no written health care preference documents. Almost all of the family members (27/30, 90%) stated that the patient had some type of formal document regarding finances or property (financial will: 22/30, 73%) and/or a standard POA allowing the family member to handle the patient's personal or financial matters (POA: 25/30, 77%).

What Prompts Advance Planning for Persons With Dementia?

Common themes emerged among all 3 areas of advance planning discussions and were often interrelated. Data are presented for all themes collectively.

First, caregivers described the theme of prompting planning within which were 2: (1) active planning and (2) reactive planning (Fig. 1). Active planning involved patients or patients and their family members making an effort to “put their affairs in order.” Discussions with a lawyer or an accountant prompted slightly more than half of the sample to have these discussions (15/30; 50%). One wife stated, “...actually it was the fact that we realized that everything was in my husband's name and our attorney suggested that we change our finances so that I would be protected. So that we were able to split our assets.” Approximately one-third of the family members (n = 9/30; 30%) stated that having a discussion with a health care professional, such as a physician, nurse, or social worker, helped them to have a discussion and, in many cases, put an advance directive together.

Caregivers also described reactive planning. This involved patients reacting to an event that prompted planning. The most frequently identified event that prompted a discussion about future preferences was a medical, living situation, or financial issue associated with a friend or family member of the patient (17/30, 57%). For example, a son described how he started conversations with his mother, “(U)sually if a relative or a friend or something like that died or got sick or went through some sort of traumatic problem that's usually how it started.” Family members also explained that the experience of someone else in the family prompted having these discussions with their relative. Just slightly over one-third of the sample indicated that events with their relative, such as a medical hospitalization or change in health status or the anticipation of a change in health status prompted the discussion (11/30; 37%). For example, a wife stated why she and her husband talked about her husband's health care preferences, “... because we knew with this disease that eventually he wasn't going to be able to make decisions and somebody had to make them for him and it was I who he wanted to make them.”

Some family members reported both reactive and active planning. A wife indicated that her husband had not been well and, “...we felt that because he had been ill that perhaps we should do a living will as suggested by doctors.” In this situation, the reaction to the illness prompted the family to have the discussion but a previous suggestion from a health care professional to put together a living will also influenced how this family proceeded with advance planning.

What are the Barriers to Advance Planning for Persons With Dementia?

Caregivers identified 2 barriers to having advance planning discussions: (1) passive avoidance and (2) active avoidance. These barriers often overlapped with all 3 types of planning discussions (Fig. 1).

Passive avoidance among these family members emerged as 2 themes: (a) not recognizing the importance of advance planning until their relative's cognitive impairment had advanced so that it was too late to have the discussion and (b) never considering the need to have the discussion. Over 60% of the sample (n = 19) indicated that by the time they wanted to have an advance planning discussion, it was too late for their relative to participate. A husband stated that he felt there was, “...no sense of the need for it.” He went on to say, “It's something that can be put off, something you'll address later, you know you're busy with everything else.” A

wife when discussing why she and her husband did not have discussions about health care preferences and living situation similarly said, "It just never came up. Like I say, once we realized that we had a problem, it was too late." A daughter said, "I wish I could have had it years ago" but that it was too late by the time she chose to have the discussions with her mother.

Over half of the family members said they did not think to have the discussion with their relative (17/30). One husband stated that "...there just wasn't the perceived need for thinking about what kind of choices; you know health care choices or any kind of life care that you were going to have to make because it seemed off at some point in the future." Another husband said, "I guess you never think you're going to get that way. She was a school teacher, a very bright person, a very active person, you just, you know...my god, you never think about this stuff." When describing why they never had the conversation, a wife said, "I guess if I had to do it over again I would have made it a point to have discussed that when he was in a more cognitive state. I just never, it didn't cross my mind." Some family members also said they did not know what topics to talk about with their relative, mainly because they had no prior experience with dementia (10/30; 33%).

Three active avoidance themes emerged: (a) avoiding the discussion altogether, (b) the patient's personality being a barrier to the conversation, and (c) the patient being in denial of dementia diagnosis. Approximately half of the family members described avoiding any discussions with their relative about health care preferences, living situation, or finances (16/30; 53%). This theme emerged both as something the family member avoided and something that their relative evaded. A husband described not wanting to have a conversation about alternative living situations because he, "...was not ready at that time to admit to the possibility that (he) might not be able to take care of her." A daughter explained that her mother never wanted to talk about her health care preferences, "...she never wanted to talk about these things and you know we just kept our head in the sand." Another daughter stated, "I guess you know, its just one of those things you put on the back burner. You know what I mean? It's a subject to avoid."

Half of the sample described the patient's personality or character as a barrier to having these conversations (15/30; 50%). A daughter described her mother stating, "My mother is what I think of as the stereotypical New Englander who is very reserved and not one to talk about their emotions so there would be barriers to talking about that, that's just not something that... she would entertain easily. She's kind of stoic." In describing why she never had any advance planning discussions with her older sister, the younger sister stated that, "...she had just enough of a stubborn streak so I think she would not have liked it."

Family members talked about their relative being in denial of having a memory or thinking problem, which made it difficult to try to have these discussions (5/30; 17%). A wife stated, "...he was always in denial that he had a problem because he just figured because of age you forget things."

What Could be Done Differently?

Family members were asked what they would do differently if they could go back in time and talk to their relative when their relative could still communicate preferences. Families who had not had discussions about planning for the future often answered that they did wish they could go back and have the discussion and put documentation together. A son said in regard to his mother, "...well I would want to have a...power of attorney for one thing. I never did get power of attorney and now we're going through a whole lot of problems, because she has property, she has a house, her finances and things like that...I guess if I had to do it over again I would ask her exactly what she wanted to have done when she got older." Among family members who had talked with their relative, many said they would not do anything differently. However, these family members also said that there were additional things that they should have discussed

or “wished” they had discussed sooner with their relative such as “more specific” discussions about health care treatments (ie, feeding tube, medications) or living situations (ie, assisted living, nursing home placement).

Discussion

The aim of this study was to identify what types of planning conversations dementia patients are having with their families, what documents these patients create, and what factors facilitate or hinder planning for their future. Our data revealed that planning conversations do take place among some dementia patients and their family members but both patients and their families have barriers to planning for the future. Moreover, even family members who had conversations with their relative about future preferences would want to have had additional discussions. Limitations of this study are that the subjects were predominately white, educated, and of higher economic status. Nonetheless, we have 3 important findings.

First, the finding that family members of patients with dementia often begin discussions about health care preferences, living situations, or finances because of a specific health event such as a diagnosis of dementia, a change in the patient's health, or another life event is similar to research on advance directive completion.²³ Research with cognitively intact elders has similarly found that diagnosis, health changes, or other life events prompt the creation of advance directives.^{23,24} This opportunity for a discussion also creates potential limitations because the emotions of the event that prompted their discussion may influence what people talk about. It is possible that the patients who discussed advance planning and created advance directives suffered from comorbidities that influenced their decision to plan. Educational materials to assist people in planning for the future should recognize that these types of precipitants are often the framework within which people begin discussions. However, educational interventions alone have not been found to be as effective as when used in combination with other interventions, such as discussion sessions over multiple visits.²⁵

Second, these findings suggest several remediable barriers to having advance planning discussions, such as waiting until it was too late, not knowing what to talk about or when to talk, and avoiding the discussion. Educational materials for people with mild cognitive impairment and their families need to convey the harm of waiting to have planning discussions. For example, without planning discussions, families are left to make difficult decisions without the knowledge of what their relative would want. Also, education strategies need to provide patients and family members with a plan or guide to overcoming their reluctance to have the discussion. These documents will also need to address impairments in insight, a common problem in patients with dementia. Future research is necessary to assess methods of prompting early-stage patients to talk about planning for the future and to examine interventions to remedy the barriers to planning.

Finally, many family members identified non-health care professionals such as lawyers, accountants, and financial planners as individuals who help them plan for the future. Research has historically focused on interventions with health care professionals and patients²⁵ with mixed effectiveness on the basis of the intervention type. Educational materials designed for non-health care professionals should include information on understanding dementia and suggestions regarding ways to help people begin to have conversations about planning for the future. These non-health care professionals can play an important part in helping families begin their discussions and put together documentation to assist these families when their relative can no longer express preferences.

Some of the findings from this study may be similar to other nondementia populations. For example, among patients without dementia, the opportunity to plan may be hindered by

avoidance of planning, which is similar to the avoidance found in this population. However other findings, such as advanced cognitive impairment hindering planning, will not be common in other populations.

Having a discussion and putting together advance directives offers a way for people in the very early to early stages of dementia to express their preferences. This, in turn, can help their family members make decisions for them in the future. Our findings suggest ways to guide dementia patients, their families, health care professionals, and lawyers so as to ensure that this process occurs in a timely and productive manner.

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Themes	Categories
Prompting Planning <u>Active Planning</u> <u>Reactive Planning</u>	<ul style="list-style-type: none"> ▪ Discussions with lawyers or accountants ▪ Discussions with health professionals ▪ The impact of other people's life events ▪ Anticipation or actual changes in health status
Barriers to Planning <u>Passive avoidance</u> <u>Active avoidance</u>	<ul style="list-style-type: none"> ▪ Not recognizing the importance of timing ▪ Not considering having the discussion ▪ Avoiding the topic ▪ Denial ▪ Patient's personality

FIGURE 1.
Themes and related categories associated with advance planning.

TABLE 1

Characteristics of Patients and Caregivers (n = 30)

	Patients Mean $\pm$ SD (Range)	Caregivers Mean $\pm$ SD (Range)
Age	80.2 $\pm$ 10.3 (55-96)	64.3 $\pm$ 12.9 (42-93)
MMSE [*]	4.6 $\pm$ 3.4 (0-10)	
	N (%) [†]	N (%) [†]
Sex: female	25 (83)	16 (53)
Race: white	27 (90)	27 (90)
Education ($\geq$ college)	8 (27)	17 (56)
Married	14 (47)	26 (87)
Where patient lives		
Nursing home facility	19 (63)	
Assisted living facility	3 (10)	
With family member	8 (27)	
Relationship to patient		
Spouse		13 (43)
Child or child-in-law		13 (43)
Other family: niece/nephew		3 (10)
Other (not family): god child		1 (3)

^{*} n = 28. Some patients could not complete the MMSE.

[†] Percentages may not add up to 100% owing to rounding.

MMSE indicates Mini Mental State Examination.