Obtaining a Durable Power of Attorney for Health Care from Nursing Home Residents

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Background. A durable power of attorney for health care (DPA) allows a person to appoint a surrogate decision-maker for any future period of mental incapacity. The absence of advance directives can lead to confusion and the expenditure of resources while trying to exert a substituted judgment.

Methods. The Wisconsin DPA was presented with an organized pilot program to 150 residents who had been judged by their social workers to have the capacity to make informed decisions regarding medical care. The reasons residents gave for accepting or rejecting a DPA were analyzed.

Results. Seventy-nine percent prepared a DPA. Reasons for signing included allowing the resident to decide who would make medical decisions and assuring that specific wishes would be carried out. Twenty-one percent did not execute a DPA. Reasons were categorized as confusion and misunderstanding regarding the legal system, mistrust, or social isolation.

Conclusions. The high rate (79%) of DPA completion is probably related to individually counseling residents. However, competent residents who despite counseling do not choose to execute a DPA can have detailed advance directives ("living wills") prepared without appointing a decision-maker.

Key words. Advance directives; durable power of attorney; nursing homes.
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A living will allows an individual to specify the types of care he or she wishes to be provided if the person loses his or her decision-making capacity. Gamble and colleagues[1] found that most persons preparing a living will also wanted to appoint a family member as a surrogate decision-maker. Emanuel and colleagues[2] contend that an optimal advance directive should include a listing of preferences and designation of a proxy. An advance directive could also include statements regarding life values such as, "I want to live as long as possible, regardless of the quality of life that I experience," or "I want to preserve a good quality of life, even if this means that I may not live as long."[3]

The absence of advance directives can lead to stress, confusion, painful introspection, and expenditure of time and emotional and financial resources by both family members and health care providers who are forced to exert a substituted judgment. Attempts to predict preferred interventions have been unsuccessful.[4-6] In the absence of advance directives, a guardianship proceeding sometimes needs to be implemented for nursing home residents if there is significant disagreement among family members. This process is cumbersome and expensive,[7] and does not ensure that the appointed guardian is the decision-maker whom the patient would have wanted. In Missouri, a guardian may not or legally cannot carry out all the person's wishes without advance directives (*Cruzan v Director, Missouri Department of Health*).

Unfortunately, many nursing home residents lack the decision-making capacity to appoint a surrogate decision-maker because of the same disease states that precipitated nursing home placement. A subgroup of residents, however, often still have this capacity. Advance directives for critical health care decisions are especially

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important in nursing homes. Nursing home residents face a disproportionate burden of acute medical events over a short period. At the Wisconsin Veterans Home, 40% of residents are hospitalized within a 1-year period. The yearly mortality rate for all residents is 17%. When previously capable residents become acutely ill, they often lose their decision-making capacity.

The State of Wisconsin recently adopted legislation authorizing the appointment of a surrogate decision-maker by means of a durable power of attorney (DPA) for health care.[9] The DPA enables a competent person to designate an agent and an alternate to make critical health care decisions on that person's behalf if he or she becomes incapable of doing so. The agent may not be the person's health care provider or an employee of the health care provider or facility in which the person is a patient. The agent may not admit the person to an institution for mental diseases or consent to experimental mental health research, psychosurgery, or electroconvulsive treatment. The person may give the agent permission to order withholding or withdrawal of a feeding tube. An open section is provided in which the person designating the agent can also make a statement of any special desires, provisions, or limitations. Procedures such as cardiopulmonary resuscitation and intravenous or enteral nutrition and hydration can be addressed. This aspect of the Wisconsin DPA (what is to be done) is analogous to a living will.

In a study by Cohen-Mansfield et al,[10] most of the nursing home residents who completed a DPA reported definite preferences for or against life-sustaining measures and knew whom they wanted to make decisions for them. Gamble and co-workers[1] found that lack of communication between formal caregivers and patients and lack of knowledge were the reasons for patients not signing a living will. Overall, the actual use of advance directives has been disappointing.[11] However, recent federal legislation, the Patient Self-Determination Act of 1990,[12] may result in an increase in advance directives.

The primary objective of our pilot program was to offer the Wisconsin DPA for Health Care to our residents using a number of modalities to communicate the needed information. The program was primarily designed as a service for our residents. Many residents whose cognitive abilities have declined still retain the capacity to make some health care decisions. It is our policy to make every reasonable effort to establish an adequate degree of comprehension for an informed decision regarding medical care. This group with cognitive decline but intact capacity requires an approach adapted to individual needs.

A secondary objective was a prospective quality assurance study to improve the format of subsequent programs. Residents' responses to our program were recorded and analyzed to determine their reasons for deciding to prepare or not prepare a DPA. Data gathering was limited to the conversation that occurred during the interview in which the DPA was presented to the individual resident. Although this approach had shortcomings, we suspected that many of the residents who refused a DPA would have also refused to sign an informed consent document for a more detailed probing research study.

Methods

The Wisconsin Veterans Home is a 707-bed skilled nursing care facility. Each of the social workers in the facility selected residents on their caseload list who they felt had demonstrated the mental capacity to make informed decisions regarding medical procedures. Organic brain disease, communication dysfunction, and paranoid ideation were all considerations in determining selection, but the existence of any one of these deficits did not necessarily exclude a resident from the program. Decision-making ability was the determining factor.

All social workers at the facility were polled to determine what types of information should be provided to residents when discussing the DPA and what reasons had been given by residents who had refused to complete other medical advance directives. This information was used to formulate the reasons favoring acceptance of the DPA form. Our data-gathering techniques were piloted with 25 residents before initiating the main study.

One of the authors, a social worker (R.S.), was assigned to explain the DPA to these residents. Before meeting with individual residents, she held informational meetings for groups of residents and prepared a video tape on the DPA that was played frequently on the Veterans Home closed-circuit television channel. Residents were encouraged but not required to attend. Appointments were then made with individual residents. A DPA form was sent to the resident 1 week before the appointment. Before the meeting, R.S. consulted the resident's primary social worker regarding health care and social issues pertinent to the case and then she reviewed the patient's medical record to identify any cognitive or sensory impairments the patient had that would affect her presentation of the materials. The cognitive function of each resident had been assessed with the Mini-Mental State examination.[13] Vision and hearing had been assessed by interview. These data had been gathered by the nursing staff as part of a comprehensive resident assessment and are presented only for the purpose of characterizing the participants.

Each discussion with a resident began with the presentation of a hypothetical health scenario in which, because of coma, the resident would be unable to communicate his or her wishes regarding treatment. Without an appointed decision-maker, the resident could not be assured that the person he or she most trusted would actually make the decisions about appropriate care or that the patient's specific preferences would be carried out. The term "durable power of attorney for health care" was explained. At this point, some residents expressed their desire to execute a DPA and volunteered a reason for the decision. Others desired more discussion of the points in favor of a DPA. The points included giving the resident the power to select a health care agent; helping to ensure that one's health care wishes would be carried out; limiting the use of the DPA to the period of mental incompetence; reducing potential dissension among family members; and the option to change or revoke the DPA at any time. These points or reasons were presented in the same order to each resident. If he or she elected to prepare a DPA early in the discussion, the latter reasons were not enumerated. Some residents volunteered more than one reason. In these cases, all the reasons given were recorded as each provided insight into the patient's rationale. Since our primary purpose was to allow each individual to independently make an informed decision regarding the DPA, probing for the most important factor in the decision was considered to be unnecessarily intrusive.

If the discussion resulted in the resident's refusal to sign a DPA and the social worker was not convinced that the resident fully comprehended the situation, the resident was advised to talk to other residents who had established DPAs or to an attorney. The resident was also encouraged to talk to friends and family members about the decision not to sign a DPA. One of the authors (R.S.) met with each of these residents again 1 week later. If the resident desired, R.S. explained the DPA again and allowed further discussion. If the resident refused to assign DPA, the reason given was recorded verbatim. If residents volunteered more than one reason, all were recorded. Explanations for either accepting or rejecting the DPA were then grouped and categorized.

Results

The DPA was discussed with 150 residents (114 men and 36 women). Their average age was 75.6 years (SD = 10.8, range, 43 to 99 years). Thirty-five (23%) were married, 45 (30%) widowed, 23 (15%) divorced, and 47 (31%) had never married. One hundred fourteen residents (76%) were independent in their basic activities of daily living and another 20 (13%) required minimal supervision. Fifteen (10%) had been judged to be cognitively impaired on the basis of the Mini-Mental State examination[13] (<24 correct answers). Twenty-eight had impaired hearing and 46 had impaired vision.

Of the 150 residents counseled, 85 men and 34 women (79%) prepared a DPA. The two most frequently cited reasons for completing a DPA were to determine who would make medical decisions in the case of incapacity and to increase the likelihood that resident's health care wishes would be carried out. These two reasons, however, were also the first two points presented by the social worker in favor of the resident completing a DPA. As stated above, if at this point the resident responded by agreeing to complete the document, no other reasons were presented.

The primary health care agent appointed most often was a son or daughter (n = 42, 35%) followed by a brother or sister (n = 36, 30%). Most residents (n = 71, 60%) did not select an alternative agent, but among those who did, the first and second choices were again son or daughter and brother or sister, respectively. A majority (n = 99, 83%) gave their surrogate decision-maker the power to withhold feeding tubes.

Thirty-one residents (21%), 29 men and 2 women, refused to execute a DPA. Those who refused did not differ in age from those who executed a DPA (75.5 vs 75.6 years, respectively). A disproportionately larger number of men refused (25% of men vs 6% of women). Residents who had never married were somewhat more likely to refuse than married, widowed, or divorced residents (32% vs 16%). There was no significant association between residents signing or not signing a DPA and their cognitive, vision, or hearing status.

The reasons for refusal were categorized by similarity (Table), and closely related groups were combined to facilitate analysis. The larger categories included "confusion and misunderstanding" regarding the legal system or documents (13), "mistrust" (8), and "social isolation" (6). Confusion regarding the legal system included confusing a DPA with the living will or similar documents.

Discussion

The sample of residents counseled during this project differs from most nursing home populations. The residents in this sample were predominantly male (76%), and nearly half were divorced or had never married. However, even if our sample does not reflect the case mix of other nursing homes, any future studies of how to increase the completion rates of medical advance direc-

Categories of Reasons Given by 35 Residents Who Refused to Execute a Durable Power of Attorney for Health Care

Reason	No. of Residents Who Gave This Response
Confusion or misunderstanding	
Confusion and suspicion about "legal jargon"	1
Confusion with living will and similar legal documents	5
Belief that preexisting understandings with family and friends will provide needed decision-making	2
Don't believe that anything will ever happen to them	3
Don't want to burden family or friends	2
Mistrust	
Anger at or lack of trust in the "system"	5
Refusal to sign a "legal document"	3
Social isolation	
Don't have family or friends to serve as DPA	6
Other	8

tives or to determine why residents refuse to assign DPA can benefit from the methods and findings of our study.

Our technique of directly counseling residents overcame previously reported barriers to completing advance directives, which are a lack of knowledge and lack of an opportunity to communicate with caregivers.[1] This may have accounted for our high success rate. The reasons residents gave for deciding to execute a DPA can be summarized as extending individual autonomy and decision-making control into a time of mental incapacity by determining in advance who will make health care decisions for them and what will be done.

A number of residents still refused to sign a DPA. We categorized three significant reasons for failing to execute a DPA: confusion, mistrust, and isolation. These problems are created and compounded by the very medical and functional problems that precipitate nursing home admission such as cognitive decline, dependency, loss of mastery of one's environment, and death of significant others.

Despite our individualized educational effort and the apparent decision-making ability of our sample as judged by the primary social workers, we believe the most frequent reasons for refusing a DPA involved confusion and misunderstanding. We were not always certain in those cases that the residents fully comprehended the concept and had the capacity to make an informed decision. For assurance of comprehension, we required that the residents restate the information in their own words. Based on this criterion, some of the residents interviewed did not have the capacity to execute a DPA.

Since the completion of this study, we have formulated a more objective measure of capacity to execute a DPA that we now use when a resident's capacity is in doubt. The form consists of a series of simple questions that probe for comprehension of the basic principles of the DPA. The resident's replies are recorded verbatim. Questions include: (1) "Why did you choose [agent]?" (2) "What decisions will [agent] make for you?" (3) "Did you talk to [agent] about what medical care you would want if you were too sick to tell the doctors?" This simple questionnaire aids the caregiver in determining the resident's mental capacity to make this specific decision. An additional resource for the cognitively impaired nursing home resident is the social worker and nursing staff who have some knowledge of the commitment and motivations of the resident's proposed decision-maker.

It is the health care worker's responsibility to make every reasonable effort to establish an adequate degree of comprehension before a resident signs an informed decision regarding medical care. Many persons with cognitive impairment still have the capacity to make certain health care decisions if information is presented on their level of understanding. This requires time and effort. We consider such assistance analogous to providing an assistive device such as a cane to allow a resident to ambulate independently. Conscientious caregivers will have to determine when a resident lacks the capacity to make a particular health care decision. Caregivers must be sensitive to the possibility that a resident may interpret persistent efforts to verify comprehension as coercion.

To avoid confusion and misunderstanding, the health scenario used as an example must be presented in a simple straightforward manner to ensure residents' comprehension of the situation.[14] In our presentation we used the following example: "What if something happened to you? You fell, bumped your head, and went into a coma. You would not be able to make a decision for yourself. The durable power of attorney allows you to appoint someone you trust to make health care decisions for you." Many residents are capable of making informed decisions regarding a DPA when they are able to identify with the predicament that may arise if they have no advance directive.

Residents who refused to sign a DPA because of mistrust of "the system" could be visited again by their social worker, this time accompanied by someone the resident trusts (if such a person is available) to discuss the potential consequences of not having a designated health care agent.

Appointing an appropriate agent for DPA in situations of social isolation is more difficult. Volunteers from the community who would otherwise meet the requirements for an unrelated legal guardian could visit isolated residents to discuss their health care preferences and

express their willingness to serve as the resident's health care agent. In some cases, however, the very factors that have led to social isolation may prevent an isolated resident from forming a bond with a potential health care agent. These persons could be offered assistance in preparing detailed advance directives such as a living will without a surrogate decision-maker.

Nursing home residents are heterogeneous in personality, life experience, means of social support, and cognitive capacity. Approaches to presenting advance directives will need to be adapted to each individual. Further, while the DPA may offer the greatest flexibility among the formal types of medical advance directive documents, signing a DPA may not be the choice of every resident. Greater efforts must be placed, therefore, on finding effective techniques for obtaining valid, informed advance directives from nursing home residents, especially those with some impairment of cognitive capacity.

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