

Older Persons' Opinions About Life-Sustaining Procedures in the Face of Dementia

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Objective: To investigate the attitudes of cognitively normal older adults toward various life-sustaining procedures in the face of dementia.

Methods: Participants were 84 cognitively normal men and women (70% response rate), 65 years and older, from a variety of urban and suburban settings, including private homes, assisted-living apartments, transitional care facilities, and nursing homes. In-person interviews were conducted with each participant to obtain information about demographic characteristics, life and health, and desire for various life-sustaining procedures for 4 hypothesized levels of dementia.

Results: Approximately three fourths of participants said they would not want cardiopulmonary resuscitation, use of a respirator, or parenteral or enteral tube nutrition with the milder forms of dementia, and 95% or more of par-

ticipants would not want these procedures with severe dementia. In addition, only one third or fewer participants thought they would want to be hospitalized or given antibiotics if they were severely demented. Logistic regression analysis showed a relationship between participants' desire for life-sustaining procedures and having less education, greater independence, and a higher perceived quality of life.

Conclusions: Most surveyed individuals did not desire life-sustaining treatments with any degree of dementia, and the proportion of individuals not desiring such treatments increased with the projected severity of dementia. These findings indicate a need for including dementia in advance directives planning.

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DEMENTIA IS one of the most common and feared diseases in the elderly today. It is characterized by impairment in short- and long-term memory, disturbances in other cognitive functions (eg, abstract thinking, judgment, language, recognition), and/or personality change.¹ The prevalence of Alzheimer disease, the most common form of dementia in the elderly, has been shown to increase sharply with age. In a census study of residents from East Boston, Mass, the prevalence of Alzheimer disease increased from 3% in those 65 to 74 years old to 47% among those 85 years and older.² Given the aging nature of our population, the impact of dementia on individuals, their families, and society is profound.

For most elderly persons with dementia, the loss of cognitive function is progressive, eventually resulting in the loss of normal bodily functions and an inability to recognize loved ones. This gradual, predictable deterioration seen with Alzheimer dementia is associated with a median survival of 8 to 10 years¹; therefore, many health professionals consider de-

mentia in this population to be a terminal illness.

In the care of terminally ill patients, it is important to understand their and their family's wishes regarding end-of-life medical treatments. Advance directives provide written documentation about the medical care people desire for themselves in the event that they are later unable to make such decisions. Several investigators³⁻⁵ have looked at older persons' preferences regarding end-of-life care, and findings have generally shown a decline in desire for aggressive treatment as anticipated quality of life or chances of recovery decrease.

A few investigations have focused specifically on individuals' wishes about end-of-life treatments in the face of dementia. In 3 of the 4 studies⁶⁻⁸ that included both younger and older adults, most participants preferred not to have medical interventions such as cardiopulmonary

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SUBJECTS AND METHODS

PARTICIPANTS

Those eligible for the study included individuals 65 years and older who had normal cognitive function and who received their health care at a St Paul, Minn, clinic or who resided at 1 of 5 facilities: 3 St Paul nursing homes, a transitional care unit (providing posthospital care, usually for <2 weeks), and an assisted-living unit (providing housekeeping, optional intermittent nursing assistance, and meals for those otherwise living independently). Urban sites included 1 of the nursing homes, the assisted-living unit, and the clinic; suburban sites included 2 nursing homes and the transitional unit. These facilities were selected to represent a range of residential environments and geographic locations within a metropolitan area.

PROCEDURE

A designated staff member (nurse or social worker) at each residential facility agreed to identify all residents 65 years and older who were believed to have normal cognitive function. Similarly, 10 staff physicians from the participating clinic were asked to provide the names of their cognitively normal older patients. These staff members and physicians were told that, for the purposes of this study, persons with normal cognition were those who were oriented to time, place, and person and were able to answer questions related to their health and their wishes regarding end-of-life care. Each potential subject thus identified was contacted by one of us, either by telephone or in person, and was informed about the study and invited to participate. For those who were willing to participate, informed written consent was obtained in person by the interviewer, and a Mini-Mental State Examination was performed.¹³ Those who scored 25 or more of 30 points were formally interviewed. This cutoff was used to ensure reasonably normal cognitive function, based on previous observations that individuals with cognitive impairment had mean scores of 19 or lower.¹³ Interviews were conducted by 2 family physicians (D.K.G. and J.A.N.) and a premedical student (M.W.) from January 1996 through January 1997. Participants were usually interviewed at their place of residence; exceptions were 8 subjects living in the community who agreed to come to the clinic to be interviewed.

QUESTIONNAIRE

The questionnaire contained the following information: (1) Demographic characteristics: date of birth, sex, marital status, place of residence, ethnic origin, and education. (2) Participants' perceptions about their life, health, and social contacts: quality of life during the past 6 months (1-5 scale, where 1 indicated very unhappy with quality and 5, very happy with quality), perceived general health (1-5 scale, where 1 indicated very poor and 5, excellent), level of daily physical pain during past month (1-5 scale, where 1 indicated severe pain and 5, no pain), number of people who care about them, and average number of visits from friends and family in a 1-month period. (3) Activities of daily living (each rated on a 1-3 scale, where 1 indicated

someone else does; 2, does with help; and 3, does by himself or herself [scores were added to create a summed total]). (4) Instrumental activities of daily living (scored as described in item 3). (5) Having which of the following problems would seem worse than dying to you: losing your independence, being in constant physical pain, being a burden to your friends and family, losing your mental faculties, or being in a permanent vegetative state. (6) Desire for life-sustaining procedures if one were to suddenly become ill in one's present mental state (meaning no cognitive change). For each procedure listed below, the subject was asked to choose 1 of these responses: yes, under all circumstances; no, under all circumstances; or conditionally yes, eg, if procedure would maintain or improve health or if it was only needed temporarily. Procedures included the following: have heart restarted, be on a breathing machine, be "artificially fed through tubes in veins or stomach," be hospitalized, and receive antibiotics. (7) Desire for life-sustaining procedures in the face of dementia. Participants were asked whether they would want each of the life-sustaining procedures listed in item 5 performed if they had varying levels of dementia, characterized as follows: they became unpleasant for friends and family to be around because of personality changes, they had memory loss such that they could not remember how to do everyday things or got lost in their own neighborhood, they had memory loss such that they could no longer recognize their closest loved ones, or they were unable to care for themselves at all and could not communicate with friends or family.

Interrater reliability was examined by having each of the 3 raters separately question 6 of the participants during a 1- to 3-day period about their wishes regarding various life-sustaining procedures for various levels of dementia.

ANALYSIS

Three logistic regression analyses were performed with dependent variables selected on the basis of their greater variance in response and their clinical importance. These dependent variables included (1) desire CPR if one cannot remember how to do everyday things, (2) desire hospitalization if one cannot remember how to do everyday things, and (3) desire hospitalization if one cannot recognize loved ones. Initial regression analyses included all the following independent variables: age, sex, education, general health, physical pain, quality of life, number of people who care, number of visits, place of residence, marital status, activities of daily living, and instrumental activities of daily living. Independent variables that showed a *P* value of less than .10 in the preliminary analyses were then included in a second set of logistic regression analyses (independent variables thus identified included education, general health, quality of life during the past 6 months, place of residence, and mental status), again using the 3 dependent variables described herein.

Agreement in a participant's responses to questions about life-sustaining procedures for each of the 4 levels of dementia was measured by calculating the Cohen κ statistic¹⁴ for each pair of questions.

This study was approved by the Institutional Review Board's Human Subjects Committee at the University of Minnesota.

Table 1. Demographic Characteristics of Participants

Characteristics	No. (%) of Participants*
Age, mean (SD), y	80.5 (8.6)
Sex	
Female	64 (76)
Male	20 (24)
Place of residence	
Nursing home	39 (46)
Non-nursing home	45 (54)
Ethnic origin	
White	83 (99)
American Indian	1 (1)
Marital status	
Married	32 (38)
Widowed	37 (44)
Divorced	4 (5)
Single	11 (13)
Education	
<High school graduate	19 (23)
High school graduate	56 (67)
College graduate	9 (11)

*Data are expressed as number (percentage) except for age.

resuscitation (CPR) should they develop severe dementia. In the fourth study,⁹ most whites said that they would not want medical interventions if they were demented, while Hispanics and African Americans said that they would.

Three additional studies were performed with older participants. The first study¹⁰ sampled 64 outpatient veterans older than 74 years and found that most thought they would not desire CPR if they were to become functionally or cognitively impaired. The second study¹¹ interviewed 471 nursing home patients with varying levels of cognitive function and found that 89% would want to be hospitalized and 60% would want CPR in the event of serious illness and 33% would want tube feedings if they had permanent brain damage and required enteral feedings to continue living. A third study¹² mailed surveys to 218 community dwellers 60 years and older who were enrolled in a volunteer college registry on aging. When asked about which medical treatments they would want to sustain life if they had moderately advanced Alzheimer disease, 54% said that they would want CPR and 48% reported they would want ventilatory support.

In addition to the potential demographic biases present in these studies, previous studies have used various definitions of dementia, some of which may have been vague. For example, subjects were asked about their preferences for treatment in the event of "permanent brain damage"¹¹ in one study and "dementia"⁹ in another. It is not clear whether these phrases were defined more completely to the participants.

The results of these studies are difficult to generalize because of the unique populations that were surveyed (eg, veterans, nursing home residents, and registry members) and because of the various definitions of dementia used.

The purpose of this study was to investigate the attitudes of a group of cognitively normal persons 65 years and older, from a variety of settings, regarding life-

Table 2. Percentage of Participants Who Desire Life-Sustaining Procedures in the Event of Becoming Severely Ill Today (Assumes Current Cognitive Function)

Procedure	No. (%) of Participants		
	Yes, Under All Circumstances	Conditional Yes*	No, Under All Circumstances
Cardiopulmonary resuscitation	12 (14)	45 (54)	26 (31)
Ventilatory support (respirator)	5 (6)	41 (49)	37 (44)
Parenteral/enteral tube feedings	4 (5)	38 (45)	41 (49)
Hospitalization	17 (20)	54 (64)	11 (13)
Administration of antibiotics	27 (32)	52 (62)	3 (4)

*Yes, if treatment maintains or improves health or (in case of respirator or parenteral or tube feedings) if treatment is temporary.

sustaining medical procedures in the hypothesized setting of dementia.

RESULTS

Of 120 total eligible individuals, 84 (70%) agreed to participate, 34 refused, and 2 were deemed ineligible because of Mini-Mental State Examination scores of less than 25. Participants' demographic characteristics are shown in **Table 1**. Of the 45 non-nursing home participants, 26 lived in private homes, 11 temporarily resided in transitional care units, and 8 lived in assisted-care apartments.

On a 1 to 5 scale (1 indicating least optimal and 5, most optimal), respondents' perceived quality of life during the past 6 months was 3.7, perceived general health was 3.7, and daily physical pain was 3.0. Subjects counted an average of 4.4 people who they believed cared about them. Eighty-one subjects (96%) said they made their own medical decisions.

When asked about whether certain health problems seemed worse than death, an affirmative response was given by 50 subjects (60%) regarding the vegetative state, 34 (40%) for losing one's mental faculties, 28 (33%) for being in constant pain or being a burden to friends or family, and 20 (24%) for losing one's independence.

Subjects' desires regarding specific life-sustaining procedures (eg, CPR, use of a respirator [hereafter referred to as *assisted ventilation* or *ventilatory support*], parenteral or enteral tube feedings, hospitalization, and administration of antibiotics) in the face of current cognitive function, or with varying levels of dementia, are shown in **Table 2** and **Table 3**. Even with current cognitive abilities, nearly half of the subjects would not want to use a respirator or to be given parenteral or enteral tube feedings if these procedures were needed to sustain life. Few seniors wanted CPR, assisted ventilation, or artificial feedings unconditionally.

Participants' wishes about life-sustaining treatments in the face of dementia were even more striking (Table 3). As the hypothetical level of dementia increased, their desire for all investigated treatments de-

Table 3. Desire for Various Life-Sustaining Procedures for Different Levels of Dementia

Levels of Dementia	No. (%) of Participants				
	Cardiopulmonary Resuscitation	Ventilatory Support	Tube Feedings	Hospitalization	Antibiotics
Personality changes that make you unpleasant	23 (27)	19 (23)	20 (24)	59 (70)	62 (75)
Cannot remember how to do everyday things	20 (24)	20 (24)	20 (24)	45 (54)	46 (55)
Cannot recognize loved ones	6 (7)	7 (8)	9 (11)	33 (39)	31 (37)
Cannot care for yourself at all and cannot communicate	3 (4)	4 (5)	3 (4)	28 (33)	21 (25)

Table 4. Partial Odds Ratios for the Association Between Participants' Desire for Various Life-Sustaining Procedures and Demographic Characteristics and Quality of Life*

Independent Variables†	Cardiopulmonary Resuscitation, If One Cannot Remember How to Do Everyday Things		Hospitalization, If One Cannot Remember How to Do Everyday Things		Hospitalization, If One Cannot Recognize Loved Ones	
	OR	P	OR	P	OR	P
	Lower level of education	0.76	.02	0.81
Non-nursing home	2.43	.07	2.37	.08
Perceived higher quality of life	1.76	.04	1.49	.09

*Odds ratio (OR) is the estimated partial OR adjusted for other independent variables and determined by logistic regression analysis. Ellipses indicate data not applicable.

†Independent variables entered into each of the 3 regression equations include education, general health, quality of life during the past 6 months, place of residence, and marital status.

creased, such that fewer than 5% thought that they would want CPR, ventilatory support, or tube feedings with the most severe forms of dementia. Further, only about one fourth of the seniors wanted these procedures with even the milder forms of dementia. Fewer than 40% of participants said they would want to receive antibiotics or be hospitalized if they could not recognize their loved ones. In discussing the question of hospitalization with the participants, it was noted by the interviewers that many who indicated that they would want to be hospitalized thought they had no choice, that hospitalization would be routine, and that it would make them more comfortable.

Logistic regression analyses showed that participants' desire for various life-sustaining procedures was significantly related to lower levels of education and perceived current higher quality of life and nearly significantly related to living outside (vs within) a nursing home (Table 4).

Agreement of a participant's responses for various life-sustaining procedures was moderate to high among the 3 most aggressive procedures (CPR, ventilatory support, and tube feedings; Cohen κ , 0.58-0.90) and relatively high between the 2 less aggressive procedures (hospitalization and administration of antibiotics; Cohen κ , 0.71-0.75). Practically speaking, this implies that when a person says he or she would not want to undergo CPR, that person would also not want to receive ventilatory support or tube feedings. Similarly, one's wishes about hospitalization and antibiotics typically go hand in hand.

The consistency of responses among the 3 raters was high (97%) for questions regarding the most severe

form of dementia and moderate (67%) for the first 2 levels of dementia.

COMMENT

A key finding of this study is that most participants did not desire life-sustaining procedures such as CPR, ventilatory support, or artificial nutrition for any level of dementia, and even more noteworthy, most said they would not want to be hospitalized or given antibiotics if they were no longer able to recognize their loved ones or care for themselves. Desire for life-sustaining treatments was indirectly related to the level of dementia, such that few of our participants wanted to be resuscitated or maintained on a ventilator if they could neither care for themselves nor communicate. These preferences stand in stark contrast to existing end-of-life medical practices in so many communities in our country.

This apparent mismatch between elders' preferences and health professionals' practices regarding end-of-life care has been well documented for such terminal conditions as acute respiratory failure, chronic obstructive pulmonary disease, multiple organ system failure, malignant conditions, congestive heart failure, and cirrhosis,⁵ but it has not been as well studied with dementia. However, a recent retrospective study¹⁵ of 80 patients with advanced dementia who died during their stay at an acute care hospital in New York indicates that patients with severe dementia often receive nonpalliative interventions at the end of life, sometimes against their wishes. In this sample, 26% of elders with severe dementia had received enteral tube feedings, and CPR had been

attempted on 24% of subjects, one of whom had a do-not-resuscitate order.

Because the course of dementia in the elderly is generally one of progressive decline, similar to that seen in other terminal conditions, and because many individuals have strong feelings about the care they would like to receive if they were demented, as evidenced by this study, it is important to include the topic of dementia in advance directives planning. This recommendation is consistent with that of the Fairhill Guidelines on Ethics of the Care of People With Alzheimer's Disease. These guidelines specifically state,

The physician who provides continuing care for the person with dementia should initiate discussion with patients and families regarding the use of aggressive measures to prolong life. People with mild dementia can often respond meaningfully to questions about their wishes regarding end-of-life choices. . . . Certainly in very advanced and terminal dementia, comfort care is all that need be offered.¹⁶

Our findings add importantly to the previously conflicting literature regarding seniors' wishes about life-sustaining treatments with coexisting dementia in that they were derived from a more residentially diverse sample than was seen in many previous studies, the subjects were all cognitively normal seniors, and dementia was defined by 4 progressive levels of impairment. It is not clear whether these factors were responsible for the differences in outcomes between this study and those conducted earlier by O'Brien et al¹¹ and Reilly et al.¹² It is possible that other study characteristics, such as the training and experience of interviewers or the location of the interview, may have contributed to our outcome of subjects desiring less aggressive care. In this study, 2 of the interviewers were family physicians (the third was a pre-medical student) who may have presented the options differently than interviewers from other backgrounds. In addition, most of the interviews for this study were performed at the subject's place of residence, which may have contributed to a higher level of trust.

Limitations of this study include the relatively small sample size, lack of ethnic diversity, and the identification of potential subjects by facility-based staff. Additional studies are needed to examine more closely older persons' thought processes as they consider end-of-life medical decisions and to confirm the results seen here. These studies should include large, heterogeneous samples from multiple sites.

The central message communicated by most of our seniors was that they wanted no aggressive life-prolonging procedures if they were to become demented. Further, if they were so demented that they could not recognize loved ones, most would prefer not to be hospitalized or given antibiotics. If confirmed by additional studies, these results have important implications for end-of-life care. They reinforce the need to dis-

cuss advance directives, particularly directives in the event of dementia, with patients and family members. In addition, they provide a useful tool for communicating to family members of patients with dementia options for end-of-life treatment and other seniors' opinions about these options. By understanding patients' and family members' preferences for end-of-life care, and treating them accordingly, we respectfully preserve their human dignity. In the words of the Fairhill group, "the finest expression of this respect [for the severely demented] may be through the touch of a hand rather than through technology."¹⁶

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