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## Content of Advance Directives for Individuals with Advanced Dementia

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## Abstract

**Objectives**—To examine how people with end-stage dementia have conveyed their wishes for end-of-life care in advance directives.

**Methods**—The documents of 123 residents of three Maryland nursing homes, all with end-stage dementia, were reviewed.

**Results**—More years of education and White race were significantly associated with having an advance directive. With the exceptions of comfort care and pain treatment, advance directives were used primarily to restrict, not request, many forms of care at the end-of-life. Decisions about care for end-stage conditions such as Alzheimer's dementia are less often addressed in these documents than for terminal conditions and persistent vegetative state.

**Discussion**—In order for advance directives to better reflect a person's wishes, discussions with individuals and families about advance directives should include a range of care issues in the settings of terminal illness, persistent vegetative state or end-stage illness. These documents should be reviewed periodically to make certain they convey accurately the person's treatment preferences.

### Keywords

Living will; Treatment preferences; End-stage dementia; End of life; Health care decisions

## Content of Advance Directives for Individuals with Advanced Dementia

Advance directives (ADs) are legal documents used by individuals to convey their preferences for future treatment to caregivers and family, to designate someone to make health care decisions should the individual lose the capacity to decide, or both. States have different requirements or standards for the content of ADs (Gunter-Hunt, Mahoney, & Sieger, 2002), and it is common for documents to vary widely between individuals. Although data on the effectiveness of ADs as tools to implement the wishes of persons at the end of life and other targeted interventions to improve care are mixed (Connors et al., 1995; Ditto et al., 2001), some studies suggest that ADs may help some caregivers make choices that better reflect the true wishes of individuals (Coppola, Ditto, Danks, & Smucker, 2001). Since ADs may improve the communication of preferences for care, efforts are underway to increase the use of these documents (Hammes & Rooney, 1998; Molloy et al. 2000). Surprisingly, little is known about the wishes people actually express in such documents.

ADs are of particular importance for persons with dementia because nearly all dementias are progressive. Therefore, individuals with dementia will decline, unless they die from other causes, to a state in which they can no longer communicate their treatment wishes. They are then dependent upon caregivers, family, other surrogates and physicians to express or make healthcare decisions that include the use or withholding of life-sustaining treatments. Because persons with dementia eventually become unable to comprehend issues relevant to medical care and lose ability to evaluate their needs or express their wishes, ADs can provide important guidance.

Since 1993, the Maryland Health Care Decisions Act has contained template forms for ADs that allow an individual to name a health care agent (HCA) and to list treatment preferences for 3 conditions: terminal illness, persistent vegetative state and end-stage illness (Annotated Code of Maryland). The Act defines end-stage illness as “an advanced, progressive, irreversible condition caused by injury, disease, or illness: (1) that has caused severe and permanent deterioration indicated by incompetency and complete physical dependency; and (2) for which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective.” Other means of expressing treatment preferences, such as the Five Wishes form (Aging with Dignity, 2005) are available on the internet and provide alternative means for conveying to caregivers and potential decision-makers what one would want done or not done in certain end-of-life scenarios.

As a central component of the “life-sustaining” treatments often addressed in ADs, decisions about Do Not Resuscitate (DNR) orders are an important consideration in end-of-life treatment preferences. A DNR order on a chart does not necessarily mean that a person has completed an advance directive or that the order has been entered as part of the person's advance care planning. A person may choose to document his or her preference for or against DNR status in an AD or some other form of communication with family or caregivers, though the DNR order decision is often made by a surrogate (Torian, Davidson, Fillit, Fulop & Sell, 1992; Bedell, Pelle, Maher & Cleary, 1986). There is some evidence that having an AD does not

affect individuals' preferences for or against cardiopulmonary resuscitation, (Laakkonen, Pitkala, Strandberg, Berglind, & Tilvis, 2004), though correlations with other treatment preferences are understudied. Some data suggest that individuals with dementia are more likely to have a DNR order than those with chronic, yet potentially fatal, illnesses such as congestive heart failure (Haydar, Lowe, Kahveci, Weatherford, & Finucane, 2004). This finding was in keeping with a trend toward greater emphasis on symptom relief and anticipation of dying for patients with dementia. Another study, however, found that persons with dementia in nursing homes were less likely than persons with cancer to have DNR orders or ADs limiting care and underwent more invasive interventions (Mitchell, Kiely & Hamel, 2004).

The objectives of this study were to examine the prevalence of ADs for individuals with end-stage dementia, determine the content of these documents, and identify factors associated with having an AD. We also examined the relationship between having an AD and a DNR order.

## METHODS

### Settings and Sample

This study examines the advance directive documents of individuals who were participating in a prospective, longitudinal study of end-of-life care in people with dementia (Black et al., 2006). The participants were residents of three comprehensive nursing homes in Central Maryland chosen for their high prevalence of dementia. Two facilities are in Baltimore City and one is in a rural community. Each site is affiliated with a university teaching hospital and each is operated by a different type of organization (i.e. a university, a not-for-profit organization and a government agency). Study participants were residents of these three facilities with advanced dementia and their surrogate decision makers. This study was approved by the Institutional Review Boards (IRBs) of the Johns Hopkins Medical Institutions and the University of Maryland. The study protocol was also reviewed and approved by the research review committees at the three study sites.

All participating residents were considered to have end-stage dementia, defined as meeting hospice criteria or receiving hospice or palliative care between December 2000 and August 2003 and having a life expectancy of six months or less based on their physicians' judgments or hospice guidelines. To identify these individuals, all residents of the three facilities at the beginning of the study and all subsequently admitted residents were screened. Those not meeting eligibility criteria were then re-screened every two months. In addition, residents identified by their physicians as declining rapidly and likely to die within the two-month interval were screened as soon as possible. Inclusion criteria were: (1) having a diagnosis of dementia, (2) currently receiving hospice or palliative care, or (3) meeting existing hospice criteria for dementia patients.

Permission to approach eligible residents and their surrogates was sought from their physicians. The surrogate decision maker was defined as the resident's legally authorized representative based on either legal guardianship, a durable power of attorney for health care, or the surrogacy provisions under Maryland's Health Care Decisions Act, in that order of priority. Surrogates were contacted by letter, and stamped, self-addressed postcards were enclosed to return if they did not wish to be contacted further. If the postcard was not returned within two weeks, a research assistant contacted the surrogate, described the study and requested the surrogate's permission to enroll the resident in the study. Surrogates rather than residents were contacted initially because almost all individuals with advanced dementia lack decisional capacity. In one case, the resident was assessed as having capacity, and he gave written informed consent to participate. For all other residents, written proxy informed consent was obtained from their surrogates.

## Data Collection and Measures

We reviewed the medical records of 125 enrollees, though two were later excluded when it was determined that, despite poor prognoses as judged by their physicians, they had neither met hospice criteria nor received hospice or palliative care services. The baseline medical record review was used to collect information on residents' demographic characteristics, e.g. age, marital status, living situation prior to admission, education, as well as dementia diagnosis. DNR orders were obtained from the orders sections of the charts. We made a distinction between DNR orders in the charts and advance directive statements that described preferences for or against DNR status for different conditions. Twenty-three charts at one site contained a "DNR consent form" which was dated after admission to the facility and therefore not prepared in advance.

All documents in the chart that might have been used to express a treatment preference were reviewed. These included wills, general powers of attorney for financial affairs, documents addressing treatment preferences (e.g., living wills), and documents appointing a durable power attorney for health affairs. Two hundred and forty three such documents were reviewed for content analysis. We defined an AD as any document endorsed by a subject that expressed a treatment preference were he or she to become incapacitated or that named a HCA without specifically stating the person's treatment preferences.

A law student (S.R.F.) and a physician (P.T.) analyzed the documents, focusing initially on any mention of treatment preferences for terminal conditions, persistent vegetative state and end-stage conditions, to identify whether the resident named a HCA and/or mentioned any other treatment preferences for end of life care. With serial reviews, a pattern of categorization was created. The categories included mention of preferences for artificial nutrition and hydration, food and water by mouth, tube feedings, hospitalization for acute issues, hospice care, comfort care, pain treatment, use of mechanical ventilation, medications (and antibiotics specifically) or dialysis. We also noted whether a person mentioned a specific treatment but deferred decision making to the HCA's discretion and if a document was used as a format for conveying emotional or spiritual messages to loved ones. In cases where the content of documents was unclear, we consulted with the Director of the Health Policy Development Division of the Maryland Attorney General's office (J.S.) for interpretation. A second physician (D.A.) independently reviewed a sample of 25 documents to determine reliability of document determination. An agreement of 92% (Kappa= 0.80) was reached between the two rating physicians.

## Data Analysis

Univariate analyses were used to describe participants' demographic characteristics and document contents. Bivariate associations were assessed using t-tests and chi-square analyses or Fisher's exact test. Stepwise logistic regression analyses were used to examine the relationships between participant characteristics and having: (1) an AD, and (2) a DNR order. The data were analyzed using SPSS version 13. P-values less than 0.05 were considered statistically significant for the analyses.

## RESULTS

Characteristics of the residents are shown in Table 1. The majority of participants were female (55%), White (84%) and age 80 or older (63%). This cohort was fairly well educated, with nearly two-thirds having at least a high school diploma. Alzheimer's disease was the most common dementia diagnosis.

Eighty-one subjects (66%) had an AD in their charts. Since some residents had more than one AD, a total of 118 ADs were reviewed. Of the documents that addressed treatment preferences for end-stage conditions, we could not determine the state in which two documents were created. All other documents that addressed end-stage conditions were created in Maryland and, where the date could be determined, all were completed after the 1993 Health Care Decisions Act took effect. Forty-seven subjects created ADs in Maryland after the Act took effect on October 1, 1993, and 22 (47%) of these had documents describing their treatment preferences for end-stage conditions.

As can be seen in Table 2, residents who were married or widowed and those who lived with others prior to admission were more likely to have an AD, while African-Americans and those without a high school diploma were less likely to have an AD. There was a trend toward women being more likely to have an AD. Participants at Site B were more likely than others to have an AD. Site B residents were significantly more likely to be White, high school graduates and female than those at the other two sites ( $p \leq 0.001$  for all three factors). All variables significantly associated with having an AD based on bivariate analyses were included in a stepwise logistic regression analysis. The regression analysis showed that race (OR=8.946, 95% CI= 2.165-36.966,  $p=0.002$ ) and education (OR=2.794, 95% CI= 1.064-7.334,  $p=0.037$ ) were the only factors that remained significantly associated with having an AD.

Seventy (86%) of the 81 subjects with ADs named a health care agent. Sixty-one subjects had ADs that described their treatment preferences for terminal conditions, 47 addressed persistent vegetative state and 25 addressed end-stage conditions. Two of the ADs allowed some form of intervention for one of these conditions, but set a time limit (of 30 or 45 days); the remainder of the ADs conveyed a preference that no life-sustaining procedures be used.

As shown in Table 3, ADs were primarily used to limit care received, and often did not mention comfort care or relief of pain. A few people had documents that outlined conditional (i.e. different care preferences for different conditions) or time-limited (e.g. three months) treatment. Thirty-nine residents (48%) with ADs had documents that addressed pain treatment. The majority (85%) of people who raised this issue preferred to receive pain treatment, even if the treatment might shorten their remaining life. Forty-five residents described treatment options within the scope of the HCA's powers, but did not state their treatment preferences, deferring instead to the judgment of the named agent. No participants used the ADs to convey their wishes about hospitalization for acute issues. Two individuals specifically stated a preference for hospice treatment. Of the eight people whose ADs mentioned treatment preferences regarding use of dialysis and antibiotics, all expressed a preference for no such treatment. One person instructed specifically that antibiotics always be used in the setting of terminal illness, but for only 45 days for persistent vegetative state or end-stage illness. One individual used a document to ask for every possible treatment in case of coma.

Several ADs conveyed conflicting wishes or were improperly completed. For example, one person had two documents with differing wishes for pain treatment: one allowed for pain treatment, though a later AD asked that pain medicines not be given if it would shorten the person's remaining life. The subjects' wishes were unclear or contradictory regarding comfort care in three cases and in four ADs for pain treatment. Two documents in the survey were missing at least one page and four others were in some way incomplete including missing the person's signature or otherwise filled out incorrectly.

The majority of residents (79%) had DNR orders. These individuals were no more likely than other residents to have an AD ( $\chi^2 = 2.114$ ,  $df=1$ ,  $p=0.146$ ). Women (88%) were more likely than men (67%) to have a DNR order ( $\chi^2 = 8.015$ ,  $df=1$ ,  $p=0.005$ ). Age, education, race, living alone before admission and marital status were not associated with having DNR orders.

However, residents at Site A (59%) were less likely than those at Sites B (85%) or C (100%) to have a DNR order ( $\chi^2=17.414$ ,  $df=2$ ,  $p<.001$ ). At all three sites, no correlation was found between DNR status and having an AD. When the two variables significantly associated with having a DNR order based on bivariate analyses (gender and study site) were included in a stepwise logistic regression analysis, only study site remained in the model. Residents at Site A were significantly less likely than those at Site C (reference group) to have a DNR (OR=0.174, 95% CI 0.069-0.441,  $p<.001$ ). Persons with DNR orders were no more likely than others to express a preference for or against food, water, hospice, tube feeds, comfort care, ventilator use, dialysis or antibiotic use. For those thirty-nine residents who mentioned pain treatment, however, those with DNR orders were more likely ( $\chi^2=6.769$ ,  $df=1$ ,  $p\leq 0.01$ ) to ask for pain treatment. Thirteen people with ADs (16%) specifically asked for DNR status in their AD, and 12 of these 13 (92%) had a DNR order in the chart.

Eight residents used ADs to express to their friends and family their thoughts about the dying process and how it should affect surrogates' decisions. One example reads: "I recognize that it places a heavy burden of responsibility upon you and it is with the intention of sharing that responsibility and of mitigating any feelings of guilt that this statement is made." Four subjects expressed a wish to stay in their own homes for as long as possible and one of these individuals asked that any decision made by the health care agent consider the decision's impact on the person's family. Four residents stated that they wanted to donate their bodies or organs at the time of death for medical purposes. One person granted decision-making power to the attending physician.

## DISCUSSION

The current study demonstrates that the content of ADs for people with advanced dementia primarily expresses a preference for supportive care at the end-of-life rather than for more aggressive treatments. However, while nearly all documents reviewed stated a preference for no "life-sustaining" treatment in the setting of terminal condition, persistent vegetative state or end-stage condition, most did not delineate explicitly the various treatments they would or would not want. Comfort care and pain treatment were the most common positive requests, but pain treatment preferences, for example, were found in less than half (48%) of the ADs. Most, but not all, people who mentioned their preferences for pain treatment indicated they preferred for pain to be treated, even if it would shorten their remaining life. Wishes not to have more invasive treatment (e.g. feeding tube, dialysis) were the most common negative requests, but were mentioned in less than a quarter of all ADs. Thus, many common end-of-life care decisions faced by persons with dementia are not addressed by their ADs. For example, although most people in this study had a DNR order in their charts, wishes about resuscitation ("DNR status"), were documented by only 16% of those subjects with ADs; furthermore, no AD stated a preference regarding hospitalization for acute issues at the end of life (a finding consistent with prior studies of "Do Not Hospitalize" (DNH) directives [Degenholtz, Arnold, Meisel, & Lave, 2002; Levy, Fish & Kramer 2005; Teno et al., 1997]) despite the fact that DNH orders were present in 50 of the charts (41%). We conclude that this is a significant clinical issue not addressed by most ADs (Maust, Blass, Black & Rabins, 2007), but one that should be. Similarly, less than 10% of ADs expressed a wish about ventilator or antibiotic use. Taken together, these findings suggest that only a minority of ADs address commonly encountered and important end-of-life issues faced by persons with dementia. Our findings suggest that phrases such as "heroic measures" are so non-specific that they offer minimal guidance, and that ADs would be more useful if they either listed the range of commonly faced treatment and care issues, or if discussions about such specific issues were encouraged with those who will become substitute decision makers.

Similar to prior studies, Whites (Degenholtz et al., 2002; Hopp, 2000; Kiely, Mitchell, Marlow, Murphy, & Morris, 2001; Lahn, Friedman, Bijur, Haughey, & Gallagher, 2001; Witte, Menon, Ruskin, Wiley, & Hebel, 2003) and individuals with higher education (Bradley, Wetle, & Horwitz, 1998; Hopp, 2000) were more likely to have ADs and there was a trend for women to be more likely to have ADs than men, a finding that has been reported previously as well (Laakkonen et al., 2004). As has been noted elsewhere, efforts at increasing use of ADs have targeted people found in this study to be less likely to have an AD (Hopp, 2000; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). Strategies targeting underrepresented groups appear warranted, unless those groups have specific prohibitions or cultural dislike for such an approach.

Our sample included ADs created before and after the 1993 Maryland Health Care Decisions Act added language addressing an individual's treatment preferences for end-stage conditions, such as advanced Alzheimer's disease, in state-provided ADs. While this seems to have influenced some subjects and their lawyers to document a person's choices in this contingency, fewer than half the ADs created after 1993 mention end-stage condition treatment preferences. As this was a cross-sectional study we cannot assess the degree to which the Act changed peoples' decisions, but this finding suggests that changing a law in and of itself will not have a major effect of how ADs are completed, at least in the short run. Reasons for not addressing end-stage issues in ADs may include discomfort with discussing the issue, unfamiliarity with the law or a wish to allow surrogate decision makers more freedom in making choices.

Different states in the U.S. have different standards for content of ADs and geographic variability of advance care planning has been noted elsewhere (Kiely et al., 2001; Teno et al., 1997), and we noted differences in content and language of documents created in different states and for the one document created in Mexico. Given the mobility of the at-risk population in the U.S., patients should be made aware that different jurisdictions have different requirements that might affect how their wishes are followed. We found 13 documents in which the content was unclear. We suspect that clinicians and surrogates would also have trouble interpreting and implementing these ADs. In Maryland, a new statute includes forms that were changed to allow persons to designate the forms either as strictly binding preferences or more as flexible guidelines for their HCA (Annotated Code of Maryland). Future studies should determine whether this has improved the clarity of the wishes that have been expressed.

Several issues limit the generalizability of this study. The study was limited to three nursing homes in a single state. The overrepresentation of Whites in our study may reflect who is receiving nursing home care in the state of Maryland. Data describing patterns of use of advance directives by Hispanics, Asians and other groups are not represented here but can be found elsewhere (Degenholtz et al., 2002; Kwak & Haley, 2005; Morrison & Meier, 2004; Morrison et al., 1998). Socioeconomic status (SES) was not specifically calculated or estimated, though it may be inferred from education, but the finding that ADs are more common in those with higher education suggests that SES be further explored as a variable influencing content of ADs. Finally, the state of Maryland has passed substantial legislation on advance directives that may not be consistent with laws in other states.

In summary, many persons with advanced dementia have completed documents naming a health care agent but few list specific treatment preferences for a number of conditions and potentialities. The less educated, males and African-Americans, particularly those who live alone and have never married or are separated or divorced, are least likely to have ADs and might benefit from targeted approaches to improve communication of their treatment preferences. In order for advance directives to better reflect a person's wishes, discussions with individuals and families about care if the person should become decisionally incapacitated should include a range of care issues in the settings of terminal illness, persistent vegetative

state or end-stage illness, physicians should focus on how decisions should be made (Nolan et al., 2006; Vig, Taylor, Starks, Hopley, & Fryer-Edwards, 2006) and these documents should be reviewed periodically to make certain they convey accurately the person's treatment preferences.

## References

- Aging with Dignity. Five Wishes. Aging with Dignity; Tallahassee, FL: 2005. also available online at [www.agingwithdignity.org/5wishes.html](http://www.agingwithdignity.org/5wishes.html)
- Annotated Code of Maryland, Title 5, Death, Subtitle 6, Health Care Decisions Act. Article – Health – General, §5-601-§5-618. [8/22/06]. Available from [http://www.dsd.state.md.us/comar/Annot\\_Code\\_Idx/H-GIndex.htm](http://www.dsd.state.md.us/comar/Annot_Code_Idx/H-GIndex.htm)
- Bedell SE, Pelle D, Maher PL, Cleary PD. Do-Not-Resuscitate Orders for Critically Ill Patients in the Hospital: How Are They Used and What is Their Impact? *JAMA* 1986;256:233–237. [PubMed: 3723709]
- Black BS, Finucane T, Baker A, Loreck D, Blass D, Fogarty L, et al. Health Problems and Correlates of Pain in Nursing Home Residents with Advanced Dementia. *Alzheimer Disease and Associated Disorders* 2006;20:283–90. [PubMed: 17132974]
- Bradley EH, Wetle T, Horwitz SM. The Patient Self-Determination Act and Advance Directive Completion in Nursing Homes. *Archives of Family Medicine* 1998;7:417–423. [PubMed: 9755733]
- Connors AF, Dawson NV, Desbiens NA, Fulkerson WJ, Goldman L, Knaus WA, et al. A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA* 1995;274:1591–1598. [PubMed: 7474243]
- Coppola KM, Ditto PH, Danks JH, Smucker WD. Accuracy of Primary Care and Hospital-Based Physicians' Predictions of Elderly Outpatients' Treatment Preferences With and Without Advance Directives. *Archives of Internal Medicine* 2001;161:431–440. [PubMed: 11176769]
- Degenholtz HB, Arnold RA, Meisel A, Lave JR. Persistence of Racial Disparities in Advance Care Plan Documents Among Nursing Home Residents. *Journal of the American Geriatrics Society* 2002;50:378–381. [PubMed: 12028224]
- Ditto PH, Danks JH, Smucker WD, Bookwala J, Coppola KM, Dresser R, et al. Advance Directives as Acts of Communication. *Archives of Internal Medicine* 2001;161:421–430. [PubMed: 11176768]
- Gunter-Hunt G, Mahoney JE, Sieger CE. A Comparison of State Advance Directive Documents. *Gerontologist* 2002;42:51–60. [PubMed: 11815699]
- Hammes BJ, Rooney BL. Death and End-of-Life Planning in One Midwestern Community. *Archives of Internal Medicine* 1998;158:383–390. [PubMed: 9487236]
- Haydar ZR, Lowe AJ, Kahveci KL, Weatherford W, Finucane T. Differences in End-of-Life Preferences Between Congestive Heart Failure and Dementia in a Medical House Calls Program. *Journal of the American Geriatrics Society* 2004;52:736–740. [PubMed: 15086654]
- Hopp FP. Preferences for Surrogate Decision Makers, Informal Communication, and Advance Directives Among Community-Dwelling Elders: Results From a National Study. *The Gerontologist* 2000;40:449–457. [PubMed: 10961034]
- Kiely DK, Mitchell SL, Marlow A, Murphy KM, Morris JN. Racial and State Differences in the Designation of Advance Directives in Nursing Home Residents. *Journal of the American Geriatrics Society* 2001;49:1346–1352. [PubMed: 11890494]
- Kwak J, Haley WE. Current Research Findings on End-of-Life Decision Making Among Racially or Ethnically Diverse Groups. *The Gerontologist* 2005;45:634–641. [PubMed: 16199398]
- Laakkonen M, Pitkala KH, Strandberg TE, Berglind S, Tilvis RS. Living Will, Resuscitation Preferences, and Attitudes towards Life in an Aged Population. *Gerontology* 2004;50:247–254. [PubMed: 15258431]
- Lahn M, Friedman B, Bijur P, Haughey M, Gallagher EJ. Advance Directives in Skilled Nursing Facility Residents Transferred to Emergency Departments. *Academic Emergency Medicine* 2001;8:1158–1162. [PubMed: 11733294]



- Levy CR, Fish R, Kramer A. Do-Not-Resuscitate and Do-Not-Hospitalize Directives of Persons Admitted to Skilled Nursing Facilities Under the Medicare Benefit. *Journal of the American Geriatrics Society* 2005;53:2060–2068. [PubMed: 16398888]
- Maust DT, Blass DM, Black BS, Rabins PV. Treatment Decisions Regarding Hospitalization and Surgery for Nursing Home Residents with Advanced Dementia: The CareAD Study. *International Psychogeriatrics* 2007:1–13.
- Mitchell SL, Kiely DK, Hamel MB. Dying with Advanced Dementia in the Nursing Home. *Archives of Internal Medicine* 2004;164:321–326.
- Molloy DW, Guyatt GH, Russo R, Goeree R, O'Brien BJ, Bedard M, et al. Systematic Implementation of an Advance Directive Program in Nursing Homes: A Randomized Controlled Trial. *JAMA* 2000;283:1437–1444. [PubMed: 10732933]
- Morrison RS, Meier DE. High Rates of Advance Care Planning in New York City's Elderly Population. *Archives of Internal Medicine* 2004;64:2421–2426. [PubMed: 15596631]
- Morrison RS, Zayas LH, Mulvihill M, Baskin SA, Meier DE. Barriers to Completion of Health Care Proxies: An Examination of Ethnic Differences. *Archives of Internal Medicine* 1998;158:2493–2497. [PubMed: 9855388]
- Nolan MT, Hughes M, Narenda DP, Sood JR, Terry PB, Astrow AA, et al. When Patients Lack Capacity: The Roles That Patients with Terminal Diagnoses Would Choose for Their Physicians and Loved Ones in Making Medical Decisions. *Journal of Pain and Symptom Management* 2006;30:342–353. [PubMed: 16256898]
- Teno JM, Branco KJ, Mor V, Phillips CD, Hawes C, Morris J, et al. Changes in Advance Care Planning in Nursing Homes Before and After the Patient Self-Determination Act: Report of a 10-State Survey. *Journal of the American Geriatrics Society* 1997;45:939–944. [PubMed: 9256845]
- Torian LV, Davidson EJ, Fillit HM, Fulop G, Sell LL. Decisions for and against Resuscitation in an Acute Geriatric Medicine Unit Serving the Frail Elderly. *Archives of Internal Medicine* 1992;152:561–565. [PubMed: 1510746]
- Vig EK, Taylor JS, Starks H, Hopley EK, Fryer-Edwards K. Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision-Making. *Journal of the American Geriatrics Society* 2006;54:1688–1693. [PubMed: 17087695]
- Witte TH, Menon AS, Ruskin PE, Wiley C, Hebel JR. Advance Directives Among Elderly Veterans. *The Journal of Applied Gerontology* 2003;22:197–213.

**Table 1**

## Residents' Characteristics (n=123)

Characteristics	n	%	Other Values
Gender			
Male	55	44.7	
Female	68	55.3	
Age			
< 80 years	45	36.6	Range 61-101
80-89 years	63	51.2	Median 80.8
≥ 90 years	15	12.2	Mean 81.5 (SD=7.1)
Race			
White	103	83.7	
African American	20	16.3	
Education <sup>a</sup>			
< High School Graduate	40	34.2	
≥ High School Graduate	77	65.8	
Marital Status			
Married or widowed	105	85.4	
Separated, divorced, never married	18	14.6	
Living Situation Before Admission <sup>a</sup>			
Lived alone	10	8.1	
Lived with others	112	91.1	
Study Site			
Site A	41	33.3	
Site B	60	48.8	
Site C	22	17.9	
Dementia Diagnosis <sup>b</sup>			
Alzheimer's disease (AD)	71	57.7	
Vascular dementia (VD)	13	10.6	
Mixed AD & VD	15	12.2	
Dementia NOS	17	13.8	
Other <sup>c</sup>	8	6.4	

<sup>a</sup>Missing data – education (n=6, 4.9%), living situation (n=1, 0.8%)

<sup>b</sup>One case had two diagnoses

<sup>c</sup>Disseminated Lewy Body (n=3, 2.4%), Frontotemporal Dementia (n=2, 1.6%), HIV Dementia (n=1, 0.8%), Parkinson's-related Dementia (n=1, 0.8%), Alcohol-related Dementia (n=1, 0.8%).

**Table 2**  
 Bivariate Relationships Between Resident Characteristics and Having an Advance Directive<sup>a</sup> (AD) (n=123)

Characteristics	Total			No AD			Has AD			Statistic, p-value
	N	N	%	N	N	%	N	N	%	
Gender										
Male	55	23	41.8	32		58.2				$X^2=2.604, p=.017$
Female	68	19	27.9	49		72.1				
Age										
< 80 years	45	19	42.2	26		57.8				$X^2=2.971, p=.226$
80-89 years	63	17	27.0	46		73.0				
≥ 90 years	15	6	40.0	9		60.0				
Race										
White	103	26	25.2	77		74.8				Fisher's, $p<.001^b$
African American	20	16	80.0	4		20.0				
Education										
< High School Grad	40	24	60.0	16		40.0				$X^2=17.998, p<.001$
≥ High School Grad	77	16	20.8	61		79.2				
Marital Status										
Married or widowed	105	32	30.5	73		69.5				$X^2=4.298, p=.038$
Sep, div, never mar	18	10	55.6	8		44.4				
Living Situation Before Admission										
Lived alone	10	7	70.0	3		30.0				Fisher's, $p=.019^b$
Lived with others	112	35	31.2	77		68.8				
Study Site										
Site A	41	20	48.8	21		51.2				$X^2=16.129, p<.001$
Site B	60	10	16.7	50		83.3				
Site C	22	12	54.5	10		45.5				

<sup>a</sup> Advance directives are documents created before admission to facility describing treatment preferences, designating a health care agent, or both.

<sup>b</sup> Fisher's Exact Test

Table 3

Residents' Specified Treatment Wishes for End-of-Life Care (n=81)

Treatment Wishes	Wants		Forbids		Conditional or Time-Limited		Unclear / Contradictory		No Preference Stated		
	%	%	%	%	%	%	%	%	%	%	
<u>Supportive Care</u>											
Food by mouth	13.6 <sup>a</sup>		3.7 <sup>b</sup>		0.0		0.0		0.0		82.7
Water by mouth	13.6 <sup>a</sup>		3.7 <sup>b</sup>		0.0		0.0		0.0		82.7
Comfort care	35.8		0.0		0.0		3.7		0.0		60.5
Pain treatment	40.7		2.5		0.0		4.9		0.0		51.9
Hospice	2.5		0.0		0.0		0.0		0.0		97.5
<u>Active Treatment Interventions</u>											
Artificial nutrition & hydration	7.4		46.9		6.2		0.0		0.0		39.5
Tube feeding	1.2		9.9		0.0		0.0		0.0		88.9
Ventilator	0.0		12.4		1.2		0.0		0.0		86.4
Antibiotics	0.0		8.6 <sup>c</sup>		1.2		0.0		0.0		91.4
Dialysis	0.0		8.6 <sup>c</sup>		1.2		0.0		0.0		91.4
Hospitalization	0.0		0.0		0.0		0.0		0.0		100.0

<sup>a</sup>Same patients.<sup>b</sup>Same patients.<sup>c</sup>Same patients.