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## Level of Care Preferences Among Nursing Home Residents With Advanced Dementia

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### Abstract

**Context**—Delivering goal-directed care is a hallmark of high-quality palliative care, but requires an understanding of preferences.

**Objectives**—To describe and identify factors associated with level of care preferences among proxies of nursing home (NH) residents with advanced dementia.

**Methods**—NH residents with advanced dementia and their proxies ( $N = 402$  dyads) were recruited from 62 Boston-area facilities as part of an ongoing randomized clinical trial. At baseline, all proxies were asked to select which level of care they felt the resident should receive: intensive, basic, or comfort care. Multivariable logistic regression identified resident and proxy factors associated with a preference for comfort care (vs. basic or intensive medical care).

**Results**—Proxy level of care preferences were: comfort, 62.2%; basic, 31.1%; and intensive medical care, 6.5%. In multivariable analyses, proxy perception that the resident had less than six months to live was most strongly associated with a preference for comfort-focused care (adjusted odds ratio 12.25, 95% CI 4.04–37.08). Additional factors significantly associated with a preference for comfort care included older resident age, worse resident cognitive impairment, and the proxy having been asked about goals of care preferences by a NH health care provider (adjusted odds ratio 1.71, 95% CI 1.07, 2.74).

**Conclusion**—Most proxies select comfort as the preferred level of care for NH residents with advanced dementia. Discussions regarding prognosis, as well as inquiry about goals of care, are modifiable factors that may promote a preference for comfort care in this population.

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#### Disclosures

The authors declare no conflicts of interest.

## Keywords

Dementia; palliative care; preferences; nursing home; surrogate decision-making

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## Introduction

Alzheimer disease affects over five million Americans, and is the sixth most common cause of death in the U.S.<sup>1</sup> Research has helped characterize the clinical course of advanced dementia,<sup>2</sup> providing an opportunity for patients and their families to be informed about what to expect toward the end-stage of this disease and consider their treatment preferences. Despite this opportunity, the level of medical care desired by patients with advanced dementia as perceived by their proxies, and factors that influence these preferences are not well-described.

Delivering goal-directed care is a hallmark of high-quality palliative care,<sup>3</sup> but requires an understanding of preferences. Many factors potentially drive such preferences, including the clinical situation, how well patients or their proxies understand that situation, the quality of communication, and personal values. Prior work describing care preferences in advanced dementia is limited. In two large observational studies conducted by our group,<sup>2,4</sup> proxies of nursing home (NH) residents with advanced dementia were asked the extent to which they agreed or disagreed with the following statement: “The most important goal of [PATIENT]’s health care at this time is to keep [PATIENT] as comfortable as possible even if that means avoiding potentially life-prolonging medical interventions that may cause discomfort.” Although approximately 95% of proxies agreed or strongly agreed with this statement, interpretation of this finding is limited because treatment options are broader and more complex than the framing of this question. Another study, testing the effect of a video decision support tool, more explicitly described three goals of care options (i.e., comfort, basic, or life prolonging care), but participants were healthy older adults asked to hypothetically choose the care they would want if they had advanced dementia.<sup>5</sup> To our knowledge, no prior research has reported factors influencing level of care preferences among proxies of persons with advanced dementia.

To better examine treatment preferences in advanced dementia, we leveraged baseline data from an ongoing National Institutes of Health-funded randomized controlled trial (Educational Video to Improve Nursing home Care in End-stage dementia [EVINCE]). The objectives were to 1) describe level of care preferences among proxy decision-makers for NH residents with advanced dementia and 2) identify resident and proxy factors associated with a preference for comfort care.

## Materials and Methods

The Hebrew SeniorLife Institutional Review Board approved this study’s conduct. Data were obtained from the baseline assessments ascertained in the EVINCE study, an ongoing cluster randomized controlled trial being conducted in 62 Boston-area NHs (31 facilities/arm) evaluating an advance care planning video for advanced dementia. In both arms, proxies of recruited residents with advanced dementia participated in a baseline 10 minutes,

in-person interview with a research assistant that ascertained the proxies' perspectives about which of the three following levels of care the resident should receive: intensive medical care, basic medical care, or comfort care. Immediately following this interview, proxies in the intervention arm were shown a short video describing these levels of care using narration and video images, after which they were asked again about their preferred level of care. Proxies in the control arm were given no further information or asked any additional questions after the baseline interview.

The main EVINCE trial will compare pre-specified resident/proxy outcomes between the intervention and control facilities over 12 months. In this report, combined data from the baseline proxy interviews in both arms (i.e., pre-video in intervention arm) were analyzed to describe and identify resident and proxy factors associated with level of care preferences. Baseline proxy interviews began March 19, 2013 and were completed August 3, 2016. Twelve-month follow-up will be completed by August 30, 2017.

## Population

Residents' eligibility criteria included age  $\geq$  65 years, dementia (any type, from chart), an available English-speaking proxy, and Global Deterioration Scale (GDS) score of 7 (from nurse; range 1–7, higher scores indicate worse dementia).<sup>6</sup> A GDS score of 7 is characterized by profound memory deficits (cannot recognize family), verbal ability of less than five words, incontinence, and non-ambulatory. The proxy was the individual formally or informally designated to make medical decisions for the resident as documented in the medical record. At the time of facility recruitment and every three months thereafter, nurses on each NH unit were asked to identify residents with dementia at GDS Stage 7 and their proxies. Age and diagnosis of dementia were confirmed by chart review. Proxies of eligible residents were mailed study information and telephoned two weeks later to solicit their participation and obtain informed consent for themselves and the residents.

## Outcome

The outcome was the preferred level of care for the resident as ascertained at the proxy baseline interview. Proxies were read descriptions of three levels of care, and then asked to select the level that fit closest with the type of care they felt the resident should receive. The three levels were described exactly as follows: 1) Intensive medical care, includes the use of all medical treatments available, such as cardiopulmonary resuscitation (CPR), breathing machines, and feeding tubes. With intensive care, patients are sent to the hospital for serious illnesses and admitted to an intensive care unit if necessary; 2) Basic medical care, includes some, but not all, available medical treatments. Patients choosing basic care may get treated with antibiotics, fluids, or other medicines through a tube placed in a vein, and may be sent to the hospital for sudden illnesses. People choosing basic care want to avoid intensive medical treatments including CPR, breathing machines, tube-feeding, or treatment in an intensive care unit; and 3) Comfort care, includes only treatments that help relieve uncomfortable symptoms, for example, medications to relieve pain, and oxygen to reduce trouble breathing. People choosing comfort care do not want CPR, breathing machines, tube-feeding, or additional fluids, or medications given through a tube placed in a vein. With

comfort care, hospitalization is avoided unless the hospital is needed to relieve pain, such as to fix a hip fracture.

### Independent Variables

Independent variables were selected from the EVINCE database that were felt “a priori” to be potentially related to a level of care preference based on the literature<sup>2,4,5,7-9</sup> and our clinical experience. Baseline resident data abstracted from the chart included demographics (age, gender, and race [white vs. other]), etiology of dementia (Alzheimer disease vs. other), and common comorbidities (chronic obstructive pulmonary disease, congestive heart failure, and diabetes). Cognition was assessed directly by resident interview using the test for severe impairment (TSI; range 0–24, lower scores indicate greater impairment; dichotomized to either equal to 0 or greater than 0).<sup>10</sup> Nurses quantified functional status using the Bedford Alzheimer Nursing Severity-Subscale (BANS-S; range 7–28; higher scores indicate greater disability).<sup>11</sup> Other data abstracted from the chart included whether there was a documented discussion about goals of care between any NH provider and the proxy in the prior three months, and whether the resident experienced a hospital transfer (hospitalization or emergency room visit) or other sentinel event in the prior three months. Sentinel events were defined as any new major medical illness that could significantly alter the resident’s health status such as hip fracture, stroke, myocardial infarction, major gastrointestinal bleed, or new diagnosis of cancer (other than localized skin cancer).

Other proxy data ascertained in the baseline interviews included age, gender, years as proxy, relationship to resident (dichotomized as child vs. other), and whether they visited the resident over seven hours each week. Proxies were asked the following related to advance care planning: 1) if any health care provider had asked their opinion regarding the goals of care since NH admission, 2) whether any physician had ever counseled them about what types of health problems the resident may experience in advanced dementia, 3) whether they had ever participated in treatment decisions for the resident, and 4) whether they expected the resident to die within six months.

### Analysis

Analyses were conducted with SAS, version 9.4 (SAS Institute, Inc., Cary, NC). Variables were described using means with SDs and frequencies for continuous and categorical variables, respectively. Logistic regression was used to identify factors associated with whether the comfort was the preferred level of care vs. basic or intensive medical care. We considered analyzing the outcome as a three-level ordinal measure, but opted for the dichotomized format because the proportion of proxies opting for intensive medical care was relatively small.

Bivariate analyses were conducted to examine the unadjusted association between each independent variable and having comfort as a preferred level of care. Variables associated with outcome at  $P = 0.10$  in these unadjusted analyses were entered into a multivariable model. The final adjusted model included those variables significantly associated with a preference for comfort care at a  $P < 0.05$ . Generalized estimating equations accounted for clustering at the facility level. Odds ratios with 95% CIs were computed.

## Results

### Subject Characteristics

There were 1074 eligible residents with advanced dementia and their proxies identified of whom 402 resident/proxy dyads (37%) were recruited, a proportion comparable with prior studies involving similar cohorts.<sup>2,4,9</sup> Proxy refusal ( $N = 672$ ) was the only reason for non-participation. Non-participating and participating eligible residents did not differ with respect to age or gender.

Baseline resident characteristics included (Table 1) mean age,  $86.7 \pm$  (SD) 7.4 years; female, 80.3%; and white, 87.1%. A total of 47.3% residents had TSI scores of 0, and their mean BANS-S score was  $20.1 \pm$  (SD) 2.8, indicating severe cognitive impairment and functional impairment, respectively. Only 13.9% of residents had a documented goals of care discussion during the prior three months, and 8.2% had experienced a hospital transfer or other sentinel event during that period.

Proxies' characteristics were as follows (Table 1): mean age,  $62.3 \pm 10.8$  (SD) years; female, 66.2%; years as proxy,  $9.4 \pm 6.8$  (SD); child of resident, 63.7%; and visits more than seven hours per week, 21.4%. In terms of advance care planning, 68.4% of proxies stated that an NH provider had asked their opinion about the residents' goals of care since admission, whereas only 25.1% had been counseled about the types of health problems to expect in advanced dementia. Most proxies (89.3%) had participated in prior treatment decisions for the resident, and only 13.2% thought the resident had less than six months to live.

### Level of Care Preferences

The distribution of the proxies' preferences for the level of care they felt was the best fit for the residents was comfort care, 62.2% ( $N = 250$ ); basic medical care, 31.3% ( $N = 126$ ); and intensive medical care, 6.5% ( $N = 26$ ).

In the unadjusted analyses, the following resident variables were associated with a preference for comfort care at a  $P < 0.10$  and entered into the multivariable model: older age, female, white, Alzheimer disease (vs. other dementia), TSI score = 0, and worse functional status (higher BANS-S score). Proxy variables associated with a preference for comfort care at a  $P < 0.10$  in the bivariate analyses and entered into the multivariable model were more years as proxy, previously asked about goals of care, and perception the resident had less than six months to live. Being a child of a resident (vs. other relationship) was also associated with a lower likelihood of opting for comfort care in the bivariable analyses and entered into the adjusted model.

In the final multivariable model, the variable most strongly associated with a preference for comfort-focused care was the perception the resident had less than six months to live (adjusted odds ratios (AOR) 12.25, 95% CI 4.04–37.08). Other variables that remained independently associated with a preference for comfort care included older resident age (AOR 1.04, 95% CI 1.01, 1.07), TSI = 0 (AOR 2.04, 95% CI 1.32, 3.12), and the proxy having been asked about goals of care (AOR 1.71, 95% CI 1.07, 2.74).

## Discussion

In this report, most proxies preferred comfort care for NH residents with advanced dementia, with a minority opting for intensive medical treatments, and roughly one-third choosing basic medical care. The proxy's perception that the resident had less than six months to live was very strongly associated with a preference for comfort care. Discussions regarding prognosis, as well as inquiry about goals of care, are modifiable factors that may promote a preference for comfort care in this population.

This study confirms and furthers what is currently known about care preferences in advanced dementia. In our prior studies, approximately 95% of proxies agreed that comfort was their goal of care, but in the framing of the question, alternative options were not presented.<sup>2,4</sup> The present study suggests that embedded in that 95% are approximately one-third of proxies who would opt for basic medical care, which may include potentially curative treatments (e.g., antimicrobials) and hospitalization. The proportion of proxies strictly choosing comfort care (62%) was similar to that found in a comparable cohort when options were presented as three goals of care; "prolonging life, supporting function, or improving comfort."<sup>9</sup> As in earlier research,<sup>2,4,5,9</sup> only a small proportion of proxies felt residents with advanced dementia should receive intensive medical care (6.5%).

Our study identifies modifiable factors associated with a preference for comfort care, most notably, the proxy's belief that the resident had less than six months to live. A similar finding has been reported among cancer patients.<sup>12</sup> In a prior study, residents with advanced dementia whose proxies perceived their life expectancy was less than six months, received less aggressive care at the end-of-life (tube-feeding, hospitalization, or intravenous therapy).<sup>2</sup> Taken together, an understanding by proxies of the poor prognosis in advanced dementia appears to influence both expressed preferences and care received. It is challenging to precisely estimate survival in advanced dementia,<sup>13</sup> and the accuracy of the proxy's prognostic estimates are not known. Nonetheless, advanced dementia is characterized by a very high mortality rate and significant palliative care needs.<sup>2</sup> Thus, counseling of proxies that includes an explanation of this general poor prognosis, may shift the direction of care toward comfort. The finding that proxies who had been asked about goals of care were also more likely to prefer comfort care, further supports the role of counseling in this respect.

This study's limitations warrant discussion. As in other advanced dementia studies involving primary data collection,<sup>2,4,9</sup> there was a high proxy refusal rate. Although preferences may have differed between proxies who did and did not participate, this possibility is less likely to have impacted the analyses examining factors associated with a preference for comfort care. Other factors that may influence preferences, such as cultural beliefs, provider attitudes, or quality of counseling, were not examined. There also may have been inadequate power to find significant associations between some independent variables and a preference for comfort, particularly race. Finally, generalizability is limited to a mostly white cohort in Boston.

This study highlights several factors for clinicians to consider when discussing treatment preferences with proxies of NH residents with advanced dementia. First, it is important not

to simply present options as a dichotomous choice between comfort-focused vs. intensive medical care, as many proxies may feel treatments that lie between the two extremes best align with their goals. Second, counseling that includes a discussion of the limited life expectancy in advanced dementia and solicitation of treatment goals may be particularly pertinent to a proxy's decision to guide care toward a palliative approach.

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**Table 1**

Resident and Proxy Characteristics and Their Associations With a Preference for Comfort Care at Baseline ( $N = 402$  Resident/Proxy Dyads)<sup>a</sup>

Characteristic	No. (%) or Mean $\pm$ SD	Odds Ratio <sup>b</sup> (95% CI)	
		Unadjusted	Adjusted
Resident			
Age	86.7 $\pm$ 7.4	1.04 (1.01, 1.06) <sup>c</sup>	1.04 (1.01, 1.07)
Female	323 (80.3)	1.59 (0.96, 2.63) <sup>c</sup>	
White	350 (87.1)	2.62 (1.18, 5.79) <sup>c</sup>	
Alzheimer dementia (vs. other)	283 (70.4)	1.48 (0.93, 2.35) <sup>c</sup>	
Chronic obstructive pulmonary disease	48 (11.9)	0.91 (0.52, 1.61)	
Congestive heart failure	57 (14.2)	0.73 (0.43, 1.24)	
Diabetes	79 (19.7)	0.73 (0.42, 1.25)	
TSI = 0 <sup>d</sup>	190 (47.3)	1.89 (1.25, 2.86) <sup>c</sup>	2.04 (1.32, 3.12)
BANS-S <sup>e</sup>	20.1 $\pm$ 2.8	1.15 (1.07, 1.23) <sup>c</sup>	
Documented goals of care discussion in prior three months	56 (13.9)	0.94 (0.60, 1.48)	
Hospital transfer or other sentinel event in prior three months <sup>f</sup>	33 (8.2)	0.48 (0.20, 1.16)	
Proxy			
Age	62.3 $\pm$ 10.8	1.00 (0.98, 1.03)	
Female	266 (66.2)	1.19 (0.83, 1.69)	
Years as proxy	9.4 $\pm$ 6.8	1.03 (1.00, 1.06) <sup>c</sup>	
Child of resident	256 (63.7)	0.86 (0.52, 1.42) <sup>c</sup>	
Visits resident more than seven hours per week	86 (21.4)	0.72 (0.43, 1.21)	
Asked about goals of care by any health care provider since nursing home admission	275 (68.4)	1.73 (1.13, 2.65) <sup>c</sup>	1.71 (1.07, 2.74)
Received counseling about expected health problems in advanced dementia by a physician	101 (25.1)	0.81 (0.51, 1.28)	
Participated in prior treatment decision for the resident	359 (89.3)	1.11 (0.59, 2.08)	
Proxy perceived resident has less than six months to live	53 (13.2)	12.85 (4.25, 38.90) <sup>c</sup>	12.25 (4.04, 37.08)

TSI = test for severe impairment; BANS-S = Bedford Alzheimer's Nursing Severity-Subscale.

<sup>a</sup>62.2% ( $N = 250$ ) of proxies preferred comfort care vs. 37.8% ( $N = 152$ ) who wanted intensive or basic care.

<sup>b</sup>Unadjusted and adjusted odds ratios account for clustering at the facility-level using generalized estimating equations.

<sup>c</sup>Variables that were significant at  $P < 0.10$  in bivariable analyses and entered into the multivariable model.

<sup>d</sup>TSI, range 0–24, lower scores indicate greater cognitive impairment.

<sup>e</sup>BANS-S, range 7–28, higher scores indicate more functional disability.

<sup>f</sup>Hospital transfer includes hospitalization or emergency room visit. Sentinel events defined as any new major medical illness that significantly altered the resident's health status such as hip fracture, stroke, myocardial infarction, major gastrointestinal bleed, and/or new diagnosis of cancer (other than localized skin cancer).