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Health Care Proxies of Nursing Home Residents with Advanced Dementia: Decisions They Confront and Their Satisfaction with Decision-Making

Jane L Givens, MD, MSCE^{1,2,3}, Dan K Kiely, MPH, MA², Kristen Carey, BS, BA³, and Susan L Mitchell, MD, MPH^{1,2,3}

¹Beth Israel Deaconess Medical Center, Division of Gerontology, Boston, MA

²Hebrew SeniorLife Institute for Aging Research, Boston, MA

³Harvard Medical School, Boston, MA

Abstract

Objectives—To describe the medical decisions confronting health care proxies (HCPs) of nursing home (NH) residents with advanced dementia and identify factors associated with greater decision-making satisfaction.

Design—Prospective cohort study.

Setting—22 Boston-area NHs.

Participants—323 NH residents with advanced dementia and their HCPs.

Measurements—Decisions made by HCPs over 18-months were ascertained quarterly. After making a decision, HCPs completed the Decision Satisfaction Inventory (DSI) (range 0–100). Independent variables included HCP and resident sociodemographics, health status, and advance care planning. Multivariable linear regression identified factors associated with higher DSI scores (greater satisfaction).

Results—Of 323 HCPs, 123 (38.1%) recalled making at least one medical decision. A total of 232 decisions were made, concerning feeding problems (27.2%), infections (20.7%), pain (12.9%), dyspnea (8.2%), behavior problems (6.9%), hospitalizations (3.9%), cancer (3.0%) and other complications (17.2%). The mean DSI score was 78.4 ± 19.5 (SD), indicating high overall satisfaction. NH provider involvement in shared decision-making was the area of least satisfaction. In adjusted analysis, greater decision-making satisfaction was associated with the resident living on a special care dementia unit ($p=0.002$), greater resident comfort ($p=0.004$), and the HCP not being the resident's child ($p=0.02$).

Conclusion—HCPs of NH patients with advanced dementia can most commonly expect to encounter medical decisions relating to feeding problems, infections and pain. Inadequate support

Corresponding author: Jane L Givens, MD, MSCE, Hebrew SeniorLife Institute for Aging Research, 1200 Centre Street, Boston, MA, 02131., Tel: 617 363-8865, Fax: 617 363-8936. JaneGivens@hrca.harvard.edu.

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from NH providers is the greatest source of HCP dissatisfaction with decision-making. Greater resident comfort and care in a special care dementia unit are potentially modifiable factors associated with higher decision-making satisfaction.

Keywords

Health care proxy; surrogate decision-making; advanced dementia

INTRODUCTION

Dementia is an increasingly common and morbid condition. In the year 2000, an estimated 4.5 million Americans were affected with dementia, a number expected to exceed 13 million by the year 2030.¹ Nursing homes (NHs) play an important role in the care of patients with end-stage dementia. As many as 90% of patients with end stage dementia can expect to be cared for in a NH², and this will be the site of death for 70% of Americans with dementia.³

The course of advanced dementia is one of progressive but often erratic decline. During the end-stage of this disease, patients typically experience “sentinel events” that require decision-making to direct care either towards palliation or more aggressive measures. These events may include the onset of clinical complications that are expected in end-stage dementia (e.g., eating difficulties, recurrent infections), as well as the occurrence of acute conditions common among frail NH residents (e.g., hip fracture). Decision-making is particularly challenging in advanced dementia owing to the lack of high quality outcome data, the inability to accurately estimate life expectancy, reliance on surrogate decision-making and emotional and value-laden choices.

Surrogate decision making for patients with advanced dementia is common,⁴ although prior research suggests that surrogates feel unprepared and unsupported in making medical decisions in the NH setting.^{5–7} Limitations of this earlier work include the utilization of hypothetical scenarios to investigate surrogate decision-making^{8, 9}, retrospective study designs⁶ and small sample sizes.⁸ The types of decisions actually confronted by surrogates of NH residents in the final end-stages of dementia and the quality of the decision-making process have never been rigorously described. Therefore, this study utilized data from a prospective cohort of 323 NH residents with advanced dementia and their surrogates in order to: 1. determine the types of medical decisions that arise during the end-stage of the disease; and 2. to identify factors associated with greater satisfaction with the decision-making process.

METHODS

The institutional review board of Hebrew SeniorLife approved this research study.

Study Population

Participants were from an on-going, prospective cohort study of NH residents with advanced dementia and their health care proxies (HCPs) entitled Choices, Attitudes and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE).¹⁰ The CASCADE study population is comprised of NH resident and HCP dyads. NH residents were recruited from 22 NHs within a 60-mile radius of the city of Boston and larger than 60 beds, based on the following eligibility criteria: 1) age > 60; 2) a diagnosis of dementia (any type); 3) Cognitive Performance Score¹¹ (CPS) of 5 or 6; and 4) a Global Deterioration Scale¹³ (GDS) score of 7. NH residents in subacute rehabilitation units were excluded.

The CPS uses 5 variables from the Minimum Data Set (MSD)¹² to group patients into the following 7 cognitive performance categories: 0=intact, 1=borderline intact, 2=mild impairment, 3=moderate impairment, 4=moderately severe impairment, 5=severe impairment,

and 6=very severe impairment. The MDS is a federally mandated, standardized assessment instrument completed on all NH residents. The GDS classifies dementia into 7 stages (1–7) based on broad descriptions of their cognitive and functional impairment. At GDS stage 7, dementia patients have very severe cognitive deficits (cannot recognize family members), minimal verbal communication, total functional dependence, incontinence of urine and stool, and inability to ambulate independently.

Finally, NH residents were also required to have a designated HCP who could be contacted, provide informed consent (for the resident and themselves) and communicate in English. The HCPs were designated in the medical record as the resident's Health Care Agent, empowered to make medical decisions under the Massachusetts Health Care Proxy Law.

Data Collection

Resident data were obtained from baseline and quarterly reviews of medical records, interviews with nursing staff and brief clinical examinations. HCP data were obtained from baseline and quarterly telephone interviews conducted by trained research assistants. Resident/HCP dyads were followed until death of the resident for a maximum of 18 months. If the resident died, a resident death assessment was conducted within 14 days of death and their HCP was interviewed 2 months post-death.

Medical Decision-Making

At the quarterly and 2-month post death interviews, HCPs were asked if they had made any decisions regarding the resident's medical treatment during the intervening assessment period. The nature of all decisions were ascertained and grouped into the following categories, (determined *a priori*): eating and drinking problems; pneumonia; febrile illness; pain; hip fracture; acute stroke; myocardial infarction; gastrointestinal bleeding; cancer; shortness of breath; behavior problems; or transfer to the hospital. Decisions that did not fit into one of these *a priori* categories were recorded verbatim.

Satisfaction with Medical Decision-Making

In order to evaluate the quality of the decision-making process, the Decision Satisfaction Inventory (DSI)¹⁴ was administered to the HCPs at each assessment if they had participated in at least one decision during the intervening period. Only one DSI score was collected at each assessment even if the HCP had made more than one decision during the intervening 3-month interval period (i.e., DSI score reflected overall satisfaction with medical decision-making, but did not necessarily pertain to a single decision). The DSI is a comprehensive, validated measure that captures many components of the decision-making process. It consists of 15 items divided into two subscales. Items 1–12 measure aspects of the "decision-making process" (alpha statistic = 0.95), which address issues including: 1. the degree to which HCPs felt involved in the process; 2. the support and reassurance provided by health care professionals; 3. the amount of information received; and 4. the level of interest, attention and time spent by the health care professional. Answers are rated on a 5-point Likert scale ranging from strongly disagree to strongly agree. Items 13–15 measure satisfaction with the "decision made" (alpha statistic = 0.85), and address the degree to which the HCP felt the right decision was made. Answers are rated on a 5-point scale ranging from poor to excellent. (Table 2) The total DSI score as well as the subscale scores reflect the summation of items transformed onto a scale from 0–100 with higher scores reflecting greater satisfaction.

HCP and Resident Characteristics

HCP and resident characteristics potentially related to satisfaction with the decision-making process were selected for analysis 'a priori'.⁸ HCP characteristics obtained at baseline included:

age; sex; race (white vs. other); marital status (married/living with partner vs. other); educational level (college education or greater vs. other); work status (full time vs. other); primary language (English vs. other); relationship to resident (child vs. other); years as HCP; whether the HCP lived with resident prior to entry into NH; and whether the HCP spent at least 15 minutes talking to a health care professional about advance directives at time of resident entry into the NH. HCP information obtained at each assessment included: the SF-12,¹⁵ a measure of physical and mental health (US population normative mean of 50 with a standard deviation of 10 points, higher scores indicating greater physical or mental health); the time the HCP spends visiting resident (greater than 7 hours/week vs. other); whether the HCP believes the resident has 6 months or less to live; whether the HCP believes dementia is a terminal illness; whether the HCP's goal for resident treatment is comfort care; and whether the HCP has an understanding of the medical complications that may occur in end-stage dementia.

Baseline NH resident characteristics included the following: sociodemographic measures (age, sex, race [white vs. other], marital status); whether the resident lived on a special care dementia unit; and the length of NH stay. In addition, at each assessment the following information was ascertained from a nurse with primary care responsibilities for the resident: the Bedford Alzheimer's Nursing Severity Subscale¹⁶ (BANS-S) which is a measure of functional status (range 7–28, higher scores indicate greater functional disability); resident comfort as measured by the Symptom Management at End-Of-Life in Dementia scale¹⁶ (SM-EOLD) (range 0–45, higher scores indicate greater comfort); and overall quality of life as measured by the Quality of Life in Late-Stage Dementia¹⁷ (QUALID) (range 11–55, lower scores indicate higher quality of life). Finally, cognitive status was measured at each assessment by direct examination of the resident using the Test for Severe Impairment¹⁸ (TSI) (range 0–24, lower scores indicate greater impairment). As 90.2% of residents scored 0 on the TSI, this variable was dichotomized as > 0 vs. 0.

Statistical Analysis

Descriptive statistics including means and proportions were calculated for all HCP and resident characteristics. For baseline characteristics, these descriptive statistics were based on the total number of HCPs who made at least one decision in the follow-up period. For measures obtained at each quarterly assessment, statistics were based on the total number of assessments where decisions were made. The types of decisions made were described using proportions. The mean total DSI score and subscale scores were calculated, as well as the frequencies of responses to the individual DSI items. The mean scores for the subscales were compared using t-tests.

Linear regression was used to identify HCP and resident characteristics (independent variables) associated with greater decision satisfaction (DSI score)(outcome). The unit of analysis was the assessment. HCPs who were involved in medical-decision making at more than one assessment had the potential to contribute multiple DSIs over the entire 18-month follow-up period. Whenever possible, independent variables were selected from the same assessment from which the DSI was ascertained. Fixed HCP and resident variables (e.g., age and gender) were brought forward from the baseline assessment. A small number of variables were not collected at the resident death assessment (e.g., BANS-S), and therefore were brought forward from the assessment immediately preceding death. Unadjusted associations between each individual HCP and resident characteristic with the total DSI score were determined. All variables significantly associated with the DSI score in the unadjusted analyses at the level of $p < 0.1$ were included in the multivariable linear regression model. Given that individual HCPs had the potential to complete more than one DSI score, multivariable analyses were adjusted for clustering at the level of the individual using a robust estimate of variance. All statistical analyses were performed using STATA SE version 10.0 (STATA Corporation, College Station, TX).

RESULTS

Health Care Proxy and Resident Characteristics

Of 323 HCPs of residents with advanced dementia, 123 (38.1%) recalled having made at least one medical decision during the study period. HCPs who made medical decisions were younger (mean age 57.5 vs. 61.4, $p = 0.003$), and more likely to be married (75.6% vs. 63.0%, $p = 0.019$) compared to those who did not make any medical decisions. The characteristics of the 123 HCPs who made decisions, and the residents they represented are displayed in Table 1. The mean age of the HCPs was 57.5 ± 10.5 (SD) years, and the majority were female (62.6%), white (93.5%), married (75.6%), and college educated (61.8%). The distribution of their relationship to the residents was: child (74.0%); spouse (9.8%); niece or nephew (7.3%); sibling (2.4%); grandchild (0.8%); legal guardian (3.3%); other (2.4%). Just over one-third of HCPs (35.8%) lived with the resident prior to NH entry, the average time as HCP was 7.3 ± 4.8 (SD) years, and 23.0% visited the resident more than 7 hours per week. The HCP's SF-12 mean physical and mental subscale scores were 50.9 ± 9.6 (SD) and 50.7 ± 9.4 (SD) respectively. A total of 27.1% of HCPs felt that the resident had more than six months to live, although the majority (74.1%) believed that dementia was a terminal illness. An overwhelming majority of HCPs (96.6%) felt that comfort care was the goal of treatment, and most felt they understood the medical aspects of advanced dementia (83.6%). Only 50.4% of HCPs had spent at least 15 minutes discussing advance directives with a NH provider at the time the resident was admitted.

The mean age of the residents was 84.0 ± 7.0 (SD) years, the majority were female (91.1%), white (94.3%), and married (18.7%). A total of 43.9% of the residents lived on a special care dementia unit and 59.2% had a do-not-hospitalize (DNH) order. Health status assessments including the BANS-S and TSI scores indicated that the residents had advanced functional and cognitive impairment. The mean resident symptom (SM-EOLD) and quality of life (QUALID) scores were 34.7 ± 8.8 (SD) and 24.2 ± 6.6 (SD), respectively.

Decisions and Satisfaction with Decision-Making

A total of 232 decisions were made by 123 HCPs, 109 of whom made more than one decision. Figure 1 presents the nature of these 232 decisions. The most commonly encountered decisions involved the management of eating and drinking problems (27.2%), closely followed by the treatment of infections (combined pneumonia and febrile illness categories) (20.7%). Pain was the next most commonly encountered decision (12.9%). The remaining decisions included treatments related to: shortness of breath (8.2%); behavioral problems (6.9%); hospitalizations (3.9%); cancer (3.0%); and other conditions (17.2%). Categories within the other conditions grouping include: seizures (3.8%), hematological issues (2.6%), dental problems (2.2%), fracture (any type) (2.2%), swollen limb (1.3%), vomiting (1%), nephrolithiasis (1%), management of benign tumors (1%), stroke (1%), other surgery (0.4%), hospice referral (0.4%), peptic ulcer (0.4%), medication changes (0.4%).

Only one DSI score was ascertained at each quarterly assessment, even when the HCP had been involved in multiple decisions during the intervening 3-month interval period. Thus, although a total of 232 decisions were made, only 174 DSIs scores were collected and available for analysis. The mean total DSI score was 78.4 ± 19.5 (SD). The mean score for the 12-item decision-making process subscale was significantly lower than that for the 3-item decision subscale [76.7 ± 21.2 (SD) vs. 85.5 ± 16.4 (SD) respectively] ($p < 0.001$). Table 2 presents the percent responses for each individual DSI item. Responses indicating the lowest levels of satisfaction were those related to the HCP's rating of the primary care provider's reassurance and support (fair or poor, 19%), the amount of information received about the problem and its

treatments (fair or poor, 15%), and the time spend with the primary care provider (fair or poor, 15%).

Table 1 presents the unadjusted associations of each HCP and resident characteristic with greater total DSI scores. Variables associated with greater DSI scores in these unadjusted analyses at a $p < 0.1$ level included: HCP was not the resident's child, HCP lived with resident prior to NH admission, HCP visited the resident greater than seven hours per week, higher scores on the HCP SF-12 mental subscale, goal of treatment is comfort care, resident lived on a special care unit, greater resident length of NH stay, higher SM-EOLD scores (greater resident comfort), and having a DNH order. After entering these variables into a multivariable linear regression model accounting for clustering at the level of the HCP, higher DSI scores were significantly associated with the following: HCP not being a child of the resident, the resident living on a special care unit, and higher SM-EOLD scores (Table 3).

DISCUSSION

To our knowledge, this is the first study to prospectively examine decision-making among HCPs of NH patients with advanced dementia. Of 323 HCPs in our cohort, 123 (38.1%) recalled having made at least one medical decision over the 18-month follow-up period, of which the most frequently encountered involved the treatment of eating and drinking problems, infections and pain. Satisfaction with decision-making was generally high, although there was relatively greater satisfaction with the decision itself, compared to the decision-making process. Specifically, HCPs were least satisfied with the perceived level of involvement of NH primary care providers in the shared decision-making process. Modifiable factors associated with higher levels of overall decision satisfaction included the resident living on a special care dementia unit and greater resident comfort. Our finding that children of NH residents with advanced dementia were relatively less satisfied with decision-making may be helpful for NH providers to target those in need of greater decision-making support.

Our work supports prior research demonstrating that feeding problems, infectious episodes and pain are common clinical complications in dementia,^{19–22} but furthers this earlier work by showing that these problems are not only burdensome to the resident, but also to their HCPs in terms of decision-making. Advance care planning is a key process in choosing care at the end-of-life. Prior research has shown that families of dementia patients often feel unprepared about what to expect at the end of life.²³ Thus, an understanding of the most common types of decisions likely to arise in end-stage dementia provides an opportunity for HCPs and patients with early disease to prepare for the difficult choices they will face, and for them to consider their preferences for care in advance.

Despite the inherent challenges involved in surrogate decision-making for persons with advanced dementia, HCPs in our study reported relatively high levels of overall decision satisfaction. Satisfaction with the process of decision-making was significantly lower than satisfaction with the decision itself, most notably due to dissatisfaction with the level of perceived involvement by NH primary care providers. Decision-making support from health care professionals is a key component of quality end-of-life care.^{24,5} Unfortunately, prior research has shown that families often feel that this support is inadequate, particularly in the NH setting.^{6, 23, 25, 26} As such, our findings further support the notion that greater communication, provision of information, reassurance and support by NH providers to HCPs during times of decision-making offers an opportunity to improve overall end-of-life care in the NH setting.

In this study, the strongest predictors of satisfaction with decision-making were the resident living on a special care dementia unit and higher levels of resident comfort. It is reasonable to

assume that HCPs will be more comfortable with their decisions when their loved ones experience less suffering. The reason why satisfaction with decision-making was higher on these units cannot be determined from our study. However, prior research in advanced dementia has shown that HCP overall satisfaction with end-of-life care and residents' symptom control are better on special care dementia units compared to general NH units.^{27, 28} Finally, we found that HCPs who were children of residents were less satisfied with decision-making compared to other surrogates. Prior work has shown that HCPs who are children are also less likely to forgo hospitalizations for NH residents with advanced dementia.²⁹ Taken together, these findings suggest that children may derive particular benefit from counseling by health care professionals when faced with treatment decisions for their parents with end-stage dementia.

The results of this study should be interpreted in light of certain limitations. Although data were collected from multiple NHs, the fact that the HCPs and residents were mostly white, predominantly women, and all lived in the Boston area, may limit the generalizability of our findings. In this study, we relied on HCP self-report of medical decisions, which introduces the possibility of recall bias; it is possible that HCPs did not recall some decisions in which they participated in, or their recall may have been affected by the outcome of the decision, which was not examined in this analysis. It is also possible that HCPs were not contacted by NH providers to discuss all the treatment decision opportunities that arose during the residents' course.

Surrogate decision-making is challenging in advanced dementia. The findings of this study offer some approaches that may alleviate this burden. Knowing which decisions are most likely to arise during the end-stage of the disease could ease decision-making by allowing the surrogate to anticipate their choices and by providing the opportunity for advance care planning. Our findings further underscore that providing adequate decision support is a critical means by which NH providers can help minimize the challenge of decision-making for proxies. Further, care directed towards maximizing resident comfort may ease the decision-making burden experienced by surrogates. Finally, additional research is needed to elucidate the mechanisms by which specialized dementia care units promote greater decision-making satisfaction, and thus, to identify strategies to disseminate their success to other NH settings.

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Figure 1.
Frequency of the types of medical decisions made by health care proxies of nursing home patients with advanced dementia (N=232 decisions)

Table 1

Characteristics of Health Care Proxies and Nursing Home Residents with Advanced Dementia (N=123); and Their Unadjusted Association with Greater Satisfaction with Decision Making*

Characteristic	N (%) or mean ($\pm$ SD)	p-value	Beta coefficient (95% Confidence Interval)
Health Care Proxy			
Age in years, mean ($\pm$ SD)	57.5 (10.5)	0.27	0.16 (−0.13,0.45)
Female gender, n (%)	77 (62.6)	0.14	−4.48 (−10.50,1.55)
Race, white vs. other, n (%)	115 (93.5)	0.76	−2.07 (−15.26,11.13)
Married vs. other, n (%)	93 (75.6)	0.11	−5.46 (−12.09,1.16)
College education or greater, n (%)	76 (61.8)	0.29	−3.31 (−9.42,2.79)
Currently working full time, n (%)	63 (51.2)	0.93	0.34 (−7.10,7.78)
English is primary language vs. other, n (%)	121 (98.4)	0.47	8.18 (−14.24,30.61)
HCP is not the resident's child, n (%)	32 (26.0)	0.05	6.38 (−0.05, 12.81)
Lived with resident prior to NH, n (%)	44 (35.8)	0.01	−7.85 (−13.82,−1.88)
Visits resident > seven hours per week, n (%)	40 (23.0) [†]	0.004	−9.93 (−16.72,−3.15)
Years as HCP, mean ($\pm$ SD)	7.3 (4.8)	0.15	0.47 (−0.17, 1.11)
SF-12: physical [‡] , mean ($\pm$ SD)	50.9 (9.6) [†]	0.95	0.01(−0.30,0.32)
SF-12: mental [§] , mean ($\pm$ SD)	50.7 (9.4) [†]	0.03	0.35 (0.04–0.66)
Believes resident has $\leq$ 6 months to live, n (%)	45 (27.1) [†]	0.93	0.32 (−6.45,7.10)
Believes dementia is a terminal illness, n (%)	129 (74.1) [†]	0.28	−3.63 (−10.29,3.02)
Goal of treatment is comfort care, n (%)	168 (96.6) [†]	0.04	16.44 (0.61,32.27)
HCP believes they know the problems to expect in late dementia, n (%)	142 (83.6) [†]	0.35	3.72 (−4.03,11.47)
$\geq$ 15 min discussing advance directives, n (%)	59 (50.4)	0.27	3.38 (−2.60,9.37)
Resident			
Age in years, mean ($\pm$ SD)	84.0 (7.0)	0.50	0.14 (−0.27,0.56)
Female gender, n (%)	112 (91.1)	0.46	3.67 (−6.16,13.50)
Race, white vs. other, n (%)	116 (94.3)	0.88	−1.05 (−15.01,12.91)
Married vs. other, n (%)	23 (18.7)	0.13	−6.03 (−13.83,1.76)

Characteristic	N (%) or mean ($\pm$ SD)	p-value	Beta coefficient (95% Confidence Interval)
Lives on special dementia unit, n (%)	54 (43.9)	<0.001	10.72 (5.09,16.34)
Baseline length of stay in weeks, mean (SD)	192 (171)	0.08	0.02 (−0.00,0.03)
BANS-S [¶] , mean ($\pm$ SD)	21.7 (2.2) [†]	0.78	0.19 (−1.12,1.49)
TSI [#] > zero, n (%)	17 (9.8) [†]	0.75	1.61 (−8.24,11.45)
SM-EOLD ^{**} , mean ($\pm$ SD)	34.7 (8.8) [†]	0.001	0.55 (0.23,0.87)
QUALID ^{††} , mean ($\pm$ SD)	24.2 (6.6) [†]	0.34	−0.22 (−0.66,0.23)
Do not hospitalize (DNH) order on file, n (%)	103 (59.2) [†]	0.03	6.53 (0.67,12.40)

* Decision-making satisfaction was measured with the Decision Satisfaction Inventory, (DSI) (range 0–100, with higher scores indicating greater satisfaction)

[†] Indicates number and percent out of 174 assessments where a medical decision was made

[‡] SF-12 physical —Medical Outcomes Survey 12-item Short Form (US population normative mean of 50 with a standard deviation of 10, higher scores indicating greater physical health)

[§] SF-12 mental —Medical Outcomes Survey 12-item Short Form (US population normative mean of 50 with a standard deviation of 10, higher scores indicating greater mental health)

[¶] BANS-S—Bedford Alzheimer Nursing Scale—Severity Subscale (possible scores 7–28; higher scores indicate greater functional disability)

[#] TSI – Test for Severe Impairment (possible scores 0–24; lower scores indicate greater impairment)

^{**} SM-EOLD—Symptom Management at the End-of-Life in Dementia Scale (possible scores 0–45; higher scores indicate greater comfort).

^{††} QUALID—Quality of Life in Late-Stage Dementia (possible scores 11–55; lower scores indicate greater quality)

Table 2
Individual Decision Satisfaction Inventory Item Percent Responses (N=174), As Reported by 123 Health Care Proxies

Decision Satisfaction Inventory items	% Item Response				
	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
Satisfied my opinion was important*	64	29	2	5	0
Feel that the right choice was made [†]	61	34	2	2	1
Satisfied with the decision made [†]	60	36	1	2	1
I had enough input in treatment decision*	56	38	2	4	0
I received enough information about problem*	53	32	3	10	1
I was adequately informed about treatment choices*	52	35	5	7	2
I relied too much on the doctor's opinion*	1	9	1	54	35
	Excellent	Very good	Good	Fair	Poor
Treatment decision [†]	47	31	16	3	2
Primary care provider's personal interest*	43	27	17	5	8
Primary care provider's attention given to my opinion*	43	31	18	6	2
Primary care provider's reassurance and support*	41	23	17	8	11
Amount of information about problem and treatments*	41	27	17	10	5
Explanation of treatments*	39	32	18	4	8
Time spent with primary care provider*	37	25	23	9	6
Amount of help from primary care provider in making decision*	36	28	25	6	5

* Item included in satisfaction with the decision-making process subscale

[†] Item included in satisfaction with the decision made subscale

Table 3

HCP and Resident Characteristics Associated with Greater 15-item Decision Satisfaction Inventory Scores in Adjusted Linear Regression, (N=174)

Characteristic	p-value	Beta coefficient (95%CI) [*]
Health Care Proxy is not the resident's child	0.02	7.10 (1.12,13.07)
Resident lives on special care dementia unit	0.002	9.48 (3.52,15.44)
SM-EOLD [†]	0.004	0.49 (0.16,0.83)

^{*} Also adjusted for resident length of stay, DNH status, HCP lived with resident, HCP visits resident >7 hrs per week, SF-12 mental subscale, stated goal is comfort care.

[†] SM-EOLD—Symptom Management at the End-of-Life in Dementia Scale (possible scores 0–45; higher scores indicate greater comfort)