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Advance Care Planning in Nursing Homes and Assisted Living Communities

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Abstract

Objectives—To determine the prevalence and characteristics of advance care planning (ACP) among persons dying in long-term care (LTC) facilities, and to examine the relationship between respondent, facility, decedent, and family characteristics and ACP.

Design—After-death interviews of family members of decedents and facility liaisons where decedents received care.

Setting—Stratified sample of 164 residential care/assisted living facilities and nursing homes in Florida, Maryland, New Jersey, and North Carolina.

Subjects—Family members and facility liaisons who gave 446 and 1014 reports, respectively, on 1015 decedent residents.

Measurements—Reports of death/dying discussions, known treatment preferences, and reports and records of signed living wills (LW), health care powers of attorney (HCPOA), do-not-resuscitate orders, and do-not-hospitalize orders.

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CONFLICTS OF INTEREST None

Results—Family respondents reported a higher prevalence, compared with facility reports, of HCPOAs (92% vs 49%) and LWs (84% vs 43%). In family reports, non-white race and no private insurance were significantly associated with lower prevalence of LWs and HCPOAs; additionally, residing in nursing homes (vs assisted living facilities) and in North Carolina were associated with lower prevalence of reported LWs. In facility reports, non-white race, unexpected death and residing in North Carolina or Maryland were significantly associated with lower prevalence of LWs, whereas high Medicaid case mix, intact cognitive status and high family involvement were associated with lower prevalence of HCPOAs. Concordance of family and facility reporting of HCPOAs was significantly greater in facilities with fewer than 120 beds.

Conclusions—The prevalence of ACP in LTC is much higher than previously described, and there is marked variation in characteristics associated with ACP, despite moderately high concordance, when reported by the facility or family caregivers.

Keywords

Advance care planning; end-of-life care; long-term care; nursing home; assisted living

INTRODUCTION

Advance care planning (ACP) – the process of reflection, discussion, and communication of treatment preferences among dying patients, family members, and care providers – has been advocated as a primary goal of quality end-of-life care.[1–3] ACP involves an active interchange among stakeholders that occurs predominantly within healthcare settings when individual values are considered and communicated in light of treatment options.[2, 4] As a result, ACP is often focused on the documentation of decision-making in the form of advance directives (ADs) within institutional contexts, such as hospitals[5, 6] and nursing homes.[7–14]

Long-term care (LTC) facilities are becoming more frequent settings where patients live their final weeks and experience death; in fact, the proportion of deaths occurring in nursing homes is expected to double over the next 20 years.[15] Epidemiologic studies report that 25% of deaths in older adults occur in nursing homes (NHs)[16] and that two-thirds of NH residents remain in a LTC facility until their death, rather than being transferred to the hospital.[17] These studies also report that annual mortality rates for residents of residential care/assisted living (RC/AL) facilities (i.e., those that provide room, board, assistance with activities of daily living and protective oversight) range from 16% to 22%.[16]

Ideally, ACP within LTC facilities should be individualized for each resident. Further, cognitively unimpaired residents, family members, and staff should be well-informed and concordant in their understanding about decisions made about treatment options.[3, 13, 18] Unfortunately, this is not always the case. Prior research that has examined the prevalence and factors associated with advance directives in NHs has utilized administrative datasets,[7–10] chart abstractions of NH records,[11–14] and interviews with facility staff or resident proxies.[13, 14] For example, an analysis using the 1993 Minimum Data Set reported a 17% prevalence of do-not-resuscitate orders (DNRs)[7] while a chart review of NH records from 10 states in the same period documented a DNR prevalence of 31%.[12] It could be that heterogeneity in data sources and outcome measures contributes to wide variation in the reported prevalence of ADs within NHs, but other factors may be operative as well.[19] Earlier studies of ACP have also been restricted to NH settings, which limits understanding of other long-term care venues such as assisted living. No prior study has examined characteristics that relate to the concordance of ACP reporting by family members and LTC staff, which would be helpful to understand in instances when conflict occurs.

As part of a study of end-of-life care experiences in RC/AL facilities and NHs in four states, we sought to describe, compare, and evaluate the structure and process of end-of-life care for residents who died in, or were transferred up to three days before their death from LTC facilities. After-death interviews with family members of decedents and their staff caregivers from a stratified sample of 164 LTC facilities were used to address the following study aims: (1) to determine the prevalence of ACP in LTC; (2) to examine the relationship between resident, family, and facility characteristics and ACP among dying residents in LTC facilities, and; (3) to identify factors that relate to the concordance of facility and family reports of ACP.

METHODS

Identification and Recruitment of Study Facilities and Subjects

A total of 230 RC/AL facilities and NHs from four states (Florida, Maryland, New Jersey, North Carolina) participating in the Collaborative Studies of Long-Term Care (CS-LTC) agreed to identify decedents for this project. Sample facilities included NHs and three types of RC/AL facilities: (1) facilities with fewer than 16 beds; (2) larger “new-model” facilities, tending to have nursing support available and private accommodations; and (3) larger “traditional” facilities that do not meet the “new-model” definition established in previous work.[20] Details and an overview of the CS-LTC typology are described elsewhere.[21]

At the time of facility recruitment, a facility liaison (the administrator, care supervisor or a designee) was identified and later contacted monthly by telephone to determine if any residents had died in the preceding 30 days. To be eligible, residents had to have died in a participating CS-LTC facility, or within three days of leaving the facility by transfer or discharge. Since we were examining end-of-life care in LTC, resident deaths were eligible only for those who had been living in the facility for at least 15 days in the last month of life. If the decedent was eligible, the facility liaison was asked to provide the name and contact information of a family member or responsible party who was most familiar with the decedent’s care in the last month of life.

Data Collection

Once eligibility was determined, the liaison provided information about the AD on file. Also, a condolence letter and consent form introducing the study was mailed four weeks after the date of death to the deceased resident’s identified family member. Interviewers followed up at least six weeks after the date of death to obtain verbal consent and conduct a telephone interview with family members; interviews lasted 45 to 90 minutes. A staff caregiver also provided data, and facility-level data were collected via telephone interviews with facility administrators. Reports were obtained on 1,015 decedent residents from 164 facilities. Facility reports were obtained for 1,014 of the decedents, and family reports were obtained from 446 families of decedents. In all, 31 NHs, 62 RC/AL facilities (<16 beds), 23 traditional RC/AL facilities, and 48 new-model RC/AL facilities participated. The study was reviewed and approved by the Institutional Review Board of the University of North Carolina at Chapel Hill prior to its initiation.

Study Measures

The facility liaison reported demographic information about the decedent resident, (including gender, race, age and length of stay) as well as whether the decedent had ADs known to the facility. Family respondents provided demographic information about themselves and their relationship to the decedent. They also reported their level of involvement with the resident’s care and if the death was expected or not, as well as the resident’s insurance status. A resident was considered cognitively impaired if staff or family respondents reported any one of the following: a) that, 1 or 3 months prior to death, the decedent was an “Alzheimer’s type resident,” in other words with significant memory problems, confusion, and difficulty making decisions or communicating, or had a related disease or another dementia; b) that the decedent was unable to speak or write in a meaningful way during the last month of life; or c) that the decedent was unconscious during all of the last month of life. If the staff report was unavailable, the determination was based on the same information reported by the family respondent.

Family members were presented with the following items related to ACP: (1) before he/she was near death, did you ever discuss issues or express ideas about death or dying with him/her?; (2) did [resident] have a durable power of attorney for health care decisions, that assigned someone else the legal power to make decisions about his/her health care if he/she could not speak for himself/herself?; (3) did [resident] have a signed document about end-of-life care, like a living will, giving directions for the kind of medical treatment he/she would want if he/she could not speak for himself/herself?, and; (4) to what extent did you know the kinds of medical treatment he/she preferred?

Facility liaisons reported facility organizational characteristics (e.g., bed size, proprietary status, case-mix) and whether each of the following advance directives was on file: (1) a living will (LW) that was signed by the resident; (2) a Do-Not-Resuscitate (DNR) order that was signed by a physician; (3) a Do-Not-Hospitalize (DNH) order that was signed by a physician, and; (4) a health care power of attorney (HCPOA) that was signed by the resident (which is sometimes referred to as a durable power of attorney for health care[DPOAHC]).

Data Analysis

We determined the prevalence of various forms of ACP by simple descriptive statistics, using both sources of information – the facility liaison and the family member. To evaluate whether the decedent sample for whom family ACP information was available (N=445; note one decedent is excluded who did not have a facility report) was a biased sample of all the decedents for whom a facility report was available (N=1,014), we used a logistic regression model with presence/absence of family data as the dependent variable and facility report of specified advance directive (yes/no) as the independent variable, controlling for facility type and profit status and decedent age, race and gender and accounting for within-facility clustering using Generalized Estimating Equations (GEE)[22] and specifying an exchangeable correlation.

To simultaneously identify individual and facility characteristics that were associated with having a LW or HCPOA, as well as characteristics associated with concordance between family and facility report, we used an implementation of GEE known as alternating logistic regressions.[23] This procedure provided fits of three models, logistic regressions for family and facility reports, and a model for the concordance between facility and family report using the pair-wise odds ratio (POR). The POR has the same interpretation as the usual odds ratio: given that a facility reports the existence of a particular advance directive (AD), what are the odds that the family member also reports the same AD, relative to the odds of a family member reporting the AD, given the facility report of no AD. The POR between facility and family report can be computed from a 2 × 2 table constructed using data from residents having both reports. However, due to intra-cluster correlation within LTC facilities, we used alternating logistic regression in order to obtain correct standard errors for the PORs (on the log scale) leading to confidence intervals for PORs (on the untransformed scale) that appropriately account for clustering. All analyses were conducted using SAS software (version 9.1, SAS Institute, Cary, NC).

RESULTS

Over 3,106 facility-months of death ascertainment, 1,484 deaths were identified and of these deaths, 1,020 (68.7%) were eligible. Of the 464 excluded decedents, 319 had been out of the facility more than 3 days and the remaining 145 had not been in the facility at least 15 days in the last month of life. Data on ACP documentation from the facility liaison were available for 1,014 (99.4%) of the eligible decedents from 164 facilities. Between July 2002 and January 2005 we completed interviews with 451 family members of decedents (44% of eligible decedents, 68% of those for whom we were able to identify and contact an eligible family member). ACP data were provided by family respondents for 446 (98.9%) of these decedents, representing 127 facilities.

Table 1 contains characteristics of the facilities, decedents, and family respondents who participated in the study. Most facilities were for-profit (81%), had high resident occupancy (average 83%), and reported at least weekly visits by medical care providers (67%); however only 26% of RC/AL facilities had an RN/LPN available on site. The demographic characteristics of the decedents included an average age of 85 years; most were female (71%), white (88%), and cognitively impaired (77%). Resident death had been expected by about half (53%) of reporting family members. Family respondents were predominantly children of decedents (67%), and the majority reported their involvement with the decedent during the last month of life as either high (26%) or very high (52%).

Table 2 presents the prevalence of various forms of ACP as reported by either the facility or the family respondent. The table compares the prevalence of each type of ACP for decedents with and without family respondent information. Family respondents reported a high prevalence of HCPOAs (92%), known treatment preferences (91%), and signed LWs (84%). Facilities, however, reported a much lower prevalence of signed HCPOAs (49%) and LWs (43%). We found no difference when comparing the prevalence of facility-reported LWs, DNR, and DNH orders, however the prevalence of HCPOAs was higher for those with family information compared to those without (54% vs. 45%, p=0.013).

Table 3 displays the association of facility, decedent, and family characteristics with the resident having a LW, and the within decedent concordance of family and facility reporting. Per the family report, facilities that were NHs and those located in North Carolina were associated with a lower prevalence of LWs. Facilities that were located in North Carolina and Maryland were also associated with a lower prevalence of LWs according to the facility report. Non-white race and having no private insurance were decedent characteristics associated with a lower prevalence of LWs, per the family report. Per facility reporting, non-white race and a death that was not expected were associated with lower LW prevalence. Family members were much more likely to report that the resident had a LW than were facility staff (OR = 6.46, 95% CI = 4.67, 8.93; p<0.001). Although we found statistically significant concordance between family and facility reporting of LWs (POR = 5.53, 95% CI= 2.31, 13.19; p<0.001), we found no resident, facility, or family characteristics that were associated with such concordance.

Table 4 presents the association of facility, decedent, and family characteristics with the resident having a HCPOA and the within decedent concordance of family and facility reporting. While no facility characteristics were significantly associated with having a HCPOA as per family report, two were marginally significant: nursing home residence (p=0.058) and being in North Carolina (p=0.079); both of which were associated with lower use. Facilities that had a high Medicaid case mix were associated with a lower prevalence of HCPOAs, per the facility report. According to family report, non-white race and having no private insurance were decedent characteristics associated with lower HCPOA prevalence. Intact cognitive status and high family involvement were decedent characteristics associated with a lower prevalence of HCPOAs, per facility reporting. Family members were much more likely to report that the resident had a HCPOA than were facility staff (OR = 10.55, 95% CI = 7.00, 15.90; p<0.01). Overall, we found statistically significant concordance between family and facility reporting of HCPOAs (POR = 3.81, 95% CI= 1.41, 10.25; p<0.01). Concordance of family and facility reporting of HCPOAs was significantly greater in facilities with fewer than 120 beds, compared to larger facilities (p=0.042).

DISCUSSION

Long-term care facilities are playing an increasingly prominent role in end-of-life care.[24] To provide the highest quality care in these settings, LTC stakeholders need an understanding of the individual and organizational factors that relate to the ACP processes of reflection, discussion, and communication of treatment preferences among dying patients, family members, and care providers.[24] To our knowledge, this study is the first to comprehensively describe the prevalence of, and factors associated with, ACP across a range of LTC facilities that includes RC/AL settings. We found that the prevalence of all measures of ACP was much higher than previously reported; Table 5 presents our data comparatively with prior studies.

There are two interpretations for the rise in ACP prevalence. First, since passage of the Patient Self Determination Act in 1990 there has been increased awareness in improving the documentation of ADs, especially in NHs.[25] Table 5 demonstrates a progressively upward trend of ADs over time which may reflect a heightened regulatory attention to protecting residents' rights.[26] A second interpretation considers how ACP is measured and estimated in LTC facilities. To begin, the wide variation in reported AD prevalence has been attributed to heterogeneity in both data sources and outcome measures.[19] The reliance on administrative datasets, such as Medicare claims data[8] and the Medical Expenditure Panel Survey,[9] has been another limitation. Further, although prevalence estimates generally use all members of a population that are captured as the denominator, many of these members are not at high risk of death.[27] Therefore, to estimate the prevalence of ACP in LTC facilities, the true "at risk" population would not include the total population of LTC residents, such as those undergoing a short rehabilitation, but only those most "at risk" of dying within the facility. We used decedents from LTC facilities as our denominator population at risk which provided a more accurate estimate of ACP for those who truly needed it.

The existing literature on ACP has focused largely on NHs[7–14] and little data from RC/ALs have previously been reported.[28] Our study, the first to include RC/AL facilities in examining this topic in depth, suggests that both resident and facility level factors relate to ACP across the spectrum of LTC. At the facility level, use in these settings was 5–10% higher than NHs; also geographic location and facility type were associated with the prevalence of ADs in our study. The geographic variation in ADs previously described in the literature has been attributed to several factors: (1) the variation in available healthcare resources, such as hospital beds; (2) state laws regarding the documentation of care preferences; and (3) regional variation in protocols for care at the end of life.[8, 29] Although differences in state regulations have been proposed as a plausible, unifying theory to account for variation in ADs, no study has investigated the effect of state policies on AD completion.[8]

At the individual level, two resident factors, non-white race and having no private insurance, were associated with a lower prevalence of ADs in our study, which is consistent with prior work.[8, 30] We also found that residents with intact cognitive status, who had high family involvement, and who had a death that was unexpected were less likely to have ADs. These data direct attention to factors that may contribute to the restricted communication and limited care planning discussions among care providers, residents with decisional capacity, and family members.[31] Similarly, other studies found that nearly half of NH residents with DNR orders who could have participated in discussions about life-sustaining treatment report that they do not discuss these issues with their caregivers.[11] In addition, most family caregivers of dying LTC residents receive little information about what to expect, and are not well informed from physicians.[32]

Poor communication among stakeholders may account for the striking variance in facility and family reporting of ACP found in Table 2. The increased prevalence of ACP reported by family respondents may reflect either lack of adequate communication between families and facility staff or, alternatively, their lack of understanding of the various AD documents, such as DNR and DNH orders. Concordance of family and facility reporting was greater in smaller facilities (i.e., <120 beds), when compared to larger facilities. However, although facility size may facilitate better communication among physicians, staff, and family members – and theoretically greater concordance –our prior work found no association between facility bed size and family member perceptions of physician communication at the end of life.[32]

There were several limitations to our study. First, the sample for which family data were available represented a relatively small percentage of decedents (44% of eligible decedents, 68% of those for whom we were able to identify and contact an eligible family member) and sample sizes for some of the analyses were small. Specifically, African Americans and families from nursing homes (vs RC/AL facilities) had a slightly higher refusal rate than others (12% vs 7% for African Americans vs others; and 68% vs 56% for nursing homes vs RC/AL settings). Second, all individuals who died more than three days after transfer out of the LTC facility were excluded from study; the extent to which hospice use might have related to the resulting sample and ACP is unknown. Third, we used a retrospective design which introduces the possibility of recall bias.

The use of surrogate respondent reports raises some question regarding the validity of our primary outcome, ACP. There has been reported discordance between elderly patients and their surrogates regarding end-of-life care.[33, 34] A systematic review, for example, found that surrogates predicted patients' preferences with 68% accuracy.[35] Twelve studies assessed the type of surrogate error made: 3 studies found error due to providing undesired interventions, 1 study found error by withholding desired interventions, and; 8 studies found no trend regarding surrogate error.[35] Therefore, while interviewing bereaved family members is a well-recognized methodology in end-of-life care research,[36] further study examining the accuracy of such reporting would benefit the field. In addition, further study is needed to examine whether individuals understand the meaning of the form they have signed, as the limitations of such forms are not always clear.[37] Finally, our interview was comprised primarily of closed-ended questions regarding ACP, which may have limited respondents in their understanding and description. On the other hand, the questionnaire provided a standardized way to capture a range of ACP outcomes.

CONCLUSION

In summary, we found that the prevalence of various types of ACP in LTC was much higher than previously reported; was 5–10% higher in RC/AL than in nursing homes as per family report; that reported prevalence varied by state and by respondent status (facility staff or family caregiver); and that concordance of family and facility reporting of HCPOAs was greater in smaller (i.e., <120 beds) facilities. Future efforts to improve ACP should consider how these facility-level factors relate to an ongoing communication process of negotiating and formulating pathways of care for residents living in the light of death.

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Table 1

Characteristics of the study sample

	N (Percent)	Mean (SD)
Characteristics of Facilities (n=164)[a]		
Facility		
RC/AL <16 beds	62 (37.8)	
Traditional RC/AL	23 (14.0)	
New-Model RC/AL	48 (29.3)	
Nursing Home	31 (18.9)	
State		
Florida	49 (29.9)	
Maryland	45 (27.4)	
North Carolina	41 (25.0)	
New Jersey	29 (17.7)	
For-profit facility	128 (81.0)	
Part of a chain	88 (57.1)	
Bed size		53.2 (45.3)
Percent with Medicaid as primary payer		29.7 (31.7)
Occupancy percent		83.4 (18.4)
Staffing ratio (per 10 resident)[b]		5.1 (2.2)
Aide ratio (per 10 resident)[b]		4.1 (1.9)
Visits by MD, PA, NP at least weekly	99 (66.9)	
RN/LPN on site[c]	30 (25.6)	
RN/LPN on call 24/7[c]	74 (63.2)	
At least 1 FTE RN	79 (53.4)	
Characteristics of Decedents (n=1,015)[d]		
Age		85.1 (9.5)
Male gender	297 (29.3)	
Nonwhite race	121 (11.9)	
Length of stay (yrs)		2.2 (2.6)
Self-pay or commercial insurance[e]	403 (92.4)	
Cognitively intact[e]	181 (23.1)	
Number of ADL dependencies (0–3)[e]		1.6 (1.2)
Death was expected by family[e]	236 (52.8)	
Characteristics of Family Respondents (n=446)[f]		
Relationship to decedent		
Spouse	38 (8.5)	
Child	299 (67.0)	
Other relative	80 (17.9)	
Other	29 (6.5)	
Age		60.4 (11.5)
College graduate	216 (49.0)	
Days visited resident in last month		15.3 (10.4)

	N (Percent)	Mean (SD)
Self-reported involvement		
Moderate, low, or very low	97 (22.1)	
High	115 (26.3)	
Very high	226 (51.6)	

[a] Sample includes all facilities with at least one eligible decedent for which the facility provided information about advance directives. Sample size for specific variables ranges from 146 to 164 because of missing data on some items.

[b] Staffing ratio includes RNs, LPNs and aides (# full time + ½ part-time for each) per 10 residents; aide ratio is # full time + ½ part-time aides per 10 residents.

[c] RC/AL only (N=117 with data on these items).

[d] Includes all eligible decedents for which the facility or the family provided information about advance directives.

[e] Insurance information and expectation of death obtained on family interview, available for 436 and 447 decedents respectively; cognitive status information obtained from staff or family interview, available for 785 decedents; ADL status obtained on staff interview, available for 664 decedents.

[f] Includes family members of all eligible decedents for whom both the facility and the family provided information about advance directives. Sample size for specific variables ranges from 433 to 446 because of missing data on some items.

Table 2

Prevalence of advance care planning among long-term care residents

Item and Source	**Overall**	**Among those with Family Respondent Data**	
	n (Percent)	**n (Percent)**	**p-value**[a]
As Reported by Facility (N=1,014)[b]			
Signed living will	432 (43.0)	201 (46.0)	0.514
Do not resuscitate order, signed by physician	786 (78.0)	352 (79.5)	0.145
Do not hospitalize order, signed by physician	190 (19.0)	89 (20.4)	0.432
Health Care Power of Attorney	489 (48.9)	237 (54.1)	0.013
As Reported by Family Respondent (N=446)[c]			
Discuss issues of death/dying with resident	258 (58.1)	*same as overall*	
Signed living will[d]	373 (84.4)	“ ”	
Health Care Power of Attorney	409 (92.1)	“ ”	
Known treatment preference	405 (91.2)	“ ”	

[a] Comparing prevalence of specified type of advance directive (per facility report) for decedents with and without family information on advance care planning; based on logistic regression model with presence/absence of family data as the dependent variable and facility report of specified advance directive as the independent variable, controlling for facility type and profit status, and decedent age, race and gender and accounting for within-facility clustering of responses using GEE.

[b] Number of eligible decedents for whom the facility provided information regarding at least one of the four documents listed; N varies from 1,001 to 1,008 among the four documents.

[c] Number of eligible decedents for whom the family respondent provided information regarding at least one of the four items listed; N varies from 442 to 444 among the four items.

[d] Family indicated that there was a living will OR that he/she knew the decedent’s treatment preferences “very much.”

Table 3

Association of facility, decedent and family characteristics with decedent having a living will according to family and facility report and with concordance of those reports

	Marginal association with report that resident had living will				Concordance (within resident)		
	Family report		Facility report				
	%	p-value	%	p-value	POR (95% CI)		p-value for difference*
Facility Characteristics							
Facility							
Nursing home	79.8	0.008	39.5	0.141	6.31	(1.92, 20.79)	0.590
RC/AL	89.3		48.2		4.05	(1.35, 12.11)	
Profit status							
For-profit	82.3	0.071	39.9	0.231	5.88	(2.14, 16.17)	0.698
Not for-profit	89.8		51.2		4.00	(0.76, 20.94)	
State[a]							
Maryland	86.5	0.978	29.1	<0.001	14.57	(2.33, ∞)	0.251
North Carolina	74.8	0.043	25.1	<0.001	2.27	(0.81, 7.43)	0.702
Florida	92.3	0.197	64.0	0.295	15.01	(1.70, 721.3)	0.308
New Jersey	86.4		57.3		3.34	(0.88, 15.74)	
Medical care provided							
Weekly medical visits	83.8	0.531	44.6	0.221	6.05	(2.22, 16.47)	0.991
Visits less than weekly	87.3		39.3		6.12	(0.91, 41.17)	
Medicaid case mix							
High (> 50%)	84.5	0.364	40.4	0.181	9.49	(1.27, 70.67)	0.466
Low (≤ 50%)	85.2		48.5		3.93	(1.12, 13.76)	
Facility size							
≥ 60 beds	82.8	0.314	40.4	0.392	11.50	(2.36, 55.96)	0.074
< 60 beds	87.2		49.5		2.07	(0.74, 5.76)	
≥ 120 beds	79.5	0.064	43.5	0.701	11.78	(1.48, 94.02)	0.298
< 120 beds	86.9		42.8		3.58	(1.53, 8.39)	
Decedent or Family Characteristics							
Decedent gender							

	Marginal association with report that resident had living will				Concordance (within resident)	
	Family report		Facility report			
	%	p-value	%	p-value	POR (95% CI)	p-value for difference*
Male	82.5	0.443	40.6	0.817	10.69 (2.48, 46.06)	0.301
Female	85.1		44.0		4.41 (1.62, 11.97)	
Decedent race						
White, non-Hispanic	87.5	<0.001	47.3	<0.001	5.20 (2.10, 12.88)	0.190
Other	53.7		11.6		1.75 (0.39, 7.92)	
Decedent age						
≥ 90 yrs	87.5	0.250	48.7	0.066	4.26 (1.46, 12.48)	0.537
< 90 yrs	82.6		40.1		6.14 (2.28, 16.55)	
Insurance status[a]						
Self-pay/ private	86.0	0.025	47.0	0.512	13.00 (1.74, ∞)	0.298
No private insurance	71.9		40.6		4.73 (2.26, 10.88)	
Length of stay						
≥2.5yrs	85.1	0.595	47.2	0.392	8.62 (2.48, 29.93)	0.414
<2.5yrs	84.0		41.2		4.51 (1.52, 13.38)	
Cognitive status						
Intact	83.8	0.608	40.4	0.941	6.00 (1.20, 29.93)	0.924
Impaired	84.5		44.8		5.45 (1.93, 15.38)	
Expectation of death						
Death expected	85.5	0.330	49.1	0.048	5.65 (1.91, 16.69)	0.942
Death not expected	83.1		42.7		5.40 (2.06, 14.20)	
Family involvement						
Very involved	82.1	0.957	41.2	0.956	5.93 (2.29, 15.37)	0.963
Low-moderate	85.5		47.6		5.77 (2.11, 15.80)	

Analyses use alternating logistic regression to simultaneously model the marginal association of the characteristics shown with family and facility report of living will as well as the within-resident agreement of the family and facility report. Each model contains a single characteristic in both the marginal model and the association model. The association model also adjusts for the similarity of reports from different respondents for different residents within a facility, and for the facility characteristics it additionally accounts for the association between the facility reports for different residents.

[*] This is the p-value for the test of whether the pair-wise odds ratio (POR) differs based on the characteristic shown.

[a] Because of computational difficulties due to a zero cell in the 2×2 table for the POR, the marginal probabilities of family and facility reports are modeled separately using logistic regression models fitted with GEE, specifying independent working correlation matrices. The POR and its 95% confidence interval for each level of the characteristic are based upon small sample methods, namely median unbiased estimates obtained from SAS PROC Logistic with an option for exact estimation. The statistical significance of the difference in PORs is tested using Zelen's exact test for homogeneity of odds ratios as implemented by StatXact-4 software.

Table 4

Association of facility, decedent and family characteristics with decedent having a health care power of attorney according to family and facility report and with concordance of those reports

	Marginal Association with report that resident had health care power of attorney				Concordance (within resident)		
	Family Report		Facility report				p-value for difference*
	%	p-value	%	p-value	POR (95% CI)		
Facility Characteristics							
Facility							
Nursing home	89.6	0.058	45.9	0.431	2.39	(0.81, 7.04)	0.153
RC/AL	94.9		53.1		14.57	(1.57, 135.6)	
Profit status[a]							
For-profit	90.7	0.115	49.2	0.992	3.13	(1.32, 8.04)	0.300
Not for-profit	85.8		49.1		8.36	(1.11, ∞)	
State[a]							
Maryland	96.2	0.347	49.8	0.342	3.29	(0.25, 178.0)	0.413
North Carolina	86.4	0.079	44.2	0.755	3.54	(1.09, 13.56)	0.542
Florida	94.2	0.766	60.7	0.052	2.11	(0.27, 16.69)	0.252
New Jersey	93.2		40.6		8.72	(1.27, ∞)	
Medical care provided[a]							
Weekly medical visits	92.0	0.761	51.9	0.105	2.97	(1.22, 7.75)	0.552
Visits less than weekly	93.1		38.8		5.87	(0.76, ∞)	
Medicaid case-mix							
High (> 50%)	90.8	0.246	41.1	0.046	3.81	(0.91, 15.89)	0.999
Low (≤ 50%)	93.8		59.4		3.80	(0.54, 22.55)	
Facility size							
≥ 60 beds	90.2	0.063	46.4	0.381	2.95	(1.02, 8.52)	0.355
< 60 beds	95.5		55.0		9.72	(0.98, 96.26)	
≥ 120 beds	90.8	0.455	48.8	0.609	1.50	(0.39, 5.78)	0.042
< 120 beds	92.8		49.0		11.83	(2.75, 50.99)	
Decedent or Family Characteristics							

	Marginal Association with report that resident had health care power of attorney				Concordance (within resident)		
	Family Report		Facility report				
	%	p-value	%	p-value	POR (95% CI)		p-value for difference*
Decedent gender							
Male	93.7	0.605	45.9	0.165	10.27	(0.27, 395.6)	0.248
Female	91.5		50.1		2.99	(1.14, 7.89)	
Decedent race							
White, non-Hispanic	93.8	<0.001	49.7	0.060	4.23	(1.48, 12.12)	0.555
Other	76.2		42.0		2.62	(0.63, 10.98)	
Decedent age							
≥ 90 yrs	93.8	0.221	51.5	0.276	1.91	(0.54, 6.76)	0.101
< 90 yrs	91.2		47.5		5.36	(1.73, 16.57)	
Insurance Status							
Self-pay/ private	93.8	0.002	55.2	0.564	5.46	(1.41, 21.13)	0.499
No private insurance	71.9		50.0		2.42	(0.42, 13.82)	
Length of stay							
≥2.5yrs	92.5	0.835	48.7	0.987	5.90	(1.17, 29.78)	0.544
<2.5yrs	91.9		49.0		3.20	(1.00, 10.29)	
Cognitive status							
Intact	90.1	0.501	42.9	0.050	3.49	(0.74, 16.45)	0.915
Impaired	92.7		51.3		3.82	(1.32, 11.10)	
Expectation of death							
Death expected	89.8	0.058	55.6	0.392	4.35	(1.58, 11.97)	0.662
Death not expected	94.7		52.7		4.83	(1.20, 19.37)	
Family involvement							
Very involved	91.7	0.246	45.3	0.034	10.13	(2.14, 47.86)	0.107
Low-moderate	92.6		57.3		2.96	(1.01, 8.66)	

Analyses use alternating logistic regression to simultaneously model the marginal association of the characteristics shown with family and facility report of living will as well as the within-resident agreement of the family and facility report. Each model contains a single characteristic in both the marginal model and the association model. The association model also adjusts for the similarity of reports from different respondents for different residents within a facility, and for the facility characteristics it additionally accounts for the association between the facility reports for different residents.

[*] This is the p-value for the test of whether the pairwise odds ratio (POR) differs based on the characteristic shown.

[a] Because of computational difficulties due to a zero cell in the 2×2 table for the POR, the marginal probabilities of family and facility reports are modeled separately using logistic regression models fitted with GEE, specifying independent working correlation matrices. The POR and its 95% confidence interval for each level of the characteristic are based upon small sample methods, namely median unbiased estimates obtained from SAS PROC Logistic with an option for exact estimation. The statistical significance of the difference in PORs is tested using Zelen's exact test for homogeneity of odds ratios as implemented by StatXact-4 software.

Table 5

Reported Prevalence of Advance Care Planning in Long-Term Care Facilities

Advance Care Planning Measure	Year	Prevalence by Facility Type %				Reference
		Nursing Home	Smaller RC/AL	Traditional RC/AL	New-Model RC/AL	
Living will	1991	12				Terry & Zweig, 1994
	1993	13				Teno, Branco, et al, 1997
	1993	11				Suri, Egleston, et al. 1999
	1996	21				Dobalian, 2006
	1997	32				Levin, Wenger, et al, 1999
	2005	42	48	69	47	Current study; facility report
	2005	80	93	92	97	Current study; family report
Do not hospitalize order	1993	4				Teno, Branco, et al, 1997
	2001	2				Levy, Fish, Kramer, 2005
	2005	24	15	3	22	Current study; facility report
Health care power of attorney	1991	12				Terry & Zweig, 1994
	1993	19				Teno, Branco, et al, 1997
	2005	52	50	66	58	Current study; facility report
	2005	90	93	91	97	Current study; family report
Do not resuscitate order	1993	52				Teno, Branco, et al, 1997
	1993	17				Suri, Egleston, et al. 1999
	1996	39				Dobalian, 2006
	1997	74				Levin, Wenger, et al, 1999
	2001	32				Levy, Fish, Kramer, 2005
	2005	85	68	77	76	Current study; facility report
Care planning discussions	1997	29				Levin, Wenger, et al, 1999
	2005	58				Current study; family report

Note: Prevalence estimates are from different long-term care samples