

Advance Directives in Nursing Home Residents Aged ≥ 65 Years: United States 2004

Helaine E. Resnick, PhD, MPH,
Jeremiah D. Schuur, MD, MHS, Janice Heineman, PhD,
Robyn Stone, DrPH, and Joel S. Weissman, PhD

In 1996, 53% of US nursing home residents had advance directives. This report defines documentation of advance directives in a nationally representative survey of US nursing home residents aged ≥ 65 years in 2004, as well as advance directive use in relation to demographic factors and receipt of specialty services including hospice/palliative care. In 2004, advance directives were documented in 69.9% of US nursing home residents aged ≥ 65 years and in 93.6% of residents receiving hospice/palliative care. Documentation of advance

directives increased substantially between 1996 and 2004 and is nearly universal among residents receiving hospice/palliative care services. However in 2004, 3 of every 10 US nursing home residents did not have documentation of advance care plans. Continued efforts are needed to promote the importance of advance care planning among US nursing home residents.

Keywords: advance directives; nursing home; survey; long term care; aging

Introduction

The Patient Self-determination Act (PSDA) of 1990 formalized advance care planning by requiring many Medicare and Medicaid providers, including nursing homes (NHs), to give adult individuals, at the time of inpatient admission or enrollment, certain information about their rights under state laws governing advance directives (ADs) including: (a) the right to participate in and direct their own health care

decisions; (b) the right to accept or refuse medical or surgical treatment; (c) the right to prepare an AD, and (d) information on the provider's policies that govern the use of these rights.¹

In 1995, the General Accounting Office reported that although most health care providers were informing patients of their rights to have ADs, only 10% to 25% of Americans had documented their end-of-life choices or appointed a health care agent to do so.² Early studies of ADs in NH showed that use of ADs increased following passage of the PSDA,^{3,4} but remained low overall.

A representative sample of US NH residents from 1996 showed that 53% of residents had ≥ 1 AD, and 39% had a do-not-resuscitate (DNR) order.^{5,6} This work also showed that ADs were less common among nonwhites and residents at for-profit facilities.

A study using nearly 2 million Minimum Data Set (MDS) admission assessments of residents admitted under the Medicare benefit showed that in 1991, only 32.3% of the sample had a DNR order.⁷ This study also showed that nonwhites, younger individuals, and residents of for-profit facilities were

From Institute for the Future of Aging Services, American Association of Homes and Services for the Aging (HER, JH, RS), Department of Medicine, Georgetown University (HER), Washington, DC; Department of Emergency Medicine, Brigham and Women's Hospital; Department of Medicine, Harvard Medical School Boston (JDS); and Department of Health Care Policy, Harvard Medical School and the Department of Health Policy and Management, Harvard School of Public Health, Institute for Health Policy, Massachusetts General Hospital (JSW), Boston, Massachusetts.

Address correspondence to: Helaine Resnick, Institute for the Future of Aging Services, American Association of Homes and Services for the Aging, 2519 Connecticut Ave, NW, Washington, DC 20008; e-mail: hresnick@aahsa.org.

less likely to have a DNR. A second study⁸ of >550 000 MDS NH admission assessments from 2001 showed striking rural/urban differences in use of AD, with DNR documented in only 32.7% to 47.6% of these admissions. A third study⁹ examined MDS assessments of NH residents, both at admission and at 12 months for each year during the period 2000-2004. This report showed that the prevalence of having any of several AD rose between admission and 12 months in each of the years studied, and that at 12 months postadmission, the prevalence of AD rose from 59.5% to 62.7% between 2000 and 2004.

Taken together, published data on ADs in NHs suggest that in the years since passage of the PSDA the prevalence of ADs has increased. However, a consistent interpretation of trends in ADs has not been straightforward due to differences in methodology, including approaches to sampling—particularly those involving reporting of ADs at admission versus later in the NH stay—as well as differences in which types of ADs are examined. We examined a representative cross section of US NH residents in 2004 to report the most recent prevalence of ADs, to further understand the associations of race, facility characteristics, and length of stay (LOS) with AD, and to provide new information on the documentation of ADs among NH residents receiving hospice and palliative care services.

Methods

Survey Design and Sampling

Data in this report are from the 2004 National Nursing Home Survey (NNHS) which is conducted by the National Center for Health Statistics (NCHS).¹⁰ In the 2004 NNHS, 1500 facilities were selected from a sampling frame of US NHs drawn from the Centers for Medicare and Medicaid Services and State licensing lists. Because some facilities went out of business or became ineligible for the scope of the survey between the time they were selected and when the survey was conducted, the 2004 NNHS is based on data collected in 1174 facilities with data for 13 507 residents. When weighted, these residents represent approximately 1.49 million persons in US NH at the time of the survey.

Data Collection Procedures

The current resident portion of the NNHS was completed by staff members familiar with the care

received by the sampled resident using available medical records. No residents were directly interviewed in the NNHS.

Ascertainment of ADs

Eight categories of ADs were ascertained in the NNHS using standardized coding from the MDS¹¹ living will; DNR; do not hospitalize (DNH); organ donation; request for autopsy; feeding restrictions; medication restrictions; and an additional category labeled “other treatment restrictions.”

Four response variables were defined based on the desire to compare current findings to previous reports on overall AD use “ ≥ 1 AD” and to understand the relationship of independent variables to specific ADs: DNR, DNH, and living wills (Table 1).

Demographics, Living Arrangements, Sources of Payment, and LOS

Data on residents’ marital status, race/ethnicity, gender, age, and living arrangements prior to NH admission were collected. Length of stay represents time that a resident was in the facility at the time of the survey. A 4-level ordinal variable that partly reflects Medicare reimbursement policy was constructed from the LOS variable: (0-20 days; 21-100 days; 101-365 days; and >365 days).

Receipt of Specialty Services and Facility Characteristics

Data were collected on whether residents were receiving services from a specialty program at the time of the survey including hospice/palliative/end-of-life care, dementia care, and pain management. Individuals receiving these services were of interest because they may reflect groups of especially vulnerable residents who would benefit from advanced care planning. Bed size was categorized as 3-49, 50-99, 100-199, and ≥ 200 beds. Ownership status was dichotomized as for-profit versus all others.

Statistical Analysis

Analyses were conducted with the PROC SURVEY procedures in SAS version 9.1 (SURVEYFREQ, SURVEYLOGISTIC). These approaches were used to study proportions and binary response models, respectively, accounting for the complex sample

Table 1. Odds Ratios^a and Confidence Intervals Describing the Association Between Selected Characteristics and Odds of Having Advance Directives, United States, 2004

Characteristics (n)	Any Advance Directive		DNR		DNH		Living Will	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
RESIDENT CHARACTERISTICS								
Age (years)								
65-74	1.0		1.0		1.0		1.0	
75-84	1.43	1.20-1.70	1.45	1.24-1.70	0.70	0.46-1.08	1.33	1.08-1.64
85+	2.30	1.95-2.71	2.32	1.98-2.71	1.31	0.74-1.73	1.46	1.18-1.80
Gender								
Female vs male	1.24	1.09-1.42	1.24	1.10-1.41	1.07	0.77-1.49	1.10	0.94-1.29
Race								
White	1.0		1.0		1.0		1.0	
Black	0.28	0.23-0.34	0.32	0.26-0.39	0.37	0.18-0.77	0.31	0.22-0.43
Hispanic	0.43	0.31-0.60	0.50	0.35-0.71	0.79	0.35-1.77	0.16	0.07-0.33
Marital status								
Single	1.0		1.0		1.0		1.0	
Married	1.60	1.23-2.09	1.78	1.36-2.32	1.05	0.54-2.04	1.22	0.85-1.75
Widowed	1.32	1.02-1.72	1.61	1.24-2.09	0.92	0.48-1.73	1.03	0.73-1.46
Divorced	1.11	0.83-1.48	1.39	1.02-1.89	0.90	0.43-1.91	0.95	0.64-1.41
Separated	0.65	0.33-1.29	1.00	0.50-2.01	0.97	0.12-7.72	0.48	0.18-1.33
Never married	1.00	0.73-1.38	1.21	0.88-1.67	0.52	0.22-1.22	0.75	0.48-1.17
Prior living arrangements								
Assisted living	1.0		1.0		1.0		1.0	
Private residence	0.79	0.64-0.98	0.84	0.69-1.03	0.76	0.46-1.24	0.85	0.68-1.06
Nursing home	0.88	0.67-1.15	0.94	0.73-1.21	0.74	0.44-1.24	0.65	0.50-0.85
Hospital SNF	0.74	0.54-1.00	0.73	0.54-0.98	0.63	0.34-1.17	1.13	0.84-1.52
Acute care hospital	0.71	0.56-0.88	0.77	0.62-0.95	0.72	0.46-1.14	0.67	0.53-0.83
Other	0.44	0.32-0.61	0.54	0.40-0.74	0.36	0.15-0.91	0.77	0.50-1.19
Use of special services								
Hospice								
Yes vs no	5.68	3.30-9.78	4.50	2.89-7.01	3.02	1.83-4.96	1.41	1.00-1.98
Dementia								
Yes vs no	1.39	1.08-1.79	1.63	1.28-2.09	1.89	1.09-3.25	0.87	0.65-1.16
Pain								
Yes vs no	1.10	0.88-1.39	1.96	1.57-2.45	2.45	1.53-3.93	0.73	0.54-0.98
Length of stay (days)								
0-20	1.0		1.0		1.0		1.0	
21-100	2.00	1.60-2.49	1.96	1.57-2.45	1.25	0.59-2.67	1.46	1.10-1.92
101-365	2.91	2.36-3.59	2.84	2.28-3.55	1.52	0.78-2.97	1.77	1.35-2.31
>365	3.53	2.89-4.32	3.91	3.17-4.83	2.10	1.07-4.12	1.61	1.24-2.09
FACILITY CHARACTERISTICS								
Ownership								
Nonprofit vs for profit	1.63	1.40-1.90	1.31	1.11-1.53	1.13	0.75-1.71	1.87	1.53-2.28
Bed size								
3-49	1.0		1.0		1.0		1.0	
50-99	1.19	0.92-1.54	1.09	0.85-1.41	1.01	0.52-1.96	1.02	0.75-1.38
100-199	0.99	0.77-1.28	0.92	0.71-1.19	0.99	0.51-1.94	0.94	0.70-1.27
≥200	0.61	0.44-0.86	0.60	0.42-0.85	0.47	0.17-1.35	0.66	0.43-1.02
Metropolitan								
Metropolitan	1.0		1.0		1.0		1.0	
Micro-politan	1.07	0.90-1.27	1.31	1.09-1.57	0.31	0.19-0.51	0.94	0.75-1.18
Neither	0.89	0.73-1.08	1.07	0.88-1.30	0.40	0.23-0.70	0.82	0.65-1.04

Abbreviations: CI, confidence interval; DNH, do not hospitalize; DNR, do not resuscitate; SNF, skilled nursing facility.

^a Adjusted odds ratios estimated using logistic regression.

design used in the NNHS. Bivariate analyses were performed on each of the 4 AD outcomes to test associations with the factors described above. To determine whether observed associations persisted following adjustment for confounding, we conducted logistic regression analyses of each AD response variables in separate models that included covariates found to be significant at the $P < .05$ level in descriptive analyses. Model diagnostics indicated that collinearity was quite minimal and that it did not materially affect our results.

Results

Of the 13 507 persons in the 2004 NNHS, 11 939 were ≥ 65 years and data on ADs were missing for 96 persons in this group. Thus, an unweighted analysis sample of 11 843 residents aged ≥ 65 years with AD data, representing approximately 1.3 million NH residents was used in this report. The sample was 74.4% women, 84.5% whites, and 51.3% were aged 85+ years.

Among all residents, 69.9% had ≥ 1 AD, 60.3% listed DNR, 3.9% listed DNH, and 19.9% had a living will (Figure 1). At the time of the survey, 43.4%, 17.7%, 5.7%, and 3.1% had 1, 2, 3, and 4 ADs, respectively. Less than 1% of residents listed organ donation as an AD and the prevalence of ADs for autopsy was especially small and could not be estimated reliably.

Due in part to the large weighted sample size, documentation of ADs differed significantly by virtually all demographic, clinical, and facility characteristics examined in this report. Briefly, ADs were significantly ($P < .0001$) more common among older residents, women, whites, married, and widowed residents, those who previously resided in assisted living environments, residents with increasing LOS, those at nonprofit NH, those at smaller NHs, and residents who were receiving hospice, dementia, and pain management services. Notable among the initial findings was the strong relationship between AD use and LOS—ADs were used among 47.3% of residents with LOS 0-20 days but use increased to 74.6% among residents with LOS >365 days. Strong associations were also observed for race, with 74.7% of whites listing ADs, compared to only 40.5% of blacks, and 49.7% of Hispanics. As expected, similar patterns were noted for DNR, and to a lesser extent for living wills due to the lower overall prevalence

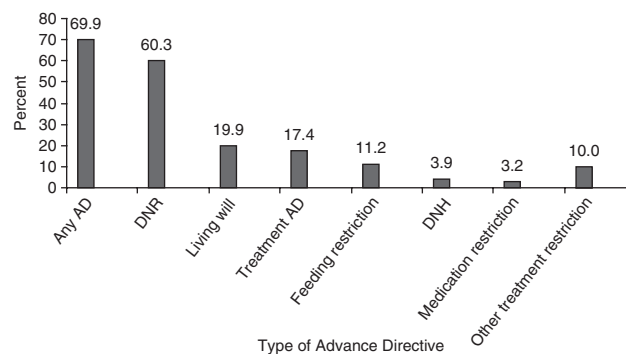


Figure 1. Advance directives among nursing home residents aged ≥ 65 years, United States, 2004.

of the latter AD. Of all variables examined in this report, ADs were most prevalent among persons receiving hospice services, with 93.6% of this group having documentation of 1 or more ADs in the medical record.

Results of multivariable adjusted analyses are presented in the table. Relative to whites, black NH residents were significantly less likely to have ≥ 1 AD, DNR, DNH, and living wills, and Hispanic residents were less likely to have ≥ 1 AD, DNR, and living wills. There were significant stepwise increases in ≥ 1 AD, DNR, and living wills with increasing LOS. Residents in nonprofit facilities were significantly more likely to have ≥ 1 AD, DNR, and living wills than their counterparts in for-profit facilities. Finally, patterns consistent with lower use of ADs in larger facilities were noted. Of all variables examined in this report, the strongest association with documentation of AD was observed for residents who were receiving hospice services. NH residents receiving these services were 5.68 times more likely to have ADs documented than those not receiving these services.

Discussion

This report presents the most recent estimates of the frequency and correlates of ADs in a representative cross section of US NH residents. Nearly 70% of all US NH residents aged ≥ 65 years had documentation of ≥ 1 AD, a figure that is considerably higher than results from early studies on ADs^{3,4} as well as those based on data collected at NH admission.⁷⁻⁹

Our data also show that NH residents who receive specialty services—particularly hospice services—are

especially likely to have documentation of ADs. Nearly 94% of residents receiving hospice services had ≥ 1 AD, and the adjusted odds of having an AD among persons receiving these services was nearly 5.7 times higher than among those not receiving these services. Although a somewhat intuitive finding, to the extent that variables identifying specialty services such as hospice care and pain management also identify NH residents with a clinical profile that may hinder effective expression of care choices, our data may provide some evidence that ADs are differentially distributed in a manner that is consistent with the goal of the PSDA, which is to ensure resident care choices are known, including in settings where effective communication of these choices may be hindered. However, it is important to note that the time at which ADs are documented is not available in the NNHS. Thus, it is not possible to address issues related to how soon after admission, or conversely, how far along in the course of a long NH stay ADs are documented. The latter question is relevant to persons who receive specialty services, particularly if they choose to wait until they are gravely ill to document their advance care plans. Against this backdrop, it should be noted that NH residents who participate in specialty care programs may be more likely to receive AD education beyond what is federally mandated as part of those programs and that care providers who staff these programs may also be more familiar with AD and care planning. Thus, participation in these programs may result in more widespread use of AD. Although data in the NNHS do not permit direct investigation of these issues, factors that underpin the increased frequency of ADs among persons in specialty care programs warrant further attention because they may serve to inform on approaches to increase use of ADs among all NH residents overall.

Our sample, which represents a true cross section of all US NH residents in 2004 is similar in design to a 1996 survey⁵ showing that 53% of US NH residents had ≥ 1 AD and 39% had a DNR. The corresponding figures for our 2004 data were 69.9% and 60.3%, indicating that the overall increase in AD in NH residents during 1996-2004 resulted from a substantial increase in documentation of DNR in the medical records of US NH residents.

Our data show that ADs become more common as LOS increases. Although only 47% of residents with LOS between 0 and 20 days (the period for

which Medicare pays 100% following a qualifying hospital stay) had ADs documented, nearly 75% of residents with LOS > 1 year had them. These findings highlight the importance of considering LOS when interpreting NH AD data. It is likely that over time as residents and their families become increasingly familiar with residents' clinical status, trajectory of care and likelihood of live discharge, the perceived use of ADs may change. Additionally, the NH staff may frame the discussion around ADs differently for similar patients based on their LOS.

Twenty-six percent of NH residents in this sample had ≥ 2 ADs, suggesting that a sizeable proportion of residents are documenting care planning beyond DNR. It is notable in this context that 10% of the sample documented treatment restrictions "other" than those specified in the survey. Although it is unfortunate that data describing the nature of these other restrictions are unavailable in the NNHS, it is nonetheless intriguing that 1 in 10 US NH residents have specified such a restriction.

Finally, our data, as well as those from previous studies have consistently shown that ADs are documented less frequently among nonwhites in ambulatory¹² as well as long-term care settings.^{4,6-8,13} Our analyses indicated that black and Hispanic NH residents were more likely to have a number of characteristics that were associated with lower odds of ADs including being single, young, being admitted from an acute care hospital, being in a for-profit facility, and being in a facility with > 200 beds. Nevertheless, a persistent effect of race on odds of ADs was observed after adjustment for these factors in multivariate analyses. This could indicate a strong cultural preference against ADs among nonwhites, perhaps due to lack of trust in the medical care system,¹⁴ or bias in discussing and documenting patients' wishes. Unfortunately, neither our analysis nor prior research can explain whether health care providers discuss, explain, and document ADs with similar levels of cultural competence among different ethnic groups. Changing demographic trends in the United States, particularly the rapid growth of the Hispanic population, raise important questions about whether current approaches to provision of information under the PSDA will be adequate to meet the changing demographic mix of the US NH population in a manner that maximizes use of the Act as a means to ensure that NH residents' care accurately reflects their wishes. The countervailing

argument is that there may be true differences in how diverse groups value AD, thereby explaining the observed variation in their use. Two potentially important variables that were not collected in the NNHS was religious affiliation, both of the resident and the NH. Because religious practices regarding end-of-life care may vary, a potentially important avenue for future research is the role of religion in AD use.

This report has several important limitations. First, the current resident portion of the NNHS is based on interviews with care providers who are familiar with the sampled resident, not on direct interviews with the resident. Data collected in these interviews were supported by information in the resident's medical record. Although data collection from chart review has a number of well-documented limitations,¹⁵ this approach was appropriate in an NH setting, because the patient population is characterized by extreme frailty and in many cases cognitive deficit that would likely have a negative impact on the quality of self-reported data. Moreover, this report is explicitly focused on the extent to which ADs are documented in the medical record, an objectively ascertained outcome.

A second limitation is that the variables on types of ADs collected in the NNHS may involve some interpretation, as different states and facilities may have different methods for documenting and defining ADs for their residents. However, the NNHS used a standardized coding from the MDS to define ADs; this scheme is widely used in practice for federally regulated data collection in NH, thereby limiting concerns about the quality of these data elements.¹¹ A third limitation is the possibility that observed associations between key variables in AD, such as those noted for race, could be due to residual confounding by variables that were not examined in our models or not collected in the NNHS. This is a common limitation that suggests the need for conservative interpretation of findings. Nonetheless, data from representative samples such as the NNHS allow national estimates of important measures including AD, and are therefore a valuable tool for assessing progress on certain aspects of patient-centered care practices in the United States.

In summary, documentation of ADs continues to increase in United States NHs, indicating a strong and growing acceptance of written advance care planning in this setting. Although nearly 70% of NH residents aged ≥ 65 years had at least 1 AD in 2004, ADs

are still documented much less frequently among nonwhite residents, and facility characteristics such as ownership and bed size continue to be associated with ADs. The fact that nearly 94% of NH residents receiving end-of-life care have ADs suggests that for at least some subsets of NH residents, the original objectives of the PSDA are being met.

Acknowledgments

The authors would like to thank Ms Sherry Giles for valuable editorial support during the preparation of this manuscript.

References

1. Patient Self-Determination Act, 42USC §§1395cc, 1396a (1994).
2. GAO. Patient self-determination act: providers offer information on advance directives but effectiveness uncertain. Washington, DC. 1995. Pub. GAO-HEHS-95-135.
3. Bradley EH, Wetle T, Horwitz SM. The patient self-determination act and advance directive completion in nursing homes. *Arch Fam Med*. 1998;7:417-423.
4. Castle NG, Mor V. Advance care planning in nursing homes: pre- and post-Patient Self-Determination Act. *Health Serv Res*. 1998;33:101-124.
5. Medical Expenditures Panel Web site. Available at: <http://www.meps.ahrq.gov/mepsweb/>. Accessed June 1, 2007.
6. Dobalian A. Advance care planning documents in nursing facilities: Results from a nationally representative survey. *Arch Gerontol Geriatr*. 2006;43:193-212.
7. 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. *J Am Geriatr Soc*. 2005;53:2060-2068.
8. Buchanan RJ, Bolin J, Wang S, Zhu L, Kim M. Urban/rural differences in decision making and the use of advance directives among nursing home residents at admission. *J Rural Health*. 2004;20:131-135.
9. McAuley WJ, Buchanan RJ, Travis SS, Wang S, Kim M. Recent trends in advance directives at nursing home admission and one year after admission. *Gerontologist*. 2006;46:377-381.
10. National Center for Health Statistics. Available at: <http://www.cdc.gov/nchs/about/major/nnhsd/nnhsdesc.htm>. Accessed April 17, 2007.
11. Centers for Medicare & Medicaid Services. Available at: <http://www.cms.hhs.gov/NursingHomeQualityInits/downloads/MDS20RAIUsersManual.zip>. Accessed August 1, 2007.

12. McKinley ED, Garrett JM, Evans AT, Danis M. Differences in end-of-life decision making among black and white ambulatory cancer patients. *J Gen Intern Med.* 1996;11:651-656.
13. Degenholtz HB, Arnold RA, Meisel A, Lave JR. Persistence of racial disparities in advance care plan documents among nursing home residents. *J Amer Geriatr. Soc.* 2002;50:378-381.
14. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist.* 2005;45:634-641.
15. Stange KC, Zyzanski SJ, Smith TF, et al. How valid are medical records and patient questionnaires for physician profiling and health services research? A comparison with direct observation of patients visits. *Med Care.* 1998;36:851-867.