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Ethnic Differences in Advance Directive Completion and Care Preferences: What Has Changed in a Decade?

Jaclyn Portanova, MSG, RN, Jennifer Ailshire, PhD, Catherine Perez, MS, Anna Rahman, PhD, and Susan Enguidanos, PhD, MPH

Leonard Davis School of Gerontology, University of Southern California, Los Angeles, California

Abstract

Studies have documented ethnic differences in advance directive (AD) completion, with lower rates in minority groups. Of those with ADs, blacks are more likely than whites to prefer aggressive care, but little is known about how these differences in preferences have changed over time in ethnic groups. This nationally representative study aimed to investigate whether these differences in AD development persisted after adjusting for important confounding variables. Year of death was analyzed to see how AD completion changed over time within ethnic groups, and for those with an AD, the association between these factors and opting for aggressive care was investigated. Data from the 2000 to 2012 Health and Retirement Study (HRS) exit interviews from 7,177 decedents were used. Analyses included logistic regression to determine the relationship between ethnicity and AD completion and preferences for aggressive care and how it changed over time in ethnic groups. Forty-six percent of decedents had completed an AD (whites 51.7%, Hispanics 18.0%, blacks 15.0%). Of blacks completing an AD, 23.8% elected prolonged care, compared with 13.3% of Hispanics and 3.3% of whites. Logistic regression revealed that blacks 75% lower odds of completing an AD and Hispanics had 70% lower odds. Model covariates had a small influence on ethnic differences, although in examining the change in AD completion over time, the odds of having an AD increased with each subsequent death year for blacks and whites but not Hispanics. Additional research is needed to investigate the effect of cultural differences in AD completion rates of ethnic minority groups to ensure that preferences are honored in the clinical setting.

Keywords

advance directive; care preferences; ethnic differences; advance care planning; aggressive care

Advance directives (ADs) allow individuals to document the type of care they would like to receive if they are unable to express their wishes. It also allows them to designate a healthcare proxy to make decisions on their behalf should they be unable to communicate their care preferences. Studies have found that completion of an AD increases the likelihood of care congruent with an individual's wishes and reduces proxy decision-making burden for the family and physicians.¹

Several studies have found racial and ethnic differences in AD completion rates and end-of-life care preferences.^{2,3} Blacks are less likely to complete ADs than whites and other racial and ethnic groups.³⁻⁵ After controlling for other demographic characteristics, racial and ethnic differences in AD completion remain statistically significant.⁴⁻⁶

Numerous studies have shown that blacks are more likely than whites to pursue aggressive care at the end of life. A previous study,⁷ for instance, found that blacks were more likely than other ethnic groups to prefer life support. These differences in care preferences persist even after hospice enrollment. Blacks are more likely than whites to exit hospice to pursue aggressive care³ and less likely to return after disenrollment.⁸

Less is known about Hispanics. According to the Institute of Medicine report, “Dying in America,” Hispanics are the least-studied population in terms of care preferences and decision-making at the end of life.⁹ The few studies of Hispanics have found that they are less likely than whites to have an AD and to report having discussions about ADs.¹⁰⁻¹³ It was also found that Hispanics were less likely to believe that a formal healthcare proxy was needed when family was in the healthcare setting.¹⁴

Previous studies investigating racial and ethnic differences in AD completion have found that age, income, medical diagnoses, and religion influence completion rates.^{5,6,15} For example, older adults are more likely to complete ADs than younger adults,^{16,17} and lower income has been associated with lower rates of AD completion.⁶ Other studies have found that a cancer diagnosis and renal dysfunction are independent predictors of AD completion.¹⁸ Religious beliefs also may influence AD completion rates and end-of-life care preferences.¹ Some religious individuals, for instance, prefer aggressive care regardless of their prognosis because of their belief in God’s will.¹⁹ Similarly, another study found that individuals who completed ADs reported receiving less strength and comfort from religion than those who chose not to complete ADs.²⁰

Gaps in Current Research

Over the last decade, there have been significant efforts to understand and reduce racial and ethnic disparities in AD development, yet gaps remain. The Institute of Medicine, in its recent report, “Dying in America,” identified the need to understand ethnic differences in AD use so that patient and provider education programs that are sensitive to these differences can be developed.⁹ Lack of nationally representative analytical samples have limited most studies, and many racial and ethnic comparisons are limited to blacks and whites, with few studies including Hispanics. A previous study using a similarly representative dataset is dated and failed to include Hispanics in its analysis.²¹ In addition, few studies have investigated whether and how potentially influential characteristics such as age, income, education, and medical diagnoses account for differences in AD completion rates between different ethnic groups. Finally, no studies have examined change in AD completion rates over time in ethnic groups.

Study Overview and Contribution

This study investigated differences in AD completion rates of whites, blacks, and Hispanics in a nationally representative sample while adjusting for important confounding variables (e.g., education, income, diagnoses, religious attendance). Factors associated with AD completion rates within each ethnic group were also examined. Given recent attention and efforts to reducing the gap in AD completion rates between white and minority groups, change in AD completion rates over time were examined.

METHODS

Data and Sample

Data were used from the Health and Retirement Study (HRS) exit interviews conducted with proxy respondents of persons in the HRS who died between 2000 and 2012. Proxy respondents were typically widows, widowers, and other family members who were knowledgeable about the deceased person. Proxy respondents reported on variables such as AD status at the time of their relative's death. The HRS collects longitudinal, cross-sectional data that are nationally representative of adults aged 50 and older. The HRS sample is a multistage probability sample of the United States. The HRS design includes three oversamples to increase the number of blacks, Hispanics, and residents of Florida. Sample weights are provided to compensate for the unequal probabilities of selection to achieve unbiased estimates of population parameters.

A total of 12,987 HRS participants died between 1998 and 2013 and had valid information on timing of death. Those without an exit interview after 2000 ($n = 3,763$), and who died after 2011 ($n = 1,403$) were excluded from this analysis. Individuals for whom the time between death and the exit interview was longer than 3 years were also excluded ($n = 235$). Respondents who did not report on AD status ($n = 198$) or care preferences ($n = 51$); identified as a race other than black, Hispanic, or white ($n = 91$); or did not have a valid sample weight ($n = 69$) were also excluded. The final sample included 7,177 participants.

Outcomes of Interest

The two primary outcomes of interest were AD completion status and, in those with an AD, preference for aggressive care. Proxies were interviewed and asked whether the decedents had written instructions about their care preferences before death. For the purposes of this study, written instructions are referred to as ADs but could also include Physician or Medical Orders for Life-Sustaining Treatment, do-not-resuscitate orders, or other written directives. If an AD was completed, the proxy was asked whether the participant's instructions expressed a desire to receive "all care possible under any circumstances in order to prolong life" (referred to herein as aggressive care), to limit care in certain situations (limited care), or to be kept comfortable and pain free but forgo aggressive measures to prolong life (comfort care). This item was recoded dichotomously (aggressive care vs all other care preferences).

Covariates

Covariates included demographic, social, and health characteristics. Demographic variables included age, sex, marital status (married, divorced or separated, widowed, never married), education (greater vs less than or equal to high school education), and income (quartiles). Health conditions were coded dichotomously and included lung disease, heart condition, depression, stroke, memory impairment, and cancer. Religious attendance was evaluated according to the proxy's report of how often the decedent attended religious services during the last year of life. Following the method used in a previous study,²¹ religious attendance was recoded as a dichotomous variable (did vs did not attend religious services in the last year of life). The decedent's death was coded as expected or unexpected based on proxy report. To determine whether there was a longitudinal trend in AD completion rates over time for blacks, whites, and Hispanics, year of death was included as a continuous variable in the analytical model.

Analyses

Descriptive statistics were used to characterize the full sample and report AD completion rates according to race and ethnicity and, in those with an AD, preferences for aggressive care according to race and ethnicity. Logistic regression models were then used to determine whether the likelihood of AD completion varied according to race and ethnicity, and in those with a completed AD, whether there were racial and ethnic differences in preference for aggressive care. Demographic, social, and health characteristics were adjusted for. Then, a series of stratified models were conducted separately for blacks, Hispanics, and whites to determine how demographic, socioeconomic, and health characteristics influenced AD completion. These analyses also examined change in AD completion over time in each racial and ethnic group.

Missing data were corrected for in the analyses using multiple chained equations, which is a simulation-based approach for analyzing incomplete data that results in valid statistical inference.²² Approximately 11% of respondents had missing depression data, mainly from 2002 because of a system error in the HRS, and an additional 8% were missing data on other covariates included in the analysis. The multiple chained equations procedure replaces missing values with multiple sets of simulated values to complete the data, applies standard analyses to each completed dataset, and adjusts the obtained parameter estimate for missing data uncertainty. All analyses were weighted using sample weights that the HRS provided and were analyzed using Stata version 13.1 (Stata Corp., College Station, TX).

RESULTS

Participants

The sample included 7,177 HRS participants who had died between 1997 and 2013. There were slightly more women (53.2%) than men (46.8%). The mean age of the sample at the time of death was 80.3 ± 10.5 (range 51–112). Whites accounted for 76.7% of the sample, blacks 15.8%, and Hispanics 7.5%. Educational attainment varied, with 36.6% of participants obtaining less than a high school education, 32.7% completing high school, and 30.7% pursuing education after high school. Most participants were widowed (43.9%) or

married (39.2%), with 12.6% divorced and 4.4% single or never married. More than half (54.7%) of participants had attended religious services at least once during their final year of life.

More than half (54.1%) of participants had a heart-related condition, and 51.6% experienced depression in the last 12 months before death. More than one-third (36.5%) of participants had been diagnosed with cancer, 25.5% with lung disease, and 27.2% with stroke. Approximately one in five (20.6%) had memory impairment. Proxies reported that death was expected for 60.5% of the decedents. Table 1 presents sample characteristics.

Prevalence and Predictors of AD Completion

Overall, 46.0% of participants had completed an AD. Whites had the highest AD completion rate (51.7%). The completion rate was 15.0% for blacks and 18.0% for Hispanics.

Logistic regression was conducted to identify variables that influenced AD completion. In the regression model, age, being female, having an expected death, being widowed or never married, having 12 years or more education, and year of death were positively associated with AD completion. Having income in the second to fourth quartiles and being diagnosed with lung disease, a heart condition, depression, or cancer were associated with higher AD completion. Religious attendance was positively associated with AD completion. Blacks had 77% lower odds of AD completion than whites and Hispanics had 70% lower odds (Table 2).

Prevalence and Predictors of Aggressive Care

Descriptive results showed that blacks had the highest preference rate for aggressive care (23.8%). By comparison, 13.3% of Hispanics and 3.3% of whites elected aggressive care.

In the regression model, the odds of preferring aggressive care was 6.4 times as great for blacks as for whites and 3.3 times as great for Hispanics. Factors negatively associated with electing aggressive care included having an expected death; being divorced, separated, or widowed; having more than 12 years of education; and having memory impairment. Year of death was positively associated with electing aggressive care (Table 2).

Longitudinal Trends in and Predictors of AD Completion According to Race and Ethnicity

Separate logistic regressions were run for whites, blacks, and Hispanics to explore predictors of and longitudinal trends in AD completion for each group (Table 3).

Whites who had died more recently were significantly more likely to have completed an AD; they had 3% greater odds of AD completion for each year later that they died. Other significant predictors of AD completion were older age; being female; having an expected death; being widowed; having 12 years or more of education; having income in the second to fourth quartile; being diagnosed with lung disease, a heart condition, depression, or cancer; and attending religious services.

Blacks who had died more recently were significantly more likely to have completed an AD; they had 10% greater odds of AD completion for each year later that they died. Additional

significant predictors of AD completion were older age; being female; having income in the second quartile; and being diagnosed with lung disease, a heart condition, memory impairment, or depression.

For Hispanics, year of death was not significantly associated with AD completion; there was no trend in longitudinal completion rates for Hispanics. Significant predictors of AD completion included age; being divorced, separated, widowed, or never married; having income in the third or fourth quartile; and being diagnosed with a heart condition or depression.

DISCUSSION

Using data from a nationally representative sample of older Americans, this study breaks new ground by examining longitudinal trends in AD completion by whites, blacks, and Hispanics. Study results allowed predictors of AD completion of these three groups to be compared.

AD completion rates confirmed results reported in previous studies showing that blacks have the lowest rates of AD completion and whites have the highest rate.^{4,21} Blacks 77% lower odds of completing an AD than whites, and Hispanics had 70% lower odds. In addition Hispanics, who are frequently not included in studies of this kind, have low rates of AD completion.

This study, like others before it,^{3,7,23,24} also found that, of individuals with an AD, blacks were most likely to prefer aggressive care, followed by Hispanics. Whites were least likely to prefer aggressive care. In this nationally representative sample, nearly one-quarter of blacks completing ADs elected aggressive care.

This study found differences according to ethnicity in the demographic, socioeconomic, and health characteristics that influenced a particular ethnic group's completion of an AD. These findings are in keeping with qualitative findings reported in the literature. The finding that Hispanics are more likely to complete an AD if they are divorced, separated, never married, or widowed suggests that Hispanics without a marital partner are less likely to rely on family-centered decision-making and more likely to adopt a standardized approach to end-of-life care planning (AD completion). One possible explanatory pathway is that the AD replaces less-formal family decision-making for single Hispanics. In a previous qualitative study²⁵ some Hispanics cited close family ties as a reason why they did not perceive advance care planning as relevant. These findings were not consistent in blacks and whites; none of the marital status variables were significant in blacks, and only being widowed was significant in whites.

Exploring longitudinal trends in AD completion showed that, although blacks and Hispanics had similar rates of AD completion overall (~16%), blacks but not Hispanics had increasing rates of AD completion between 1998 and 2012. It was also found that whites had increasing rates of AD completion between 1998 and 2012. Increasing use of ADs by blacks but not Hispanics may be indicative of education programs targeted primarily towards blacks. Such selective targeting may be in response to the plethora of research documenting

low rates of ADs among blacks, whereas as noted earlier, Hispanics' use of ADs is understudied. Language barriers may also hamper AD outreach to and education of Hispanics.

There are many factors that may contribute to the ongoing racial and ethnic disparity in AD completion and preference for aggressive care. Previous research suggests that cultural factors, including beliefs about and attitudes toward end-of-life care choices—factors that are not accounted for in the current study—may contribute to these differences. For example, distrust of the healthcare system influences blacks' choices about end-of-life care.^{3,26} It has also been suggested that members of ethnic minorities may prefer to make end-of-life care decisions as a family.¹ The individualistic decision-making style that whites generally accept may be one reason why AD completion rates are highest among whites.¹ Religious beliefs, which often vary according to ethnic group, may also influence AD development and care preferences.¹ Knowledge, attitudes, and beliefs are important personal factors to consider when exploring why some people choose to complete an AD while others do not.²⁷

Limitations

This study's findings should be considered in light of its limitations. Although it was possible to examine differences between black, white, and Hispanic decedents, information was lacking on other racial and ethnic groups such as Asian Americans, American Indians, and Pacific Islanders. The racial and ethnic identity of these groups is masked in HRS to preserve the confidentiality of respondents belonging to groups with small sample sizes. Future studies are needed to examine the influence of acculturation on AD development. Finally, religious attendance was reported for decedents' final year of life, and their illness may have limited and thus may not have accurately reflected their actual level of religiosity.

Policy Implications

Given the potential benefits of having an AD, including provision of care consistent with the individual's preferences and reduced burden arising from proxy decision-making, improving rates of AD completion is important.¹ Physician–patient communication about advance care planning is an important aspect of providing person-centered care. This is reflected in Medicare's new provision for reimbursement for these discussions. Some care preferences stated in ADs may reflect cultural values, and physicians should recognize that ethnically diverse individuals may have different sets of values regarding aggressive care. Furthermore, greater physician and patient education and ongoing communication on benefits of ADs, including possible benefits and consequences of receiving aggressive care, are needed to ensure the people are making informed decisions and that those decisions are documented in ADs.

Future Research

Future research is needed to explore how cultural factors influence AD completion and care preferences. Research that sheds light on how families influence their loved one's AD development and care preferences may provide additional insight into the data. Research exploring whether individuals from various ethnic backgrounds receive the type of end-of-

life care that is congruent with their wishes is also needed. This research will increase understanding about providing end-of-life care to individual from diverse backgrounds.

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Table 1

Description of Sample: Health and Retirement Study Exit Interviews 2000–2013

Characteristic	Total Sample, N=7,177	White, n=5,508	Black, n=1,132	Hispanic, n=537
	n (%)			
Advance directive completed	3,119 (46.0)	2,848 (51.7)	181 (15.0)	90 (18.0)
Age				
50–74	2,227 (33.5)	1,535 (31.1)	478 (47.0)	214 (43.8)
75–84	2,290 (31.8)	1,802 (32.1)	322 (29.7)	166 (31.9)
85	2,660 (34.7)	2,171 (36.8)	332 (23.3)	157 (24.3)
Sex				
Male	3,321 (46.8)	2,565 (46.7)	498 (45.2)	258 (52.2)
Female	3,856 (53.1)	2,943 (53.3)	634 (54.7)	279 (47.8)
Marital status				
Married	2,913 (39.2)	2,323 (40.5)	363 (28.4)	227 (40.1)
Divorced, separated	776 (12.6)	513 (11.1)	198 (22.1)	65 (17.4)
Widowed	3,219 (43.8)	2,504 (44.6)	492 (40.8)	223 (37.7)
Never married	269 (4.4)	168 (3.8)	79 (8.7)	22 (4.8)
Education, years				
<12	2,905 (36.5)	1,813 (31.6)	690 (57.8)	402 (72.6)
12	2,231 (32.7)	1,898 (34.8)	262 (24.6)	71 (14.7)
>12	2,041 (30.7)	1,797 (33.5)	180 (17.7)	64 (12.7)
Income quartile				
0–25%	3,125 (42.1)	2,011 (37.3)	737 (66.1)	377 (70.6)
25–50%	2,164 (30.1)	1,824 (32.1)	237 (19.7)	103 (18.6)
50–75%	1,242 (17.7)	1,090 (19.4)	112 (9.4)	40 (7.4)
75–100%	646 (10.0)	583 (11.1)	46 (4.8)	17 (3.4)
Health conditions				
Cancer	2,510 (36.5)	2,031 (37.6)	349 (32.2)	130 (26.9)
Lung disease	1,777 (25.5)	1,465 (26.7)	204 (18.9)	108 (20.3)
Heart	3,898 (54.1)	3,100 (55.2)	558 (48.5)	240 (46.6)
Depression	3,592 (51.5)	2,837 (52.5)	459 (41.0)	296 (57.0)
Stroke	1,998 (27.2)	1,493 (26.6)	367 (32.4)	138 (26.5)
Memory	1,547 (20.6)	1,177 (20.7)	260 (21.1)	110 (17.5)
Religious attendance	4,056 (54.7)	2,927 (52.2)	782 (68.9)	347 (66.7)
Expected death	4,317 (60.5)	3,436 (62.0)	574 (49.4)	307 (57.9)

Unweighted n's, weighted percentages.

Table 2

Logistic Regression Analyses of Advance Directive Completion and of Those Who Completed, Those Who Opted for Aggressive Care: Health and Retirement Study Exit Interviews 2000–2013

Characteristic	Advance Directive Completion, n=7,177	Aggressive Care, n=3,119
	Odds Ratio (95% Confidence Interval)	P-Value
Race (reference white)		
Black	0.23 (0.19–0.29) <.001	6.41 (3.94–10.41) <.001
Hispanic	0.30 (0.22–0.40) <.001	3.32 (1.49–7.42) <.001
Age	1.03 (1.03–1.04) <.001	0.98 (0.96–1.00) .10
Female	1.17 (1.03–1.34) .01	1.08 (0.70–1.67) .74
Expected death	1.25 (1.10–1.41) <.001	0.53 (0.35–0.80) <.001
Marital status (reference married)		
Divorced or separated	1.07 (0.86–1.33) .57	0.52 (0.26–1.02) .06
Widowed	1.38 (1.19–1.61) <.001	0.48 (0.26–0.88) .02
Never married	1.45 (1.04–2.01) .03	0.65 (0.23–1.82) .41
Education, years (reference <12)		
12	1.40 (1.21–1.61) <.001	0.86 (0.55–1.35) .51
>12	1.92 (1.65–2.24) <.001	0.54 (0.31–0.92) .02
Income quartile (reference 0–25%)		
25–50%	1.23 (1.06–1.43) .01	0.73 (0.42–1.27) .27
50–75%	1.43 (1.19–1.73) <.001	0.56 (0.28–1.13) .11
75–100%	1.98 (1.54–2.54) <.001	0.52 (0.22–1.20) .13
Health conditions		
Cancer	1.41 (1.25–1.60) <.001	0.75 (0.49–1.15) .19
Lung disease	1.19 (1.04–1.37) .01	1.25 (0.82–1.90) .30
Heart	1.20 (1.07–1.35) <.001	1.05 (0.70–1.59) .80
Depression	1.30 (1.14–1.48) <.001	1.18 (0.79–1.76) .43
Stroke	0.98 (0.86–1.12) .80	1.38 (0.88–2.19) .16
Memory	1.01 (0.88–1.17) .88	0.49 (0.29–0.82) .01
Religious attendance	1.18 (1.05–1.33) .01	0.97 (0.66–1.43) .89
Death year	1.03 (1.01–1.05) <.001	1.10 (1.04–1.16) <.001

Table 3

Logistic Regression Analyses of Advance Directive Completion According to Race and Ethnicity: Health and Retirement Study Exit Interviews 2000–2013

Characteristic	Black, n=1,132	Hispanic, n=537	White n=5,508
	Odds Ratio (95% CI) <i>P</i> -Value		
Age	1.04 (1.02–1.06) <.001	1.04 (1.01–1.07) .01	1.03 (1.03–1.04) <.001
Female	1.61 (1.03–2.52) .04	1.18 (0.61–2.27) .62	1.15 (1.00–1.32) .05
Expected death	1.25 (0.81–1.90) .31	0.87 (0.48–1.58) .64	1.25 (1.10–1.43) <.001
Marital status (reference married)			
Divorced or separated	1.45 (0.75–2.81) .27	6.44 (2.30–18.07) ^a <.001	0.95 (0.75–1.20) .66
Widowed	1.35 (0.79–2.31) .28	4.12 (1.82–9.30) <.001	1.36 (1.15–1.59) <.001
Never married	1.11 (0.42–2.90) .83	6.64 (1.97–22.44) ^a <.001	1.41 (0.98–2.04) .06
Education, years (reference <12)			
12	1.67 (1.01–2.76) .05	1.89 (0.94–3.80) .07	1.37 (1.18–1.59) <.001
>12	1.44 (0.86–2.39) .16	1.30 (0.55–3.08) .54	1.95 (1.66–2.30) <.001
Income quartile (reference 0–25%)			
25–50%	2.33 (1.39–3.90) <.001	1.12 (0.51–2.48) .77	1.18 (1.01–1.38) .04
50–75%	1.84 (0.91–3.72) .09	4.58 (1.59–13.17) ^a <.001	1.36 (1.12–1.65) <.001
75–100%	1.86 (0.66–5.25) .24	6.94 (1.11–43.53) ^a .04	1.87 (1.44–2.43) <.001
Health conditions			
Cancer	1.29 (0.83–2.00) .25	1.37 (0.75–2.49) .30	1.42 (1.24–1.62) <.001
Lung disease	1.66 (1.04–2.65) .03	1.50 (0.69–3.23) .30	1.17 (1.01–1.35) .03
Heart	1.78 (1.20–2.65) <.001	1.97 (1.09–3.57) .03	1.14 (1.01–1.30) .04
Depression	1.64 (1.10–2.44) .02	2.16 (1.17–3.96) .01	1.27 (1.11–1.46) <.001
Stroke	0.81 (0.53–1.24) .33	0.82 (0.40–1.64) .57	1.00 (0.87–1.15) .99
Memory	0.61 (0.37–0.98) .04	0.96 (0.50–1.83) .90	1.03 (0.89–1.21) .67
Religious attendance	0.89 (0.58–1.35) .57	0.85 (0.47–1.51) .57	1.21 (1.07–1.37) <.001
Death year	1.10 (1.04–1.17) <.001	1.07 (0.98–1.16) .11	1.03 (1.01–1.05) <.001

^aThe wide confidence intervals (CIs) for Hispanics are due to small cell sizes.