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Discussion as a Factor in the Racial Disparity in Advance Directive Completion at Nursing Home Admission

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Abstract

Studies have consistently shown racial disparities in advance directive completion among nursing home residents but have not examined whether this disparity is due to differences in interactions with healthcare providers. This study had two aims: to determine whether the racial disparity in advance directive completion by nursing home residents is related to differences in discussion of treatment restrictions with healthcare providers, and to examine if there is a racial disparity in perceptions of residents' significant others that additional discussions would be helpful. Participants were 2,171 white or black (16% of sample) residents newly admitted to 59 nursing homes. Data were collected from structured interviews with residents' significant others and review of nursing home charts. Questions included whether advance directives were completed, whether treatment restrictions were discussed with the resident and/or family, and whether more discussion would have been helpful. Frequencies by race were determined for each question; p-values and logistic regression models were obtained using SAS. Black residents were less likely to have completed any advance directives ($p < 0.001$). Also, black residents ($p < 0.001$) and their family members ($p < 0.001$) were less likely than whites to have discussed treatment restrictions with healthcare providers. Logistic regression models indicated that disparity in treatment restrictions narrowed when these discussions occurred. Significant others of black residents were more likely to consider further discussion helpful ($p < 0.001$), especially with physicians. Racial disparity in treatment restrictions may be due in part to a difference in discussion with healthcare providers; increasing discussion may narrow this disparity.

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Keywords

advance directives; racial disparity; treatment restrictions; physician discussion; nurse discussion

INTRODUCTION

The Terri Schiavo case focused attention on the use of advance directives¹ (AD) to indicate individuals' wishes for treatment should they become incompetent to make medical treatment decisions or to designate others to make such decisions.² Common ADs include living wills (LW), healthcare powers of attorney (HCPOA), and treatment restrictions.³ One concern about ADs is a racial difference in the frequency of their completion.

Research has shown that advance directive completion (ADC) is less common for black nursing home residents than whites.²⁻⁷ While this finding has been reported across patient populations,⁸⁻¹¹ nursing home residents are an especially important cohort to consider when examining ADC, as nursing homes are a common place of death.¹²⁻¹³ Since the Patient Self-Determination Act requires that nursing home residents be provided with information about ADs at the time of admission,¹⁴ this event may signal an opportunity for residents and families to consider documenting preferences for end-of-life care.

One suggested cause for the racial disparity in ADC in nursing home residents is a difference in communication with healthcare providers about the end of life.^{2,7,15,16} This suggestion is supported by findings in non-nursing home populations that a lack of explanation of ADs is a commonly cited barrier to ADC,^{17,18} and evidence that discussion of end-of-life issues is more likely to occur with whites than blacks.^{10,16,19} To examine the role of discussion in the racial disparity in ADC, this study aims to: (1) examine whether racial disparity in ADC existed in an admission cohort of nursing home residents and whether discussions with physicians or nursing home staff about treatment restrictions modified this relationship; and (2) examine if there was a racial difference in whether residents' significant others reported that additional discussions about medical treatments would have been helpful.

METHODS

Study Population

Data for this study came from the Epidemiology of Dementia in New Admissions to Nursing Homes Study.²⁰ Subjects were 2,171 residents newly admitted to 59 nursing homes. Nursing homes were randomly selected from 221 licensed long-term care facilities in Maryland, after stratification for geographic region and facility size. New admissions to these nursing homes during September 1992–March 1995 were identified for the study. Admissions were eligible if they were aged 65 and older and had not resided in a nursing home for 8 or more days during the previous year. A significant other (SO), usually a family member, was identified for each resident as the person most knowledgeable about the resident's health prior to nursing home admission. Informed consent was obtained from the resident or the SO if the resident was impaired. SOs also provided consent for their own participation. The protocol was approved by the University of Maryland, Baltimore Institutional Review Board.

Of 3,851 eligible residents identified by the nursing homes, data collection for 568 individuals was not possible within the interview timeframe (<65 days after admission). Of the remaining 3,283 individuals, 2,285 (69.6%) enrolled. Enrolled subjects were older (81.5 vs. 80.6 years, $p < .001$) and more often female (71.6% vs. 68.8%, $p < .05$) than eligible non-

participating individuals.²⁰ Compared to new admissions in the five states in the Nursing Home and Quality Demonstration project, enrollees had a similar age and sex distribution and a similar proportion of white residents, although the study sample had a greater proportion of blacks (18.8% in study sample vs. 8.4% in the 5-state data) and a lower proportion of other races.²⁰ Twenty-eight residents missing race or ADC data, and 86 non-white, non-black residents were dropped from these analyses, so the final sample was 2,171 residents.

Data Collection

Data were collected from structured interviews with nursing staff and SOs, and from chart abstraction of medical records for the first week in the nursing home including the Minimum Data Set (MDS) completed at admission.

Measures

Resident race was categorized as non-Hispanic white, black, or other based on information provided by the SO, or based on the nursing home record if the SO report was missing. A resident was designated as having completed a LW or HCPOA if reported by either the MDS or SO interview. Treatment restrictions noted on the MDS included do-not-resuscitate orders, do-not-hospitalize orders, feeding restrictions, medication restrictions, and other treatment restrictions. A summary variable for completion of any treatment restriction (yes/no) was calculated for analysis.

SOs were asked whether a discussion about treatment restrictions occurred between the physician and resident (resident discussion) and whether any discussion about treatment decisions occurred between nursing home staff and the resident's family members (family discussion). The definition of treatment restrictions in these questions matched that described above. SOs who reported a family discussion were asked with whom (among nursing home staff) the discussion occurred and whether this discussion resulted in a treatment decision. All SOs were asked whether further discussions about medical treatments would have been helpful, and if so, with whom these discussions should be held.

Covariates

The SO's relationship to the resident was identified during the SO interview. All other potential covariates were chosen a priori based on their status as significant confounders in prior studies of racial disparity in ADC in nursing homes,²⁻⁷ or based on their known associations with race (marital status, diagnoses of hypertension or diabetes mellitus). Resident demographic variables included age, gender, marital status, educational status, and having a living child. These variables were defined based on SO report, or by the MDS if the SO report was missing. Medicaid status and an explicit terminal diagnosis were noted in the MDS. Disease diagnoses included arthritis, dementia, hypertension, stroke, congestive heart failure (CHF), diabetes mellitus, allergies, cancer, and depression. These were defined in accordance with prior research and defined based on the MDS and SO interview, except dementia diagnosis, which was determined by an expert panel.²¹ Weight status was based on body mass index (BMI) derived from the weight and height in the medical chart. Functional status was provided by interview with the facility care provider, based on the modified Katz Activities of Daily Living Scale (ADL).²² Cognitive status was determined according to the MDS Cognition Scale, derived from the MDS.²³

Categories of age, marital status, and educational status were defined as in prior research,²⁻⁷ while weight, functional, and cognitive status were categorized by commonly accepted classification groups. Thus, three age groups were used: 65-74 years, 75-84, and 85 and older. Marital status was dichotomized (married or not married), as was educational status

(less than high school [<12 years of education] or completed high school [≥ 12 years]). Categories for weight were: underweight (BMI <18.5), normal weight (18.5–24.9), overweight (25.0–29.9), and obese (≥ 30.0).²⁴ Functional status categories were: 0–1, 2–3, and 4–6 ADL impairments. Cognitive status categories were: cognitively intact (0–1 on the MDS Cognition Scale), mild/moderately impaired (2–4), and severe/very severely impaired (5–10).

Statistical Analysis

Frequencies by race and p-values of chi-square were obtained for SO relationship, resident characteristics, and the variables of interest (resident discussion, family discussion, LW, HCPOA, treatment restrictions, and additional discussions helpful). Two logistic regression models were run for each variable of interest using SAS, version 9.1 (SAS Institute, Cary, NC): (1) a bivariate model with race; and (2) a multivariable model adjusted for all covariates significantly associated with race ($p<.05$) and for resident and family discussion variables. Odds ratios (OR) and 95% confidence intervals (CI) for variables of interest by race were determined, using white race as the reference.

Interactions between race and each discussion variable were examined for significance in the adjusted models. Interactions were significant in models for family discussion and treatment restrictions, so ORs for race are reported by whether or not a discussion with healthcare providers occurred.

Frequencies by race and p-values of chi-square were obtained for additional questions asked of SOs who indicated that a family discussion occurred and for questions asked of SOs who indicated that further discussions would be helpful, except for the p-value for discussion with other personnel, which had small cell sizes and required a Fisher's exact test.

RESULTS

Resident Demographics, Health and Functional Status, by Race

Most residents in the sample were white ($n=1814$, 83.6%) but the sample included a substantial fraction of black residents ($n=357$). The majority of SOs were family members (82.9%), and white residents were significantly more likely than blacks to have a spouse or child as their SO ($p<.001$, Table 1). Also, white residents were more likely than blacks to be in an older age group ($p<.001$), to be female ($p=.02$), and to have completed high school ($p<.001$). White residents were significantly less likely than blacks to have Medicaid as a payor for their care ($p<.001$).

Very few residents (0.96%) had a terminal diagnosis indicated and there was no significant difference by race (0.96% for whites vs. 0.92% for blacks, $p = .94$). Similarly, there was no significant difference by race in the frequency of arthritis, CHF, or cancer diagnoses ($p>.30$ for each). Thus, these four variables were not included in the multivariable models. Dementia was significantly more common in black residents than whites (61.9% vs. 46.1%, $p<.001$), while depression was significantly more common in whites than blacks (11.6% vs. 4.6%, respectively, $p<.001$). Whites were significantly less likely than blacks to have 4–6 ADL impairments (59.2% vs. 73.9%, $p<.001$), or to be severe/very severely cognitively impaired (34.8% vs. 53.1%, $p<.001$).

Discussions of Treatment Restrictions and Completion of Advance Directives, by Race

Black residents were significantly less likely than whites to have discussed treatment restrictions with their physicians (16.7% vs. 32.2%, respectively, $p<.001$), even after adjustment for significant covariates (OR 0.42, 95% CI 0.22–0.78, Table 2). Similarly,

families of blacks were less likely than those of whites to have discussed treatment decisions with nursing home staff (35.6% vs. 51.2%, $p < .001$; OR 0.54, 95% CI 0.34–0.86).

Resident discussion significantly modified the association between race and family discussion in the adjusted model. When no resident discussion occurred, discussion was significantly less likely among families of blacks than among those of whites (OR 0.45, 95% CI 0.27–0.74). However, when resident discussion occurred, families of blacks were more likely to have had a discussion than those of whites, although this difference was not significant (OR 1.91, 95% CI 0.48–7.57).

Black residents were also significantly less likely than whites to have each AD ($p < .001$), as indicated by the MDS for: LW (3.5% vs. 25.9%), HCPOA (5.3% vs. 28.5%), and treatment restrictions (11.3% vs. 31.9%); and by the SO interview for: LW (15.2% vs. 50.4%) and HCPOA (40.6% vs. 63.2%). The odds for blacks having completed a LW, HCPOA, or treatment restriction remained significantly less than for whites, even after adjustment for significant covariates and resident and family discussions (ORs 0.20 to 0.33).

Documentation of Advance Directives

Frequencies of completion of LWs or HCPOA were substantially higher as reported by the SO than on the MDS. To examine whether this difference had an impact on the overall disparity, we examined concordance of ADC reporting by race. Black residents were significantly more likely than whites to have a LW reported by an SO but not documented on the MDS (11.6% vs. 25.5%, respectively, $p < .001$), the opposite relation to the overall disparity. Blacks and whites were about equally likely to have a HCPOA reported by an SO but not documented on the MDS (35.7% vs. 37.3%, $p = .62$). Controlling for source of documentation did not affect the finding of racial disparity in ADC.

Interaction of Discussion and Completion of Treatment Restrictions

Both resident and family discussion variables significantly modified the association between race and completion of treatment restrictions. Models adjusted for significant covariates showed significantly lower odds of treatment restrictions for blacks relative to whites if no resident discussion occurred (OR 0.20, 95% CI 0.09–0.44) or if no family discussion occurred (OR 0.13, 95% CI 0.05–0.40). If discussion occurred, then the racial disparity in treatment restrictions narrowed and was no longer significant. With resident discussion, the OR was 0.98 (95% CI 0.30–3.19), and with family discussion, the OR was 0.52 (95% CI 0.23–1.14). Resident or family discussion of treatment restrictions did not significantly modify the association of race with LW or HCPOA completion.

Characteristics of Family Discussion of Treatment Decisions

SOs reported that family discussions with nursing home staff (including physicians) were very likely to result in a treatment decision (Table 3). Frequency of decision-making did not differ significantly by race (80.3% for whites, 82.0% for blacks, $p = .70$). SOs were asked whether these discussions occurred with nurses, doctors, social workers, administrators, other admitting personnel, and/or others; little difference by race was noted for who held these discussions. The only significant difference was that families of blacks were more likely than those of whites to have discussions with “other admitting personnel” (50.0% vs. 37.5%, $p = .02$).

Additional Discussions Considered Helpful, by Race

SOs of blacks had 2.40 times greater odds than those of whites to think that additional discussions about medical treatments would be helpful, after adjustment for significant covariates (95% CI 1.46–3.94; Table 2). Even among those reporting a family discussion,

SOs of blacks were significantly more likely than those of whites to think that further discussions would be helpful (34.1% vs. 17.7%, $p < .001$, Table 3). SOs of blacks were significantly more likely than those of whites to want to discuss treatments further with a doctor (89.9% vs. 77.0%, $p = .004$). The two groups did not differ significantly in wanting to discuss restrictions with nursing home staff (82.6% vs. 75.1%, $p = .11$) or others (40.8% vs. 38.8%, $p = .72$).

DISCUSSION

To our knowledge, this is the first study to examine discussion of treatment decisions with healthcare providers as a possible factor in the racial disparity in ADC among nursing home residents. Confirming prior studies,²⁻⁷ we found that black residents were significantly less likely than whites to complete ADs, even after adjustment for numerous resident characteristics. While prior reports have speculated about the reasons for this disparity, none have directly examined whether differences in discussion with healthcare providers contributed to the result. Our research had a number of findings that advance the understanding of racial disparities in ADC.

Black residents and their families were less likely to have discussed treatment restrictions with physicians and nursing home staff than were whites and their families. As discussed in prior studies, this disparity may relate to a differential acceptance of treatment restrictions based on a history of limited access to care and spiritual beliefs that deny the inevitability of death,^{8,16,19,25} but it may also represent a difference in care provision based on external factors such as healthcare provider expectations or facility quality.^{5,16,18}

We found that racial disparity in treatment restrictions narrowed and was no longer significant when discussion about them occurred. Also, families of black and white residents were equally likely to make a treatment decision as a result of their discussions. These results indicate that such discussion may provide important information and override concerns or beliefs. Alternately, those who are more receptive to ADC may be more likely to engage in these discussions. Either way, the importance of such discussion cannot be overlooked. While other differences between races may also be involved in the disparity in ADC by nursing home residents and the personal style of the discussants, their level of rapport, and the choice of words may all affect the outcome of a discussion, our results suggest that discussion with physicians and nursing home staff may be a critical factor in eliminating this disparity. Therefore, physicians and nursing home staff should not neglect these discussions, particularly during the admission process, which provides the opportunity for dialogue about care decisions that may be difficult in other contexts. Of course, some patients and families may choose not to put treatment restrictions into place even after discussion.

We also found that SOs of black residents were more likely than those of whites to report that additional discussions would be helpful, particularly with physicians. Consequently, attempts by physicians and staff to discuss these difficult issues are likely to be welcomed by many family members. This result is consistent with findings from studies in other populations,^{8,16} and suggests that physicians should be strongly encouraged to discuss ADs with nursing home residents and their families, particularly black families. At the same time, there is increasing recognition of the limited role of physicians in long-term care settings,^{26,27} so physicians' efforts may be augmented by those of nursing home social workers. These workers are also involved in end-of-life discussions²⁸ and have guidance from recent professional standards for palliative and end-of-life care,²⁹ but there is a need to better prepare social workers and others to have these discussions with residents and families.

Another important finding is the underreporting of LWs and HCPOA in the MDS compared to SO report for both races. ADs were about half as likely to be reported on the MDS compared to SO report for blacks and were even less likely for whites. The disparity disfavored whites, so it does not affect our main results, but such differences indicate a need for better communication and documentation for both races.

Some limitations of this study must be acknowledged, particularly the age of the data, as it was collected between 1992 and 1995. However, several studies using more recent data have demonstrated the same racial disparities in ADC,2·4·5·7·15 suggesting that any changes in communication between healthcare providers and nursing home residents have not altered the environment leading to a disparity. Another limitation was the use of proxy respondents, although their use allowed broader study participation given the high prevalence of dementia in this population.20·30 Finally, this study could not establish that such discussions resulted in the completion of ADs. As suggested earlier, it is instead possible that residents or families who already intended to complete ADs sought out this communication. Still, there is cause to believe that such discussion will result in more ADC. Thus, these limitations do not detract from the central message that more discussions of ADC are recommended, especially for black nursing home residents. Further study is needed to understand the dynamic of communication, and to determine whether discussions of ADs other than treatment restrictions have a similar role in the racial disparity in ADC.

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Table 1

Resident Demographic Characteristics, Health, and Functional Status, by Race*

Characteristic of Resident	White (n=1814)	Black (n=357)	p-value [†]
	%	%	
Percent of sample	83.6	16.4	
Relationship of significant other respondent			<.001
Spouse	11.9	8.4	
Child	56.0	38.7	
Sibling	5.2	9.2	
Other relative	10.9	21.3	
Legal guardian or other legal responsibility	0.3	0.8	
Non-relative	4.1	7.0	
Unknown	11.6	14.6	
Age			<.001
65–74 years	17.8	28.3	
75–84 years	43.6	42.0	
85 years and older	38.6	29.7	
Gender			.02
Male	27.9	34.2	
Female	72.1	65.8	
Marital status			.007
Married	25.1	18.5	
Not married	74.9	81.5	
Education			<.001
Less than high school (< 12 years)	45.2	68.2	
Completed high school (≥ 12 years)	54.8	31.9	
Has a living child	79.5	64.5	<.001
Medicaid payor	19.0	47.8	<.001
Terminal diagnosis	0.96	0.92	.94
Disease diagnoses			
Arthritis	62.1	59.3	.31
Dementia	46.1	61.9	<.001
Hypertension	38.7	49.2	<.001
Stroke	32.2	40.2	.004
Congestive heart failure	31.1	30.3	.76
Diabetes mellitus	19.4	26.7	.003
Allergies	16.9	5.9	<.001
Cancer	16.3	14.9	.51
Depression	11.6	4.6	<.001
Weight status			.03
Underweight (Body mass index < 18.5)	18.4	22.5	

Characteristic of Resident	White (n=1814)	Black (n=357)	p-value [†]
	%	%	
Normal (Body mass index 18.5–24.9)	50.8	48.7	
Overweight (Body mass index 25.0–29.9)	20.8	15.4	
Obese (Body mass index ≥ 30)	10.1	13.4	
Physical function (ADL [‡])			<.001
0–1 impairments	21.5	13.6	
2–3 impairments	19.3	12.6	
4–6 impairments	59.2	73.9	
Cognitive status (MDS-COGS [§])			<.001
Cognitively intact (0–1)	38.1	21.0	
Mild/moderately impaired (2–4)	27.1	25.9	
Severe/very severely impaired (5–10)	34.8	53.1	

* Percentages for some variables may not total to 100 due to rounding.

[†] p-value derived from Chi-square (χ^2) test on categories of all variables.

[‡] ADL: Activities of Daily Living

[§] MDS-COGS: Minimum Data Set Cognition Scale

Table 2
Odds of Discussion, Advance Directives and Perception that Additional Discussion Would Be Helpful, by Race

Variable of Interest	Unadjusted Model*		Adjusted Model [†]		Effect Modification p-value [§]
	Race OR [‡]	95% CI	Race OR [‡]	95% CI	
Discussion					
Resident discussion of treatment restrictions ^{//}	0.42	(0.30, 0.59)	0.42 ^{††}	(0.22, 0.78)	NA
Family discussion of treatment decisions					
Without effect modification	0.53	(0.40, 0.69)	0.54 [#]	(0.34, 0.86)	.049
When resident discussion did not occur	NA	NA	0.45 ^{**}	(0.27, 0.74)	NA
When resident discussion occurred	NA	NA	1.91 ^{**}	(0.48, 7.57)	
Advance directives					
Living will	0.17	(0.12, 0.24)	0.20 ^{††}	(0.11, 0.36)	.736
Healthcare power of attorney	0.33	(0.26, 0.43)	0.33 ^{††}	(0.21, 0.52)	.489
Treatment restrictions ^{//}					
Without effect modification	0.27	(0.19, 0.39)	0.29 ^{††}	(0.15, 0.55)	.025
When resident discussion did not occur	NA	NA	0.20 ^{††}	(0.09, 0.44)	
When resident discussion occurred	NA	NA	0.98 ^{††}	(0.30, 3.19)	
When family discussion did not occur	NA	NA	0.13 ^{§§}	(0.05, 0.40)	
When family discussion occurred	NA	NA	0.52 ^{§§}	(0.23, 1.14)	
Perception of additional discussion					
More discussions about medical treatments helpful	2.46	(1.88, 3.21)	2.40 ^{††}	(1.46, 3.94)	.407

* NA: Not applicable. Due to missing data, n for unadjusted models ranges from 1715 to 1906.

[†] All models adjusted for covariates of relationship of significant other (including unknown), age, gender, marital status, educational status, has a living child, Medicaid payor, dementia, hypertension, stroke, diabetes mellitus, allergies, depression, weight status, physical function, and cognitive status. Due to missing data, n for adjusted models ranges from 821 to 858.

[‡] White residents are the reference group for odds ratios (OR). CI: Confidence Interval

[§] p-values derived from Chi-square test of interaction term in adjusted model. NA: not applicable

^{//} Treatment restrictions include do-not-resuscitate or do-not-hospitalize order, or feeding, medication or other treatment restrictions.

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† Also adjusted for family discussion of treatment decisions.

Also adjusted for resident discussion of treatment restrictions.

** Adjusted for all variables in # **plus** interaction between race and resident discussion variables.

†† Also adjusted for resident discussion of treatment restrictions and family discussion of treatment decisions.

‡‡ Adjusted for all variables in †† **plus** interaction between race and resident discussion variables.

§§ Adjusted for all variables in †† **plus** interaction between race and family discussion variables.

Table 3

Characteristics of Discussion of Treatment Restrictions with Family Members, by Race *

Characteristic of Discussion	White (n=745)	Black (n=93)	p-value [†]
	%	%	
Made treatment decision	80.3	82.0	.70
Discussed but did not make decision	19.7	18.0	
Who discussed [‡]			
Nurse	22.8	23.3	.90
Doctor	36.7	34.8	.71
Social worker	33.8	34.4	.90
Administrator	32.4	30.8	.75
Other admitting personnel	37.5	50.0	.022
Other person	4.4	3.3	.79 [§]
More discussions helpful	17.7	34.1	<.001

* Frequencies are based on those significant others who indicated that a family discussion of treatment restrictions occurred. Due to missing data, n for individual items ranges from 806 to 819.

[†] p-values derived from Chi-square (χ^2) test except where noted.

[‡] Discussions could be with more than one type of staff, so percentages do not total to 100.

[§] p-value derived from Fishers exact test.