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Unintended harm? Race differences in the relationship between advance care planning and psychological distress at the end-of-life

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Abstract

Context: Research has revealed racial disparities in advance care planning and intensity of end-of-life care. Studies of the relationship between advance care planning and sadness and anxiety at the end-of-life are inconclusive.

Objective: To determine the extent to which the relationship between advance care planning and sadness and anxiety at the end-of-life differs by race.

Methods: Study analyzes data from 315 Medicare beneficiaries from the 2011–2016 National Health and Aging Trends Study. Caregiver-assessed sadness/anxiety at decedent's end of life was categorized as none, managed needs, and unmanaged needs. We used multinomial logistic regression and calculated relative risk and predicted probability of reporting sadness/anxiety by race and advance care planning status, controlling for demographic and health characteristics.

Results: Among non-Hispanic black/African-Americans who died, end-of-life discussions and having a healthcare proxy increased the predicted probability of caregivers reporting unmanaged needs related to sadness/anxiety by factors of 2.6 and 3.5, respectively (discussions: from 15% to 39%, p=.03; healthcare proxy: from 12% to 42% p=.008). In contrast, among non-Hispanic white decedents, end-of-life discussions and naming a healthcare proxy was not associated with caregivers reporting unmanaged needs related to sadness/anxiety.

Conclusion: Advance care planning may not work the same way for black and white individuals. End-of-life discussions and naming a healthcare proxy are potentially harmful to dying black patients' mental health. This finding suggests a need for additional research to understand why caregivers report unmanaged sadness/anxiety for dying black patients who engaged in advance care planning, and increased attention to these patients' mental health at the end-of-life.

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Disclosures
Dr. Luth has nothing to disclose.
Dr. Prigerson has nothing to disclose.

Keywords

end-of-life; advance care planning; racial disparities; psychological distress; sadness/anxiety

Introduction

In the case of end-of-life (EoL) care, physicians' mandate to avoid harming their patients, physically and psychologically,[1,2] is not always accomplished,[1,3] and is differentially experienced based on patients' race. Dying patients tend to receive aggressive, burdensome, and potentially futile care, as evidenced by the fact that over 40% of hospitalized patients are admitted to an intensive care unit during their last six months of life.[4] This trend is disproportionately borne out among black patients, who consistently receive more aggressive, burdensome, and potentially futile care than white patients.[4,5] Advance care planning (ACP) can help reduce aggressive and potentially futile care at EoL[6–9] and help patients obtain care that is consistent with their values and preferences.[10] However, the benefits of ACP do not apply evenly to black and white patients. Even when ACP is in place, black patients are still at higher risk of aggressive and burdensome care.[5]

While treatment of physical symptoms at EoL is documented, as are racial disparities in the potentially mitigating effect of ACP, much less is known about mental health of dying patients. Psychological distress is increasingly common among older adults at EoL,[11] yet mental health services are underutilized by the Medicare population.[12,13] Moreover, although ACP has been shown to help dying patients prepare mentally for death,[14,15] the potential for ACP to mitigate psychological distress at EoL is not well understood. Research suggests ACP has no relationship to[8,9,16–20] or is associated with a decrease in[19,21,22] mental health symptoms among dying patients. However, previous studies tend to focus on a specific disease population, such as patients with cancer or early stage-dementia,[9,19,21,22] involve small samples,[19–21] or do not account for respondents' race.[8,19–21] We cannot presume the neutral or beneficial effect of ACP on mental health at EoL observed for white patients extends to black patients. Moreover, given documented racial disparities in patterns of EoL care with respect to physical symptoms and potential benefits of ACP in mitigating those symptoms, we need to be aware of and attend to the possibility that similar racial disparities are present with respect to black patients' psychological distress at EoL.

We know of no studies that explore potential racial differences in the relationship between ACP and sadness/anxiety at EoL. This lack of attention is surprising, given how important mental health is at EoL, documented racial disparities in aggressive and burdensome EoL care, and differential impact of ACP in mitigating disparities in EoL treatments. Seriously ill individuals, bereaved family members, and EoL healthcare providers identify anxiety as an important factor at EoL.[14] Studies of EoL care quality ask respondents about sadness and anxiety as indicators of psychological distress.[23] This study uses longitudinal, population-based survey data to answer the question: Do the effects of ACP on caregiver reports of dying individuals' sadness and anxiety differ by their race?

Methods

Study Sample

Data are from six rounds of the National Health and Aging Trends Study (NHATS), a longitudinal population-based survey of older adults. The NHATS is comprised of a random sample of 8,245 noninstitutionalized Medicare enrollees age 65 and over in the contiguous United States in 2011 and oversampled black persons and those age 90 and older. Others have described sampling and weighting strategies in detail.[24,25] This analysis includes 315 participants who: 1) were randomly selected to answer the EoL plans and care module in round two (2012), 2) died in rounds three to six (2013–2016), 3) identified as black or white, and 4) had no missing values on outcome or predictor measures. The Johns Hopkins Institutional Review Board approved the protocol for the NHATS data collection. The Weill Cornell Medicine Institutional Review Board deemed this study exempt from needing approval and informed patient consent.

Measures

EoL sadness/anxiety was measured by survey responses from individuals familiar with the decedent's EoL care, most often a family member ("caregivers"). Caregivers answered questions about whether the decedent experienced sadness/anxiety in their last month of life, whether they received help for their sadness/anxiety, and whether it was the right amount if help. These questions are validated elsewhere[23] and were part of the Family Evaluation of Hospice Care survey.[26] Our resulting outcome measure had three categories for decedent sadness/anxiety: none, managed and unmanaged.

The NHATS decedents self-reported their race and ACP completion in survey waves prior to their deaths. We limited the analysis to black and white decedents and used three measures of ACP: end-of-life discussions, healthcare proxy (HCP), and living will. Our analyses also adjusted for self-reported decedent demographic, health, and death data linked to sadness/ anxiety, race, and/or ACP: sex,[27,28] education,[29,30] age,[31] importance of attending religious services,[32,33] number of serious diagnoses[34] that are also leading causes of death among older adults (heart disease, cancer, diabetes, stroke, lung problems, dementia),[35] number of recent hospitalizations,[36] home death,[37] and hospice involvement in the last month of life.[9] We control for these variables because previous research shows they have been linked higher rates of mood disorders such as anxiety and depression and poorer mental health[9,27,28,33,34,36], race,[30,31] and/or ACP completion.[9,29,32,37]

Statistical Analysis

We applied analytic survey weights to adjust for differences in nonresponse based on respondent race and age and county and census-level tract data.[25] Descriptive statistics reflect national estimates for the overall sample analyzed, as well as for black and white respondents (Table 1). We calculated multinomial logistic regression models for each type of ACP (discussions, HCP, living will) to determine the relationship between race, ACP, and the interaction of race and ACP on caregiver assessments of the decedent's sadness/anxiety at EoL (to test moderation effects), after controlling for the decedent demographic and health characteristics listed in the previous paragraph. We used analytic survey weights to adjust all analyses for complex survey design. All analyses were conducted using statistical software (STATA, version MP15; StataCorp LP).

Results

Table 1 provides weighted descriptive statistics for the analyzed sample (n=315), which represents 1,126,644 black and white Medicare recipients age 65 and older. Of these, 89.7% were white, 43.7% male, and 47.6% had more than a high school education. On average, decedents were 80–84 years old when they died, although white decedents were significantly older than black decedents at death (white: 80–84 years old; black: 75–79 years old). Caregivers reported no, managed needs, or unmanaged needs related to decedents' sadness/anxiety in relatively equal proportions (35.8%, 37.6%, and 26.6%, respectively), and there were no differences between reports for black and white decedents (p=.22). White decedents were more likely than black decedents to have reported having EoL discussions (69.1% vs 39.8%, p=.0002), HCPs (67.2% vs 44.2%, p=.0006), and living wills (67.9% vs 33.9% (p=.0000).[38]

Multinomial logistic regression models adjusted for decedent sociodemographic, health, and death information found that when black decedents reported EOL discussions or naming an HCP, caregivers were more likely to report the dying individual experienced unmanaged needs related to sadness or anxiety at EOL than if no ACP were reported. There was no relationship between ACP and sadness or anxiety for white decedents or for living wills for either race (Table 2). For EoL discussions, interaction and main effects were significant for none versus unmanaged needs related to sadness/anxiety (race: ARR=0.20, 95% CI: 0.06–0.64; discussions: ARR=0.19, 95% CI: 0.06–0.61; race* discussion: ARR=9.37, 95% CI: 2.64–33.26). Similar patterns were observed for HCPs (race: ARR=0.24, 95% CI: 0.07–0.80; HCP: ARR=0.14, 95% CI: 0.04–0.52, race* HCP: ARR=6.42, 95% CI: 1.33–33.10). Interaction, but not main effects were significant for met versus unmanaged needs related to sadness/anxiety (race*discussion: ARR=5.19, 95% CI: 1.21–22.28; race*HCP: ARR=7.96, 95% CI: 1.19–53.14). Main and interaction effects were not significant for living wills.

Because interpreting coefficients and relative risk ratios for main and interaction effects in multinomial logistic regression models is cumbersome and unintuitive, we calculated predicted probabilities of none, managed needs, and unmanaged needs related to sadness/anxiety at EoL by decedent race and ACP completion, holding all other variables at their means. Figure 1 graphs predicted probabilities for EoL discussions and HCPs for four groups: black decedents with no ACP, black decedents with ACP, white decedents with no ACP, and white decedents with ACP. We excluded living wills because there were no significant differences by race and ACP in that analysis.

Three patterns emerge from the data. First, as reported by caregivers, black decedents with no ACP had the highest predicted probability of no sadness/anxiety at EoL of any group, and in some cases, nearly double that for other groups. For example, black decedents with no ACP had a 59% predicted probability of no sadness/anxiety at EoL compared to 31% for white decedents with no ACP. Second, among black decedents, EoL discussions and having a HCP increase the predicted probability of unmanaged needs related to sadness/anxiety by factors of 2.6 and 3.5, respectively (discussions: from 15% to 39%, p=.03; healthcare proxy: from 12% to 42% p=.008). In contrast, there was no relationship between ACP and unmanaged needs related to sadness/anxiety among white decedents (discussions: from 35% to 23%, p=.08; healthcare proxy: from 29% to 26% p=.66). Third, predicted probabilities of caregivers reporting decedents' needs related to sadness/anxiety at EoL were met are relatively similar across groups.

Discussion

We found that black decedents who complete ACP were more likely to have unaddressed mental health needs than those who did not complete ACP. This result held only for black decedents: there was no relationship between ACP completion and caregiver reported anxiety or sadness among white decedents. Consistent with previous research,[8,9,16,19,20] we found no significant relationship between ACP and sadness/anxiety at EoL for white decedents. In contrast, we find that EoL discussions and having a HCP are associated with negative outcomes for black decedents, reducing the predicted probability of no caregiver reported sadness/anxiety by over 40%, while increasing the predicted probability of unmanaged needs related to sadness/anxiety by a factor of 2.6 and 3.5, respectively. Moreover, results suggested that completing ACP resulted in black decedents not having any sadness/anxiety at EoL to experiencing sadness/anxiety *and* not receiving adequate help with those symptoms.

One possible explanation for the observed differences in unmanaged needs related to sadness/anxiety among black decedents could be that there is something psychosocially distinctive about black individuals who complete ACP that leads to psychological distress at EoL. However, supplementary analyses do not support this explanation in these data. Supplementary analyses indicate these patterns persist regardless of decedent education, religiosity, and recent hospitalizations (which were all significant in adjusted multinomial logistic regression models). Nor was the difference attributable to higher levels of depression and anxiety among black decedents who complete ACP, as black decedents had reported similar levels of depression and anxiety in the survey interview prior to their deaths regardless of whether they completed ACP and as white decedents.

The difference in caregiver assessments of black decedents' psychological distress at EoL based on ACP completion may be the result of something about the ACP process for black individuals that leads to distress at EoL, underscoring the need for culturally sensitive, tailored approaches to ACP and EoL care[1,39] that focus on building rapport with black patients. The difference in assessments may also be attributed to something that happens through the course of EoL care to black patients who complete ACP. Consistent with the original intent of ACP, black patients desiring less aggressive care may complete ACP, but still receive aggressive care at EoL,[7] resulting in increased psychological distress. Although these data do not track actual treatment received, supplementary analyses do not support this idea. Rather, in these data, caregivers report black decedents received unwanted care at similar, low rates, regardless of ACP completion and as white decedents. In contrast, black patients may desire more aggressive care at EoL[1,40] and complete ACP to that effect. Failing to receive care consistent with their preferences may cause increased psychological distress.

These data do not allow us to examine the content of ACP or whether individuals failed to receive treatment they would have wanted. In either scenario, psychological distress at EoL is more probable and not addressed adequately for black individuals who complete ACP.

Additional research is needed to understand why caregivers for black decedents who complete ACP are predicted to report unmanaged needs related to sadness/anxiety, and at such higher levels than black decedents who do not complete ACP. This study also suggests a need for ACP completion processes tailored to the needs of older black individuals. Clinicians should be particularly attentive at EoL to the psychological well-being and needs of their black patients who report completing ACP, perhaps by working with caregivers to detect, determine the sources of, and address psychological distress.

While the patterns described above are consistent for EoL discussions and HCPs, we found no differences based on completion of a living will. This could be due to a lack of statistical power, given that only 27 black decedents in the unweighted sample had previously reported a living will. However, there may be greater barriers associated with completing a living will compared to discussing EoL or naming a HCP.[41]

This study has limitations. The data focus on Medicare enrollees over 65, and different relationships between race, ACP and sadness/anxiety at EoL may exist among younger or middle-aged adults or among older adults who do not receive Medicare. However, adults over 65 comprise nearly three-quarters of all annual deaths in the US,[31] and Medicare coverage extends to 93% of these,[42] so understanding patterns among these individuals is important. This study is a secondary analysis of existing data, and so we relied on measures that were available in the data. We are not able to use assessments of sadness or anxiety at EOL obtained directly from the NHATS respondent. However, all other measures were obtained prospectively, and obtaining information about EoL retrospectively from individuals familiar with care is a recognized[43,44] and commonly used mechanism[11,45,46] in EoL research, particularly given the ethical considerations of collecting direct reports from dying individuals in their final month.[44] Moreover, doing so is not feasible in a study of this scale and for which the study design allows for data collection only during certain months of the year.

Conclusion

Advance care planning may not work the same way for black and white individuals. Namely, ACP is associated with increased risk of negative mental health outcomes at EoL for black individuals, but not for white individuals. Our findings underscore an urgent need for additional research to understand why caregivers report unmanaged sadness/anxiety for dying black patients who completed advance care planning, so that we can better understand why a tool intended to improve EoL care is associated with increased and unaddressed distress among older black adults. Our findings also highlight a need for clinicians to pay increased attention to and work with caregivers to address these patients’ mental health as life draws to a close.

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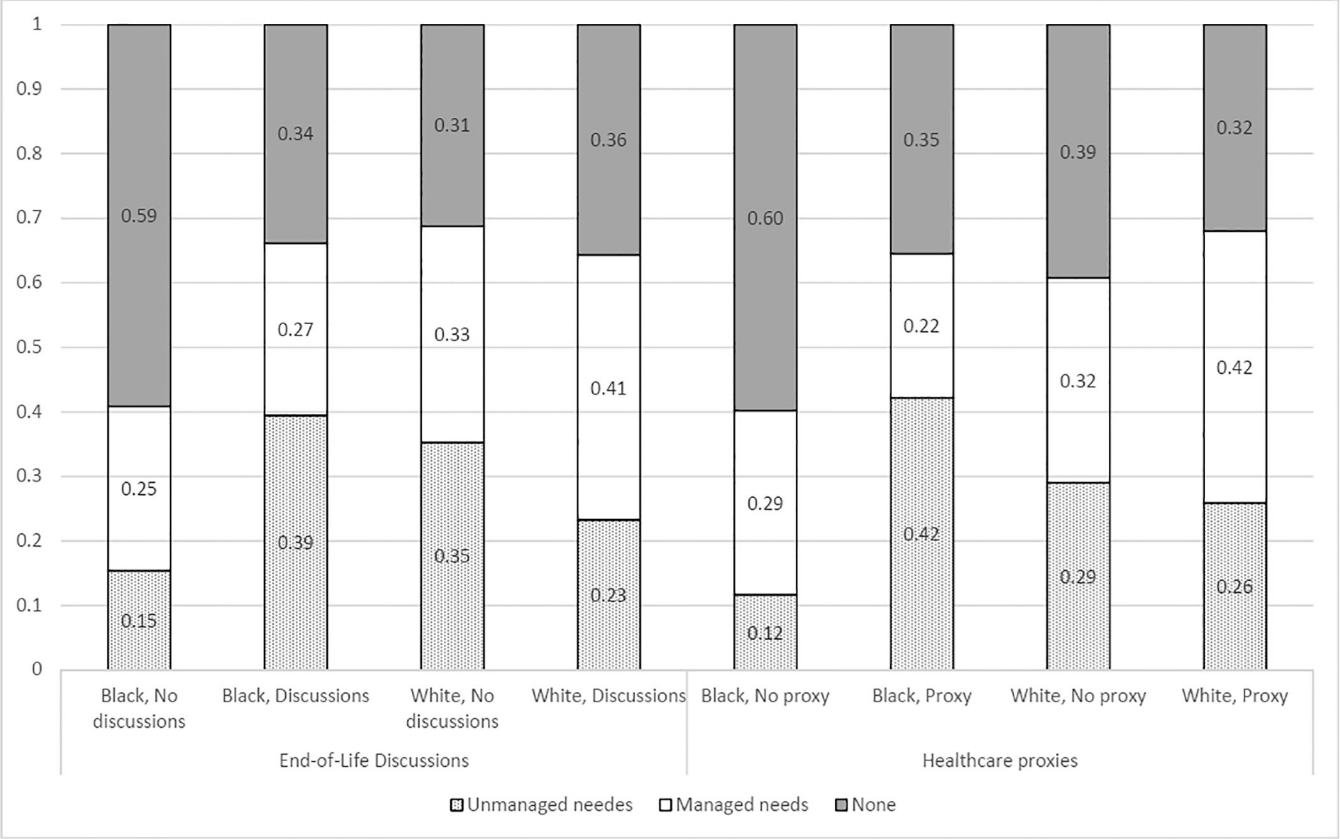

Figure 1. Predicted probabilities of sadness/anxiety at end of life by race and advance care planning

Data pooled from 2011–2016 National Health and Aging Trends Study. Estimates adjusted for complex survey design to reflect population of 2011 Medicare enrollees over 65 and for covariates listed in Table 1. All covariates held at their means.

Table 1.

Weighted descriptive statistics for NHATS respondents representing 1,126,644 Medicare enrollees age 65 and older (unweighted n=315)

	All respondents		**Non-Hispanic white**		**Non-Hispanic black / African-American**		
	Proportion or means (SD)	***LSE***	***Proportion or means (SD)***	***LSE***	***Proportion or means (SD)***	***LSE***	***P value***[a]
Outcomes (last month of life)							
Sadness/Anxiety							0.22
Unmanaged needs	0.27	0.030	0.27	0.034	0.27	0.052	
Managed needs	0.38	0.031	0.39	0.035	0.27	0.063	
None	0.36	0.029	0.35	0.033	0.46	0.058	
Predictors							
Non-Hispanic white	0.90	0.013					
EOL discussions	0.66	0.029	0.691	0.035	0.398	0.052	0.0002
Health care proxy	0.65	0.030	0.672	0.034	0.442	0.049	0.0005
Living will	0.64	0.030	0.679	0.035	0.339	0.042	0.000
Covariates							
Male	0.44	0.034	0.43	0.038	0.46	0.065	0.77
More than high school education	0.48	0.035	0.49	0.0391	0.35	0.0587	0.055
Age[c]	4.13 (0.09)	0.09	4.19 (1.27)	0.095	3.63 (2.15)	0.176	0.005[b]
65–69	0.01	0.009	0.01	0.010	0.02	0.022	0.068
70–74	0.14	0.027	0.13	0.028	0.26	0.058	
75–79	0.19	0.032	0.19	0.034	0.18	0.044	
80–84	0.21	0.030	0.20	0.034	0.29	0.039	
85–89	0.22	0.032	0.23	0.034	0.14	0.037	
90+	0.22	0.026	0.23	0.029	0.12	0.030	
Religious attendance very important	0.41	0.035	0.39	0.038	0.54	0.060	0.029
Number of serious diagnoses[d]	1.98 (0.10)	0.10	1.97 (1.08)	0.106	2.10 (1.90)	0.127	0.41[b]
0	0.09	0.017	0.09	0.019	0.12	0.031	0.0797
1	0.28	0.035	0.29	0.038	0.20	0.042	
2	0.33	0.033	0.34	0.037	0.28	0.059	
3	0.14	0.027	0.13	0.030	0.27	0.059	
4+	0.15	0.024	0.15	0.027	0.13	0.036	
0 or 1 hospital stay in year before death (ref=2 or more stays)	0.79	0.027	0.80	0.030	0.70	0.043	0.047
Home death	0.40	0.039	0.40	0.043	0.35	0.051	0.43
Hospice involved in last month of life	0.58	0.041	0.58	0.045	0.54	0.050	0.54

NHATS, National Health and Aging Trends Study; SD, standard deviation; LSE, linearized standard error. Analysis pools data from 2011–2016 annual surveys. Estimates adjusted for complex survey design to reflect population of 2011 Medicare enrollees over 65. Estimates based on sample size of 315 NATS respondents who answered the 2012 module on end-of-life planning, subsequently died (2013–2016), for whom a caregiver answered questions about sadness/anxiety in the last month of life, and who are not missing on any other covariates.

[a] Except where noted, p value comparing white and black is based on Pearson’s chi square calculated from F statistic adjusted for complex survey design.

[b] p value based on adjusted Wald test of difference of means.

[c] Average ages for each group are: sample=80–84, white=80–84, black=75–79

[d] Diagnoses: heart disease, diabetes, stroke, lung problems, kidney problems, and probable dementia.

Table 2.

Adjusted risk ratios and 95% confidence intervals for multinomial logistic regression of caregiver reported sadness or anxiety in NHATS decedent's last month of life for three types of advance care planning

	Unmanaged needs (reference)	**Unmanaged needs vs Managed needs**				**Unmanaged needs vs None**			
	ARR	***ARR***	***95% CI***		***p value***	***ARR***	***95% CI***		***p value***
End-of-Life Discussions									
White	1.00	0.55	0.17	1.83	0.32	0.20	0.06	0.64	0.01
Discussions	1.00	0.38	0.10	1.39	0.14	0.19	0.06	0.61	0.01
White * discussions	1.00	5.19	1.21	22.28	0.03	9.37	2.64	33.26	0.00
Health Care Proxy									
White	1.00	0.43	0.09	1.96	0.27	0.24	0.07	0.80	0.02
Health care proxy	1.00	0.19	0.03	1.13	0.07	0.14	0.04	0.52	0.00
White * health care proxy	1.00	7.96	1.19	53.14	0.03	6.42	1.33	31.10	0.02
Living Will									
White	1.00	1.62	0.53	5.00	0.39	0.45	0.14	1.52	0.19
Living will	1.00	1.54	0.51	4.67	0.43	0.78	0.20	3.02	0.72
White * living will	1.00	0.66	0.16	2.70	0.56	1.79	0.32	10.03	0.50

NHATS, National Health and Aging Trends Study; ARR, adjusted risk ratio; 95% CI, 95% confidence interval; ACP, advance care planning. Analysis pools data from 2011–2016 annual surveys. Models adjust for decedent sex, education, age, religiosity, number of serious diagnoses, number of recent hospitalizations, home death, and hospice involvement at end of life. Estimates adjusted for complex survey design to reflect population of 2011 Medicare enrollees over 65.