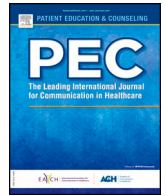




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Completion of advance directives among African Americans and Whites adults

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ABSTRACT

Objective: The primary purpose of this study was to analyze the completion of advance directives among African American and White adults and examine related factors, including demographics, socio-economic status, health conditions, and experiences with health care providers.

Methods: This study used data from the Survey of California Adults on Serious Illness and End-of-Life 2019. We compared correlates of completion of advance directives among a sample of 1635 African American and White adults. Multivariate analysis was conducted.

Results: Whites were 50% more likely to complete an advance directive than African Americans. The major differences between African Americans and Whites were mainly explained by the level of mistrust and discrimination experienced by African Americans and partially explained by demographic characteristics. Our study showed that at both bivariate and multivariate levels, *participation in religious activities* was associated with higher odds of completion of an advance directive for both African Americans and Whites. **Conclusion:** Interventional studies needed to address the impact of mistrust and perceived discrimination on advance directive completion.

Practical implications: Culturally appropriate multifaceted, theoretical- and religious-based interventions are needed that include minority health care providers, church leaders, and legal counselors to educate, modify attitudes, provide skills and resources for communicating with health care providers and family members.

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1. Introduction

In recent years, advance care planning has evolved as a fundamental component of patient-centered care [1]. Highlighted as an essential process, advance care planning centers on future decision-making and preparation for care related to managed conditions and illnesses [2,3]. Documentation of completed advance directives also incorporates patients' wishes concerning medical care when they no longer can make decisions or communicate, which is heavily influenced by their beliefs, values, and wishes.

Advance care planning was previously regarded as informal conversations held among family members [4]. However, this

approach is currently undergoing expansion by health care organizations and professional societies in the United States and other international countries [5–7]. Health care professionals providing medical and mental care are now expected to initiate advance care planning conversations and documenting the progress of these conversations in the health records of patients, especially for older adults [8–10]. Advance care planning is now strongly recommended for all ages regardless of health status and conditions.

During the past three decades, issues related to end-of-life care, particularly completion of advance directives for medical care, has been well examined [11–17]. A comprehensive review of the literature revealed that various targeted strategies have been tested and evaluated to promote the completion of advance directives [18]. However, there is a major difference in the rate of completed advance directives by Whites compared to racial/ethnic minority groups, who have lower rates of advance directive completion [19]. While several studies have focused on end-of-life disparities

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between Whites and racial/ethnic minorities [20–29], most national and state data do not include sufficient information on contributing factors leading to the different perspectives regarding end-of-life issues. In particular, population-based data are lacking information regarding minority groups, especially older adults [11].

Few studies have evidenced that social and environmental disparities, such as low educational attainment [30] and financial difficulties [31], can greatly impact the initiation and engagement of advance directives and its completion. Additionally, the lack and type of health care coverage are contributing factors to the decreased interest in engagement in completion of advance directives [32,33]. Other studies have attributed low engagement in advance care planning to perceived attitudes and beliefs of health care providers, who may exhibit avoidance, discrimination, and unprofessionalism toward patients [34–37]. Low initiation of advance care planning and low completion of advance directives may also be linked to mistrust in the health care system among various populations, specifically racial/ethnic minorities [37,38].

A recent systematic review of 40 studies found that unwillingness to participate in advance care planning is related to fear of the advance care planning process and previous experiences within the health care system [39]. Therefore, it is important to understand how specific factors, such as mistrust and discrimination, can impact advance care planning and completion of advance directives. These conditions may be more common in racial/ethnic minority populations, especially for those managing multiple and complex illnesses [40,41].

To develop effective interventional studies to promote completion of advance care directives among racial/ethnic minority adults, additional research is needed to carefully examine factors related to the completion of advance directives. The main purpose of this study was to characterize advance directive completion among African American and White adults and examine factors associated with their completion, such as demographic characteristics, socioeconomic status, health conditions, and their experiences with their current and past providers. We also examined perceived racial and insurance/income-based discrimination and levels of mistrust toward their health care providers, and its impact on completion of advance directives among African Americans and Whites.

2. Methods

2.1. Data sources

The survey of California Adults on Serious Illness and End-of-Life is a cross-sectional representative survey of California residents. The survey was conducted by the *California Health Care Foundation* from June 2019 through July 2019. The survey included 722 African Americans and 913 Whites. The eligibility criteria for participation in the survey were 1) being a California resident and 2) identifying as 18 years of age or older. Participants were drawn from Ipsos' KnowledgePanel, the first representative online research panel in the US. Panel members were randomly recruited through address-based sampling (ABS) methods. All households were provided with Internet access and necessary hardware, if requested. The survey also utilized supplemental, nonprobability sampling to recruit more African American respondents.

2.2. Measurements

2.2.1. Independent variable

2.2.1.1. Demographic and socio-economic characteristics. Age, gender, educational attainment, marital status, ethnicity, and household income was measured. Gender was a dichotomous measure [male = 1, female = 0 (reference group)]. Age was a continuous variable. Educational attainment was operationalized as a continuous

variable with a range between 0 and 14, with a higher score reflecting increased years of education/school completion. Marital status was measured as a dichotomized variable (not married, widowed, and separated participants were all coded as 0, while married or living with partners were coded as 1). Race/ethnicity was self-identified, and was treated as a dichotomous variable, with Whites designated as the reference category.

Household income was measured using the federal poverty level (FPL), also known as the "poverty line" and is classified as the annualized income earned by a household. Household incomes below the FPL are eligible to receive certain welfare benefits at the local and state level. The poverty level for participants in this study was calculated based on the designated criteria published by the federal government for 2019. The FPL for a household with 2, 3 and 4 members in 2019 was \$16,460, \$20,780, and \$25,100, respectively [42]. Household income was categorized to three levels: 1) $\geq 400\%$, 2) 150–399%, and 3) under 150% of the FPL.

2.2.1.2. Perceived discrimination. Perceived discrimination was measured with an 8-item questionnaire. These items were previously selected from other standardized instruments that measure perceived discrimination based on race/ethnicity, income, and lack or type of insurance [43–45]. For all 8 items, participants indicated whether they perceived discrimination by health care providers due to their race/ethnicity, income, or medical coverage.

2.2.1.3. Perceived discrimination due to income and insurance. The first 6 items measured perceived discrimination associated with income, type of insurance, and being uninsured. Cronbach's alpha coefficient for these 6 items was calculated to be 0.84. The six items are: 1) "Have you ever felt judged or treated differently by a health care provider because of your income?", 2) "Have you ever felt judged or treated differently by a health care provider because of the type of insurance you have?", 3) "Have you ever felt judged or treated differently by a health care provider because of being uninsured?", 4) "Have you ever felt like you could not get health care services you needed because of your income?", 5) "Have you ever felt like you could not get health care services you needed because of the type of insurance you have?", and 6) "Have you ever felt like you could not get health care services you needed because of being uninsured?" This was indexed by counting number of "yes" responses to these six items. A higher score indicated greater perceived discrimination due to income or insurance.

2.2.1.4. Perceived racial and ethnic discrimination. The second index produced by counting number of "yes" responses to two items that measured perceived discrimination because of race/ethnicity. Participants were asked: 1) "Have you ever felt judged or treated differently by a health care provider because of your race or ethnicity?", 2) "Have you ever felt like you could not get health care services you needed because of your race or ethnicity?" with response options of 1 = Yes, and 0 = No. Pearson r coefficient between these two items was 0.64. A higher score indicated a greater degree of perceived racial and ethnic discrimination.

2.2.1.5. Level of mistrust. Mistrust was measured with a single item asking participants, "In general, how much do you trust your health care providers to act in your best interest?" Response options included "not at all," "not too much," "some," and "a lot." We used the following coding: 1 = "a lot," 2 = "some," and 3 = "not at all/not too much."

2.2.1.6. Number of chronic conditions. The number of chronic conditions was measured based on self-report of being diagnosed with: 1) emphysema or chronic obstructive pulmonary disease, 2) heart disease, 3) cancer, 4) stroke, 5) HIV/AIDS, 6) cirrhosis or

Table 1
Characteristics of sample (n = 1635).

Independent variable	Total N (%) [mean ± SD]	White N (%) [mean ± SD]	African Americans N (%) [mean ± SD]	Sig.
Gender				0.001
Male	695 (43)	457 (50)	238 (33)	
Female	940 (57)	456 (50)	484 (67)	
Age				0.001
18–44	647 (40)	218 (24)	429 (59)	
45–64	556 (34)	320 (35)	236 (33)	
65+	432 (26)	375 (41)	57 (8)	
Education (0–14)	[10.70 ± 1.66]	[10.91 ± 1.67]	[10.44 ± 1.61]	0.001
Married				0.001
No	837 (51)	381 (42)	456 (63)	
Yes	798 (49)	532 (58)	266 (37)	
Ethnicity				N/A
Whites	913 (56)	N/A	N/A	
African Americans	722 (44)	N/A	N/A	
Poverty				0.001
≥400%	561 (34)	396 (43)	166 (23)	
150–399%	551 (34)	300 (33)	251 (35)	
Under 150%	523 (32)	217 (24)	306 (42)	
Religious services (1–7)	[3.16 ± 2.14]	[2.81 ± 2.81]	[3.61 ± 2.16]	0.001
Chronic conditions (0–13)	[1.35 ± 1.52]	[1.37 ± 1.40]	[1.33 ± 1.68]	0.575
Mistrust				0.001
A lot	735 (46)	476 (53)	259 (37)	
Some	669 (42)	337 (38)	332 (47)	
No	191 (12)	78 (9)	113 (16)	
Racial discrimination (0–2)	[0.24 ± 0.59]	N/A	[0.49 ± 0.76]	N/A
Insurance/income-based discrimination (0–6)	[1.18 ± 1.77]	[0.91 ± 1.63]	[1.51 ± 1.89]	0.001

late-stage liver disease, 7) chronic or end-stage kidney disease, 8) hypertension, 9) diabetes, 10) depression, 11) anxiety disorder, 12) bipolar disorder, and 13) any other serious illness.

2.2.1.7. Religious organization participation. This variable was assessed with a single item asking participants to report how often they attend religious services with a seven-level response scale, where 1 designated “not at all” and 7 represented “more than once a week.”

2.2.2. Outcome variable

2.2.2.1. Completion of advance directives. The end-of-life questions were similar to the national survey questionnaire conducted by the Health Style survey in 2013 [11]. Respondents were asked several questions regarding their preferences and wishes for their end-of-life care, followed by questions asking whether they discussed their treatment preferences and plans with anyone in the event of a serious illness. Finally, they were asked “Do you have your wishes regarding the medical treatment you would want in a written document?” with response options of “no” = 0 and “yes” = 1.

2.3. Statistical analysis

We used SPSS 23.0 to perform our data analysis. For descriptive statistics, we reported means and proportions (frequencies). For bivariate analysis, we used Chi Square or *t*-tests. For multivariable models, we employed the multiple logistic regression technique. Adjusted Odds Ratios (ORs), 95% Confidence Intervals (95% CI), and *p*-values were reported. *P*-values equal or less than 0.05 was used as significant. Multivariate logistic regression technique was employed to estimate independent impact of the following variables on rates of completion of advance directives: 1) demographic characteristics, 2) socio-economic status, 3) health status, 4) religious organization participation, 5) level of racial and non-racial perceived discrimination with the health care system, and 6) trusting relationship with current health care providers.

3. Results

Table 1 reports the characteristics of the study sample. This study included 1635 individuals including 722 African Americans and 913 Whites aged 18 years and older (mean 51 ± 18.3). More than 22% of our sample reported having a high school diploma, and 8% reported 0–11 years of education. One-third of the participants reported a household income under 150% of the federal poverty level (Table 1). More than 12% of participants indicated medical mistrust (mistrust in their health care providers), whereas 42% and 46% of participants reported “some” or “a lot” of trust in their health care providers.

A total of 657 (41%) respondents reported they had an advance directive, whereas 966 (59%) reported that they did not have one. Thirty-three percent (33%) of African Americans and 47% of Whites claimed that they had written advance directives, respectively. An estimated 59% of participants indicated that it was very important to have their end-of-life wishes recorded in writing. At least 14% of participants claimed that “doctors might not give me care that could help if my wishes are in writing. The top reasons participants stated for not having an advance directive were: 1) “I trust my family to make decisions for me,” 2) “I do not want to think about death or dying,” 3) “I am too busy right now with other things,” and 4) “I don’t know how to put wishes in a legal document.” Finally, 50% of respondents reported not having discussed their wishes for end-of-life treatment with the person(s) they wanted to make decisions about their care if they could not make their own decisions due to serious illness.

3.1. Bivariate correlations

Table 2 (columns 2–4) shows bivariate correlations between all the independent variables and completion of advance directives among the entire sample of African Americans and Whites. At the bivariate level, all independent variables showed significant associations with completion of advance directives, except two indices that measure racial and insurance/income-based discrimination. Participants who were White, male, older adult, higher education level, higher income, increased number of chronic conditions, and

Table 2

Bivariate correlates between completion of advance directives and independent variables (N = 1635).

Independent variable	Completion of advance directives								
	African Americans and Whites			Whites			African Americans		
	No N (%) [mean ± SD]	Yes N (%) [mean ± SD]	Sig.	No N (%) [mean ± SD]	Yes N (%) [mean ± SD]	Sig.	No N (%) [mean ± SD]	Yes N (%) [mean ± SD]	Sig.
Gender									
Male	381 (55)	309 (45)	0.002	231 (51)	222 (49)	0.102	150 (63)	87 (37)	0.155
Female	585 (63)	348 (37)		255 (56)	197 (44)		330 (69)	151 (31)	
Age									
18–44	455 (71)	187 (29)		155 (72)	59 (28)		300 (71)	128 (30)	0.001
45–64	354 (64)	198 (36)	0.001	199 (63)	118 (37)	0.001	155 (66)	80 (34)	
65+	157 (37)	272 (63)		132 (35)	242 (65)		25 (46)	30 (55)	
Education (0–14)	[10.57 ± 1.66]	[10.91 ± 1.65]		[10.72 ± 1.66]	[11.15 ± 1.63]		[10.41 ± 1.61]	[10.48 ± 1.62]	0.593
Married									
No	512 (62)	318 (38)	0.001	212 (56)	165 (44)	0.001	300 (66)	153 (34)	0.641
Yes	454 (57)	266 (43)		274 (52)	254 (48)		180 (68)	85 (32)	
Ethnicity									
Whites	486 (54)	419 (46)	0.069	N/A	N/A	0.197	N/A	N/A	N/A
African Americans	480 (67)	238 (33)		–	–		–	–	
Poverty									
≥400%	277 (50)	279 (50)		176 (45)	215 (55)		101 (61)	64 (39)	0.001
150–399%	351 (64)	195 (36)	0.001	168 (57)	129 (43)	N/A	183 (74)	66 (26)	
Under 150%	338 (65)	183 (35)		142 (65)	75 (35)		196 (65)	108 (35)	
Religious services	[2.98 ± 2.06]	[3.42 ± 2.24]	0.001	[2.61 ± 1.98]	[3.03 ± 2.16]	0.003	[3.36 ± 2.08]	[4.10 ± 2.23]	0.001
Chronic conditions	[1.23 ± 1.43]	[1.53 ± 1.63]	0.001	[1.29 ± 1.38]	[1.47 ± 1.42]	0.046	[1.17 ± 1.50]	[1.65 ± 1.95]	0.001
Mistrust									
A lot	368 (50)	364 (50)	0.001	211 (50)	263 (56)	0.001	157 (61)	101 (39)	0.002
Some	418 (63)	245 (37)		201 (63)	132 (40)		217 (66)	113 (34)	
No	147 (77)	44 (23)		57 (77)	21 (27)		90 (80)	23 (20)	
Racial discrimination	[0.25 ± 0.60]	[0.24 ± 0.57]	0.598	[0.06 ± 0.30]	[0.04 ± 0.22]	0.119	[0.25 ± 0.60]	[0.24 ± 0.57]	0.010
Insurance/income-based discrimination	[1.25 ± 1.76]	[1.08 ± 1.79]	0.068	[1.10 ± 1.72]	[0.70 ± 1.50]	0.001	[1.25 ± 1.76]	[0.108 ± 1.79]	0.018

higher engagement and attendance at religious services were more likely to have completed advance directives.

Table 2 (columns 5–10) shows the bivariate associations between the independent variables and completion of advance directives among Whites and African Americans separately. The main differences between these columns are as follows: 1) no significant correlation between gender and completion of advance directives was detected among African Americans and Whites, 2) a significant correlation between education and completion of advance directives among Whites and not African Americans, 3) a significant bivariate association between both indices that measure discrimination and completion of directive among African Americans, and 4) indices that measured discrimination associated with income, type of insurance, and lack of insurance that showed a similar significant bivariate correlation among African Americans and Whites when the sample is divided into two subsamples of African Americans and Whites.

3.2. Multivariate analysis

Table 3 represents multiple logistic regression analysis between all independent variables and dependent variables for the total sample in the two models. Knowing that the two indices that measure racial and insurance/income-based discrimination are strongly associated and may produce harmful multi-collinearity if indices are included in the same equation, two models were analyzed. The first model includes only racial/ethnic discrimination and the second model includes insurance/income-based discrimination as one of the independent variables. These models show that controlling for all other variables, older participants, those with a higher level of household income, those who reported more frequent participation in religious activities all had higher odds of having completed an advance directive. First, race/ethnicity shows no main effect in multivariate analysis. Second, the variable that measures mistrust and indices that measure discrimination show

significant, but competing, association with completion of an advance directive. Mistrust of current providers leads to lower odds of completion of advance directives, whereas being exposed to discrimination by health care providers in the past leads to higher odds of having completed an advance directive.

Table 4 reports the results of multiple logistic regression for African Americans and Whites separately. The models 1 and 2 of this table include all independent variables as well as insurance/income-based discrimination for African Americans and Whites separately. Model 3 of Table 4 replaced insurance/income-based discrimination with racial discrimination for African Americans only. We did not conduct the same model for Whites because racial/ethnic discrimination among Whites was not significant in the previous models and did not cause significant change in any of the odds ratios or *p* values (Table not reported here). The first model of Table 4 shows that at the multivariate level, when all other variables were held constant, older age (OR: 0.228; 95% CI: 0.151–0.343; *p* < 0.0001 for 1–44 years of age and OR: 0.33; 95% CI: 0.234–0.464; *p* < 0.001 for 45–64 years of age), higher level of education (OR: 1.15; 95% CI: 1.044–1.270; *p* < 0.001), higher level of household income (OR: 2.04; 95% CI: 1.328–3.146; *p* < 0.0001), and higher number of chronic conditions all lead to a higher odds for completion of advance directives among Whites. Discrimination and mistrust were not associated with completion of an advance directive among Whites.

Models 2 and 3 of Table 4 (multivariate logistic regression for African Americans) revealed that the variables measuring mistrust in current providers showed a negative association with the completion of an advance directive among African Americans (OR: 2.78; 95% CI: 1.557–4.964; *P* < 0.002 and OR: 2.344; 95% CI: 1.349–4.071; *P* < 0.001). Second, a higher level of racial and insurance/income-based discrimination experienced by African Americans led to a higher odds of completion of an advance directive (OR: 1.170; 95% CI: 1.063–1.237; *p* < 0.001 for insurance/income-based discrimination and OR: 1.424; 95% CI: 1.134–1.788; *P* < 0.002 for racial discrimination). Furthermore, knowing that perceived discrimination and medical mistrust showed

Table 3

Multiple logistic regression analysis between independent variables and completion of advance directives for total sample (N = 1635).

Independent variable	African American and White Adults					
	Model 1			Model 2		
	OR	95% CI	Sig.	OR	95% CI	Sig.
Gender						
Male	0.874	0.696–0.097	0.246	0.868	0.691–1.090	0.223
Female	1.000			1.000		
Age			0.001			0.001
18–44	0.299	0.219 – 0.410	0.001	0.307	0.225–0.419	0.001
45–64	0.331	0.248–0.442	0.001	0.340	0.255–0.454	0.001
65+	1.000			1.000		
Education	1.055	0.981–1.134	0.147	1.060	0.986–1.139	0.115
Married						
No	0.959	0.761–1.208	0.721	0.965	0.766–1.217	0.765
Yes	1.000			1.000		
Ethnicity						
Whites	1.073	0.832–1.383	0.588	1.187	0.909–1.549	0.209
African Americans	1.000			1.000		
Poverty			0.000			0.001
≥400%	1.573	1.155–2.141	0.004	1.463	1.082–1.979	0.013
150–399%	0.817	0.615–1.083	0.160	0.790	0.595–1.048	0.102
Under 150%	1.000			1.000		
Religious services	1.101	1.046–1.159	0.001	1.101	1.046–1.159	0.001
Chronic conditions	1.074	0.998–1.156	0.057	1.075	0.999–1.156	0.054
Mistrust			0.001			0.001
A lot	2.338	1.556–3.513	0.001	2.333	1.559–3.491	0.001
Some	1.817	1.222–2.702	0.003	1.832	1.233–2.722	0.003
No	1.000			1.000		
Racial discrimination	1.082	1.010–1.159	0.024	–	–	–
Insurance/income-based discrimination	–	–	–	1.339	1.090–1.645	0.005

Table 4

Multiple logistic regression analysis between independent variables and completion of advance directives among African Americans (N = 722) and Whites (N = 913).

Independent variable	Whites			African Americans					
	Model 1: with insurance/income-based discrimination			Model 2: with insurance/income-based discrimination			Model 3: with racial discrimination		
	OR	95% CI	Sig.	OR	95% CI	Sig.	OR	95% CI	Sig.
Gender									
Male	1.039	0.764–1.412	0.809	0.820	0.574–1.173	0.277	0.777	0.574–1.173	0.166
Female	1.000	–	–	1.000	–	–	1.000	–	–
Age			0.001			0.034			0.050
18–44	0.228	0.151–0.343	0.001	0.439	0.234–0.822	0.010	0.467	0.250–0.873	0.017
45–64	0.330	0.234–0.464	0.001	0.469	0.249–0.883	0.019	0.480	0.254–0.905	0.023
65+	1.000	–	–	1.000	–	–	1.000	–	–
Education	1.151	1.044–1.270	0.005	0.973	0.866–1.093	0.647	0.985	0.878–1.106	0.802
Married									
No	0.968	0.704–1.332	0.843	0.883	0.621–1.254	0.487	0.930	0.653–1.323	0.685
Yes	1.000			1.000	–	–	1.000	–	–
Poverty			0.002			0.007			0.011
≥400%	2.044	1.328–3.146	0.001	1.273	0.795–2.039	0.315	1.107	0.698–1.754	0.666
150–399%	1.226	0.810–1.855	0.335	0.634	0.423–0.952	0.028	0.603	0.402–0.906	0.015
Under 150%	1.000			1.000	–	–	1.000	–	–
Religious services	1.087	1.014–1.166	0.019	1.132	1.046–1.224	0.002	1.135	1.050–1.227	0.002
Chronic conditions	1.051	0.943–1.171	0.369	1.101	0.992–1.223	0.070	1.109	1.000–1.230	0.050
Mistrust									
A lot	1.757	0.967–3.193	0.097	2.845	1.593–5.079	0.002	2.780	1.557–4.964	0.002
Some	1.354	0.750–2.446	0.064	2.370	1.366–4.112	0.001	2.344	1.349–4.071	0.001
No	1.000	–	0.315	1.000	–	0.002	1.000	–	0.002
Insurance/income-based discrimination	0.996	0.900–1.103	0.946	1.170	1.063–1.287	0.001	N/A	N/A	N/A
Racial discrimination	N/A	N/A	N/A	N/A	N/A	N/A	1.424	1.134–1.788	0.002

associations only among African Americans, we evaluated the potential role of mistrust as mediator between both indices of discrimination and advance directives. Results showed that mistrust did not mediate the effect of perceived discrimination. Instead, mistrust was observed as a suppressant and increased the predictive validity and effect of discrimination on advance directives. Finally, African Americans and Whites who reported a higher level of attendance in religious services were more likely to have completed an advance directive than those who reported lower levels of participation in religious services.

4. Discussion and conclusion

4.1. Discussion

Our findings revealed that one out of three African Americans indicated that they have completed an advance directive, compared to almost one out of two among Whites. Among African Americans, mistrust of current health care providers was more likely to be associated with lower odds of advance directive completion. Interestingly,

however, racial and insurance/income-based discrimination and greater participation in religious services were more likely to be associated with higher odds of advance directive completion.

Controlling for all other variables, mistrust in current health care providers was associated with lower odds of completion of advance directives among African Americans only. There is an established body of literature that indicate African Americans consistently report higher levels of mistrust in the health care system than Whites [46–48]. A recent systematic review documented that medical mistrust acted as a barrier to advance care planning and completion of advance directives among African Americans [37]. Mistrust regarding advance care planning may be related to the impact of unethical and historical medical events (e.g. Tuskegee experiment) [49] and unawareness of cultural beliefs among healthcare providers [50]. Indeed, multiple studies illustrate that medical mistrust is multifaceted [38,51]. For example, lower levels of socioeconomic status [52], community-level social capital [53], income [52], poor quality of life [54], and insecurity about obtaining health care and social support for families [55] are all related to mistrust in the healthcare system. Therefore, multilevel and upstream interventions are required to target systemic racism and increase racial/ethnic minorities' trust in the healthcare system.

This finding is in line with previous studies demonstrating that African Americans often have high levels of mistrust in their health care providers [34,38,56]. One recent study found that half of its study participants had completed a written advance directive and yet did not inform their physician, which implies that they did not trust their physician [57], which is similar to the findings of our study. When African American participants in our study were asked why they have not completed an advance directive, 16% agreed with the highly mistrustful statement, "Doctors might not give me care that could help if my wishes are in writing." This is in line with other studies which have found that racial/ethnic minorities are less likely than Whites to communicate their end-of-life wishes to their doctors [20,21,24]. Racial/ethnic minorities, specifically African Americans, are more likely than Whites to have less knowledge about advance directives, and when they do complete an advance directive, they are more likely than Whites to report less satisfying outcomes with the process [58,59].

Another interesting finding of this study is the correlation between engagement and attendance with religious activities and advance directive completion. Our study shows that at both the bivariate and multivariate levels, engagement and attendance with religious activities was associated with higher odds of completion of an advance directive for both Whites and African Americans. Findings from multiple studies have stated that religion impacts end-of-life planning and decision making, but with mixed results [24,60]. Several researchers have documented a negative association [24,29,61]. Specifically, Koss found that in their sample of 1180 older African Americans, and older 5681 Whites in the Health and Retirement study, older Whites were twice as likely to engage in advance care planning as their African American counterparts, and religiosity index did not close these gaps [26]. Additionally, Koss documented that the frequency of service attendance was positively associated with completion of advance care directives for both African American and White older adults [26]. Our study, in agreement with the Koss Health and Retirement Study [26], points to a very important finding that African Americans with a higher engagement and attendance of religious services have higher odds of completing an advance directive. Even though the Koss study and our analyses included a large sample of African Americans, our sample included all adults. Nonetheless, both studies showed an association between service attendance and advance directive completion to be consistently positive and substantial in models even after other religiosity variables controlled for [26].

Another important finding of our study that merits discussion is the role of perceived discrimination across the life cycle on advance directive completion. Consistently, in bivariate and multivariate analyses, we found that African Americans who reported higher levels of lifelong racial and insurance/income-based discrimination were more likely to complete advance directives. Indeed, the variable that measures the mistrust and indices of discrimination showed significant, but competing associations with advance directive completion. Mistrust of health providers led to lower odds of completion of advance directives, but past exposure to discrimination by health providers led to higher odds of having completed an advance directive. However, it is important to note that our study documented strong association between mistrust in health providers and completion of advance directives, which is consistent with previous studies [37–39]. However, the positive association between discrimination across the life cycle and completion of advance directives may reflect a fear of continuation of discrimination at the end-of-life. In other words, discrimination by health care providers may motivate African Americans to complete advance directives. Additional studies are needed to examine the complex role of discrimination by the health care system and mistrust in providers on completion of advance directives among racial/ethnic minority communities.

Our findings also uncovered that almost six of ten participants believed it is very important to complete an advance directive. However, 85% of participants reported that they have never had a healthcare provider ask them about their wishes for medical treatment at the end-of-life. Furthermore, only 27% of participants who completed an advance directive stated that a health provider had discussed their wishes for medical treatments at the end of life. These results highlight that health providers, particularly physicians and health practitioners, are not fully engaging in advance care planning with patients.

In order to incentivize health care providers to engage in advance care planning, the Centers for Medicare & Medicaid Services (CMS) began reimbursing healthcare providers (including physicians, clinical nurse specialist, nurse practitioners, and physician assistants) for advance care planning discussions with Medicare beneficiaries in January 2016 [62]. The CMS utilizes two current procedural terminology (CPT) reimbursement codes (99497 and 99498) for these discussions. The CPT code 99497 is used for the initial 30 min of advance care planning with patients and reimburses providers \$86 and \$80 for outpatient and inpatient visits, respectively. The CPT code 99498 is used thereafter and provides payment of \$75 for each additional 30-minute period of advance care planning [62]. It is important to note that other payers frequently adopt Medicare billing and payment rules, but they are not required to do so. For example California's Medicaid program now reimburses Medi-Cal providers for advance care planning discussions [63]. Additionally, the California *Health Decision Act* established a standardized and statutory advance care directive form, which requires certification by a notary public official [64]. This form, recognized as a living will, was designed to simplify the process for California residents to document their wishes and identify a power of attorney for their healthcare. Similar types of policies and forms which address these advance care planning options should be integrated within all insurance plans offered by various public and private organizations and companies, who may be able to function as a bridge between healthcare providers and those who are insured [57].

Finally, correlates between completion of advance directives and demographic and socioeconomic characteristics of participant also worth noting. Age, gender, education and level of poverty together explain a much higher variation of the completion of advance directives among Whites than their African American counterparts. This is another piece of evidence that points to the detrimental roles of social determinants of health among minority populations.

There were few limitations with this study. First, this was a cross-sectional study, which prevents any determination of causal relationships. A second limitation was the use of self-reported measures, which results in a degree of bias. Third, consecutive address-based sampling was utilized, which may limit generalizability. Additionally, the sample only consisted of California adults and the results of our study may not be generalizable to other states, due to different rates in various states. Finally, we admit that there are other important factors such as health literacy as well as cultural sensitivity and readability (limitation language) of standard directive forms and its availability, forms and type of delivery must be examined [65–67]. Despite these limitations, this is a novel study that contributes to the current knowledge on completion of advance directives among all adults rather than only older adults with serious medical illnesses.

4.2. Conclusion

This study provided an in-depth examination of advance directive completion among California residents, which revealed that mistrust, frequency of religious participation, and racial and insurance/income-based discrimination, are all associated with completion of advance directives. Controlling for all other relevant variables, African Americans who have higher engagement and attendance with religious services had higher odds of completing an advance directive. Greater efforts should be directed toward increased trust-building between African Americans and their health care providers. Moreover, tangible results can be expected when healthcare systems self-assess and utilize evidence-based approaches to reduce systemic racism and discrimination. This essential reconstructive step must be performed by healthcare systems to increase patient and community engagement and trust.

4.3. Practice implications

In light of these findings, it is essential that medical mistrust be addressed and innovative approaches be developed and implemented to increase advance care planning minorities, especially African Americans. Many studies have shown that such racial/ethnic minority groups desire initiatives and approaches that are sensitive to their religious values and cultural beliefs [22,23,27,50,68–71]. These strategies would likely increase minority participation in advance care planning. In addition, our study findings reveal that frequency of religious service attendance is positively associated with completion of an advance directive, which can greatly impact promotion of advance care planning within African American communities. This finding is interesting and has important implications. To promote advance directives within African American communities, multidisciplinary church-based interventions are needed that include 1) minority health care providers (e.g. physicians, nurses, social workers), 2) church leaders, 3) community advocates and leaders, 4) family members who have experienced losing loved ones with or without an advance directive, and 5) legal counselors. This multilevel design should utilize theoretical and conceptual models that are culturally-driven and provide structural and culturally sensitive education. The outcomes of these interventions should modify attitudes toward advance care planning, enhance skills and resources for patient/family-provider communication, and address social and environmental barriers (mistrust and discrimination) for advance directive completion among African Americans.

An additional implication of this study include the need for federal, state, and local level policy changes to increase advance care planning and advance directive engagement, specifically with health care providers. Health providers should implement culturally-tailored methods to initiate advance directives and care planning

discussions and improve end-of-life communication with patients, especially underserved groups and racial/ethnic minorities [72]. There is an urgent need for advance care planning discussions to occur with various specialties in healthcare systems, due to projections of future gaps in palliative care delivery and practitioners [3]. Systematic level changes within healthcare will need to occur to ensure effective implementation of advance care planning. Future studies analyzing advance directive completion with innovative designs and strategies may test its effectiveness by engaging multiple health professionals, including physicians, nurses, social workers, and physical therapists, who may enhance content delivery and patient preparation.

Ethics approval

This study is using secondary non-identifiable data. Dr. Bazargan, the corresponding author, is responsible for ensuring that the descriptions are accurate and agreed by all authors.

Authors' contributions

Mohsen Bazargan design research hypothesis and data analysis. Drs. Cobb and Assari both contributed to the conceptual model and drafts and revisions. I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Conflicts of interest

The authors declare no conflicts of interest.

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