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End-of-Life Wishes Among Non-Hispanic Black and White Middle-Aged and Older Adults

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Abstract

Purpose Although some research has been done on end-of-life (EOL) preferences and wishes, our knowledge of racial differences in the EOL wishes of non-Hispanic White and non-Hispanic Black middle-aged and older adults is limited. Previous studies exploring such racial differences have focused mainly on EOL decision-making as reflected in advance healthcare directives concerning life-sustaining medical treatment. In need of examination are aspects of EOL care that are not decision-based and therefore not normally covered by written advance healthcare directives. This study focuses on racial differences in non-decision-based aspects of EOL care, that is, EOL care that incorporates patients' beliefs, culture, or religion.

Aim To test the combined effects of race, socioeconomic status, health status, spirituality, perceived discrimination and medical mistrust on the EOL non-decision-based desires and wishes of a representative sample of non-Hispanic White and non-Hispanic Black older California adults.

Methods This cross-sectional study used data from the Survey of California Adults on Serious Illness and End-of-Life 2019. To perform data analysis, we used multiple logistic regression models.

Results Non-Hispanic Blacks reported more EOL non-decision-based desires and wishes than non-Hispanic Whites. In addition to gender, age, and education other determinants of EOL non-decision-based medical desires and wishes included perceived and objective health status, spirituality, and medical trust. Poverty level, perceived discrimination did not correlate with EOL medical wishes.

Conclusion Non-Hispanic Blacks desired a closer relationship with their providers as well as a higher level of respect for their cultural beliefs and values from their providers compared with their White counterparts. Awareness, understanding, and respecting the cultural beliefs and values of older non-Hispanic Black patients, that usually are seen by non-Hispanic Black providers, is the first step for meaningful relationship between non-Hispanic Black patients and their providers that directly improve the end-of-life quality of life for this segment of our population.

Keywords Population groups · Race · Ethnicity · Ethnic groups · Blacks · African Americans · End-of-life · Discrimination · Mistrust

Background

To provide optimal care at the end of life (EOL), it is important for healthcare providers to know their patients' wishes, goals, and preferences for terminal illness management. Providers who exhibit successful communication skills and collaborative planning with their patients will have a greater understand of their needs. Moreover, effective patient-provider conversations about patient's serious conditions and their prognosis enable better planning [1]. While 90% of adults in the USA believed that EOL wishes are important, only 27% have communicated these wishes to their providers [2]. In addition, there are currently no national standards for best practices in EOL care [3].

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A systematic review of a large number of studies shows strong evidence that EOL planning positively impacts the quality of EOL care [4]. Planning for EOL care can increase patient and family satisfaction and reduce symptoms of mental health issues for family members, such as stress, anxiety, and depression [5, 6]. Another systematic review of literature shows that EOL planning increases concordance between preferences for care and delivered care, which leads to improvements in positive communication outcomes for patients and their loved ones [7]. Patients' EOL preferences are influenced by many factors: demographic characteristics including age, gender, and ethnicity; subjective and objective health status and stages of illness; the type of decision they need to make; and their past experiences of interacting with health providers [8].

Racial and cultural factors lead to a variety of attitudes toward EOL planning. In some ethnic groups, such as Chinese Americans, adherence to EOL wishes is viewed positively and decreases family burden with greater psychosocial integrity [5]. Other racial and ethnic minorities, such as non-Hispanic Blacks, are less likely to complete EOL planning activities, including drafting advance directive documents or communicating their EOL desires and preferences to their providers [9–14]. Racial and ethnic groups may avoid communication about their EOL wishes with healthcare providers and their families or may be unaware of its benefits [15]. As a result, ethnic minority groups are more likely to experience dissatisfying and poorer health outcomes than their non-Hispanic White counterparts [16]. This has been attributed to how healthcare systems support minority and non-Hispanic White patients differently at their EOL stage [16]. Additionally, completion of EOL planning among non-Hispanic Blacks can be hindered by the fear that expressing their EOL wishes may cause providers to deliver inadequate care and hasten their death, in addition to possibly conflicting with patients' faith and religious beliefs [17].

Recent literature revealed that older non-Hispanic Black adults prefer to avoid EOL planning conversations with their children and family to protect them from distressing conversations [18]. Moreover, a qualitative study conducted among non-Hispanic Blacks found that those who did not complete EOL planning believed that they could trust their families to make the appropriate medical decisions. They were also certain that their families knew what EOL treatments they wanted, even though they never discussed their EOL preferences with family members [19]. Yet, some of those who expressed a preference for EOL to be made by their family admitted that their family members may not make decisions reflecting their own preferences. After all, non-Hispanic Blacks desire better communication and meaningful trusting relationships with their healthcare providers [20]. In addition, adults who considered advance care decision-making important desired their healthcare provider to initiate this conversation during their visits [21].

Within EOL care planning, patients have to consider the following decision-making topics: (1) nutrition and hydration choices, (2) ventilation support, and (3) resuscitation actions [22]. Additionally, EOL care decision-making includes the completion of advance directives, such as proxies, and methods of technologies, such as videoconferencing and telemonitoring [23]. There are additional aspects of EOL care planning that do not involve making decisions per se, such as seeking providers with greater cultural and linguistic competence or developing a better relationship with existing providers. Moreover, there are very limited studies that evaluate the impact of ethnicity/race on the specific desires, expectations, and demand for EOL care, which include both major and minor patient-behavior decisions.

The objective of this study is to examine the impact of the relationship with healthcare providers, including perceived discrimination and level of mistrust, on patients' EOL medical wishes. Using multivariate analysis, and adjusting for demographic and socio-economic variables, we sought to estimate the potential independent impact of level of mistrust, perceived discrimination, objective and subjective health status, and level of spirituality on non-decision-based desires and wishes not typically covered by written advance healthcare directives. In particular, we are interested to analyze racial differences in EOL wishes between non-Hispanic White and non-Hispanic Black middle-aged and older adults.

Methods

Design and Settings Survey of California Adults on Serious Illness and End-of-Life is a cross-sectional representative survey of residents of California in 2019. The study fielded June 6 through July 2, 2019. The study was conducted for the California Health Care Foundation.

Participants and Sampling This study includes 773 non-Hispanic Blacks and non-Hispanic Whites 55 years of age and older. The survey was administered using Ipsos's KnowledgePanel, which is the first online research panel that is representative of the US population. Panel members are randomly recruited through address-based sampling methods, and households are provided with hardware and access to the Internet if needed. A sample of California households was invited to join the "KnowledgePanel" to complete the survey through a series of mailings, including an initial invitation letter, a reminder postcard, and a subsequent follow-up letter. Invited Californian households could join the panel by the following: (1) completing and mailing back a paper form in a postage-paid envelope; (2) calling a toll-free hotline phone number maintained by Ipsos; or (3) going to a designated Ipsos website and completing the recruitment form online. The survey also increased the number of Black respondents by using supplemental, nonprobability sampling. Participants answered the questions of the survey in their home online.

Measurements

Independent Variable Demographic and socio-economic characteristics include age, gender, educational attainment, marital status, ethnicity, and household income. 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 which a higher score reflected a higher number of schooling. Not married, widowed, and separated participants were coded 0, while married or living with partners was coded 1. Income was measured as annual household income for previous years. Income was categorized to three levels: (1) under 150%, (2) 150–399%, and (3) ≥ 400% of poverty level. Self-identified race and ethnicity were dichotomous variables, with non-Hispanic Whites designated as the reference category.

Self-rated health status was measured using a single item [24–27]. Participants reported their overall health. Response options were coded as (1) excellent, (2) very good, (3) good, (4) fair, and (5) poor. The Institute of Medicine (IOM) has recommended self-rated health status for monitoring the health of the US general population.

Perceived Discrimination Perceived discrimination was measured using a 10-item questionnaire. For all 10 items, participants indicated whether they agreed or disagreed with each statement indicating whether they had experienced discrimination from healthcare providers because of ethnicity/race, language, income, or medical insurance coverage. Cronbach's alpha coefficient for these 10 items was calculated to be 0.815. Furthermore, the Cronbach's alpha coefficients if any 10 items were deleted ranged from 0.722 to 0.813 indicating that no single item decreased reliability appreciably. We used a summed score of these 10 items as the index measuring discrimination. A higher score indicated a higher level of perceived or experienced discrimination.

Level of medical 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?" Responses were divided into two categories: 1 = a lot and 0 = not enough/some.

The number of chronic conditions was measured based on self-report of being diagnosed with the following: (1) emphysema or chronic obstructive pulmonary disease, (2) heart, (3) cancer, (4) stroke, (5) HIV/AIDS, (6) cirrhosis or late-stage liver disease, (7) chronic or end-stage kidney disease, (8) hypertension, (9) diabetes, (10) depression, (11) an anxiety disorder, (12) bipolar disorder, or (13) other serious illness.

Spirituality was measured with a single item asking participants, "How important is religion or spirituality in your life?", with a response of 1 = very important to 4 = not at all important.

Outcome Variable

End-of-Life Non-decision-based medical desires and wishes not typically covered by written advance healthcare directives were measured with four items asking participants, "How important is each of the following to you at the end of your life?", including (1) being comfortable and without pain, (2) having doctors and nurses who will respect my cultural beliefs and values, (3) making sure my wishes for medical care are followed, and (4) a close relationship with my doctor. All items are based on a 1-to-7 scale, from 1 being "not at all important" to 7 being "extremely important." Cronbach's alpha coefficient for these 4 items was calculated to be 0.76. Furthermore, the alpha scores if items were deleted ranged from 0.571 to 0.645 indicating that no single item decreased reliability appreciably. Additionally, factor analysis produced only one index, which convinced us that a summed score of these four items was the best representative index to measure EOL medical wishes. The summed score was extremely exuded to the left; therefore, it was dichotomized into two categories (0 = less and 1 = more than 2/3 of percentile).

Statistical Analysis Our analysis had three parts. The first section was a descriptive analysis of all participants. This descriptive part reported means and standard deviations for continuous measures and frequency and percentages for categorical variables. Then we ran both the Chi-square and independent *t*-tests to compare participants with lower and higher levels of non-decision-based medical desires and wishes (less than and more than two-thirds percentile). For multivariable models, we employed the multiple binary logistic regression technique. Adjusted odds ratios (ORs), 95% confidence intervals (95% CI), and *p* values were reported. *P* values less than 0.05 were considered significant. We used SPSS 24.0 to perform our data analysis.

Results

Table 1 reports the characteristics of the study sample. This study included 733 individuals, including 190 non-Hispanic Blacks and 583 non-Hispanic Whites aged 55 years and older (mean 67.14 ± 8.30). Almost 20% of the sample reported having a high school diploma, and 2% reported 0–11 years of education. Almost 42% and 38% of participants reported some college or college degrees, respectively. More than 33% of participants reported their household income in the

Table 1 Characteristics of sample ($n = 773$)

	n	%
Gender		
Male	373	48.3
Female	400	51.7
Household income		
Under 150%	196	25.4
150–399%	257	33.2
≥ 400%	320	41.4
Ethnicity/race		
White, Non-Hispanic	583	75.4
Black, Non-Hispanic	190	24.6
Marital status		
Not married	377	48.8
Married	396	51.2
Trusting healthcare providers*		
No/some	307	40.5
A lot	451	59.5
		Mean ± SD
Age (years: 55–93)		67.14 ± 8.30
Education attainment (1–14)		10.83 ± 1.56
Self-rated health (1–5: excellent–poor)		2.61 ± 0.96
Number of chronic conditions (1–13)		1.62 ± 1.44
Spirituality/spirituality (1 important–4 not at all)		2.02 ± 1.09
Perceived discrimination		1.78

*This variable has 15 missing cases

range of 150 to 399% of the federal poverty level, while almost 41% reported their household income as under 150% of the federal poverty level (Table 1). Only 11% of participants reported their health as excellent, whereas 18% reported their health as poor or fair. Interestingly enough, 40.5% of participants disclosed that they do not trust their healthcare providers to act in their best interests. As expected, 69% indicated that religion or spirituality is very (44%) or somewhat (25%) important in their lives.

Table 2 reports four items that measure the EOL wish lists of both non-Hispanic Whites and Blacks aged 55 years and older who participated in this study. This table shows that non-Hispanic Blacks desired a higher level of respect for their cultural beliefs and values from their providers than their White counterparts (6.26 ± 1.36 vs. 5.48 ± 1.86; $p < 0.001$). Similarly, non-Hispanic Blacks wished to have a closer relationship with their providers than non-Hispanic Whites (5.98 ± 1.39 vs. 5.55 ± 1.50; $p < 0.001$). Seventy-four percent of non-Hispanic Blacks and 59% of non-Hispanic Whites indicated that having a close relationship with their providers at their EOL is very/extremely important to them. Furthermore, 83% of non-Hispanic Blacks and 63% of non-Hispanic Whites indicated that it is very/extremely important to them to have doctors and nurses who will respect their cultural beliefs and values in the EOL stage.

Table 3 shows the bivariate association between the independent variables and the index that measures EOL medical wishes. At the bivariate level, all independent variables, except marital status, household income, and perceived discrimination, were associated with the dependent variables. Females, non-Hispanic Whites, those less educated, those with better self-rated health, those with fewer chronic conditions, those with a higher level of religiosity or spirituality, and those who showed more trust in their providers were all more likely to have stronger feelings about their EOL medical wishes.

Table 4 reports the results of the multiple logistic regression estimating independent association and independent variables. This table shows that adjusting for demographic characteristics, SES status, and other relevant variables, ethnicity remained a strong correlate of the dependent variables. Non-Hispanic Blacks expressed much stronger feelings about their EOL wishes than their non-Hispanic White counterparts (OR = 2.92; 95% CI 1.91–4.47; $p < 0.0001$). Among demographic characteristics, gender showed a strong association with the dependent variables, indicating that controlling for all other variables, women were 2.03 (95% CI 1.427–2.884; $p < 0.00001$) times more likely to express strong feelings about their EOL medical wishes. Similarly, those participants who expressed strong trust in their providers were 2.1 (95% CI 1.464–3.051; $p < 0.0001$) times more likely to have strong feelings about their EOL medical wishes. Controlling for all other relevant variables, a higher level of self-rated health and higher number of chronic conditions were both associated with stronger feelings about their EOL medical wishes. Finally, participants who expressed less religiosity or spirituality were 0.839 times less likely to express strong feelings about their EOL medical wishes (OR = 0.839; 95% CI 0.709–0.998; $p < 9.05$).

Discussion

This study highlights the critical need for further examination of the end-of-life non-decision-based desires and wishes among older non-Hispanic Blacks. This community-based study revealed that non-Hispanic Blacks, women, older adults, those with greater trust in their providers, those with higher educational attainment, those who place a higher importance on religion and spirituality, and those with better self-rated health had stronger feelings about their EOL medical wishes. These wishes encompassed (1) a desire to have their cultural beliefs and values respected, (2) a wish for a close relationship with providers, (3) the desire to be comfortable and pain-free at the EOL, and (4) the demand that their medical wishes be followed at the EOL. To the best of our

Table 2 End-of-life wish list among non-Hispanic Black and Whites aged 55 years and older (*n* = 773)

Wish lists	Mean ± SD	Sig.	Very/extremely important *N* (%)
Being comfortable and pain-free		0.95	
Non-Hispanic Blacks	6.49 ± 1.03		318 (87.0)
Non-Hispanic Whites	6.34 ± 1.14		487 (83.6)
Providers respect beliefs and values		< 0.001	
Non-Hispanic Blacks	6.26 ± 1.36		156 (83.0)
Non-Hispanic Whites	5.48 ± 1.86		363 (62.7)
Medical wishes are followed		0.310	
Non-Hispanic Blacks	6.55 ± 1.02		168 (90.3)
Non-Hispanic Whites	6.47 ± 0.99		501 (86.3)
Close relationship with providers		< 0.001	
Non-Hispanic Blacks	5.98 ± 1.39		137 (73.7)
Non-Hispanic Whites	5.55 ± 1.50		342 (58.9)
Average of summative items 1–4		< 0.001	
Non-Hispanic Blacks	6.10 ± 0.85		N/A
Non-Hispanic Whites	5.59 ± 0.88		

Table 3 Bivariate correlates between independent variables and medical-related wish among non-Hispanic Black and White middle-aged and older adults (*n* = 773)

Independent variables	Medical-Related Wish		
	< 66% *N* (%) (X ± SD)	≥ 66% *N* (%) (X ± SD)	Sig.
Gender			
Male	283 (76)	90 (24)	< 0.001
Female	219 (55)	180 (45)	
Age	(66.7 ± 8.08)	(67.9 ± 8.68)	0.070
Education	(11.0 ± 1.55)	(10.4 ± 1.49)	< 0.001
Marital status			
Not married	237 (63)	139 (37)	0.258
Married	265 (67)	131 (33)	
Household income			
Under 15%	116 (60)	79 (40)	0.136
150–399%	168 (65)	89 (35)	
≥ 400%	218 (68)	102 (32)	
Ethnicity/race			
White, Non-Hispanic	405 (70)	178 (30)	< 0.001
Black, Non-Hispanic	97 (51)	92 (49)	
Trusting healthcare providers*			
No or some	221 (72)	86 (28)	< 0.001
A lot	268 (59)	183 (41)	
Self-rated health status	(2.64 ± 0.96)	(2.59 ± 0.95)	< 0.05
Number of chronic conditions	(1.53 ± 1.41)	(1.80 ± 1.49)	< 0.05
Level of spirituality/spirituality	(2.16 ± 1.11)	(1.75 ± 1.00)	< 0.001
Perceived discrimination	(1.00 ± 1.78)	(0.91 ± 1.78)	0.545

*This variable has 15 missing cases

Table 4 Multivariate logistic regression estimating the association between independent variables and end-of-life medical wish among non-Hispanic Black and White middle-aged and older adults (*n* = 758)

Independent variable	OR	95% CI	Sig.
Gender			
Male	1.000		
Female	2.028	1.427–2.884	< 0.001
Age	1.029	1.007–1.051	< 0.010
Education	0.743	0.659–0.838	< 0.001
Marital status			
Not married	1.000		
Married	1.133	0.786–1.634	0.504
Ethnicity			
White, Non-Hispanic	1.000		
Black, Non-Hispanic	2.924	1.912–4.473	< 0.001
Household income			
Under 15%	1.000	–	0.268
150–399%	1.110	0.692–1.782	0.665
≥ 400%	0.788	0.524–1.186	0.254
Spirituality/spirituality	0.839	0.706–0.998	< 0.05
Trust with healthcare providers			
No or some	1.000		
A lot	2.113	1.464–3.051	< 0.001
Self-rated health	0.802	0.655–0.983	< 0.05
Number of chronic conditions	1.170	1.027–1.330	< 0.05
Perceived discrimination	0.974	0.876–1.083	0.624
− 2 log likelihood	863.8		
Nagelkerke	0.202		

knowledge, no other studies have compared non-decision-making medical wishes among non-Hispanic Whites and Blacks. It is important to note that previous studies mainly focused on EOL decision-making (e.g., directives concerning life-sustaining medical treatment), whereas this study focused on non-decision-based desires and wishes not typically covered by written advance healthcare directives (e.g., the wish that EOL care be rendered with special attention to the patient's beliefs, culture, or religion).

This study found that reporting greater trust in healthcare providers is associated with stronger feelings about one's EOL wishes. Even though non-Hispanic Blacks are less likely than their White counterparts to have advance directives, they desire communication, information, respect, and a trusting doctor-patient relationship [20]. Several studies have shown that minority groups desire EOL care that is sensitive to their religious values and cultural assumptions [9–14, 28]. At the same time, a large number of studies testify that non-Hispanic Blacks consistently report higher levels of mistrust in the healthcare system than Whites [29–33]. Quite similarly, our study documented that non-Hispanic Blacks desire a higher level of respect regarding their cultural beliefs and values from their providers than their White counterparts.

Our findings also revealed that compared with 56% of non-Hispanic Whites, 74% of non-Hispanic Blacks indicated that having a close relationship with their providers at their EOL is very/extremely important for them. These results add to the established body of literature indicating that conversations surrounding EOL wishes are associated with greater trust in providers [34, 35]. Dillworth and colleagues (2016) reported that healthcare providers believe that poor and ineffective physician-patient/family relationships and communication led to issues regarding EOL decision-making [36]. Additional evidence found that minority groups' EOL wishes include being pain-free and having a trusting relationship with their healthcare providers [5]. High levels of trust in healthcare providers have also been documented as important to increasing care coordination and quality of death [37]. It is imperative that the patient, family members, and providers implement focused strategies to build trust that will lead to effective communication and delivery of EOL wishes. Therefore, it is not surprising that the non-Hispanic Blacks in our study expressed stronger wishes for a close relationship with their providers at their EOL than did non-Hispanic Whites.

Our results also showed that women were more likely to have stronger feelings about their EOL medical wishes. This is not an uncommon finding as gender has been found to influence EOL preparedness and wishes [38]. Crouch and colleagues (2018) found that women are more likely to utilize EOL support services, such as hospice, home health services, and inpatient services for EOL [39]. Existing gender norms include the expectation that women should be the primary caregivers [40]. Williams and colleagues (2017) revealed that women typically adhered to gender norms that identified them as primary caregivers, even if they are facing considerable burdens themselves [40]. These gender expectations may contribute to our finding that women are more likely to have stronger EOL wishes. Additionally, a systematic review found that women believe that they should provide a greater degree of care for family members who are in the EOL phase [41]. Women's greater exposure to the EOL process may influence their own personal EOL wishes.

An interesting finding of our study was that older adults may also have stronger feelings about their EOL wishes. This finding corroborates previous studies which have shown that older adults are more motivated to complete advance care planning and are also more likely to communicate their EOL wishes to their providers [42]. Due to the aging process and the presence of multiple conditions, older adults experience physical and mental changes that may make them more aware of the need to prepare for EOL. Also, social factors, such as retirement and the death of people in their network, may lead to enhanced consciousness of their own EOL and incite them to make preparations [30]. Kaplan and colleagues (2020) acknowledge that older adults believe that initiating EOL planning is important, but barriers may limit their engagement. Older adults should be encouraged to document their EOL wishes with their healthcare providers during routine office visits to ensure optimal care during their EOL [30].

Interestingly, possessing stronger feelings about their EOL wishes was associated with the higher self-rated health and outcomes in our study. Our finding adds to the growing literature that discussions about EOL wishes are associated with having higher health status. Quality of life, including self-perceived health, is important to assess when discussing EOL preferences [43]. However, those who rate their quality of life as poor may not be prepared for discussions regarding EOL wishes. It is imperative that self-rated health be explored in future studies analyzing perceptions of EOL care. In relation to this finding, Davies and colleagues (2019) found in their systematic review of 209 studies that poor socioeconomic status is a risk factor for low quality EOL care, which may include fragmented care [44]. This is an indication that providers also should account for socioeconomic factors, in addition to quality of health status, when considering EOL wishes.

According to our findings, those who must manage multiple and complex chronic diseases are more likely to engage in EOL preparation than those who do not have chronic diseases [45]. However, some chronic diseases may lead to greater EOL preparation than others. For example, Hash and colleagues (2018) found that diabetic patients were less likely to have formal EOL care plans compared with those with cardiovascular disease [45]. Furthermore, individuals with multiple comorbidities are more likely to have an advance directive but no other form of EOL care planning [45].

Various chronic disease trajectories and different illnesses appear to result in different outcomes with regard to EOL care planning. More study is needed to examine the illness patterns of chronic conditions and their relationship with EOL wishes.

One of the interesting findings of our study was the strong positive association between religion and spirituality and non-decision-based EOL wishes. Several studies have examined how religiosity and religious affiliation influence advance care planning, often with mixed results [46, 47]. Numerous studies testify that religion directly or indirectly impacts EOL decision making and planning [38, 48]. In addition, there is strong evidence that religion plays a major role in the life of non-Hispanic Blacks. Evidence that religiosity accounts for lower rates of EOL care planning among non-Hispanic Blacks is limited [46]. Carr (2011) has documented that the Black-White gap in advance care planning was attributed to non-Hispanic Blacks' belief that the timing and nature of their death are controlled by higher powers [49]. Similarly, other researchers have documented a negative association [48, 50, 51], and a handful of studies have reported no association between religiosity and EOL planning [46, 49]. However, no study, to the best of our knowledge, documented a positive association between EOL planning and religiosity among African Americans. The explanation for this discrepancy, we speculate, is that previous studies mainly focused on EOL decision-making, whereas our study focused on non-decision-based desires and wishes not typically covered by written advance healthcare directives.

Implications

Understanding and respecting the cultural beliefs and values of older adults, particularly non-Hispanic Blacks (who in many cases have non-Hispanic White providers), is the first step toward developing meaningful relationships between non-Hispanic Black patients and their providers. In light of the growing awareness for improved EOL care, patient-provider communication about EOL wishes should be integrated into the continuity and coordination of patient care. A recent systematic review of current literature showed that non-Hispanic Black patients consistently experienced poorer quality of provider communication, information-giving, and participatory decision-making compared with non-Hispanic White patients. Healthcare systems should create health policies that incentivize providers to initiate early EOL discussions with their patients and document their patients' wishes. Many providers, especially those in primary care settings, may feel inadequately prepared to provide EOL counseling and care. Therefore, training in these EOL areas, such as the delivery and communication of EOL, should be a mandatory element of the medical school curriculum and residency training. Healthcare systems should also consider integrating technological applications and clinical decision tools that may contribute to the assessment and improvement of EOL care. Special focus should be given to minority populations, including non-Hispanic Blacks, who face multiple healthcare disparities and would benefit from culturally sensitive approaches regarding EOL from their provider.

We found that the non-Hispanic Black participants in our study expressed a strong desire for providers who respect their beliefs and values. Given this finding, we suggest that ethnic matching between providers and patients may substantially improve communication and trust between providers and their non-Hispanic Black patients at the end-of-life. Moreover, it may reduce patient concern regarding their providers' respect for their religious/spiritual concerns and beliefs, particularly at the-end-of-life stage. Multiple studies show that the ethnic matching leads to improved treatment outcomes and reduction in risky and harmful health behaviors [52, 53]. Ethnic matching between providers and patients may be a unique strategy to improve patient-provider challenges [54]. To fulfill the goal of ethnic matching for patients, there will need to be an increase in the population of minority providers. Policymakers and institutions can develop incentives that increase recruitment and retention for minority students at health professional schools, such as scholarships or specific endowments.

Moreover, providers should be encouraged by healthcare systems to start initiating advance care planning with patients, which may lead to greater adherence to EOL wishes [4, 6]. Planning for EOL care should also involve discussions of patient preferences for palliative care [55]. Providers should introduce mechanisms that build trust and cultural competence, especially for minority groups [56]. Delivery of effective communication fosters trust with patients and enhances providers to offer high quality of care to establish and sustain optimal EOL. Specifically, addressing both mistrust and ineffective communication skills at the same time and focusing on solutions that both providers (particularly primary care providers) and non-Hispanic Black patients agree to may lead to better patient-centered practices. National and local dialogs between providers and non-Hispanic Black patients are needed to address appropriate communication that promotes mutual trust, prompting further research. Additionally, future research should involve community and faith-based partners and their approaches, which would likely lead to non-Hispanic Blacks' participation in end-of-life care planning, including hospice care and completion of advance care planning.

Limitations

This study would not be complete without acknowledging its limitations. First, this study has a cross-sectional design, which prevents determination of causal relationships. Second, all measures were self-reported, which may lead to some degree of bias. This can also be linked to the lack of access to clinical records to validate health conditions. To replicate these findings, future studies should include review of medical charts. However, this study is unique as it employed a random sampling of California adults to increase generalizability. Moreover, this data will add to the growing literature on EOL wishes, with emphasis on related factors, such as race and ethnicity.

Conclusion

Our findings show that EOL non-decision-based desires and wishes can be influenced by race and ethnicity as well as other health-related factors, such as trust in providers and quality of life among adults in California. Compared with their White counterparts, non-Hispanic Blacks more strongly desire a close relationship with their providers as well as a higher level of respect for their cultural beliefs and values from their providers. Understanding how these complex factors contribute to EOL wishes may influence social and cultural mechanisms at the individual, community, and organizational levels, leading to greater awareness of and support for EOL communication and care between patients and providers. It is recommended that providers, including those in primary care, initiate and continue conversations regarding EOL non-decision-based medical desires and wishes with their Black patients. Understanding and respecting the cultural beliefs and values of older non-Hispanic Black patients, who in many cases are seen by non-Hispanic Black providers, is the first step for providers to develop a meaningful relationship with their Black patients, a relationship that can directly impact the quality of life of this segment of our population.

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Code Availability Not applicable.

Authors' Contributions Mohsen Bazarga desgined the research hypothesis and anlyzed the data set. In addition, he created the first draft of study.

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Data Availability Please visit CA Health Foundation Site.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethics Approval This study is using secondary unidentified data.

Consent to Participate Conducted by the agency who collected the data.

Consent for Publication N/A.

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