

Disparities in Palliative and Hospice Care and Completion of Advance Care Planning and Directives Among Non-Hispanic Blacks: A Scoping Review of Recent Literature

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Abstract

Objectives: Published research in disparities in advance care planning, palliative, and end-of-life care is limited. However, available data points to significant barriers to palliative and end-of-life care among minority adults. The main objective of this scoping review was to summarize the current published research and literature on disparities in palliative and hospice care and completion of advance care planning and directives among non-Hispanic Blacks. **Methods:** The scoping review method was used because currently published research in disparities in palliative and hospice care as well as advance care planning are limited. Nine electronic databases and websites were searched to identify English-language peer-reviewed publications published within last 20 years. A total of 147 studies that addressed palliative care, hospice care, and advance care planning and included non-Hispanic Blacks were incorporated in this study. The literature review include manuscripts that discuss the intersection of social determinants of health and end-of-life care for non-Hispanic Blacks. We examined the potential role and impact of several factors, including knowledge regarding palliative and hospice care; healthcare literacy; communication with providers and family; perceived or experienced discrimination with healthcare systems; mistrust in healthcare providers; health care coverage, religious-related activities and beliefs on palliative and hospice care utilization and completion of advance directives among non-Hispanic Blacks. **Discussion:** Cross-sectional and longitudinal national surveys, as well as local community- and clinic-based data, unequivocally point to major disparities in palliative and hospice care in the United States. Results suggest that national and community-based, multi-faceted, multi-disciplinary, theoretical-based, resourceful, culturally-sensitive interventions are urgently needed. A number of practical investigational interventions are offered. Additionally, we identify several research questions which need to be addressed in future research.

Keywords

palliative care, hospice care, advance care planning, advance directives, non-Hispanic blacks, disparity, mistrust, discrimination, religion and religiosity

Objectives

The objective of this comprehensive review is to summarize the current research and literature on disparities in serious illness care and treatment, access to palliative and hospice care, advance care planning and directives, end-of-life service utilization, and perceptions of care. Specifically, this review focuses on these matters among non-Hispanic Blacks. The first section of this article summarizes the patterns uncovered regarding palliative care, focusing particularly on national survey statistics to portray a better picture of end-of-life or serious illness health care utilization among non-Hispanic Blacks. Next we will turn to research findings regarding disparities in hospice care and completion of advance care planning and directives, again focusing on non-Hispanic Blacks. We will

review the major factors influencing patterns of palliative and hospice care usage and completion of advance care planning

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and directives, factors such as personal preferences associated with religion and beliefs, mistrust in healthcare providers, perceived or experienced discrimination with health care systems, and satisfaction with hospice and palliative care. Finally, we will synthesize the results of the review to offer suggestions for future research and practical interventions to reduce health care disparities in end-of-life care and treatment.

Methods

A comprehensive literature review of studies related to disparities in serious illness care and treatment, access to palliative and hospice care, advance care planning and directives, end-of-life service utilization, and perceptions of care was conducted. We followed the scoping review methodological framework and guidelines proposed by Arksey and O'Malley (2005),¹ and the Joanna Briggs Institute (2015),² as well as suggestions offered by Tricco and colleagues (2016).³ The draft of our protocol and manuscript was revised based on feedbacks from the 5 experts, including a health care service researcher, nursing specialist, primary care provider, and 2 associate editors of 2 peer-reviewed journals. The search was also peer-reviewed by another expert librarian.

Nine electronic databases and websites were searched to identify English-language peer-reviewed publications and grey literature (including reports and other online resources) published within last 20 years. The following Medical Subject Headings terms were used for the bibliographic search: palliative care, hospice care, advance care planning, advance directives, serious illness, and end-of-life. Qualitative and quantitative empirical studies that included at least one of the above mentioned subject headings and included Blacks/African American or non-Hispanic Blacks were reviewed. Both systematic reviews and meta-analysis were also reviewed. After searching almost fourthly-thousand citations, 284 articles were included in our study, of which 147 were manuscripts that directly addressed end-of-life and hospice care, palliative care, as well as advance care planning and directives that include non-Hispanic Blacks.⁴⁻¹⁵⁰ Table 1 reports more recent detail of studies that conducted between 2015 and 2020 on advance healthcare planning and directives, palliative and hospice care that exclusively focused on or included non-Hispanic Blacks.^{4-75,147,148,150}

Palliative and Hospice Care

The terms "palliative care" and "hospice care" are often used interchangeably, but this use is inaccurate and misleading.¹⁵¹ According to the Center to Advance Palliative Care:

"Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support.

Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment."¹⁵²

Palliative care is a resource for anyone living with a serious illness, such as dementia and Alzheimer's disease, heart failure, cancer, chronic obstructive pulmonary disease, Parkinson's disease, and many others. It is also importance to note that Palliative care can be helpful at any stage of illness and is best provided from the point of diagnosis.¹⁵³ Furthermore, Palliative care focuses on improving quality of life by addressing the physical, emotional, and spiritual needs of patients and their families. The pillars of palliative care are: 1) evidence-based curative and rehabilitative medical intervention options, 2) provision of truthful information, 3) effective discussion with patients and family, and 4) cultural sensitivity.¹⁵⁴

Hospice care is a specialized type of palliative care for patients with a terminal illness. When the likelihood of increasing the patient's quantity of life with medical treatment is or becomes extremely low, palliative care may follow the patient into hospice care, where all efforts should be directed toward the quality of the patient's remaining life and the quality of their death.¹⁵⁵ Indeed, hospice care refers to programs that provide compassionate multi-disciplinary and multi-dimensional cares for patients with terminal illness so that they may live as fully and comfortably as possible. An effective hospice care program is expected to provide services ranging from pain and symptom management to bereavement care.¹⁵⁶ Hospice care is typically provided in the patient's home. It is not intended to be a substitute for family and friends but rather an aid to them as they care for their terminally ill loved one.¹⁵¹ However, it is important to note that hospice care is not a death-bed service for people in the last few days of life. Hospice services are covered by most insurance providers, as well as Medicare and Medicaid.¹⁵¹ The recognition in 2006 of hospice and palliative medicine as its own medical subspecialty underlined the importance of palliative care to the practice of medicine.¹⁵⁷

Medical educators now more than ever agree that training in palliative and end-of-life care must be an integral part of medical education at all levels.¹⁵⁸ Underscoring the important role of palliative care at the end of life, Mehta and Smith (2020) argue that in the COVID-19 era when a large number of individuals die in a given day, palliative care is not a luxury but a necessity. They indicate that in this troubling time health care practitioners should not hold back on providing palliative care services and lean into patient care in creative ways that will define and solidify the identity of palliative care as the most compassionate and caring field.¹⁵⁹ Elbaum (2020) argues that "*in the midst of the Covid-19 pandemic, African Americans have once again been denied a say with regard to the rationing of scarce medical resources such as ventilators, in that dominant and ostensibly race-neutral algorithms sacrifice black lives.*"¹⁶⁰

Impact of palliative care on quality of life and health care utilization. Several recently published meta-analyses and systematic reviews point to the significant role of palliative care interventions on enhancing quality of life and reducing symptoms burden and health care cost and utilization.¹⁶¹⁻¹⁶⁷ A systematic search of 124 randomized controlled trials shows that palliative care improves outcome of many end-of-life conditions including cancer, chronic heart failure, chronic obstructive pulmonary disease, and dementia. These systematic reviews point to the effectiveness of communication and psychosocial support.¹⁶⁷ Similarly, another meta-analysis of randomized clinical trials reveals that palliative care interventions among adults with life-limiting illnesses were associated with improvements in patient quality of life and symptom burden.¹⁶² Moreover, reviews of current literature show that inpatient palliative care consultations have the potential to improve patient quality of life and encourage transitions to the community, thereby relieving overburdened acute care facilities.¹⁶⁵

Two other recent systematic reviews of palliative care for advanced heart failure patients reveal that palliative interventions substantially reduce hospitalizations,¹⁶³ improve patient-centered outcomes, documentation of preferences, and health care utilization.¹⁶⁴ Along the same line, another systematic review revealed that receiving palliative care was associated with lower emergency department attendance in the last year of life for older adults.⁴² One study found that when consults for palliative care were initiated within 24 hours of hospital admission, length of stay and hospital-related expenses were reduced.¹⁶⁸ Finally, reviews of research manuscripts published between January 2012 and January 2019 show that end-of-life discussions with patients with advanced cancer are associated with greater use of hospice care, greater likelihood of death outside the hospital, as well as less costly end-of-life care.²¹

Palliative care among non-Hispanic blacks. Published research in disparities in palliative care is limited.⁸³ However, available data points to significant barriers to palliative and end-of-life care among minority adults.^{47,57,75,96,101,169} Indeed, racial disparities in rates of hospice care use, a marker of the quality of end-of-life care, have been a long-standing problem.^{31,93} There are also geographic disparities in access to palliative care in United States, suggesting that access to such care is worse among more racially diverse, poorer, and more politically conservative states.⁵²

Overwhelming evidence, based on large national data sets, consistently and unequivocally points to major disparities in palliative care in the United States.^{13,39,40,55,64} One retrospective cohort study of over 5 million hospitalizations of dialysis patients revealed that non-Hispanic Black and Hispanic patients were less likely than non-Hispanic White patients to receive palliative care services in the hospital. This disparity was observed in all hospital subtypes, even hospitals with a high proportion of minority patients.¹³ Similarly, the Nationwide Inpatient Sample, which included 46,735 intracerebral hemorrhage and 331,521 ischemic stroke inpatient hospital admissions between 2007 and 2011, revealed that patients

receiving care in minority hospitals had lower odds of palliative care compared to those treated in hospitals that served mostly non-Hispanic White patients. Ethnic minorities had a lower likelihood of receiving palliative care compared to whites in any hospital stratum, suggesting system-level factors in racial disparities in palliative care use after stroke.⁶⁴

Another retrospective cohort study of the hospital-based cancer registry of 601,680 lung, colon, and breast cancer patients treated at more than 1,500 US hospitals show that minority-serving hospitals was associated with significantly lower odds of receiving any palliative care, suggesting that the site of care is also associated with race/ethnicity-based differences in palliative care.⁴⁰ Another study that identified 710,293 hospitalized intracerebral hemorrhage patients from the United States Nationwide Inpatient Sample database for the years 2006–2014 revealed that Hispanic Whites had greater utilization of palliative care, and hospice than non-Hispanic Blacks.³⁹

Furthermore, a retrospective study revealed considerable racial/ethnic disparities in the quality of palliative and end-of-life care. Minorities were more likely than non-Hispanic Whites to experience potentially preventable medical encounters in the last month of life.⁵⁰ Another retrospective cohort study of 204,175 hospital admissions of patients with advanced cancers revealed that non-Hispanic Black patients discharged from the hospital were significantly less likely to receive a palliative care consult compared to their White counterparts. Although palliative care consults are more likely to be given to non-Hispanic Black patients who die in hospital, the disparity is reversed for non-Hispanic Black patients with advanced cancer who leave the hospital alive.⁷ Retrospective cohort study (2010–2015) of hospital utilization among racial/ethnic minority patients with hematologic and non-hematologic malignancies suggested that racial/ethnic minority patients with hematologic malignancies have higher utilization of care at the end of life and lower rates of advance directives compared with non-Hispanic patients.⁴⁹ Delay of initiation of outpatient palliative care consultation among non-Hispanic Black cancer patients also highlights a racial disparity.⁵³

Ahluwalia and colleagues (2018) examined 139 systematic reviews published after 2013, when the third edition of National Consensus Project Clinical Practice Guidelines for Quality Palliative Care was published. The main objective of this comprehensive review was to provide a synthesis of the evidence in palliative care to improve the next (fourth) edition of these guidelines. One of the major recommendations of Ahluwalia and colleagues was that the existing evidence base for culturally sensitive palliative care remains very limited, underscoring the need to expand the palliative care research base.¹⁷⁰ Responding to this concern, the new (fourth) edition of the Clinical Practice Guidelines for Quality Palliative Care (2018) enhanced the social and cultural aspects of care. This domain indicates the need for “assessing and respecting values, beliefs and traditions related to health, illness, family caregiver roles and decision-making are the first step in providing culturally sensitive palliative care” and calls on palliative care interdisciplinary team members to “continually expand awareness

of their own biases and perceptions about race, ethnicity, gender identity and gender expression, sexual orientation, immigration and refugee status, social class, religion, spirituality, physical appearance, and abilities.”¹⁷¹ Even though the concept of social determinants of health has also been mentioned several times and practical examples are provided, this document refuses to directly address the discrimination and/or disparities of palliative care that non-Hispanic Black and other minority patients are experiencing. Nowhere in the official guidelines is the concept of “discrimination” or “disparities” even mentioned, other than in the bibliography. However, the new edition is to be applauded for encouraging the use of palliative care interdisciplinary teams committed to continuously practicing cultural humility and celebrating diversity.¹⁷¹

As mentioned earlier, the literature specifies race and culture as the main barriers preventing non-Hispanic Black patients from receiving effective hospice and palliative care. An important challenge is to develop an understanding of how race/ethnicity, cultural values, and preferences of non-Hispanic Black patients and their families lead to disparities in palliative and end-of-life care.¹⁷² Kross and colleagues (2020) argue that the beliefs, values, and preferences of non-Hispanic Black patients and their families *must be supported*. Additionally, they suggest that differences based on disparities in communication, referral and enrollment for palliative and hospice care, minimizing symptoms and pain etc. *must be eliminated*. The important difference between these 2 approaches may seem subtle but is actually quite significant and exposes a vital matter of contention in palliative care that researchers must address.¹⁷²

Survey of California Adults on Serious Illness and End-of-Life collected in 2019 shows that Non-Hispanic older Black adults desired a closer relationship with their providers as well as a higher level of respect for their cultural beliefs and values from their providers.¹⁵⁰ 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.¹⁵⁰ Investigational interventions are needed to assess and eliminate racial/ethnic disparities in hospice and palliative care.

Hospice care among non-Hispanic blacks. Despite gains in the availability and acceptance of hospice care, non-Hispanic Blacks remain underrepresented among hospice clients.^{11,19,39,75,101,141,142,146,173,174} It has been suggested that hospice care emphasizing family-centered care and spiritual support can be an excellent fit for non-Hispanic Blacks who are terminally ill. However, overwhelming evidence shows that non-Hispanic Blacks use hospice services at an appreciably lower rate than their non-Hispanic White counterparts.⁹⁵ One important factor behind the underutilization are untimely referrals, often made during the last weeks or days of the patient’s life.¹⁷⁵ Existing data clearly show that the odds of delayed

hospice referral near the end of life were greater in non-Hispanic Blacks than in non-Hispanic Whites.⁴⁹

The disparity in hospice use among ethnic minority populations is a complex and nuanced problem, involving numerous interrelated barriers.⁴¹ A systematic review of both qualitative and quantitative research identified factors that contribute to the underuse of hospice services by non-Hispanic Blacks. The major factors included 1) personal or cultural values in conflict with the hospice philosophy, 2) lack of awareness of hospice services, 3) concern about the economic burden on the family, 4) mistrust in the health care system, and 5) expected lack of ethnic minority employees in hospice agencies.¹⁰⁶

Analysis of longitudinal data from 145,038 Medicare beneficiaries enrolled in a national random sample of 577 hospices from the National Hospice Survey and followed until death clearly shows that after accounting for participant clinical and demographic covariates and hospice-level random effects, non-Hispanic Black hospice enrollees were significantly more likely than non-Hispanic White enrollees to be admitted to the hospital, visit the ED and dis-enroll from hospice. This study reveals that differences in patterns of care between non-Hispanic Black and White hospice enrollees persist within the same hospice.⁴⁵

Overwhelming evidence reveals that non-Hispanic Black patients are less likely to use hospice and more likely to die in the hospital than their non-Hispanic White counterparts.^{9,55,105} Recent systematic reviews of 19 studies focusing on palliative care among cancer patients also revealed that racial minorities were less likely to use palliative or hospice care.¹⁷⁶ De-identified cancer death certificates (n = 9,646,498) collected from 1999 through 2015 by the National Center for Health Statistics show that the rate of hospice facility deaths increased from almost zero to 14%.⁵⁵ This data shows that in 2015, 33% of non-Hispanic Black and 23% of White cancer patients died in a hospital. The multivariate analysis of this data show that non-Hispanic Blacks are more likely to die in the hospital than their non-Hispanic White counterparts.⁵⁵ More than 40% of the deaths that occur in the United States used hospice services, but that number is much smaller for non-Hispanic Blacks.⁸¹ Examination of trends in place of death for over 101,000 head and neck cancer patients from 1999 to 2017 revealed that minority patients were less likely to die at home or hospice.⁹

End-of-life care transition is another important factor that impacts the quality of life of non-Hispanic Black patients. Numerous studies point not only to a discriminatory pattern of hospice referral targeted toward palliative non-Hispanic Black patients, but also to discrimination in live discharge from hospice services. A retrospective cohort study of 649,477 Medicare beneficiaries revealed that, adjusting for gender and age, having at least 4 transitions was significantly more common for non-Hispanic Black patients than for non-Hispanic Whites. Such transitions can be burdensome and frequently are associated with unmet needs and poor quality of care. Non-Hispanic Black patients experience the highest number of transitions, indicating serious integration issues that must be resolved.¹⁶

Another recent study documented that compared with non-Hispanic White hospice patients with dementia, non-Hispanic Black patients with dementia experienced increased risk of live discharge.¹⁷⁷

A qualitative study conducted with non-Hispanic Black patients and lay caregivers receiving hospice care services found additional barriers to hospice enrollment, including 1) inconsistent health care access associated with economic enabling factors; 2) poor communication with providers and perceived experiences of discrimination by the health care system; 3) the bureaucratic difficulty of receiving reimbursement under the Medicare hospice benefit; and 4) the perception that hospice care is a way to abdicate responsibilities or to hasten a person's death.⁷⁴ An interesting qualitative study that examined the knowledge, beliefs and attitudes of non-Hispanic Black and White home health clients who were eligible for but refused to enroll in hospice care, found very similar perspectives among both racial groups with regard to attitudes about end-of-life care. This study revealed that an alarming proportion of non-Hispanic Black and White patients who refuse to enroll in hospice programs held erroneous ideas about hospice care and had not discussed this option with their providers. Increased referrals to home-based hospice care among patients who are reluctant to enroll in a hospice program depend on the availability and professional dissemination of accurate, spiritually sensitive information.⁶²

Other studies have found that unfamiliarity with hospice care, family-centered cultures, and preferences for more aggressive end-of-life care are among the reasons that minorities have lower hospice care utilization rates.⁵⁷ The 2018 Health Information National Trends Survey (Cycle 2) shows that 3 out of 4 (74%) non-Hispanic Black adults in the United States report not knowing about palliative care, and those who have some knowledge of palliative care are most likely to confuse it with hospice care.¹⁷ In addition, it has been documented that uninsured and minority patients are less likely to receive hospice care and are more likely to have a delay in transition to hospice care when compared to their insured Caucasian counterparts.¹⁰⁶

While a few researchers suggest that disparity in use of hospice care is due to patient preference, others suggest physician bias as a factor. However, a mail survey of 190 physicians shows that physicians demonstrated very positive attitudes toward hospice care. While they perceived many benefits to hospice care, they identified patient and family readiness as the major barriers to hospice referrals.¹⁷⁸ An anonymous survey of 111 physicians shows that while the vast majority of these providers believe that hospice care is underutilized, a large number of them (84%) were unable to identify appropriate hospice diagnoses and only 12% were aware of patient eligibility guidelines for hospice referral.¹⁷⁹

A preliminary study comparing attitudes toward hospice referral between non-Hispanic Black and White American primary care physicians suggests that attitudes toward hospice referral may differ between Black and White primary care providers.¹⁰⁰ Additionally, a recent quantitative causal-

comparative study that examined perceptions of non-physician medical providers towards hospice care services, documented that non-Hispanic Black non-physician medical providers held more negative perceptions towards hospice referrals than their White counterparts.⁶² Finally, it is known that clinicians frequently overestimate survival time in serious illness.¹⁸⁰ One study examining the connection between frequency of overestimation in palliative care and its relation with end-of-life treatment revealed that palliative care providers were substantially more likely to overestimate survival for non-Hispanic Blacks than White.³⁷ Since overestimation of survival time is substantially associated with less hospice use and late hospice enrollment, the racial/ethnic disparity in overestimation likely contributes to the racial/ethnic disparity in utilization of hospice care.³⁷

Faith-based approaches to promoting palliative and hospice care. A national sample of Medicare beneficiaries revealed that older non-Hispanic Black adults want to die in the hospital rather than at home at a rate double that of their White counterparts.¹⁰⁵ We also mentioned that non-Hispanic Blacks are more likely than non-Hispanic Whites to die in the hospital than at home. Even though non-Hispanic Blacks show a higher preference than Whites to die in the hospital as opposed to at home, the majority of older non-Hispanic Black adults would still prefer to die at home.¹⁰⁵ Research shows that there is a large incongruence between preferred and actual death place in the United States,¹⁶ which highlights the importance of health care providers discussing this issue with patients and their families.⁷⁴ Although the majority of older non-Hispanic Blacks clearly prefer to die at home or in a hospice rather than in the hospital, they are in fact more likely to die in the hospital.¹²

It is also important to note that non-Hispanic Blacks' values and beliefs may push them to a stronger desire to pursue aggressive medical care as a sign of faithfulness to Christian beliefs that honor preservation of life.¹⁸¹ It is also well documented that non-Hispanic Black patients tend to receive more life-prolonging care at the end of life than their White counterparts.^{4,81,102} Many non-Hispanic Black patients choose aggressive life-sustaining treatment at the end of life, even if that treatment seems likely to impose greater burdens with little chance of benefit.^{87,125}

Non-Hispanic Blacks are noticeably more religious than the U.S. population as a whole. They are more likely to be affiliated with a religion, attend religious services, pray, and express that religion as an important part of their life.¹⁸² Even during bereavement, spirituality remains one of the most important factors in the lives of African Americans.¹⁸³ It is also imperative to note that end-of-life decision making among non-Hispanic Blacks (most often a family decision) includes reliance on resources such as faith or spirituality alongside utilization of health care.⁵⁹ Similarly it should be noted that faith in God tremendously helps seriously ill non-Hispanic Blacks cope with their illnesses and other life difficulties and challenges.¹⁸⁴

Knowing that the majority of non-Hispanic Blacks prefer to die at home,¹⁰⁵ Payne (2016) argues that there is an opportunity to substantially increase non-Hispanic Black enrollment in hospice programs.¹⁸¹ One way this can be done is by cultivating the role of religious leaders and faith-based organizations. When religious leaders are well-informed regarding the function of hospice care, they express positive attitudes toward it and are more likely to encourage members of their faith communities to utilize it. Preliminary evidence suggests that the faith concerns of non-Hispanic Blacks can be addressed by collaboration between faith-based organizations and skilled medical teams in ways that can accommodate these spiritual views and lead to more hospice care and less aggressive hospital care at the end of life.

Townsend and colleagues (2015) make a similar argument, suggesting that Faith and Hospice can coexist and that the Black Church is the key to increased hospice utilization among African Americans.⁶¹ One qualitative study found that many non-Hispanic Blacks perceived hospice care through a religious or spiritual lens, believing that hospice permitted them to be the primary caregivers of their terminally ill family members.⁷² Recent studies show that faith-based organizational communication of appropriate information regarding hospice care may improve attitudes towards hospice care among non-Hispanic Blacks.¹¹⁴

Hospices have an opportunity to increase utilization of their services among non-Hispanic Blacks by establishing meaningful relationships with local churches to disseminate hospice information materials.⁶¹ However, recruiting participants solely from faith-based organizations is not sufficient to enhance enrollment of parishioners to hospice care.¹¹⁴ Effective and appropriate intensive interventional training programs must include comprehensive multilevel culturally sensitive messages and materials to improve communication about palliative care and hospice between patients, family and care providers.^{35,185}

Satisfaction of bereaved non-Hispanic blacks' family members with hospice care services. It is important to evaluate the satisfaction of bereaved family members with the quality of hospice care. A systematic review of 11,892 non-Hispanic Black decedents in 678 hospice programs revealed that family members of those who died in hospices that had higher proportions of non-Hispanic Blacks were less likely to have concerns about unmet pain needs and more likely to have concerns about coordination of care compared to hospices with lower proportion of non-Hispanic Blacks. Similarly, among hospices with higher proportions of non-Hispanic Blacks, family members had lower overall perceptions of quality of care.⁹⁰ However, a survey of family members of 743 ethnically diverse hospice patients showed that race/ethnicity was not significantly associated with any of the hospice interventions or outcomes.⁸⁶ Rhodes and colleagues cautiously echo this result, while pointing to tremendous opportunities to improve the quality of care for African Americans enrolled in hospice, specifically pointing to management of pain, and emotional and spiritual support.¹¹⁶

Yet a different picture is painted by other studies. When hospice interventions are evaluated, a few researchers document that non-Hispanic Black families are more likely than their non-Hispanic White counterparts to report that their patient had unmet needs for pain, dyspnea, and emotional support.¹¹⁷ Another qualitative study that focused solely on non-Hispanic Blacks who are hospice care users reported that while many hospice patients and their family were satisfied with their care, hospice enrollment alone does not ensure a positive experience at the end of life.⁷⁵ Exploring correlates of satisfaction with general inpatient hospice and home hospice cares among bereaved family members of 1,600 patients, Ong and colleagues (2015) revealed that effective communication with family members was strongly associated with greater family satisfaction across hospice care settings.¹⁸⁶ It is not surprising that almost every scholar who focused on palliative and hospice care emphasized good communication with both the patient and the patient's family. Rhodes and colleagues (218) acknowledged that the specialty of palliative care has had a long-standing commitment to teaching medical students and other medical professionals about pain management, communication, supporting patients in their decisions, and providing compassionate end-of-life care, however, they have noted a problem involving some palliative care professionals' attitudes, methods of decision making, and use of language.¹⁸⁷

Impact of education and healthcare literacy on palliative and hospice care among non-Hispanic blacks. Available research clearly reveals that non-Hispanic Blacks are not using hospice care because of cultural issues or knowledge deficits, whether through lack of communication or low literacy.⁸⁵ While it is suggested that health literacy, not race, is an independent predictor of end-of-life preferences,¹⁰⁷ others argue that literacy and race represent 2 separate but important causal pathways that must be carefully assessed to improve how the healthcare system ascertains and protects minority individuals' advance care preferences.⁸⁰ It is well documented that ethnic minorities consistently report low health literacy regarding palliative care, hospice, and advance care planning, which in turn leads to lower levels of engagement in advance care planning and discussions with health care providers.⁶⁸ Conducting a comprehensive examination of published research for overcoming barriers in palliative care for minority populations, Mayeda and Ward (2019) argued that traditional delivery of healthcare services may be insufficient and that urgent interventions are needed to overcome the barriers faced by underserved minority populations when accessing end-of-life services, including completing advance care directives, accepting palliative care, and enrolling in hospice.²⁹

Matsuyama and colleagues (2011) posed the interesting question, "Will patients want hospice or palliative care if they do not know what it is?"⁹⁷ They reasoned that awareness of service availability is a prerequisite to accessing services. Assessing awareness of hospice and palliative care among 133 non-Hispanic Black and White patients at a cancer center, they reported that knowledge of hospice care was much lower

among non-Hispanic Blacks than among Whites, and among those with limited education. They suggested that enhanced awareness of palliative and hospice care is a first step toward decreasing disparities in utilization of appropriate care for cancer patients.⁹⁷ Consistent with these findings, Arenella (2016) argues that many non-Hispanic Blacks with advanced illness are unaware of their options for palliative and hospice care and blames many misconceptions for low levels of hospice enrollment.¹⁸⁸ Similarly, another quantitative study reported that both Hispanic and non-Hispanic Blacks reported low hospice utilization because of lack of awareness of hospice and the prohibitive cost of health care.¹²⁷ Indeed, the Initiative to Improve Palliative and End-of-Life Care in the African American Community that was formed almost 20 years ago, reported that to overcome barriers of palliative and hospice care among non-Hispanic Blacks, development of new culturally appropriate models are needed to educate both non-Hispanic Blacks patients and the health care professionals who serve them.¹²²

Exploring how low health literacy influences decision making at the end of life, Melhado and colleagues (2011) argued that even though non-Hispanic Blacks want better communication with their health care providers, mistrust of the health system may persist, due in part to low health literacy.⁹⁶ Therefore, they suggested, providers should offer culturally relevant counseling regarding palliative and end-of-life care options appropriate to the patient.⁹⁶ Even though established guidelines for developing low-literacy patient education materials are available, poorly designed materials continue to be disseminated. It is strongly suggested that educational materials be revised so that the average adult is able to understand the message presented, thereby improving the ability of patients and their families to make informed end-of-life care decisions.¹⁸⁹ Indeed, most Internet articles seeking to educate the public about palliative care fail to meet national health literacy recommendations and need to be written in a more accessible style if patients and their families are to derive the most benefit.¹⁹⁰ One systematic review documented that a strong body of evidence has emerged supporting the use of video-based educational interventions in hospice and palliative care.¹⁹¹ However, the effectiveness of those videos among non-Hispanic Black populations is not known. There are only a few interventional studies that have been designed to overcome educational barriers for using hospice care or completion of advanced care planning among minority populations.^{107,192,193} There is a strong need to refine end-of-life educational resources to reach minority populations with varying needs.^{6,194}

Completion of Advance Care Planning and Directives

In recent years, advance care planning has evolved as a fundamental component of patient-centered care.¹⁹⁵ Advance care planning is a continual process in which individuals select a surrogate decision maker and document their directives and

preferences for future medical care, and should be based on the patient's values.^{196,197} The completion of an advance directive, a key component of advance care planning, provides written documentation of the patient's wishes concerning medical care when they can no longer make decisions or communicate. Advance care planning conversations frequently occur after the deterioration of a person's health condition or when they have entered the last phase of life.¹⁹⁸ Advance care planning is highlighted as an essential process, due to its focus on patients learning about the prognosis of their diagnosis and planning their care based on their values and beliefs.^{196,197} It is defined as the process in which patients plan future health care choices in consultation with healthcare providers and support individuals.^{199,200} Advance care planning was previously regarded as informal conversations held among family members.⁹⁹ However, this approach is currently undergoing expansion by health care organizations and professional societies, not only in the United States but also in other countries.²⁰¹⁻²⁰³

Healthcare providers now see the importance of initiating advance care planning with patients, especially for those with severe chronic diseases.²⁰⁴ Policies and protocols to facilitate advance care planning communication have been developed and are being increasingly adopted.⁸⁹ The literature indicates that advance care planning discussions should be integrated into various areas of the healthcare system, such as primary and emergency care, preoperative settings, and intensive care units.²⁰⁵⁻²⁰⁷ Providers across the spectrum of medical and mental diagnoses are now being tasked with the responsibility of initiating advance care planning conversations with patients and documenting the progress of these conversations in health records.²⁰⁸⁻²¹⁰

Over the last 3 decades, issues related to advance directive completion for medical care, have been well examined.^{76,113,211-215} A comprehensive review of the literature shows that targeted strategies have been tested and evaluated to promote the completion of advance directives.²¹⁶ Numerous studies have shown that demographic characteristics, social and environmental disparities, such as low educational attainment and financial difficulties, have notable effects on the initiation and completion of advance directives.^{48,56,68,71,78,94,108,185,217-220} A number of studies have also attributed low engagement in advance care planning to health care providers who exhibit negative attitudes, discrimination, and fear toward patients.^{51,88,221,222}

Completion of Advance Care Planning and Directives Among Non-Hispanic Blacks

There is a major difference in the rate of advance directives completed by non-Hispanic Whites compared to racial minority groups, with diverse groups having lower rates of advance directive completion.^{26,32,223} Only a few studies have focused on adult minority populations.^{48,56,68,71,78,94,108,111,185,219,220} Most national and state survey data do not include sufficient information on minority adults and their perspectives regarding end-of-life issues. In particular, population-

based data are lacking regarding minority groups, especially older adults.⁷⁶

Numerous studies have shown that non-Hispanic Blacks are less likely than non-Hispanic Whites to complete an advance directive,^{22,28,63,68,76,77,110,111} but the level of advance directive completion varies from study to study.⁶⁸ The national Health Styles Survey, a mail panel survey designed to be representative of the U.S. population, found that in 2013 only 17% of non-Hispanic Blacks aged 18 years and older had completed an advanced directive, compared to 31% of Whites aged 18 years and older.⁷⁶ The survey of California Adults on Serious Illness and End-of-Life (a 2019 cross-sectional representative survey of California residents) uncovered a similar disparity, but with different rates: in this study, 33% of non-Hispanic Blacks aged 18 years and older claimed that they had written end-of-life wishes, compared to 46% of non-Hispanic Whites aged 18 years and older.

Completion of advance care planning and directives among older non-Hispanic blacks. Even though older adults are more likely to complete an advanced directive than other younger age groups, persistent racial gaps have been reported among older adults.^{48,68,76,91,94,104,120} One survey conducted in a nationally representative sample found that older non-Hispanic Whites are much more likely to have completed an advance directive (44.0%) than older Blacks (24.0%).⁶⁸ Another study conducted among primary care patients aged 65 years and older, reported that 26% of non-Hispanic Blacks and 58% of Whites indicated having a durable power of attorney for healthcare.¹¹⁰ The National Health and Aging Trends Study is a nationally-representative longitudinal survey of Medicare beneficiaries living in the community, including in residential skilled care facilities, and who are 65 years of age and older. Round 2 of this national older adults survey (2012) shows that 23% of non-Hispanic Blacks and 73% of Whites answered “yes” to the question about whether they had written advance care plans.²² Finally, the Health and Retirement Study, a longitudinal survey of older adults sponsored by the National Institute on Aging and conducted by the University of Michigan from 2002 to 2012, found that only 38% of non-Hispanic Blacks had an advance directive, compared with 74% of non-Hispanic Whites.⁴⁸

Completion of advance care planning and directives among non-Hispanic blacks with serious illnesses: Additionally, similar racial gaps have been observed among individuals with serious illnesses, indicating that non-Hispanic Whites with a serious illness are more likely than their non-Hispanic Black counterparts to have an advance directive.^{30,79,117} Despite being more likely to be hospitalized due to advanced cancer with a poor prognosis, non-Hispanic Blacks have very low levels of advance care planning.⁹⁰ Using death certificates of a nationally representative sample of adults with non-traumatic causes of death who had received end-of-life care (whether in a hospital or nursing home, or via home-based medical service), researchers found that 51% of non-Hispanic Blacks and 73% of Whites had

a durable power of attorney or living will.¹¹⁷ Seriously ill African-American older adults report both individual-level and health systems-level barriers to completion of advance directives.¹¹²

Impact of mistrust with providers on completion of advance care planning and directives. 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.^{51,224} A recent systematic review of 40 studies found that unwillingness to participate in advance care planning among adults is related to fear of the advance care planning process and to previous experiences with the health care system.⁶⁶ It is important to understand how specific factors, such as mistrust and discrimination, can impact advance care planning and completion of directives. These conditions may be more common in minority populations, especially for those managing multiple and complex illnesses.^{225,226} This is in line with other studies which have found that racial minorities are less likely than Whites to communicate their end-of-life wishes to their doctors.^{56,68,94} However, minorities 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.^{46,102}

Mistrust and completion of advance directives among non-Hispanic blacks. A recent systematic review documented that medical mistrust acted as a barrier to advance care planning and directives among non-Hispanic Blacks.⁵¹ There is an established body of literature indicating that non-Hispanic Blacks consistently report higher levels of mistrust in the health care system than Whites.^{20,221,224,227,228} Using a faith-based promotion model, 3 out of 4 non-Hispanic Blacks who participated in a study that intended to promote advance care planning, refused to complete advance directives. One of major factors that influenced non-Hispanic Blacks' decisions about completion of an advance directive was mistrust in the health care system.¹¹⁴

Higher levels of mistrust in non-Hispanic Blacks may be partially explained by their position as a minority group in the United States. Centuries of racial inferiority in the United States, have led to poor health outcomes, worse health status, and low quality of care for non-Hispanic Blacks. The African American population has also experienced decades of systemic and institutionalized racism and discrimination, in addition to unethical medical experimentation conducted among these groups. One notable medical experiment, the Tuskegee Study of Untreated Syphilis, federally commissioned for 40 years until 1972, examined the effects of late-stage syphilis among hundreds of non-Hispanic Black men with no disclosure or provision of treatment.²²⁹⁻²³¹ These unethical and discriminatory research practices (e.g., Tuskegee Study) have negatively affected non-Hispanic Blacks, leaving them with long-lasting perceptions of being deceived and exploited by the health care system.²²⁶ These beliefs have undermined the trust of the Black community in the health care system and in health care

providers.²²⁶ In addition, unequal medical treatment and cultural trauma have led to increased mistrust in the Black community.^{232,233}

Medical mistrust is multifaceted.^{69,224} Literature reveals that lower levels of socioeconomic status,²³⁴ poor quality of life,²³⁵ and security about obtaining health care and social support for families²³⁶ are all related to mistrust in the healthcare system. Mistrust regarding advance care planning, in addition to unethical medical historical events, may also be related to lack of awareness of cultural beliefs on the part of healthcare providers.¹²¹ Finally, how providers address the end-of-life and palliative care needs of vulnerable, marginalized, or underserved minority populations may very well be the measure of success in integrating end-of-life care into current health systems.²³⁷ A recent study conducted among HIV positive individuals shows that only 12.5% of non-Hispanic Blacks had an advance care directive.³⁰ Another recent study conducted by Stein and colleagues (2020) revealed that the LGBT patients and their families are more likely than those who are not LGBT to receive discriminatory care from hospice personnel, which leads to delay or avoidance of hospice or palliative care.¹⁰ Stein and Colleagues surveyed 865 hospice and palliative care providers, including social workers, nurses, chaplains, and physicians. The observation that LGBT are more likely to be subject of discriminations comes from providers themselves. As an example, this study revealed that more than 64% of participants (providers) admitted that transgender patients were more likely than non-transgender patients to experience discrimination.¹⁰ Thus, interventions urgently are needed to train and modify the hospice care providers' behaviors. How could we expect that patients and their family trust the health care system when their providers, themselves, admitting discriminatory behaviors, particularly at the end-of-life, when compassionate tender loving physical and emotional care expected at the end-of-life?

Impact of religiosity and frequency of religious services participation on completion of advance care planning and directives. Religiosity involves subjective attitudes and beliefs (spirituality), as well as objective public and private conduct (religious services participation), both of which may influence health behaviors in different ways.²³⁸ Therefore, it is important to examine the potential impact of spirituality and religious services participation on completion of advance directive and planning. Many religious organizations in the United States have issued statements on the topic of end-of-life care.²³⁹ Additionally, most religious leaders hold advance care planning in positive regard.²³⁹ It is true that some religious groups place restrictions on what kinds of treatments can be specified in advance directives, or on who may be designated to resolve treatment dilemmas, but few religious groups outright prohibit their members from using advance care planning.²⁴⁰⁻²⁴² Additionally, one might expect that persons with greater religious participation would be more likely to engage in advance care planning because they would be more informed about the teachings of their religion concerning end-of-life practices. However, this expectation is not supported by empirical studies.⁸⁴ For

example, investigating the association between religiosity and advance directive completion in a nationally representative sample, Hoe and colleague (2020) documented that Protestants and Catholics had significantly lower odds of advance directive completion, compared with those with no religious preferences.²⁴³ Furthermore, this national study found that decedents who reported religion as very important to them had significantly lower odds of advance directive completion than decedents who said religion was not too important.²⁴³ Indeed, many other studies testify that religion directly or indirectly impacts end-of-life planning and decision making, but with mixed results.^{68,244} Mostly, researchers have documented a negative association between religiosity and completion of advance care planning.^{68,72,108,118} Thus, in spite of religious groups not prohibiting the use of advance care planning, people who hold spiritual and religious beliefs seem to be less disposed to engage in advance care planning. It has been speculated that, for those who believe that God determines the time and place of each person's death, completion of an advance directive is viewed as presumptuous.⁶⁰

Religiosity and completion of advance care planning and directives among non-Hispanic blacks. It is well-documented that religion and religious institutions remain an important component of the lives of many African Americans in United States.²⁴⁵ A higher level of religiosity and spirituality has been documented among older non-Hispanic Black adults that is reflected through active congregational involvement.^{63,115} A few studies reported that non-Hispanic Blacks' attitudes with regard to completion of advance directives and planning for end-of-life care vary considerably based on their individual history and religiosity.^{114,115} Analyzing the Health and Retirement Study data that included 1,180 non-Hispanic Blacks and 5,681 Whites, Koss (2018) tested whether disparities in advance care planning between older Whites and African Americans can be explained by differences in religious affiliation, behaviors, or attitudes.⁴⁸ She documented that non-Hispanic White older adults were twice as likely to engage in advance care planning as their non-Hispanic Black counterparts. In addition, she reported that older African Americans were more religious on average than their White counterparts; however, religiosity did not account for race differences in completion of advance directives.⁴⁸ Koss suggests that the relationships between religiosity and advance care planning are quite complex, varying by type of advance care planning, different aspect of spirituality and religiosity, and race.⁴⁸ Consistent with Koss's study, another national study showed that disparities in completion of advance directives between non-Hispanic Whites and Blacks were not explained by religious affiliation.⁶⁸ However, it seems that the main force that connects religiosity to completion of advance directives is this belief that God determines the place and time of death. This belief is much stronger among non-Hispanic Blacks than Whites. This is consistent with another study which found that the racial difference in the odds of engaging in advance care discussion for non-Hispanic Whites vs. Blacks was no longer statistically

significant after controlling for the belief that God determines the timing of one's death.⁹⁹

Regardless, additional religious-based interventions are needed to assess how various religious beliefs impact non-Hispanic Blacks' openness to advance care planning. Any intervention must address at least 2 main issues, and each one needs to be addressed differently. Those who believe that God has determined the timing of one's death and say we should not be presumptuous by making our own plans about end of life should be educated that advance care planning is not the attempt to determine the timing of one's death but is simply trying to make medical decisions ahead of time, with the patient's involvement while they are still capable of it. These medical decisions will need to be made anyway in the future by someone when the patient is no longer unable to, so why not make them now or at least designate the person you want to have the power of attorney to make those decisions on your behalf in accordance with your personal values. That is very different from trying to presumptuously "play God" and decide the time of one's death.

A similar approach and intervention may be used for those heavily involved in the pro-life movement and believe that we should never let serious illness take its natural course but should make every effort to preserve and extend life, including end-of-life care such as feeding tubes for those who are unconscious and unlikely to regain consciousness. Those who hold this view would be more likely to be convinced of the need for advance care planning, since they obviously have strong convictions about this issue and they would not want others making what they might think is a sinful decision for them (e.g., taking the feeding tube out and letting them die). For example, the infamous Schindler v. Schiavo case, controversial court cases where the husband and parents of Teresa Schiavo were on opposite sides of that decision and had to go to court to fight it out.²⁴⁶ For the 15 years after a cardiac-arrest, a surgically-implanted tube that provided artificial nutrition and hydration kept Teresa's body alive.²⁴⁶ If she had had an advance care directive that court-battle could have been avoided.^{247,248} However, it is well-established that some non-Hispanic Blacks are suspicious of the medical establishment and so are fearful of making an advance directive.¹¹¹ After all, education on what advance care planning is could help alleviate those fears and actually encourage them that it would be in their best interests if they have strong religious convictions on this point.

Frequency of service attendance and completion of advance directives among non-Hispanic blacks. Two recent studies documented a positive correlation between completion of advance directives and *religious organizational activities*.⁴⁸ A Nebraska-based random sample of adults showed that participants who attended religious and spiritual services regularly were more likely to have heard about advance care planning or completed an advance care directive.⁸² Similarly, the Health and Retirement Study shows that while religiosity did not account for race differences in completion of advance directives, frequency of service attendance was positively associated

with completion of advance care directives, among both non-Hispanic White and Black older adults.⁴⁸ However, another national survey documented no relationship between frequency of religious service attendance and completion of an advance directive.⁶⁸

It is suggested that participation in religious activities may bring parishioners into contact with friendly health care professionals, attorneys, or others knowledgeable about advance care planning and these individuals may be more receptive to end-of-life planning because of their shared religious beliefs.⁸² Indeed, a cross sectional study with a large convenience sample of older parishioners showed that the vast majority of non-Hispanic Blacks would welcome a church-based program focused on improving end-of-life care planning.⁷⁰ Finally, many studies have shown that minority groups desire initiatives that are sensitive to their religious values and cultural assumptions.^{26,63,71,78,92,121,219} Such initiatives deployed in faith-based settings would likely increase minority participation in end-of-life and advance care planning.^{249,250}

The finding that frequency of religious service attendance is positively associated with completion of an advance directive is exciting news for advocates promoting advance care planning in non-Hispanic Black communities. In order to promote advance directives among non-Hispanic Black communities, multifaceted church-based investigational interventions are needed that include 1) minority health care providers, 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 multifaceted design must use appropriate theoretical models and provide culturally appropriate education, modify attitudes toward advance care planning, provide skills and resources for communicating with health care providers and family members, and again last but not least, address the barriers (mistrust and discrimination) to advance directive completion among African Americans.

Children and family and end-of-life advance care planning among non-Hispanic blacks. Comprehensive literature reviews show that older non-Hispanic Black adults prefer to avoid end-of-life planning conversations with their children and family to protect them from distressing conversations.¹¹⁹ Qualitative studies among non-Hispanic Blacks showed that those who did not complete advance care planning claimed that they trusted their families to make the medical decisions and they felt certain that their families knew what end-of-life treatments they wanted, even though they never discussed their end-of-life preferences with family members.¹⁰⁹ Yet some of those who expressed a preference for end-of-life decisions to be made by their family, admitted that their children/family may not make decisions reflecting their own preferences. Therefore, innovative interventional studies are needed to educate, motivate, and provide skills and resources for children to initiate and engage in end-of-life care planning with both their parents and their parents' providers.¹⁵

Non-Hispanic black caregivers' burden. It is also important to note that the National Study of Caregiving shows that non-Hispanic Black caregivers experience higher levels of overall caregiving intensity, performed a higher number of instrumental activities of daily living, and spent a higher number of hours per month on caregiving than non-Hispanic Whites.²⁵¹ Another study documented that Non-Hispanic Black caregivers spent an average of 28.5 more hours/month on caregiving than their non-Hispanic White counterparts, which also highlights the need to understand the complexity of developing effective policies to reduce disparities and improve caregiver quality-of-life.²⁵² One meta-analysis documented that family caregivers experience a "life transition" whereby their lives are permanently altered.²⁵³ Pickard and colleagues (2018) show that to cope with the strain these responsibilities many non-Hispanic Black caregivers seek support and comfort from their faith traditions.²⁵⁴

Finally, a systematic review that was designed to evaluate end-of-life management by family caregivers identified several important issues needing urgent interventional response: inadequate knowledge and assessment skills in pain management, misunderstanding of pain medications, and poor communication with providers.²⁵⁵ Multi-faceted, educational, resourceful, culturally-sensitive interventions are urgently needed to support family caregivers to help them overcome disruptions that may eventually impact the caregivers' ability to transition and maintain their role as caregivers.²⁵³ Dionne-Odom and colleagues (2020) suggest early telehealth-base interventions targeting distressed caregivers and assessing caregiver effects on patient outcomes.²⁵⁶ They proposed an early longitudinal 6-week phone intervention that includes all aspects of palliative care and self-care.²⁵⁶ While implementation of telehealth-based interventions for underserved and rural non-Hispanic Black communities are strongly encouraged, the acceptability, feasibility, and effectiveness of these programs need to be carefully tested.³⁶

Impact of communication with providers on completion of advance care planning and directives. Cross-cultural studies identify communication and the flow of information, perceptions of hospice and palliative care, and compatibility with cultural beliefs as major barriers that profoundly impact end-of-life care services.⁵ Numerous studies, including recent systematic reviews, show that non-Hispanic Black patients consistently experience poorer communication quality, information-giving, patient participation, and participatory decision-making than their White counterparts.²⁵⁷ Community-based studies reveal that racial and ethnic minorities are less likely than Whites to communicate their advance care preferences to their healthcare providers.^{56,94} Additionally, systematic review of literature shows that interventions promoting effective communication about advance care planning improved concordance between preferences for care and delivered care.²¹² Andrea and colleagues (2016) suggest that excessive (compared to Whites) mortality of non-Hispanic Black patients in the intensive care unit undergoing life-sustaining treatment is associated with differences in patient- and/or surrogate-provider communication.⁷³

Even though non-Hispanic Blacks are less likely than their White counterparts to have advance directives, they nonetheless desire communication, information, respect, and a trusting doctor-patient relationship.⁹⁶ In order to develop effective interventions promoting completion of advance care directives among ethnic/racial minority adults, additional research is needed to carefully address factors related to the communication between providers and non-Hispanic Blacks. In addition to mistrust, researchers have posited that there are multiple barriers to effective advance care planning communication with providers, which can profoundly impact the quality of life not only of patients themselves but also of their family/caregivers.²⁵⁸

In addition, adults who considered advance care decision-making important, desired their healthcare provider to initiate this conversation during their visits.²⁵⁹ This may lead to a disconnect between patients and providers. Many healthcare providers may be reluctant to initiate discussions on advance care plan decision-making.²⁵⁹⁻²⁶² Furthermore, adults managing diverse disease trajectories may receive care in multiple settings, leading to potentially fragmented advance care planning processes.²⁶³ These advance care planning discussions should be continuously adjusted based on the disease trajectory, with oversight by healthcare providers, prompting further study of adults engaging in these talks with providers.²⁶⁴

Discussions about end-of-life values, beliefs and standards are essential for the completion of advance care planning and directives.²⁶⁵⁻²⁶⁷ Advance care planning and end-of-life discussions between health care providers and family members are essential and can contribute to patients experiencing a more peaceful death.²⁶⁸ Community-based non-traditional innovative interventions to educate and motivate non-Hispanic Blacks to complete advance directives are needed.²⁵ Van Scoy and colleagues (2020) evaluated an hour video-based low-cost end-of-life conversation game to motivate non-Hispanic Blacks to complete advance care planning.²⁶⁹ Game events were held in 53 community venues across the United States. During this intervention participants played a conversation game that prompted players to answer and discuss 20 questions about death, dying, and end-of-life care. This study claimed that 41% of non-Hispanic Black participants completed a new advance directive. Quantitative assessment of this game-based conversation intervention showed that the game was useful, provided new information and perspective, was emotionally beneficial, and empowered and motivated them to perform advance care planning.²⁶⁹

Future research should encourage new approaches leading to more systematic implementation of advance care planning. Tools to increase integration of advance care planning decisions into care should be explored, especially those that are technologically based. Studies examining advance care planning may test its effectiveness by including professionals besides physicians, such as nurses and social workers, who may enhance content delivery and patient preparation. Models that utilize collaborative approaches may increase awareness of the advantages of advance care planning within various healthcare

disciplines.²⁷⁰ In addition, community-based participatory research methods are particularly promising, since they involve community stakeholders and organizations in designing and mobilizing strategies targeted at changing perceptions of advance care planning. Providing advance care planning knowledge in non-clinical areas can lead to greater education around advance care planning and its benefits for families and communities.

Providers should implement methods to initiate advance care planning discussions and improve their communication skills with patients, especially underserved groups.²⁷¹ Healthcare providers may find it difficult to discuss advance care planning topics with patients across the life cycle, such as health care proxy designation, goals of care, or conversations about serious illness and its potential negative outcomes. This reluctance to broach the topic of advance care planning with individuals across the life span may have to be integrated in the curriculum of their educational training, such as medical school.⁶⁰ Training in advance care planning should occur across multiple health care disciplines. Utilizing tactics to build relationships and rapport with patients can facilitate advance care planning discussions with health practitioners and allied health providers. Indeed, within the United States, there is no national formalized standard for best practices in advance care planning. There is an urgent need for more advance care planning given projections of future gaps in palliative care delivery.¹⁹⁷ System level changes within healthcare will need to occur to ensure effective advance care planning implementation.

Impact of health care coverage on completion of advance care planning and directives. Evidence shows that enabling characteristics, including income level and health care coverage status, are contributing factors to decreased engagement in advance care planning and directives.^{33,65,67,67,272,273} The Nevada Behavior Risk Factor Surveillance System (BRFSS), a state-wide cross-sectional survey of 4,461 adults, discovered that health insurance is the third strongest predictor of completion of advance care directives, following age and education level.²⁷⁴ Furthermore, minorities and individuals with low socioeconomic statuses are less likely to have completed advance care planning and directives.³⁴ Specifically, the Black-White gap in advance care planning is evident for low SES populations.⁹⁴

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 2016.²⁷⁵ The CMS utilizes 2 current procedural terminology (CPT) reimbursement codes (99497 and 99498) for these discussions. The CPT code 99497 is used for the initial 30 minutes 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 advanced care planning. The patient has no out-of-pocket responsibility for advance care planning that normally occurs during their Medicare annual wellness visit.²⁷⁵ 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.²⁷⁶

Many adults may not be participating in advanced care planning discussions with their healthcare provider. In a retrospective study, Ashana and colleagues (2019) examined a database of commercial and Medicare Advantage claims for 13.7 million members belonging to a large commercial health insurer in the United States.⁴³ Their findings showed only 1.6% of Medicare beneficiaries had a billed advance care planning encounter in the first year of approved CPT codes for advanced care planning in 2016.⁴³ Belanger and colleagues (2019) conducted a similar study comparing national claims for older Medicare beneficiaries and uncovered that only 1.9% had an advance care planning visit in 2016, compared to 2.2% during the first 3 quarters of 2017.²⁷⁷ Despite this increase in advance care planning claims nationally, the authors report that the overall claim and reimbursement rate remains extremely low, particularly among non-Hispanic Blacks.²⁷⁷ Another recent study that examined 26,522 advance care planning claims in the northeastern United States revealed that being non-Hispanic Black was associated with lower odds of having an advance care planning claim.²⁷²

These studies support existing literature that posit healthcare providers, particularly physicians, lack the time, skill, and education required to engage in advance care planning.^{43,277,278} Therefore, financial incentives may not be sufficient to increase their engagement of advance care planning and directives with patients. Pelland and colleagues (2020) recommend implementing opportunities that will promote advance care planning uptake among physicians caring for minority beneficiaries during annual wellness visits and ensuring that it will be no-cost for patients.²⁷²

Moreover, the impact of advance care planning discussion reimbursement is limited to Medicare beneficiaries and other payers that have adopted Medicare billing and payment rules (such as California's Medicaid program),²⁷⁸ which may lead to health disparities for persons with no or other non-reimbursing insurance.^{271,279} Therefore, policy makers should increase this benefit to those with non-Medicare and other non-payers insurance and the uninsured. Additionally, advance care planning options should be included in healthcare packages and insurance plans provided by various organizations and companies, which may be able to function as a bridge and increase engagement between healthcare providers and those who are insured.²⁶² Furthermore, health care practitioners who are currently reimbursed for advance care planning with Medicare patients should expand this service with all patients, regardless of insurance status. Expanding access to additional incentives, resources, and tools that support health care professionals and empower patients to initiate advance care discussions are critically needed.²⁷

Table I. Studies Conducted Between 2015 and 2020 on Advance Healthcare Planning and Directives, Palliative and Hospice Care That Exclusively Focused on or Included African Americans.

Author(s) and year published	Sample size and participants	Research design	Types of disparities addressed and results
Yang, A., et al. (2020). ⁴	349 advanced colorectal cancer patients	Retrospective study of cancer registry and linked Medicaid data	No significant differences in hospice enrollment were observed by race or ethnicity. Non-Hispanic Black patients were more likely to receive aggressive End-of-Life (EOL) care.
Stephens, S. J., et al. (2020). ⁹	101,963 head and neck cancer patients	Retrospective study of death certificates	African Americans and Asian/Pacific Islanders were less likely to die at home or hospice.
Stein, G. L., et al. (2020). ¹⁰	865 hospice and palliative care providers	Cross-sectional study	Lesbian, Gay, Bisexual, and Transgender (LGBT) patients and their families are more likely to receive discriminatory care than those who are not LGBT.
Paredes, A. Z., et al. (2020). ¹¹	6,859 Medicare beneficiaries dying from pancreatic cancer	Retrospective study of Medicare claims	On multivariable analysis, after controlling for clinical factors, racial/ethnic minority patients remained 22% less likely than Whites to initiate hospice services prior to death.
Lundy, T. L. (2020). ⁸	Eleven family caregivers	Phenomenological study conducted at urban areas of NYC	Decision making among family caregivers of Black older adults with advanced chronic illnesses evolved around 4 themes: 1) living out commitments with intention; 2) making meaningful decisions situated in context; and 3) reflecting on the past, anticipating the future. Confusion about what constitutes palliative care versus hospice was also shown to be a barrier to the understanding and uptake of palliative care.
Lee, K., et al. (2020). ⁷	204,175 hospital admissions of patients with advanced cancers between 2012 and 2014	Retrospective cohort study conducted at health care facility	In multivariable logistic regression models, Black patients discharged from the hospital, were significantly less likely to receive a palliative care consult compared to White patients.
Johnson, T., et al. (2020). ⁶	5,613 patients who were discharged to hospice or died during their hospital stay between 2012 and 2014	Retrospective, cross-sectional study conducted at 4 urban hospitals with an inpatient palliative care service	After controlling for hospital site, rates of inpatient palliative care consultations between African American and White patients were similar, demonstrating significant between-hospital variation. Hispanic patients were more likely to be discharged to hospice than White or African American patients.
Herbstsomer, R. A. and S. T. Stahl (2020). ⁵	Eighteen published manuscripts	A thematic analysis of individual and family experiences of either palliative care or hospice services	Major themes identified include the following: communication and the flow of information, perceptions of hospice and palliative care, and compatibility with cultural beliefs. The findings emphasized the importance of a cross-cultural approach in a palliative care and hospice setting.
Flieger, S. P., et al. (2020). ¹⁷	2,594 US adults, of which 683 reported knowing about palliative care (data from 2018)	Cross-sectional analysis of National Health Information Trends Survey	Most US adults report that they are not aware of palliative care, and those that report having some knowledge still have misconceptions. Multivariate analysis detected no significant between knowledge and race/ethnicity.
De Souza, J., et al. (2020). ¹⁵	13 studies between 2005 and 2019	Meta-ethnography of conversations between ethnic minority elders and family about end-of-life care	Elders of Black and minority ethnic heritage avoid end-of-life planning conversations with their children to protect them from distressing conversations. Adult children block attempts by their parents to have end-of-life conversations with them. Elders of Black and minority ethnic heritage express a preference for end-of-life decisions to be made by family proxies acknowledging that these decisions may not reflect their own preferences.
Di Luca, D. G., et al. (2020). ¹⁴	397,963 patients with Parkinson's Disease from 2007 to 2014	Retrospective study of National Inpatient Sample data	There has been a significant increase in palliative care referrals among hospitalized patients with Parkinson's Disease from 2007 to 2014 in the US, although the overall rate remains low. After controlling for confounders, racial and ethnic disparities were not found.

(continued)

Table 1. (continued)

Author(s) and year published	Sample size and participants	Research design	Types of disparities addressed and results
Bazargan, M., et al. (2020). ¹⁵⁰	773 non-Hispanic Blacks and non-Hispanic Whites 55 years of age and older	Cross-sectional study using survey of California adults on serious illness and end-of-life	Non-Hispanic Blacks reported more EOL non-decision-based desires and wishes than non-Hispanic Whites. 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 to their White counterparts.
Wen, Y., et al. (2019) ¹³	76,659 hospitalizations that involved palliative care from 2006 to 2014	Retrospective cohort study using National Inpatient Sample	Black and Hispanic patients were significantly less likely than White patients to receive palliative care services. These disparities spanned all hospital subtypes, including those with higher proportions of minorities. Minority patients with lower socioeconomic status (lower level of income and non-private health insurance) were also less likely to receive palliative care.
Warraich, H. J., et al. (2019) ¹²	150 patients enrolled in palliative care in Heart Failure trial	Prospective non-blinded clinical trial	After adjusting for the study arm, African American race compared to White race was the only factor associated with an increased likelihood of dying in a health care facility. Authors suggested that the high proportion of African American patients dying in health care facilities may be due to care preference rather than access to palliative care.
Wang, S.-Y., et al. (2019). ¹⁶	649,477 who died between July 2011 and December 2015	Retrospective cohort study of Medicare beneficiaries	The mean number of care transitions within the last 6 months of life was 2.9 transitions (SD = 2.7) for Whites and 3.4 transitions (SD = 3.2) for African Americans. After adjusting for age and sex, having at least 4 transitions was significantly more common for African Americans than for Whites.
Van Scoy, L., et al. (2019). ²⁵	387 African Americans	Non-randomized interventional study of African American communities from 15 States	Community-based delivery approach may be an effective means of promoting ACP engagement behaviors among African Americans.
Turkman, Y. E., et al. (2019). ²⁴	12,725 cancer decedents between 2012 and 2015	Retrospective cohort study of Medicare beneficiaries	"No hospice" was associated with non-White and non-navigated patients, and those at a hospital with inpatient palliative care beds. "Late hospice" was associated with being male and seen at a hospital without inpatient palliative care beds.
Tella, S. H., et al. (2019). ²³	29,296 patients who died between 2004 and 2015	Retrospective study of patients with metastatic renal cell carcinoma reported to The National Cancer Database	On cox multivariate analysis, among patients that survived <6 months, receipt of palliative care was associated with better overall survival. Patients who received palliative care were more likely to be of White race, non-Hispanic origin, treated at a non-academic facility, and be more educated.
Sullivan, S. S. and K. J. Klingman (2019). ²²	1,993 subjects from 2012	Cross-sectional study of National Health and Aging Trends Study	African Americans had lower rates of written advance care planning than Whites. Only 8% of Whites and 11% of African Americans preferred to make decisions about end-of-life care options without medical advice from their providers.
Starr, L. T., et al. (2019). ²¹	Between January 2012 and January 2019	Systematic Review of 12 quantitative studies	Some studies found evidence that racial minorities were less likely than Whites to have EOL discussions with their health-care providers.
Sanders, J. J., et al. (2019). ²⁰	5 health disparities experts; 9 community members, and 11 seriously ill African American patients and their caregivers	Qualitative study	Expert participants reinforced common themes from the literature, for example, that African Americans were not interested in prognostic information because of mistrust and religion. However, seriously ill patients were more likely to express trust in their clinicians and to desire prognostic communication; they and community members expressed a desire to prepare for and control the end of life. Religious belief did not appear to negate these desires.

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Author(s) and year published	Sample size and participants	Research design	Types of disparities addressed and results
Rhodes, R. L., et al. (2019). ¹⁹	22 African American cancer patients	Qualitative study	Despite being hospitalized with advanced cancer and having poor prognosis, intent to discuss ACP options, palliative care, and hospice in this population was variable, and completion of these activities was low.
Paul, S., et al. (2019). ¹⁸	45,519 patients between 2004 and 2013	Cross-sectional study of the National Cancer Database	Non-Hispanic Blacks race were associated with less receipt of palliative care compared to non-Hispanic White patients
Orlovic, M., et al. (2019). ²⁶	6,471 patients who died between 2002 and 2014	Exit interviews with family members from the Health and Retirement Study	This study reveals significant disparities in end-of-life care and planning among studied groups. Findings reveal that racial and ethnic minorities are more likely to die in hospital and less likely to engage in end-of-life planning activities. The observed disparities are still significant but have been narrowing between 2002 and 2014.
Mehta, A. and A. S. Kelley (2019). ²⁷	26,522 ACP claims billed by 1,996 health care professionals during 2016	Retrospective observational analysis of Medicare's Advance Care Planning Billing Codes in New England.	In the fully adjusted model being Black was associated with lower odds of having a claim for an advance care planning conversation with a provider.
McAfee, C. A., et al. (2019). ²⁸	386 adults between 40 and 80 years of age (with oversampled African American and Hispanic races or ethnicities)	Randomized, observational, non-experimental, cross-sectional study of noninstitutionalized US adults	Significant differences were found by race or ethnicity: 33% of Whites had completed ACP versus 18% of Hispanics and 8% of Blacks.
Mayeda, D. P. and K. T. Ward (2019). ²⁹	Nine published interventional studies	Systematic review	Traditional healthcare service delivery may be insufficient to increase enrollment of ethnic/racial minorities in palliative care. The study reviewed 3 main avenues for overcoming barriers to minority enrollment in palliative care: (1) enhancing patient education, (2) increasing access to healthcare, and (3) improving communication to establish better rapport with the target population. Outcomes can be improved by implementing tailored interventions to overcome barriers.
Lyon, M. E., et al. (2019). ³⁰	233 adults patients living with HIV and their surrogate decision-makers	Longitudinal randomized trial using 5 hospital-based outpatient HIV clinics in Washington, DC.	A family-centered advance care planning intervention significantly improved ACP completion and advance directive documentation in the medical records among both African-American and non-African-American adults living with HIV.
Laury, E. R., et al. (2019). ³¹	9 quantitative published manuscripts between 1975 and 2016	Scoping review	Distrust has been cited as a central reason for African Americans' tendency to choose life-sustaining treatments over comfort-focused care. However, this scoping review did not support this hypothesis. The majority of studies found no significant differences in trust between African Americans and their White counterparts.
Kirkpatrick, H. (2019). ³²	11 manuscripts published between 2015 and 2019	Literature review	There is a discrepancy in the rate of advanced directives completed by Caucasian groups versus ethnically and racially diverse groups, with diverse groups having a lower rate of advance directive completion. There is little research on ACP interventions in ethnically and racially diverse populations, but the available studies do demonstrate improved ACP engagement and documentation.
Kang, J. H., et al. (2019). ³³	60,9217 community-dwelling older female nurses (between 2012 and 2014)	Retrospective study of community-dwelling female nurses living across the US.	In this population of educated health professionals, race was a strong factor associated with a lower likelihood of having ACP documentation and discussion, indicating that there are likely many substantial barriers to ACP among racial minorities.

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Author(s) and year published	Sample size and participants	Research design	Types of disparities addressed and results
Jones, L. (2019). ³⁴	20 research manuscripts published between 2013 and 2018 (adult oncology patients)	Literature review	Common themes from the literature review are patient-specific barriers, provider-specific barriers, and general communication barriers between patients and providers. Minorities and those with low socioeconomic status are less likely to have completed advance directives.
Johnson, J., et al. (2019). ³⁵	Four Baptist churches and a consortium of 3 African Methodist Episcopal churches in urban area of Philadelphia	Longitudinal interventional study of faith-based organizations	This study demonstrated the feasibility of engaging the African American church in a comprehensive, multilevel process designed to improve communication about palliative care and hospice.
Hendricks, B. A., et al. (2019). ³⁶	60 caregivers and 60 African-American patients with advanced cancer	Single-site randomized trial at the Comprehensive Cancer Center of University of Alabama (Birmingham)	This is an on-going study assessing the acceptability, feasibility, and preliminary efficacy of a lay navigator-led early palliative care coaching intervention to support underserved family caregivers of both African-Americans and rural-dwelling persons with newly-diagnosed advanced cancer.
Gramling, R., et al. (2019). ³⁷	230 hospitalized patients with advanced cancer who consulted with palliative care providers between 2013 and 2016	Cohort study at 2 large academic medical centers in the Northeast and West Coast of the US.	This study evaluated the accuracy of clinicians' survival prognoses of cancer patients in palliative care. The clinicians were substantially more likely to overestimate survival for patients who identified as Black or Latino compared to others.
Ejem, D. B., et al. (2019). ³⁸	800 older adults with serious illnesses (half African American and half White)	Longitudinal, multisite, cluster randomized trial at 10 primary care clinics in the South	This study identified several opportunities to improve ACP for African Americans within the context of existing interventions, including (1) a greater emphasis on the importance of ACP conversations with surrogates and providers even if patients do not complete legal documents; (2) flexibility in approaches to ACP based on individual preferences; (3) and the use of peer-to-peer interactions with lay ACP interventionists to build trust, increase ACP knowledge, and facilitate ACP.
Cruz-Flores, S., et al. (2019). ³⁹	710,293 hospitalized patients between 2006 and 2014	Retrospective study using the United States Nationwide Inpatient Sample	Minorities had greater utilization of lifesaving and life sustaining procedures, and longer lengths of stay. Whites had greater utilization of palliative care, hospice, and higher in-hospital mortality. These results may reflect differences in culture or access to care.
Cole, A. P., et al. (2019). ⁴⁰	601,680 individuals with metastatic prostate, lung, colon, and breast cancer in the United States between 2004 and 2015	Retrospective study of the US cancer registry combining data on patients seen at any of 1,500 Commission on Cancer-accredited institutions in the United States	This study suggests that the site of care is associated with race/ethnicity-based differences in palliative care. Treatment at a minority-serving hospital had a statistically significant association with lower odds of receiving palliative care compared with treatment at a non-minority-serving hospital; patient race/ethnicity did not.
Cicoello, K. and G. Anandarajah (2019). ⁴¹	22 individuals including physicians (5), administrators (3), chaplains (2), nurses or certified nursing assistants (6), social workers (3) and patient caregivers	Qualitative study of multiple stakeholders in hospice care for diverse communities in Rhode Island	Five themes emerged regarding barriers to hospice enrollment: 1) universal challenges of goals-of-care conversations; 2) cultural norms and beliefs; 3) language barriers; 4) provider-specific challenges; and 5) trust. In minority populations, the central theme of "challenges of goals-of-care conversations" was intensified by the other 4 themes.
Bone, A. E., et al. (2019). ⁴²	21 studies with 1,565,187 patients	Systematic review	Receiving palliative or hospice care is associated with lower emergency department attendance in the last year of life for older adults. This study found that male gender and black or minority ethnicity increased the likelihood of attending the emergency department towards the end of life.

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Author(s) and year published	Sample size and participants	Research design	Types of disparities addressed and results
Ashana, D. C., et al. (2019). ⁴³	1,113,077 visits by older Medicare beneficiaries between 2016 and 2017.	Retrospective observational analysis of the Medicare Physician/Supplier Part B claims	In adjusted analyses, non-White race and ethnicity were associated with ACP code use.
Shreenivas, A. V. (2018). ⁴⁴	61 patients diagnosed with advanced lung cancer	Prospective cohort study	Minority patients with advanced lung cancer are more likely to prefer palliative care than hospice care and hold many false beliefs about hospice.
Rizzuto, J. and M. D. Aldridge (2018). ⁴⁵	Medicare beneficiaries (N=145,038) enrolled in a national random sample of hospices (N = 577) (2009–2010).	Longitudinal cohort study using the National Hospice Survey (followed until death)	Blacks were at higher risk for hospital admission, ED visits, and hospice disenrollment. Racial differences in intensity of care at the end of life are not attributable to hospice-level variation in intensity of care. Differences in patterns of care between Black and White hospice enrollees persist within the same hospice.
Noh, H., et al. (2018). ⁴⁶	1,044 community-dwelling older adults in Alabama.	Cross-sectional study of data from a statewide survey	Black older adults were less likely to know about or document advance care planning and to have accurate knowledge of hospice care; however, despite their poorer perceived health, Black older adults reported fewer EOL concerns. Higher levels of perceived health and social and physical activities were associated with knowledge about advance care planning among White older adults but not among Black older adults.
Mohammed, K. A., et al. (2018). ⁴⁷	7,789 patients with multiple myeloma who died in the hospital between 2008 and 2014	Population-based cross-sectional study of the Nationwide Inpatient Sample	Over the last decade, there has been an increasing trend in palliative care utilization. This study highlights disparities across race/ethnicity, insurance status, geographic region, and other hospital level factors in palliative care use in terminally ill patients with multiple myeloma.
Koss, C. S. and T. A. Baker (2018). ⁴⁸	6,861 older adults	Cross sectional study of the Health and Retirement Study	White participants were twice as likely to engage in ACP. Including religiosity predictors did not close this gap. Frequency of service attendance was positively associated with AD completion for both White and African American participants. Relationships between religious affiliation and advance care discussion varied by race. For White participants only, more frequent prayer was associated with higher odds of advance care discussion.
Kirtane, K., et al. (2018). ⁴⁹	The last 30 days of life of 9,468 patients with or without hematologic malignancies (2010–2015)	Retrospective cohort study using University of Washington electronic health records and death certificates	Racial/ethnic minority patients with hematologic malignancies have higher utilization of care at the end-of-life and lower rates of advance directives compared with patients with non-hematologic malignancies.
Karanth, S., et al. (2018). ⁵⁰	154,498 older patients with non-small cell lung cancer and 27,834 with small cell lung cancer who died between 1991 and 2013	Retrospective cohort study of the Surveillance Epidemiology and End Result (SEER) program	The study found considerable racial-ethnic disparities in end-of-life care quality. Racial-ethnic minorities had higher odds of experiencing potentially preventable medical encounters in the last month of life compared with non-Hispanic Whites. Odds of delayed hospice referral and aggressive chemotherapy provision during end-of-life were lower in non-Hispanic blacks compared with non-Hispanic Whites.
Hong, M., et al. (2018). ⁵¹	26 studies published from 2006 to 2016	Systematic review	Four categories of facilitators and barriers to ACP were identified: (1) Socio-demographic factors, (2) health status, literacy and experiences, (3) cultural values, and (4) spirituality. Socio-demographic factors showed inconsistent findings regarding their association with ACP engagement. Worse health status and knowledge about ACP are common facilitators across ethnic minority groups, whereas mistrust toward the health care system was a barrier only for Blacks. Collectivistic cultural values influenced ACP engagement among Latinos and Asian Americans; however, spirituality/religion played an important role among Blacks.

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Author(s) and year published	Sample size and participants	Research design	Types of disparities addressed and results
Hoerger, M., et al. (2018). ⁵²	619,387 adults of the Statewide personality differences and combined 4 state-level data and the National Capitol.	Cross-sectional study of the state-level data for 50 U.S. states and the National Capitol	Access to palliative care was worse in states that were younger, more racially diverse, lower in socioeconomic status, more politically conservative, and lower in openness. In regression analyses that simultaneously accounted for all predictors and covariates, only lower openness continued to explain worse state-level access to palliative care. Palliative care access is worse in states where people are lower in openness, meaning residents who are more skeptical and traditional.
Blue, B., et al. (2018). ⁵³	245 cancer inpatient palliative care between January 1, 2014, to December 31, 2014	Retrospective study	Almost 16% of terminally ill cancer patients with inpatient palliative care consultations died in the hospital, the majority of whom died in the ICU. This was likely due to delays in the initiation of outpatient palliative care consultation, leading to an increased strain on tertiary referral centers. This study highlights a racial disparity in the rate of inpatient palliative care consultations in African Americans, compared to historical data.
Cervantez, S. R., et al. (2018). ⁵⁴	604 cancer patients	Prospective study of 5 South Texas NCI-designated safety net cancer centers	This study highlights disparities in access to services based on insurance coverage. The study found that the time to first scheduled palliative care visit was 4 times greater for under-insured patients than for insured patients.
Chino, F., et al. (2018). ⁵⁵	9,646,498 cancer deaths between 1999 and 2015	Retrospective study of the National Center for Health Statistics	From 1999 to 2015, hospital cancer deaths decreased by approximately one-third with commensurate increases in home and hospice facility deaths. On multivariate logistic regression, Black race was found to be associated with place of death. For Black patients, the likelihood of a hospital death increased from 1.29 times to 1.42 times that of White patients in 2015. Many sociodemographic groups experience significant disparities with regard to place of death.
Clark, M. A., et al. (2018). ⁵⁶	1,851 adults 18 years or older	Cross sectional random-digit telephone survey of adults	Racial and ethnic minorities were less likely than non-Hispanic Whites to report having designated an agent or having had conversations with someone other than a healthcare provider about their end-of-life wishes. Racial and ethnic minorities may be disadvantaged in the quality of care they receive if they have a serious illness and are unable to make decisions for themselves because most have not talked to anyone about their goals, values, or preferences for care.
Foley, R. N., et al. (2018). ⁵⁷	1,098,384 patients on dialysis dying between 2000 and 2014	Retrospective national study using United States Renal Data System files	Individual minority groups (non-Hispanic Asian, non-Hispanic Black, non-Hispanic Native American, and Hispanic) were significantly less likely than non-Hispanic Whites to experience the composite of discontinuation of dialysis and death in a nonhospital or hospice setting. There appear to be substantial race- and ethnicity-based disparities in end-of-life care practices for United States patients receiving dialysis.
Gardner, D. S., et al. (2018). ⁵⁸	22 empirical studies addressing race/ethnicity and palliative care published between 2000 and 2018	Systematic review	Social-environmental barriers and disparities distinctly affect access to palliative care for minority populations
Haines, K. L., et al. (2018).	2,966,444 trauma patients ≥ 15 years old from 2012 to 2015	Retrospective study using the National Trauma Databank	Race and ethnicity are independent predictors of a trauma patient's transition to hospice care and significantly affect length of stay. This data demonstrated that prominent racial and socioeconomic disparities exist, with uninsured and minority patients being less likely to receive hospice services and having a delay in transition to hospice care when compared to their insured Caucasian counterparts.

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Author(s) and year published	Sample size and participants	Research design	Types of disparities addressed and results
Smith, L. N., et al. (2018). ¹⁴⁸	979 patients who had colorectal, lung, and breast cancer in a safety-net hospital in 2010	Retrospective study	This study revealed that inpatient palliative care consultation orders were not associated with race and ethnicity among a cohort of patients among patients with breast, lung, and colorectal cancer hospitalized in a safety-net hospital.
Townsend, A., et al. (2017). ⁶¹	34 members of 2 African American churches	Qualitative study (6 focus groups)	Lack of knowledge about hospice services and spiritual beliefs emerged as the top 2 contributing factors for underutilization of hospice services. Study findings support partnerships between hospices and African American churches to provide hospice education to the African American community.
Rhodes, R. L., et al. (2017). ⁶⁰	17 African American physicians, nurses, chaplains, caregivers, and patients in palliative care	Qualitative interviews and focus groups conducted at UT Southwestern Medical Center	Participants felt that advance care planning, palliative care, and hospice can be beneficial to African American patients and their families but identified specific barriers to completion of advance directives and hospice enrollment, including lack of knowledge, fear that these measures may hasten death or cause providers to deliver inadequate care, and perceived conflict with patients' faith and religious beliefs.
Moss, K. O., et al. (2017). ⁵⁹	18 family caregivers of African American older adults with dementia	Qualitative study (in-depth interviews)	African American caregiver interpretation of EOL decision-making terminology varied before and/or after death. EOL decision making was most often a family decision, based on past experiences, and included reliance on resources such as faith or spirituality and health care providers. Patients and families attach meaning to health care terms that should be aligned with health care providers' understanding of those terms
Mills, T. C. (2017). ⁶²	563 nurses and social workers	Quantitative, causal-comparative study	This study confirmed that racial homogeneity between providers and patients impact providers' perceptions but not significantly. The race of the provider rendering a referral made a statistically significant difference in their perception towards hospice services based upon their own racial bias. African American non-physician medical providers held more negative perceptions towards hospice referrals. However, the interaction of race of provider and race of patient was not statistically significant.
Faigle, R et al (2017). ⁶⁴	A total of 46,735 intracerebral hemorrhage and 331,521 ischemic stroke cases.	Population-based cross-sectional study	Stroke patients receiving care in minority hospitals had lower odds of palliative care compared to those treated in majority-White hospitals, regardless of individual patient race/ethnicity. The odds of palliative care for both White and minority intracerebral hemorrhage patients was lower in minority compared to majority-White hospitals. Similar results were observed in ischemic stroke patients.
Sanders, J. et al (2016). ⁶³	38 quantitative studies on advanced directive (AD) completion	Systematic review	Compared with White Americans, African Americans prefer more aggressive care, participate less in ACP, and are more likely to discuss EOL care informally than formally. The multiple factors that impact ACP for African American are inter-related and may result in part from historical realities that shape contemporary experience.
Sangarlangkarn, A. et al (2016). ⁶⁵	11 studies conducted between 1996 and 2015, with study sizes ranging from 9 to 2,864 participants	Systematic review	Lack of ACP was most commonly associated with low income, followed by lower severity of illness, low education level, Black or Hispanic race, female sex, younger age, injection drug use, and social isolation. Practitioners reported limited time or energy and inadequate preparation or training as barriers to ACP.

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Author(s) and year published	Sample size and participants	Research design	Types of disparities addressed and results
Jonhson, J. et al (2016). ⁶⁶	Seven focus groups with 51 persons from African American Churches	Qualitative study	Participants perceived that many of their congregants harbor beliefs, perceptions, and feelings about death and dying that were often not communicated to family members or to health providers. Among African Americans, faith beliefs, emotional issues, family dynamics, and insufficient knowledge of palliative care and hospice are intertwined and influence decision making about palliative and hospice care.
Inoue, M. (2016). ⁶⁷	1,056 participants who died between 2006 and 2010	Retrospective study using Health and Retirement study	Persons who were older, who were women, who identified themselves as White, and who had higher levels of income and education were more likely to be motivated to complete advance care planning. Having a greater sense of control was found to weaken the adverse relationship between being African American and the completion of advance directives. Having cancer, suffering from illness for longer periods of time, and having experience of nursing home institutionalization also predicted the completion of advance care planning.
Huang, I. et al (2016). ⁶⁸	2,154 American adults aged 50 and older	Quantitative study (general population survey)	White participants are significantly more likely to possess advance directives than older Black Americans and Hispanics. Gender, age, retirement status, disabled employment status, educational attainment, religious affiliation, Internet access, preferences for physician-centered decision making, and desiring longevity regardless of functional status were independent predictors of advance directive possession.
Huang, C. H. et al (2016). ⁶⁹	30 community dwelling African Americans	Mixed-method randomized controlled trial	All participants reported high satisfaction and increased intent to complete an advance directives at post-intervention. A significant increase in knowledge on advance directives from baseline to post-intervention was observed in the intervention group; no significant change was found for the control group. Lack of information, mistrust of doctors, and avoidance of discussing death were primary barriers to ACP discussions.
Hendricks Sloan D. et al (2016). ⁷⁰	930 responses from 2 Baptist Churches in December, 2014	Cross-sectional study	Approximately 70% of parishioners care or have cared for someone with multiple medical problems and/or who is dying, and a vast majority (97%) believed that good EOL communication is "important" or "very important." Only 60% of respondents noted having spoken with someone who could make decisions for them if they are unable to speak for themselves. That number decreased to 28% of respondents between the ages of 65 and 80. A majority (93%) would welcome church-provided information about EOL communication.
Eneanya, D. et al (2016). ⁷¹	152 patients with Chronic Kidney Disease between 2013 and 2015	Qualitative study (content analysis of audio and video recordings of the encounters)	Black Chronic Kidney Disease patients had less knowledge of hospice compared to White patients. A small fraction of patients reported having EOL discussions with their nephrologists and the majority had no advance directives. Blacks were more likely not to have communicated their EOL preferences and were more likely to prefer life-extending treatments than Whites.
Elliott, A. M. et al (2016). ⁷³	33 hospital-based physicians in Western Pennsylvania	Randomized factorial trial	In this small regional sample, hospital-based physicians have similar verbal communication behaviors when discussing end-of-life care with otherwise similar Black and White patients but exhibit significantly fewer positive, rapport-building nonverbal cues with Black patients.

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Author(s) and year published	Sample size and participants	Research design	Types of disparities addressed and results
Dillon, P. and Basu, A. (2016). ^{74,75}	10 African American hospice patients and 16 lay caregivers	Qualitative study	Participants identified several barriers to hospice enrollment and reported how they were able to overcome these barriers by reframing/prioritizing cultural values and practices, creating alternative goals for hospice care, and relying on information obtained outside the formal health system.
Rhodes, R. L., et al. (2015). ¹⁴⁷	12 hospice and palliative medicine providers and leaders of a national health care organization	Qualitative study	Barriers to end-of-life care for African Americans included: lack of knowledge about prognosis, desires for aggressive treatment, family members resistance to accepting hospice, and lack of insurance. Providers believed that acceptance of EOL care options among African Americans could be improved by increasing cultural sensitivity through education and training initiatives, and increasing staff diversity. Respondents did not have programs currently in place to increase awareness of EOL care options for underrepresented minorities, but felt that there was a need to develop these types of programs.
Lifsey, G. (2015). ⁷²	10 African Americans aged 30 to 85 diagnosed with a terminal illness with 6 months or less to live	Qualitative study	African Americans perceived and understood hospice care through a religious or spiritual lens, and believed that hospice permitted them to continue to be the primary caregivers of their terminally ill. Results also indicated several cultural, institutional, familial, and individual barriers to hospice care. These included a lack of pastoral or local church referral to hospice care, family awareness of hospice services, revocation or discharge from hospice care, historic mistrust of the healthcare system, pain management, and prior knowledge and experience of hospice care.

Conclusions and Suggestions for Future Study

It is well-established that disparities in diversity, equity and inclusivity are widespread in American society and in the United States health care system.²⁸⁰ *Receiving palliative care for people with serious illness, and hospice services for people approaching the end of life is no exception.*^{11,13,18,23,24,37,38,44,45,47,50,52,54,58,71,74,75,83,91,93,116,141,142,173,181,188,281}

It is urgent that we understand and eliminate both disparities in serious illness care and disparities in end-of-life care. The story about race and palliative and hospice care in United States is very much the same story of racism in health care.²⁸² In a comprehensive speculative essay, Rosenblatt (2009) paints a troubling picture of racism and Black-White relationships in end-of-life care in the United States. He argues that “*the racial system operates in ways that bruise some people and that make it difficult for those who are advantaged by the system to understand the system and their place in it; and so, ideally one way for end-of-life care facilities to deal with potential difficulties in black-white relationships is to provide contexts for dealing with bruises and obliviousness.*”¹⁰³ Discrimination and racism exist and are severely impacting

the end of life of minority patients. It is more righteous to address these issues directly than to pretend they are not present or are too unimportant to address.¹⁰³ The health care system, in both private and public settings, that is engaged with financing, managing, and providing palliative and hospice care must directly address the issue of racism, discrimination, and disparities, particularly among marginalized underserved non-Hispanic Blacks. Mistrust in health care providers more than ever remains one of the most frequently mentioned barriers, and is rooted in pervasive discrimination on the part of the health care system and providers against minority populations, particularly non-Hispanic Blacks.

Additional longitudinal national surveys sufficiently representative of underserved minority population (particularly, older non-Hispanic Black adults) are needed to document patient-, provider- and system-level factors impacting end-of-life palliative and hospice care. Based on our meta-analysis, available national surveys have generally failed to collect data from minority underserved, marginalized, and vulnerable populations. In addition, knowing that most of the available national surveys were not specifically designed for non-Hispanic Blacks, future national surveys must employ instruments that are designed and validated for non-Hispanic Blacks and other minority populations. Available national data provide

only limited information regarding the cultural values, beliefs, attitudes, and different aspects of religion, religiosity and spirituality of non-Hispanic Blacks and their caregivers.

Most of the available data focusing on social and cultural aspects of palliative and hospice cares and end-of-life related issues among non-Hispanic Blacks are qualitative data with insufficient numbers of participants thus limiting the generalizability of the findings. However, a sufficient number of qualitative studies regarding the end-of-life among non-Hispanic Blacks exist that could be used to design a culturally appropriate survey instrument to capture all aspects of palliative and hospice care as well as advance care planning. Furthermore, additional qualitative and quantitative surveys are needed that specifically measure the knowledge, attitudes, and skills of hospice care providers regarding the needs of non-Hispanic Black patients. We need to conduct several comprehensive assessments of cultural competencies of hospice and palliative care providers in order to design national training programs to educate, motivate, and provide sufficient skills for them to provide bias-free, culturally sensitive and effective hospice and palliative care for non-Hispanic Black patients.

Most of the published interventional studies aimed at improving palliative and hospice utilization and completion of advance care planning and directives among non-Hispanic Blacks showed minor or mild impacts. Few were multi-disciplinary and even fewer were theory-based interventions.⁹⁸ We need innovative, multi-faceted, multi-disciplinary, theory-based, culturally sensitive, community- and faith-based participatory interventions. A handful of interventional studies using innovative video-game or telehealth approaches showed initially promising results that need to be tested on a larger scale.²⁸³

Knowing that non-Hispanic Black caregivers (typically the patient's children or other family members) experience higher levels of overall caregiving intensity and burden than non-Hispanic Whites, there is an urgent need for interventions that provide training and financial support for informal non-Hispanic Black family caregivers. Existing traditional delivery of healthcare services may be insufficient, requiring interventions to overcome the barriers faced by non-Hispanic Black underserved populations when accessing end-of-life services, including completing advance care directives, accepting palliative care, and enrolling in a hospice program.

It is well-documented that non-Hispanic Blacks desire communication, information, respect, and a trusting doctor-patient relationship.⁹⁶ Several studies have shown that minority groups desire initiatives that are sensitive to their religious values and cultural assumptions.^{26,63,71,78,92,121,219} Yet, as we have seen in the literature review above, a large number of studies testify that non-Hispanic Blacks consistently report higher levels of mistrust in the health care system than Whites.^{20,221,224,227,228} Specifically, addressing both mistrust and communications 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 dialogues between providers and non-

Hispanic patients are needed to address appropriate communication that promotes mutual trust. Community- and faith-based initiatives would likely increase non-Hispanic Blacks' participation in palliative/hospice care and completion of advance care planning. In order to develop effective interventions promoting completion of advance care directives among non-Hispanic Black adults, additional research is needed to carefully address factors related to the communication between providers and non-Hispanic Blacks.

Finally, many studies blamed lack of knowledge and information regarding both palliative and hospice cares as the main challenges facing non-Hispanic Black communities. Elbaum (2020) argue that to the extent that these patterns are attributable to knowledge and access gaps, they should be considered health care disparities in their own right.¹⁶⁰ There are only a few interventional studies that have been designed to overcome educational barriers to using palliative and hospice care as well as completion of advanced care planning among minority populations.^{107,192,193} There is a strong need to refine end-of-life educational resources to reach non-Hispanic Black populations with varying needs.^{6,194} We clearly need to overcome the challenge posed by the interesting question, "Will patients want hospice or palliative care if they do not know what it is?"⁹⁷

Traditional methods of delivery of healthcare services may be insufficient. Innovative interventions are urgently needed to overcome the barriers faced by the underserved non-Hispanic Black community when accessing end-of-life services, completing advance care directives, accepting palliative care, and enrolling in hospice programs.²⁹ We obviously need additional theory-based interventions that address the knowledge, education, attitudes, motivations, skills, and resources of non-Hispanic Blacks in order to modify their utilization of end-of-life care. Finally, systematic and in-depth reviews are needed to document effectiveness of recent interventions.


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