

Disparities in end-of-life care for racial minorities: a narrative review

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Background and Objective: The issue of racial and ethnic disparities in healthcare has been a significant concern for many years. It encompasses various aspects, including disease prevention, diagnosis, management, and end-of-life (EOL) care. Research has found that timely intervention with palliative care can result in better EOL care and reduced healthcare costs. This review aims to detail the role of healthcare disparities impacting palliative care, hospice enrollment, and EOL care in patients with serious illnesses who are facing EOL. It addresses the factors that play a role in creating these disparities and describes specific interventions that may reduce disparities in the provision of EOL care.

Methods: Authors searched, PubMed Central, Medline, and PubMed databases using Racial Disparity and End-of-Life/Palliative Care combinations. A total of 57 studies were identified. All articles were reviewed, and the available evidence was synthesized and to identify key domains in EOL care impacted by racial disparities and the factors contributing to them.

Key Content and Findings: Several patient, provider, and institutional level factors may be responsible for disparities seen in EOL care, including health literacy, access to care, mistrust of the healthcare system, social determinants of health (SDH), medical racism, cultural and religious customs, and communication at EOL. Disparities in EOL care experienced by minority patients is an extension of the systemic and institutionalized racism rampant in the healthcare system. Providers must work on multiple fronts to address this inequity and injustice, the first of which is recognition and conversation regarding disparities in EOL care.

Conclusions: Disparities in communication, palliative and hospice care utilization, and symptom management must be eradicated. Palliative care and hospice should be made accessible for all patients and families experiencing severe illness regardless of their racial or ethnic background.

Keywords: Palliative care; end-of-life care (EOL care); racial disparities

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Introduction

Each year, more than 3.4 million people die in the United States (US), with this number increasing each year due to changes in population trends, including an aging population (1). In addition to increasing mortality due to an aging population, the racial and ethnic makeup of the US population facing end-of-life (EOL) is also shifting and it is estimated that by 2050, the US population will include 33 million Black, Hispanic, Asian, American Indian, or Alaskan Native individuals aged 65 years and older (2). Currently, considerable racial and ethnic variations are seen in the care received by patients at the end of life, which places a growing demand on the US healthcare system to satisfactorily meet the EOL care needs of a rapidly changing racially and ethnically diverse patient population. EOL care includes to provision of pain and symptom management as well as psychological, social, spiritual, and practical support. Due to the cultural differences, the provision of EOL care may differ. Given the increasing need for EOL care as well as the increasing population of racially and culturally diverse patients, the National Consensus Project for Quality Palliative Care has identified culturally appropriate EOL care as one of the top priorities for healthcare providers (3).

The delivery of appropriate EOL care is complicated, involving multiple roles among different stakeholders including the patient, their support person(s), and the clinical care team. High-quality EOL care involves addressing a patient's psychosocial, spiritual and clinical needs and considering the needs of those close to them (4). A successful health system strives to deliver timely, goalconcordant, patient-centered care, the provision of which is often complicated by the multiple persons involved in medical decision making at the end of life (5). Given the emotional and physical suffering that can occur at the end of life, planning for EOL care services is imperative to honor patients' goals and values in order to uphold the patients' autonomy and allow them to have a dignified death. Planning for EOL allows for the optimal use of limited healthcare resources and accommodates the needs of patients, their caregivers, and their families by allowing the patient and their support person(s) to reduce emotional and physical suffering through choice in medical decision making.

Although all patients deserve to have a voice in medical decision making at EOL, healthcare disparities experienced by racial and ethnic minorities are extensively documented compared to Whites in the US across various diseases (6).

For example, Black and Hispanic people are provided with lower healthcare spending and are provided fewer medical services than White individuals (7); however, they are more likely to undergo aggressive life-saving interventions towards the EOL (8,9). A growing body of literature has recently demonstrated racial disparities in EOL care including the presence of advanced care directives (10). Research has differed in the causes responsible for these differences, and factors such as cultural values, healthcare literacy, distrust of the healthcare system, and socio-economic status are thought to play a role.

This review aims to detail the role of healthcare disparities impacting palliative care, hospice enrollment, and EOL care in patients with serious illnesses who are facing EOL. It addresses the factors that play a role in creating these disparities and describes specific interventions that may reduce disparities in the provision of EOL care. We present this article in accordance with the Narrative Review reporting checklist (available at https://apm.amegroups.com/article/view/10.21037/apm-23-459/rc).

Methods

The authors searched PubMed Central, Medline, and PubMed databases using Racial Disparity and End-of-Life/ Palliative Care combinations (Table 1). A total of 57 studies were identified. No parameters were set regarding time of publication or age of the article. We selected all study types within the literature published in English with an available full text. Articles were excluded when the manuscript did not meet the publication gold standard or the full text was paywalled. The authors also excluded gray literature and duplicate publications. A backward search was conducted to retrieve relevant articles within the references of articles included within the study. Additionally, a forward search was conducted to locate newer articles cited the original articles that met inclusion criteria. All articles were reviewed, by the two authors and the available evidence was synthesized and interpreted to identify key domains in EOL care impacted by racial disparities and the factors contributing to racial disparities.

Factors contributing to disparities in EOL care

Several patient, provider, and institutional level factors may be responsible for disparities seen in EOL care, including health literacy, access to care, mistrust of the healthcare system, social determinants of health (SDH), medical

Table 1 The search strategy summary

Items	Specification
Date of search	6/20/2023
Databases and other sources searched	PubMed Central, Medline, and PubMed
Search terms used	Racial Disparities and Palliative Care or End-of Life-Care in Title
Timeframe	2000–2023
Inclusion criteria	Randomized clinical trial, English language, full text only
Selection process	All articles were reviewed, and the available evidence was synthesized and interpreted by the two authors to identify key domains in end-of-life care impacted by racial disparities and the factors contributing to them
Additional considerations	Relevant articles were also found by scanning the references of found articles (backward search) and locating newer articles that included the original cited paper (forward search)

racism, cultural and religious customs, and communication at EOL.

Health literacy

Available research consistently reports low health literacy regarding palliative care, hospice, and advance care planning in ethnic minorities (11). Health literacy is an important indicator of potential health because it denotes one's ability to leverage knowledge to take action to change their personal lifestyle in order to achieve health (12). Disparities in health literacy effect the provision of high quality of health care as disparities in health literacy are associated with lower engagement in advance care planning and goals of care discussions with health care providers (11). Furthermore, low health literacy is associated with higher medical spending during EOL care despite adjusting for race, suggesting the important role health literacy may play in reducing EOL care spending (13). There are two schools of thought when it comes to the relationship between healthcare literacy, race, and EOL preferences. The first school argues health literacy is an independent predictor of EOL preferences (14), while the other proposes that health literacy and race represent two separate but essentially linked causal pathways impacting EOL care preferences (15).

Patients who have low health literacy are less likely to want hospice or palliative care, although they are unable to identify what hospice and/or palliative care medical treatments entail (16). For example, a study conducted at a cancer center which assessed 133 non-Hispanic Black and White patients found that knowledge of hospice and palliative care of hospice care was much lower among non-

Hispanic blacks those with limited education compared to Whites (17). Similarly, Koffman and colleagues report that among 252 oncology outpatients, awareness of palliative care and related EOL care services was lowest among Black and minority ethnic groups and the least affluent (18). Low levels of awareness may give birth to misconceptions and foster mistrust towards the healthcare system in minority communities which in turn may result in lower levels of engagement (19,20). Improving awareness of palliative and hospice care is the first step toward decreasing disparities in appropriate EOL care for minority patients. While the literature agrees that it is imperative to improve health literacy regarding palliative care and hospice options for patients facing EOL, the majority of patient education materials fail to meet national health literacy recommendations and urgently need to be revised to a more accessible style to allow patients and their families to derive the optimal benefit (21). Studies in other areas suggest that in order to effectively reach minority patients, the health education must be adopted culturally tailored, interactive, and community-engaged health literacy approaches (22,23) which should also be applied to palliative care and hospice medicine.

Access to care

While the majority of patients in the US die in a hospital, more than 60% of Americans die without receiving hospice every year (24). Confounding this finding is a lack of available palliative care services especially in rural communities where only 17% of hospitals with 50 beds have palliative care services available (25). Although efforts have

been made to increase number of hospice and palliative care physician training programs across the country, not all patients' EOL needs and expectations are being met equitably (26). For example, two large studies which used state-level data found that older residents geographically located in an urban environment, with higher house hold income, and lower racial diversity had higher access to palliative care and hospice (27,28). Historically, minority patients have been subject to lower socio-economic status and are significantly disadvantaged which in turn affects their ability to engage with the health care system, pay for health services, and secure transportation to receive health services (29). Although minority patients experience stifled access to health care services at EOL, interventions aimed at improving access through the delivery of in-home hospice services have had mixed results (30,31). Among the two interventional studies, they both showed that multiple home visits by a healthcare provider may result in completing advance care planning forms; however, it is unclear whether these interventions have any effect on actual practices at the end of life. As health care, especially high-quality EOL care is a fundamental human right (32), the obvious disparities in access to appropriate and high-quality EOL care calls for researchers, policymakers, and clinicians to fulfill their ethical obligation and remediate health disparities from a position of equity and social justice.

Mistrust of the healthcare system

Multiple studies have documented significant mistrust of the healthcare system among racial and ethnic minorities compared to White patients (33-35). This mistrust is, rooted in years of systemic racial injustice embedded in the healthcare system and the society at large (36-39). A deeprooted perception of exploitation by the health care system of minority patients developed from unethical medical experiments such as the Tuskegee Study of Untreated Syphilis (40), unequal medical treatment of Blacks as evidenced by poorer access to dialysis and transplantation in end-stage renal disease (41-43), decreased use of warranted cardiac procedures (44), and lower quality care for hospitalized Black patients with heart failure or pneumonia (45).

Various factors are associated with minority patients not trusting the medical community, including low socioeconomic status (46), poor quality of life (47), low ability to secure health care support (48), and health care providers engaging in poor communication (49). Medical

mistrust has proven to be a barrier to patients participating in advance care planning and completing advanced directives among non-Hispanic Blacks. Within the literature, medical mistrust is cited as one of the critical factors influencing patients' decisions not to complete advanced care directives (50,51). Additionally, healthcare providers often lack awareness of minority patients' cultural beliefs which further contributes to medical mistrust in regard to engaging in advanced care planning (52). Successful communication during EOL care includes the assessment of patients' values, beliefs, and preferences before life-altering decisions need to be made. The literature shows Black patients prefer aggressive EOL care. This preference may stem from an inherent mistrust of health care providers, including the fear that physician recommendations to limit life support may arise from financial considerations for the health care system (53).

In a randomized clinical trial examining the effect of racial concordance between providers and patients when disseminating information regarding prostate cancer, racial concordance was significantly associated with trust only among Black adults (54). Another randomized clinical trial utilized community intervention in African American patients with human immunodeficiency virus (HIV), through one-on-one counseling sessions designed to help the patient's problem solve issues with adherence to follow up with referrals, as well as to address unmet needs for SDH (e.g., housing services, food assistance). Follow up surveys of patients reported improved adherence and reduced mistrust (55).

These clinical trials highlight the importance of increasing racial diversity in the healthcare workforce and utilizing interventions that are culturally tailored to minority patients which may help mitigate mistrust with regards to EOL care in minorities.

SDH

SDH, such as nutrition, transportation, social or caregiver support, and housing, can significantly impact the trajectory of patients' health. Race is considered a social construct, and the impact of social advantage on health is substantial. It is well established that these factors contribute to racial and ethnic disparities in EOL care and are able to predict how long or well people live as well as when and how people die (56). Palliative care and hospice policy internationally prioritizes dying at home, and efforts are being made to increase home deaths and reducing deaths within acute care institutions (57). However, priorities regarding receiving

EOL care within a patient's home may look different for those who are vulnerably housed and with limited resources. For instance, Hubbell found that homeless people had several different concerns at the EOL, such as a fear of dving alone and concerns regarding burial and notification of family limiting access opportunities to palliative care (58). It has been shown that being non-Hispanic Black and having a lower income is associated with a significantly lower likelihood of enrolling in hospice (59). Similarly, dying at home with hospice care requires significant caregiving, and the economic implications of increased responsibility for care are immense for those struggling to make ends meet. It is reported that financial hardship for caregivers of patients with serious illnesses is most for minorities groups (60). Improving access to quality EOL care for those who are socioeconomically disadvantaged requires an interdisciplinary approach at all levels from individual providers to broader public health policies.

Medical racism

Systemic, institutionalized racism and explicit bias have a longstanding history within the American healthcare system (61). Recently, the presence of implicit bias that healthcare providers may harbor has been emphasized in studies (62,63). A study using Harvard's Project on Implicit Bias found that both physician and non-physician healthcare workers exhibited more implicit and explicit anti-Black and anti-Arab-Muslim prejudice when compared to the general population, which remained significant for non-physician healthcare workers after controlling for demographics (63). A national qualitative study of 74 physicians, nurses, and social workers, found that many clinicians systematically avoided advanced care planning discussions with certain minority groups, non-English or non-native English speakers, and those with certain religious beliefs. Clinicians acknowledged implicit bias and cited barriers to advanced care planning discussions, including clinicians' preconceived notions that patients from certain minority groups would not be accepting of advanced care planning and (62). Lastly, clinicians lack in diversity as a workforce and may benefit from additional training needed to address racism in health care while delivering culturally humble, patient-centered care (64,65).

Cultural and religious values of patients

Religiosity encompasses spirituality, such as attitudes and

beliefs and objective behaviors regarding religious services participation, which may influence health behaviors (66). Black adults have a comparatively active congregational presence and experience higher religiosity and spirituality compared to White adults (44). There is plethora of data to supporting the notion that religious beliefs and values may both directly and indirectly influence EOL planning and decision-making but with mixed outcomes (11,67). The central idea that links mainstream religions to EOL care is the notion that God is responsible for making final determinations regarding the time and place of death, and this belief is much more robust in Blacks than Whites (68). In alignment with the reported belief that God is responsible for final determinations, some studies have found a predominantly negative association completion of advanced care planning and a patient's religiosity (11,69,70). For example, Cykert et al. found that when asked about preferences for remaining in a severely debilitated state rather than undergoing a potentially lethal attempt at a cure, Blacks had a much higher preference to remain alive despite severe disability (71). The religious and spiritual influence found among Blacks extends to other cultures, including Latinos, as shown in a large Pew study of 4,016 Latinos which reported 92% of Latinos consider themselves religious (72,73). In a recent study of a diverse group of patients with advanced cancer, religiosity was associated with aggressive measures to prolong life, even after adjustment for race and ethnicity (72). In focus groups, Latino surrogates indicated that suffering at the end of life was to be borne as part of a test of faith (73). More data is needed to clarify the role of religious interventions in improving high-quality EOL care in minority patients; nonetheless, this is another avenue to address disparities that undoubtedly disfavors minority patients.

Communication between providers and patients

Cross-cultural studies identify communication between providers and patients to be responsible for the perception of hospice and palliative care and as one of the significant barriers profoundly impacting the receipt of EOL care services (74). It has been shown that Black patients consistently report experiencing poorer quality communication and receipt of information, in addition to having lower levels of patient participation, and shared decision-making compared to Whites (75). Additionally, studies have found that racial and ethnic minorities are less likely to communicate their advanced care planning

preferences to healthcare providers than White patients (76,77). Studies have found lower nonverbal scores between physicians and Black compared to White critically and terminally ill simulated patients, reflecting fewer favorable, rapport-building nonverbal cues (78).

Further promoting healthcare disparities are the increasing demands on healthcare providers and time constraints which further contribute to poor communication between providers and minority patients widening an already substantial gap (79). Caring for socially disadvantaged patients is challenging as they often have complex medical problems and experience poor physical and mental healthcare outcomes (80). Time pressured visits often illicit unconscious physician bias and promote physician centered communication worsening healthcare disparities for minority patients (81).

In a national survey of bereaved caregivers, surrogates of Black patients were less satisfied with the quality of EOL care received by their loved ones and provider communication than White patients (82). Black patients report concerns with providers' efforts to listen to patients and the extent of information shared with them, with heightened disparities in racially discordant physician-patient relationships (83,84). It has been found that communication outcomes vary by race, with EOL discussions between Black patients and their physician's being less likely to result in goal concordant care than White patients (85).

Work needs to be done to ensure goal concordant care that honors patient's preferences, values, and goals for ethnic minorities. To increase goal concordant care, a systematic review of the literature shows that interventions aimed at promoting effective communication about advanced care planning successfully improved the delivery of goal-concordant care (86). In addition, research suggests training physicians in cultural competence may improve physician-patient communication and collaboration, increase patient satisfaction, and facilitate adherence, thereby improving clinical outcomes and reducing health disparities (87).

Domains of EOL care impacted by health care disparities

EOL care is characterized by racial and ethnic disparities, including palliative care, addressing code status, symptom management, completion of advanced care directives, and use of hospice resources.

Use of palliative care

Palliative care has improved patient and provider satisfaction, symptom control, patient-centered goal concordant care, decreased intensity of care at the EOL, and cost-savings for healthcare systems (88). However, disparities exist in providing palliative care services to minority patients including, access to palliative care utilization (89,90). A large retrospective cohort study which included over five million dialysis patients who experienced hospitalization, found racial disparities in receipt of in hospital palliative care services with Hispanic Black and Hispanic patients being less likely to receive these services than their White counterparts. This disparity was present in all hospital subtypes, including hospitals treating high numbers of minority patients (91). The result of racial and ethnic minorities receiving palliative care at lower rates than White patients were also found in a large study which included 46,735 patients hospitalized after experiencing intracerebral hemorrhage and 331,521 hospitalized after experiencing ischemic stroke between 2007-2011 (92).

Yet following the results of the studies in stroke and dialysis patients, a large study of hospitalized patient's including 601,680 lung, colon, and breast cancer patients treated at more than 1,500 US hospitals found that patients treated at hospitals which mainly served minority patients were significantly less likely to receive palliative care, suggesting that racial and ethnic differences in palliative care receipt may be associated with the hospital treating the patient (93).

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 (93).

In a retrospective cohort study of 204,175 hospital admissions of patients with advanced cancers among those who survived, Black patients were significantly less likely to receive a palliative care consultation compared to Whites, revealing a critical disparity in the utilization of an effective medical tool that can improve health outcomes for Black patients (94).

Although prior research has identified racial disparities in palliative care utilization, some studies have found that palliative care is consulted similarly between Black and White patients. One study which included four hospital systems and ~1,300 patients with severe stroke found

no statistically significant differences in palliative care consultation between Black and White patients, even when adjusting for confounding variables in multivariable analysis (91). Similarly, a large study of 5,613 patients who were discharged to hospice or died during their hospitalization from four urban hospitals found no significant racial or ethnic disparities in the palliative care or hospice use at the EOL (26). While the majority of studies have found racial and/or ethnic disparities in the use of palliative care and hospice at EOL, most studies have also found variation across hospitals in palliative care and hospice use. The well-studied finding of disparities between hospitals in use of palliative care and hospice may explain the few studies that found no racial differences in palliative care use.

Racial disparity in pain and symptom management

Racial disparities in symptom management exist, with multiple reviews reporting high symptom burden in minority patients (92,95). Black patients are known to be less likely to have their pain evaluated by physicians (96), receive or have access to pain medications (94,97,98), and are more likely to have their pain underestimated by physicians (96). In a review addressing racial disparities in use of supportive care medications among cancer patients, results were mixed with half the studies supporting presence of racial disparities and half showing equivalent prescription patterns (99). A large cohort study of 980 patients receiving outpatient supportive care at a cancer center within an academic hospital system identified that although non-Hispanic Black and Hispanic patients reported higher symptom burden at their first visit compared to White patients, minority patients were less likely to show improvement in symptom burden at their first follow up visit compared to Whites (100). Minority cancer patients consistently report lower quality of life and worse vasomotor, gastrointestinal, and neuropsychological symptoms (101), yet, they are less likely than Whites to be prescribed supportive care medications (102). Similarly, in a study assessing disparities in the use of anti-emetics for prophylaxis of chemotherapy induced nausea and vomiting (CINV) among 1,130 women with breast cancer Black women were 11% less likely than White women to use neurokinin-1 receptor antagonists (NK1s) for CINV which was thought to be related to differential reporting of symptoms vs access to care (103). The known disparities in pain and symptom management between races need to be addressed in order to ensure equitable and just healthcare.

Disparities in advanced care directives

There are long standing and well documented racial and ethnic differences in advanced care planning (100,104). Advanced care planning includes documentation of a surrogate health care representative, advanced directives for medical treatment including living wills and Physician Orders for Life Sustaining Treatments (POLST/MOST/POST depending on your state of residence). Compared to Whites, Black and Hispanic patients are less likely to name a health care representative or to have a conversation with their health care provider about EOL preferences (74). Additionally, Hispanics and Blacks are less likely to have a documented advanced care planning document in their medical record, such as a living will, compared to Whites (74-78).

There are several reasons cited in the literature for differences in advanced care planning documents between ethnic and racial minorities compared to Whites. First, lower rates of conversations about EOL care between patient and provider, including discussions about goals and preferences for medical care are found in studies regarding advance care planning (74,78). The reasons for lower conversations have been attributed to discomfort in discussing EOL care among patients, surrogate medical decision makers, as well as low clinician confidence in their ability to deliver culturally sensitive information regarding advanced care planning (74-78). In addition to discomfort in ability to have an advance care planning conversation, studies have found an association between high religiosity and a preference for aggressive interventions at EOL among racial and ethnic minorities (105). These studies attributed faith and religion to lower rates of advance care planning (78). While ethically, engaging in advance care planning allows patients to uphold their autonomy during illness by providing guidance for surrogate medical decision makers as well as clinicians when making medical decisions, most patients do not execute advanced care planning documents.

Importantly, recent evidence has found no clear link between advanced care planning and improved EOL quality outcomes (106). Due to these recent reviews of the evidence, many clinicians and clinical organizations are deemphasizing the role of advance care planning in improving EOL care. Rather than focusing on hypothetical future planning with patients, clinicians should engage in critical illness conversations which emphasize the elicitation of patient preference, goals, and values. Additionally, clinicians

should frame their communication regarding prognosis and medical decision making within the context of the decisions facing the patient in the moment.

Goals of care conversations with critically ill patients and/or their surrogates have been found to decrease use of aggressive interventions and improve the quality of patient-centered outcomes in patients facing EOL. While racial disparities have been found in advanced care planning documentation, serious illness conversations have been associated with mitigating racial disparities in care, including increasing hospice enrollment among Black patients; however, not all studies have found this positive association.

It is important to note that although there are racial and ethnic differences in advance care planning documentation, there is a low prevalence of advance care planning documentation across all patients. Increased advanced care planning documentation and increasing the frequency of goal of care conversations held between patients, surrogates, and clinicians should be pursued in clinical practice across all specialties and with all patients regardless of race, ethnicity, age, or gender.

Hospice utilization

Hospice care is known for emphasizing family-centered care and offering spiritual support which can be culturally tailored to the needs of minority patients making it a useful resource to improve the quality of EOL care. However, overwhelming evidence shows that Black patients have an appreciably lower rate of obtaining hospice services at EOL compared to White patients and Black patients are more likely to die in the hospital (107). Black patients remained less likely to use hospice than Whites even after controlling for gender, marital status, education, existence of a living will, medical history, religiosity, income, and access to health care (108). Lack of insurance coverage among minority patients was associated with lower rates of hospice care use, and a delay in transition to hospice care when used, compared to their insured White counterparts (109). These disparities extend to the quality of care received within hospices. Additionally, studies have found that Black hospice enrollees were significantly more likely than non-Hispanic White enrollees to visit the emergency room, be hospitalized, and dis-enroll from

hospice (110). Once enrolled in hospice Black patients also experience more transitions in care which can be burdensome for patients and often indicate the provision of poor quality care (111).

This review has several limitations. Our literature search needed to be broadened to capture every access domain, so disparities may have yet to be noticed in studies reporting on hospice and palliative care. Additionally, not all aspects of provider and caregiver perspectives were included in the representative samples regarding disparity which may not have allowed us to depict an accurate sociological picture. Most studies predominantly address Black patients and cancer thus, the experience of other minorities and patients with other serious illnesses may have been missed; however, there appears to be a paucity of literature. Despite its limitations, this comprehensive review offers a deeper understanding of why and where differences exist in EOL care. This will encourage providers to introspect, question personal and system-level factors contributing to healthcare disparities, intervene, and engage in their moral and ethical obligation to help mitigate them.

Conclusions

This narrative review demonstrates that hospice and palliative care access disparities are complex and multifaceted. Additionally, this review identifies gaps in the literature regarding EOL care and health care disparities. These gaps are critical to ensure that research priorities are in alignment with the needs of clinical practice as well as identifying best clinical practices based on current evidence. The disparity in EOL care experienced by minority patients is an extension of the systemic and institutionalized racism rampant in the healthcare system. Providers must work on multiple fronts (Figure 1) to address this inequity and injustice, the first of which is recognition and conversation regarding disparities in EOL care. The healthcare workforce should focus on becoming racially and ethnically diverse, familiarize themselves with minority cultures, and learn to support the values and preferences of minority patients. Lastly, disparities in communication, palliative and hospice care utilization, and symptom management must be eradicated. Hospice and palliative care should be made accessible for all patients and families enduring severe illness regardless of their racial or ethnic background.



Figure 1 Interventions to mitigate disparities in end-of-life care.

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Footnote

Reporting Checklist: The authors have completed the Narrative Review reporting checklist. Available at https://apm.amegroups.com/article/view/10.21037/apm-23-459/rc

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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References

- 1. Xu J, Murphy SL, Kochanek KD, et al. Mortality in the United States, 2021. NCHS Data Brief 2022;(456):1-8.
- 2021 PROFILE OF OLDER AMERICANS. Available onlone: https://acl.gov/sites/default/files/Profile%20 of%20OA/2021%20Profile%20of%20OA/2021ProfileOl derAmericans 508.pdf
- National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. Available online: https://www.nationalcoalitionhpc.org/ncp.
- 4. Harding R, Simon ST, Benalia H, et al. The PRISMA Symposium 1: outcome tool use. Disharmony in European outcomes research for palliative and advanced disease care: too many tools in practice. J Pain Symptom Manage 2011;42:493-500.

- Wolf SM, Berlinger N, Jennings B. Forty years of work on end-of-life care--from patients' rights to systemic reform. N Engl J Med 2015;372:678-82.
- 6. Velarde G, Bravo-Jaimes K, Brandt EJ, et al. Locking the Revolving Door: Racial Disparities in Cardiovascular Disease. J Am Heart Assoc 2023;12:e025271.
- Walkey AJ, Barnato AE, Rinne ST, et al. Hospital Variation in Do-Not-Resuscitate Orders and End-of-Life Healthcare Use in the United States. Ann Am Thorac Soc 2017;14:1485-9.
- 8. Hanchate A, Kronman AC, Young-Xu Y, et al. Racial and ethnic differences in end-of-life costs: why do minorities cost more than whites? Arch Intern Med 2009;169:493-501.
- Ornstein KA, Roth DL, Huang J, et al. Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the REGARDS Cohort. JAMA Netw Open 2020;3:e2014639.
- 10. Koss CS, Baker TA. Race Differences in Advance Directive Completion. J Aging Health 2017;29:324-42.
- Huang IA, Neuhaus JM, Chiong W. Racial and Ethnic Differences in Advance Directive Possession: Role of Demographic Factors, Religious Affiliation, and Personal Health Values in a National Survey of Older Adults. J Palliat Med 2016;19:149-56.
- Liu C, Wang D, Liu C, et al. What is the meaning of health literacy? A systematic review and qualitative synthesis. Fam Med Community Health 2020;8:e000351.
- 13. Luo Q, Shi K, Hung P, et al. Associations Between Health Literacy and End-of-Life Care Intensity Among Medicare Beneficiaries. Am J Hosp Palliat Care 2021;38:626-33.
- Volandes AE, Paasche-Orlow M, Gillick MR, et al. Health literacy not race predicts end-of-life care preferences. J Palliat Med 2008;11:754-62.
- 15. Waite KR, Federman AD, McCarthy DM, et al. Literacy and race as risk factors for low rates of advance directives in older adults. J Am Geriatr Soc 2013;61:403-6.
- Flieger SP, Chui K, Koch-Weser S. Lack of Awareness and Common Misconceptions About Palliative Care Among Adults: Insights from a National Survey. J Gen Intern Med 2020;35:2059-64.
- 17. Matsuyama RK, Balliet WE, Ingram K, et al. Will Patients Want Hospice or Palliative Care if They Do Not Know What It Is? Journal of Hospice & Palliative Nursing 2011;13:41-6.
- 18. Koffman J, Burke G, Dias A, et al. Demographic factors and awareness of palliative care and related services. Palliat Med 2007;21:145-53.

- 19. Born W, Greiner KA, Sylvia E, et al. Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. J Palliat Med 2004;7:247-56.
- Arenella C. Hospice and Palliative Care for African Americans: Overcoming Disparities. J Palliat Med 2016;19:126.
- 21. Prabhu AV, Crihalmeanu T, Hansberry DR, et al. Online palliative care and oncology patient education resources through Google: Do they meet national health literacy recommendations? Pract Radiat Oncol 2017;7:306-10.
- 22. Ross L, Ashford AD, Bleechington SJ, et al. Applicability of a video intervention to increase informed decision making for prostate-specific antigen testing. J Natl Med Assoc 2010;102:228-36.
- 23. Broussard B, Radkins JB, Compton MT. Developing visually based, low-literacy health education tools for African Americans with psychotic disorders and their families. Community Ment Health J 2014;50:629-36.
- 24. Carlson MD, Bradley EH, Du Q, et al. Geographic access to hospice in the United States. J Palliat Med 2010;13:1331-8.
- Available online: https://reportcard.capc.org/wpcontent/uploads/2020/05/CAPC_State-by-State-Report-Card_051120.pdf.
- 26. Johnson T, Walton S Jr, Levine S, et al. Racial and ethnic disparity in palliative care and hospice use. Am J Manag Care 2020;26:e36-40.
- 27. Hoerger M, Perry LM, Korotkin BD, et al. Statewide Differences in Personality Associated with Geographic Disparities in Access to Palliative Care: Findings on Openness. J Palliat Med 2019;22:628-34.
- 28. Silveira MJ, Connor SR, Goold SD, et al. Community supply of hospice: does wealth play a role? J Pain Symptom Manage 2011;42:76-82.
- 29. Thomas BA, Rodriguez RA, Boyko EJ, et al. Geographic variation in black-white differences in end-of-life care for patients with ESRD. Clin J Am Soc Nephrol 2013;8:1171-8.
- 30. Fernandes R, Braun KL, Ozawa J, et al. Home-based palliative care services for underserved populations. J Palliat Med 2010;13:413-9.
- Fischer SM, Cervantes L, Fink RM, et al. Apoyo con Cariño: a pilot randomized controlled trial of a patient navigator intervention to improve palliative care outcomes for Latinos with serious illness. J Pain Symptom Manage 2015;49:657-65.
- 32. Available online: https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health.

- Oakley LP, López-Cevallos DF, Harvey SM. The Association of Cultural and Structural Factors with Perceived Medical Mistrust Among Young Adult Latinos in Rural Oregon. Behav Med 2019;45:118-27.
- 34. Boulware LE, Cooper LA, Ratner LE, et al. Race and trust in the health care system. Public Health Rep 2003;118:358-65.
- Frieden TR; Centers for Disease Control and Prevention (CDC). Forward: CDC Health Disparities and Inequalities Report - United States, 2011. MMWR Suppl 2011;60:1-2.
- Sanders JJ, Johnson KS, Cannady K, et al. From Barriers to Assets: Rethinking factors impacting advance care planning for African Americans. Palliat Support Care 2019:17:306-13.
- 37. McLennan VEJ, Boddy JHM, Daly MG, et al. Relinquishing or taking control? Community perspectives on barriers and opportunities in advance care planning. Aust Health Rev 2015;39:528-32.
- Kaplan LM, Sudore RL, Arellano Cuervo I, et al. Barriers and Solutions to Advance Care Planning among Homeless-Experienced Older Adults. J Palliat Med 2020;23:1300-6.
- 39. Armstrong K, Putt M, Halbert CH, et al. Prior experiences of racial discrimination and racial differences in health care system distrust. Med Care 2013;51:144-50.
- 40. Alsan M, Wanamaker M. Tuskegee and the health of black men. Q J Econ 2018;133:407-55.
- 41. Barker-Cummings C, McClellan W, Soucie JM, et al. Ethnic differences in the use of peritoneal dialysis as initial treatment for end-stage renal disease. JAMA 1995;274:1858-62.
- 42. Ayanian JZ, Cleary PD, Weissman JS, et al. The effect of patients' preferences on racial differences in access to renal transplantation. N Engl J Med 1999;341:1661-9.
- 43. Kjellstrand CM, Logan GM. Racial, sexual and age inequalities in chronic dialysis. Nephron 1987;45:257-63.
- 44. Wenneker MB, Epstein AM. Racial inequalities in the use of procedures for patients with ischemic heart disease in Massachusetts. JAMA 1989;261:253-7.
- 45. Ayanian JZ, Weissman JS, Chasan-Taber S, et al. Quality of care by race and gender for congestive heart failure and pneumonia. Med Care 1999;37:1260-9.
- 46. Buttrick NR, Heintzelman SJ, Oishi S. Inequality and well-being. Curr Opin Psychol 2017;18:15-20.
- 47. Kinlock BL, Parker LJ, Bowie JV, et al. High Levels of Medical Mistrust Are Associated With Low Quality of Life Among Black and White Men With Prostate Cancer. Cancer Control 2017;24:72-7.
- 48. Arcos E, Vollrath A, Sánchez X, et al. Motherhood

- inmigrant women in Chile: A qualitative study. Midwifery 2018;66:182-6.
- 49. Cuevas AG, O'Brien K, Saha S. African American experiences in healthcare: "I always feel like I'm getting skipped over". Health Psychol 2016;35:987-95.
- 50. Hong M, Yi EH, Johnson KJ, et al. Facilitators and Barriers for Advance Care Planning Among Ethnic and Racial Minorities in the U.S.: A Systematic Review of the Current Literature. J Immigr Minor Health 2018;20:1277-87.
- 51. Bullock K. Promoting advance directives among African Americans: a faith-based model. J Palliat Med 2006;9:183-95.
- 52. Bazargan M, Cobb S, Assari S, et al. Preparedness for Serious Illnesses: Impact of Ethnicity, Mistrust, Perceived Discrimination, and Health Communication. Am J Hosp Palliat Care 2022;39:461-71.
- 53. Blackhall LJ, Frank G, Murphy ST, et al. Ethnicity and attitudes towards life sustaining technology. Soc Sci Med 1999;48:1779-89.
- 54. Loeb S, Ravenell JE, Gomez SL, et al. The Effect of Racial Concordance on Patient Trust in Online Videos About Prostate Cancer: A Randomized Clinical Trial. JAMA Netw Open 2023;6:e2324395.
- 55. Bogart LM, Mutchler MG, Goggin K, et al. Randomized Controlled Trial of Rise, A Community-Based Culturally Congruent Counseling Intervention to Support Antiretroviral Therapy Adherence Among Black/ African American Adults Living with HIV. AIDS Behav 2023;27:1573-86.
- 56. Rowley J, Richards N, Carduff E, et al. The impact of poverty and deprivation at the end of life: a critical review. Palliat Care Soc Pract 2021;15:26323524211033873.
- 57. Robinson J, Gott M, Gardiner C, et al. The 'problematisation' of palliative care in hospital: an exploratory review of international palliative care policy in five countries. BMC Palliat Care 2016;15:64.
- 58. Hubbell SA. Advance care planning with individuals experiencing homelessness: Literature review and recommendations for public health practice. Public Health Nurs 2017;34:472-8.
- 59. Karikari-Martin P, McCann JJ, Farran CJ, et al. Race, Any Cancer, Income, or Cognitive Function: What Influences Hospice or Aggressive Services Use at the End of Life Among Community-Dwelling Medicare Beneficiaries? Am J Hosp Palliat Care 2016;33:537-45.
- 60. Tilden VP, Tolle SW, Drach LL, et al. Out-of-hospital death: advance care planning, decedent symptoms, and

- caregiver burden. J Am Geriatr Soc 2004;52:532-9.
- 61. Yearby R, Clark B, Figueroa JF. Structural Racism In Historical And Modern US Health Care Policy. Health Aff (Millwood) 2022;41:187-94.
- 62. Ashana DC, D'Arcangelo N, Gazarian PK, et al. "Don't Talk to Them About Goals of Care": Understanding Disparities in Advance Care Planning. J Gerontol A Biol Sci Med Sci 2022;77:339-46.
- 63. Green TL, Vu H, Swan LET, et al. Implicit and explicit racial prejudice among medical professionals: updated estimates from a population-based study. Lancet Reg Health Am 2023;21:100489.
- 64. Jones KF, Laury E, Sanders JJ, et al. Top Ten Tips Palliative Care Clinicians Should Know About Delivering Antiracist Care to Black Americans. J Palliat Med 2022;25:479-87.
- 65. Struck BD, Brown EA, Madison S. Advance Care Planning in the Outpatient Geriatric Medicine Setting. Prim Care 2017;44:511-8.
- 66. Taylor RJ, Chatters LM, Brown RK. African American Religious Participation. Rev Relig Res 2014;56:513-38.
- 67. Carr D, Khodyakov D. End-of-life health care planning among young-old adults: an assessment of psychosocial influences. J Gerontol B Psychol Sci Soc Sci 2007;62:S135-41.
- 68. Carr D. Racial differences in end-of-life planning: why don't Blacks and Latinos prepare for the inevitable? Omega (Westport) 2011;63:1-20.
- 69. Smith AK, McCarthy EP, Paulk E, et al. Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgment, religiousness, and treatment preferences. J Clin Oncol 2008;26:4131-7.
- True G, Phipps EJ, Braitman LE, et al. Treatment preferences and advance care planning at end of life: the role of ethnicity and spiritual coping in cancer patients. Ann Behav Med 2005;30:174-9.
- Cykert S, Joines JD, Kissling G, et al. Racial differences in patients' perceptions of debilitated health states. J Gen Intern Med 1999;14:217-22.
- 72. Balboni TA, Vanderwerker LC, Block SD, et al. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. J Clin Oncol 2007;25:555-60.
- 73. Braun UK, Beyth RJ, Ford ME, et al. Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. J Gen Intern Med

- 2008;23:267-74.
- 74. Herbstsomer RA, Stahl ST. Cross-Cultural Experiences of Hospice and Palliative Care Services: A Thematic Analysis. Omega (Westport) 2021;84:551-66.
- 75. Shen MJ, Peterson EB, Costas-Muñiz R, et al. The Effects of Race and Racial Concordance on Patient-Physician Communication: A Systematic Review of the Literature. J Racial Ethn Health Disparities 2018;5:117-40.
- Clark MA, Person SD, Gosline A, et al. Racial and Ethnic Differences in Advance Care Planning: Results of a Statewide Population-Based Survey. J Palliat Med 2018;21:1078-85.
- Carr D. Racial and ethnic differences in advance care planning: identifying subgroup patterns and obstacles. J Aging Health 2012;24:923-47.
- Elliott AM, Alexander SC, Mescher CA, et al. Differences in Physicians' Verbal and Nonverbal Communication With Black and White Patients at the End of Life. J Pain Symptom Manage 2016;51:1-8.
- Fiscella K, Epstein RM. So much to do, so little time: care for the socially disadvantaged and the 15-minute visit. Arch Intern Med 2008;168:1843-52.
- 80. Gupta RS, Carrión-Carire V, Weiss KB. The widening black/white gap in asthma hospitalizations and mortality. J Allergy Clin Immunol 2006;117:351-8.
- 81. Fiscella K, Franks P, Gold MR, et al. Inequality in quality: addressing socioeconomic, racial, and ethnic disparities in health care. JAMA 2000;283:2579-84.
- 82. Welch LC, Teno JM, Mor V. End-of-life care in black and white: race matters for medical care of dying patients and their families. J Am Geriatr Soc 2005;53:1145-53.
- 83. Gordon HS, Street RL Jr, Sharf BF, et al. Racial differences in doctors' information-giving and patients' participation. Cancer 2006;107:1313-20.
- 84. Smith AK, Davis RB, Krakauer EL. Differences in the quality of the patient-physician relationship among terminally ill African-American and white patients: impact on advance care planning and treatment preferences. J Gen Intern Med 2007;22:1579-82.
- 85. Mack JW, Paulk ME, Viswanath K, et al. Racial disparities in the outcomes of communication on medical care received near death. Arch Intern Med 2010;170:1533-40.
- 86. Houben CHM, Spruit MA, Groenen MTJ, et al. Efficacy of advance care planning: a systematic review and meta-analysis. J Am Med Dir Assoc 2014;15:477-89.
- 87. Kripalani S, Bussey-Jones J, Katz MG, et al. A prescription for cultural competence in medical education. J Gen Intern Med 2006;21:1116-20.

- 88. Murtaugh CM, Beissner KL, Barrón Y, et al. Pain and Function in Home Care: A Need for Treatment Tailoring to Reduce Disparities? Clin J Pain 2017;33:300-9.
- 89. Cole AP, Nguyen DD, Meirkhanov A, et al. Association of Care at Minority-Serving vs Non-Minority-Serving Hospitals With Use of Palliative Care Among Racial/Ethnic Minorities With Metastatic Cancer in the United States. JAMA Netw Open 2019;2:e187633.
- 90. Islam JY, Deveaux A, Previs RA, et al. Racial and ethnic disparities in palliative care utilization among gynecological cancer patients. Gynecol Oncol 2021;160:469-76.
- 91. Comer AR, Williams LS, Bartlett S, et al. Palliative and End-of-Life Care After Severe Stroke. J Pain Symptom Manage 2022;63:721-8.
- 92. Heitner R, Rogers M, Chambers B, et al. The Experience of Black Patients With Serious Illness in the United States: A Scoping Review. J Pain Symptom Manage 2023;66:e501-11.
- 93. Cruz-Flores S, Rodriguez GJ, Chaudhry MRA, et al. Racial/ethnic disparities in hospital utilization in intracerebral hemorrhage. Int J Stroke 2019;14:686-95.
- 94. Lee K, Gani F, Canner JK, et al. Racial Disparities in Utilization of Palliative Care Among Patients Admitted With Advanced Solid Organ Malignancies. Am J Hosp Palliat Care 2021;38:539-46.
- 95. Clarke G, Chapman E, Crooks J, et al. Does ethnicity affect pain management for people with advanced disease? A mixed methods cross-national systematic review of 'very high' Human Development Index English-speaking countries. BMC Palliat Care 2022;21:46.
- 96. Cintron A, Morrison RS. Pain and ethnicity in the United States: A systematic review. J Palliat Med 2006;9:1454-73.
- 97. Meghani SH, Byun E, Gallagher RM. Time to take stock: a meta-analysis and systematic review of analgesic treatment disparities for pain in the United States. Pain Med 2012;13:150-74.
- 98. Lee P, Le Saux M, Siegel R, et al. Racial and ethnic disparities in the management of acute pain in US emergency departments: Meta-analysis and systematic review. Am J Emerg Med 2019;37:1770-7.
- 99. Awunti M, DeRemer DL, Rogers S, et al. A Scoping Review on the Relationship between Race/Ethnicity and

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- the Receipt of Supportive Care Medications during Cancer Treatment: Implications for the Clinical Pharmacist. J Am Coll Clin Pharm 2022;5:1284-96.
- 100. Saeed F, Ladwig S, Allen RJ, et al. Racial Disparities in Health Beliefs and Advance Care Planning Among Patients Receiving Maintenance Dialysis. J Pain Symptom Manage 2023;65:318-25.
- 101. Kim SJ, Retnam RP, Sutton AL, et al. Racial disparities in opioid prescription and pain management among breast cancer survivors. Cancer Med 2023;12:10851-64.
- 102. Griggs JJ. Disparities in Palliative Care in Patients With Cancer. J Clin Oncol 2020;38:974-9.
- 103. Check DK, Reeder-Hayes KE, Zullig LL, et al. Examining racial variation in antiemetic use and post-chemotherapy health care utilization for nausea and vomiting among breast cancer patients. Support Care Cancer 2016;24:4839-47.
- 104.Mindo-Panusis D, Sudore RL, Cenzer I, et al. Disparities in advance care planning among older US immigrants. J Am Geriatr Soc 2023;71:3244-53.
- 105. Phelps AC, Maciejewski PK, Nilsson M, et al. Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. JAMA 2009;301:1140-7.
- 106. Sean Morrison R. Advance Directives/Care Planning: Clear, Simple, and Wrong. J Palliat Med 2020;23:878-9.
- 107. Barnato AE, Anthony DL, Skinner J, et al. Racial and ethnic differences in preferences for end-of-life treatment. J Gen Intern Med 2009;24:695-701.
- 108. Greiner KA, Perera S, Ahluwalia JS. Hospice usage by minorities in the last year of life: results from the National Mortality Followback Survey. J Am Geriatr Soc 2003;51:970-8.
- 109. Washington KT, Bickel-Swenson D, Stephens N. Barriers to hospice use among African Americans: a systematic review. Health Soc Work 2008;33:267-74.
- 110. Rizzuto J, Aldridge MD. Racial Disparities in Hospice Outcomes: A Race or Hospice-Level Effect? J Am Geriatr Soc 2018;66:407-13.
- 111. Wang SY, Hsu SH, Aldridge MD, et al. Racial Differences in Health Care Transitions and Hospice Use at the End of Life. J Palliat Med 2019;22:619-27.