

Racial and Ethnic Disparities in Palliative Care

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Abstract

Racial and ethnic disparities in health care access and quality are well documented for some minority groups. However, compared to other areas of health care, such as disease prevention, early detection, and curative care, research in disparities in palliative care is limited. Given the rapidly growing population of minority older adults, many of whom will face advanced serious illness, the availability of high-quality palliative care that meets the varied needs of older adults of all races and ethnicities is a priority. This paper reviews existing data on racial and ethnic disparities in use of and quality of palliative care and outlines priorities for future research.

Introduction

CURRENTLY, 8.1 MILLION or 20% of older adults are racial or ethnic minorities—8.4% are African Americans, 6.9% Hispanics of any race, 3.5% Asians or Pacific Islanders, and less than 1% American Indians. Over the next two decades the growth in the proportion of minority older adults will substantially outpace that of Non-Hispanic whites. Specifically, the population of older Non-Hispanic whites is expected to increase by only 59% compared to 160% for older minorities—202% for Hispanics, 114% for African Americans, 145% for American Indians, and 145% for Asians and Pacific Islanders.¹ Given the influence of cultural beliefs and preferences on the experience of serious illness and death,^{2,4} and the disproportionate burden of pain,⁵ disability,^{1,6} and advanced disease^{1,7-9} among some minority groups, research aimed at eliminating racial and ethnic disparities in palliative care is essential. As the evidence base for the benefits of palliative care continues to grow¹⁰⁻¹⁴ it is imperative that these services are equally accessible, of similar quality, and meet the needs of older adults of all races and ethnicities.

Available Evidence on Racial and Ethnic Disparities in Palliative Care

Broadly defined, disparities in health care are differences in the presence of disease, health outcomes, quality of care, and access to care that exist across racial and ethnic groups. Health care disparities are widely documented for African Americans and Hispanics compared to whites across a range of diseases, including cancer and cardiovascular disease.⁷⁻⁹ While much of the research in this area has focused on disease

prevention, early diagnosis, and curative treatment, there is growing evidence that racial and ethnic disparities also exist in access to palliative care and in clinical outcomes such as symptom management and communication.^{5,15,16} As in other areas of disparities research, the body of work in palliative care has largely focused on differences between whites and African Americans, and to a lesser extent, Hispanics. The discussion below mirrors this tendency, but also includes what is known about disparities related to other minority groups when data are available.

Disparities in the Quality of Care

A number of studies document lower-quality palliative care for minorities across multiple domains, including satisfaction, communication, and pain management. In a national survey of bereaved family members, surrogates of African Americans were less satisfied with the quality of end-of-life care and more often reported concerns about provider communication.¹⁵ Similarly in other studies, compared to whites, African Americans report less satisfaction with the quality of communication, including the extent to which providers listen and share information, with greater disparities in racially discordant patient-provider relationships.^{17,18} Further, there is evidence from a prospective study of cancer patients that outcomes of communication differ by race, with end-of-life discussions between physicians and their African American (versus white) patients less likely to result in care consistent with patient preferences.¹⁶ A large body of research documents disparities in the assessment and treatment of pain for African Americans and Hispanics versus whites across age groups, diagnoses, and settings, with similar trends for Asians

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and Native Americans in nursing homes. Also, minorities face challenges in access to pain medicines, as pharmacies in some predominantly minority neighborhoods are less likely to stock adequate supplies of opioids.^{5,19}

Other research on disparities in outcomes of care for seriously ill patients has examined differences in the intensiveness of care and documentation of treatment preferences. Compared to whites, minorities are more likely to die in the hospital, and African Americans and Hispanics are more likely to be hospitalized and to receive intensive aggressive care in the last six months of life.^{20,21} While there are some inconsistencies, in most studies, compared to whites, African Americans, Hispanics, and Asians are less knowledgeable about advance directives and less likely to complete them.²²⁻²⁴

Disparities in the Use of Palliative Care Services

Studies consistently document lower rates of hospice use for minority older adults than for whites across diagnoses, geographic areas, and settings of care, including nursing homes.²⁵⁻³¹ Among Medicare beneficiaries who died in 2010, 45.8% of whites used hospice compared to 34% of African Americans, 37% of Hispanics, 28.1% of Asian Americans, and 30.6% of Native North Americans.³² Data on disparities in the experiences of minority hospice enrollees are limited. There is some evidence that disparities in the quality of care are smaller between whites and African Americans enrolled in hospice compared to those in the general population.³³ Other studies document higher rates of hospice disenrollment for African Americans than whites and more concerns about care coordination and quality among hospices with a higher proportion of African American enrollees.³⁴⁻³⁶ Overall, hospice lengths of stay tend to be similar across racial and ethnic groups or longer for minorities than whites.^{34,37,38}

Research is minimal on disparities in the use of nonhospice-based palliative care. Small studies of home-based palliative care and inpatient palliative care consultation have reported favorable outcomes for African Americans, Hispanics, and Asians/Pacific Islanders, including increased satisfaction, greater rates of home deaths and hospice referrals, and increased documentation of treatment preferences.³⁹⁻⁴² In contrast, a single study of cancer patients at a supportive care clinic found persistent disparities in symptom burden, with Hispanics and African Americans less likely than whites to report improvement in pain or fatigue at follow-up.⁴³

Factors Contributing to Disparities in Palliative Care and Interventions

Factors contributing to disparities in the use of palliative care are not well understood. Research in this area has focused on racial and ethnic differences in knowledge, cultural beliefs, and treatment preferences as barriers to the use of palliative care. Studies document a disproportionate gap in knowledge about palliative care among minority older adults.⁴⁴⁻⁴⁸ Other research suggests that among African Americans in particular, spiritual and religious beliefs may conflict with the goals of palliative care, and mistrust of the health care system due to past injustices in research and ongoing disparities may lead to concerns about forgoing curative care as required by the Medicare Hospice Benefit.^{49,50} Further, studies consistently document greater preference for life-sustaining therapies

regardless of prognosis among African Americans and Hispanics compared to whites, while preferences for Asians vary with acculturation.^{3,22,51} However, research suggests that among African Americans with advanced cancer stated preferences for care are not consistently related to actual treatment received.¹⁶ Other cultural beliefs that may present a barrier to the use of palliative care include less positive attitudes toward disclosure of terminal illness among Asians and Hispanics.²² While empiric research is minimal, potential organizational barriers to the use of palliative care by racial and ethnic minorities include the absence of minority staff, interpreters, and community outreach to diverse communities.^{52,53}

There are few studies of interventions to reduce disparities. Research has included the development of culturally competent hospice educational materials,⁵⁴ videos to improve health literacy,^{55,56} and patient navigation to address disparities in care for African Americans and Latinos.⁵⁷ Other work has examined how peer support can extend care to African Americans with advanced cancer.⁵⁸

Content and Methodological Gaps

Although there is increasing interest in disparities in palliative care, the overall body of research is narrow in focus. There are limitations and gaps in which groups have been studied, what has been studied, and how the research has been conducted.

As in research in health care disparities in general, studies in disparities in palliative care have largely focused on African Americans and to a lesser extent Hispanics, the two largest minority groups; there are considerably fewer studies that include other minorities. Additionally, cancer patients, often in outpatient settings, are relatively well represented in the current literature, while there is less research examining disparities in palliative care for minority older adults with other highly prevalent conditions, such as heart failure or dementia, or across care settings, such as nursing homes or assisted living facilities. Despite the importance of informal caregivers in assisting with decision making and providing care, particularly for minority older adults, there is little research examining disparities in their experience.

Although there is a sizable body of literature documenting disparities in hospice enrollment, data on racial and ethnic disparities in access to and use of nonhospice-based palliative care are lacking. There are few studies examining disparities in quality (e.g. symptom management, psychosocial support) for those receiving hospice or nonhospice-based palliative care. There are even fewer studies examining potential determinants of disparities or variability within rather than between racial and ethnic groups. That is, little research has attempted to identify moderators and mediators of disparities among patients (e.g., health literacy, socioeconomic status); providers (e.g., communication skills); organizations (community partnerships); or regions (supply of other health care resources). Studies of the rigorous development and testing of interventions with measurement of outcomes, such as reduced disparities or improved quality, are also absent.

There are significant methodological limitations in the published work. The most commonly used methods include small to large secondary data analyses, retrospective studies of surrogates, qualitative studies of patients' beliefs and preferences, cross-sectional analyses of small convenience

TABLE 1. RESEARCH PRIORITIES FOR RACIAL AND ETHNIC DISPARITIES IN PALLIATIVE CARE

<i>Research priority</i>	<i>Objective</i>	<i>Setting</i>	<i>Sample</i>	<i>Design</i>
Detecting disparities	Examine disparities in utilization of nonhospice-based palliative care Examine disparities in the quality of hospice- and nonhospice-based palliative care	Inpatient Outpatient Long-term care Home-based	Racially and ethnically diverse older adults with serious illness	Secondary analysis of large datasets (e.g., Medicare claims, health system data) Prospective or retrospective studies of patient and caregiver experiences using appropriate quality measures
Understanding the determinants of disparities	Identify modifiable factors associated with disparities in utilization and quality of palliative care			Prospective, longitudinal studies of seriously ill patients with collection of potential moderators and mediators of disparities across multiple levels—patient, provider, health system, health policy
Eliminating disparities	Develop and test interventions to reduce disparities in utilization and quality based on evidence resulting from research in understanding disparities			Pilot studies, randomized control trials, and pragmatic trials of patient, provider, community, health system, and health policy interventions

samples, and surveys with investigator-developed measures, often with little validation in minority groups. Many studies do not report race and ethnicity discretely and include only a small number of minority older adults and so have inadequate power to examine differences in outcomes by age (≥ 65 versus < 65) and race or ethnicity. While plentiful, studies examining cultural beliefs and preferences that may impact decision making have often included only community dwelling, well, older minority adults rather than those with serious illness actively facing treatment decisions. The absence of prospective, longitudinal studies including adequate numbers of seriously ill minority older adults with appropriate measurement of patient, provider, and health system or organizational variables does not allow for a full exploration of factors that may contribute to racial disparities or provide an evidence base for the design of effective interventions.

Priorities for Future Research

Research on health care disparities includes three phases: detecting differences in health and health care, understanding the determinants that underlie disparities, and intervening to eliminate them.⁵⁹ Given gaps in current work, efforts to reduce disparities in palliative care for older adults necessitate research in all of these phases. Table 1 lists priorities for future research in each area. The success of this work will depend on the ability and commitment of palliative care researchers to recruit racial and ethnic minority study participants. This is especially challenging considering the difficulty of enrolling seriously ill patients in research in general, and the lower rates of re-

search participation among minorities. Recruiting and retaining adequate numbers of minorities will require multisite study designs and targeted strategies, such as community engagement, culturally diverse staff, clear articulation of benefits of research, and other efforts to address barriers to participation.⁶⁰

Detecting disparities in palliative care

Most of the work in detecting disparities in palliative care has focused on hospice. With the growth in nonhospice-based palliative care, one priority is to examine disparities in access to and use of these services. Secondary analyses of existing large datasets (e.g., Medicare claims, health care system databases) are often used to examine differences in service utilization; however, in some cases this will require more consistent documentation and coding of palliative care encounters for seriously ill patients across settings of care. Additionally, because of variation in the presence and extent of disparities, similar analyses of smaller populations of racially and ethnically diverse older adults within a common region, health system, state, or community are also useful for identifying best practices (no disparities) and targeting areas for intervention (large disparities). This work should move beyond simply documenting disparities in utilization to examining disparities in quality—that is, determining whether there are equally favorable outcomes for all older adults who access palliative care. Using prospective or retrospective study designs, this work should examine disparities in appropriate measures of quality (e.g., symptom management, communication, psychosocial support) for seriously ill older adults and their caregivers of all

racess and ethnicities across care settings (nursing home, inpatient, home, hospital).

Understanding the determinants of disparities in palliative care

Research is needed to understand the determinants of disparities in palliative care. This work should include prospective, longitudinal studies of seriously ill patients actively involved in medical decision making who are receiving or who may benefit from palliative care. Studies in this phase should measure potential moderators and mediators of disparities at multiple levels: patient (e.g., sociodemographics, preferences, spiritual beliefs, illness severity, knowledge, acculturation); provider (e.g., knowledge, attitudes, bias, communication skills); and health care system or organization (e.g., community outreach, racial/ethnic makeup of staff, goals and culture pertinent to diversity and inclusion). These studies should also consider the context in which palliative care is provided, including setting of care, regional factors associated with treatment intensity (e.g., supply of other health care resources), health care policies and models for providing palliative care. With an eye towards intervening to improve the delivery of palliative care for minority older adults of all racial and ethnic groups, research in this area should rigorously examine those factors that may be most amenable to change via well-designed interventions (i.e., health literacy, communication skills, models of care).

Eliminating disparities

The ultimate goal of research in health care disparities is to reduce or eliminate them. Ideally, the work proposed above in understanding modifiable factors associated with disparities in palliative care should inform areas for intervention. One important priority in this area is to develop and test models of care that accommodate a range of cultural beliefs and values and integrate palliative care across the continuum of care. Rather than supporting a narrow approach to the provision of palliative care (e.g., care focused on either cure or comfort), these models should consider the varied needs and preferences of older adults across and within racial and ethnic groups. Other research priorities include the development and testing of interventions based on existing and evolving evidence in the field and successful interventions in other areas of health care disparities, targeting patients, providers, organizations, health systems, and policy.⁵⁸ Examples include efforts to increase patient knowledge about palliative care, improve health literacy, address language barriers for specific groups of older minorities, improve provider communication skills, and promote community-based partnerships with stakeholders and leaders in minority communities while increasing access to resources to support the delivery of palliative care (e.g., availability of pain meds). These studies should move towards measuring the effect of the interventions at reducing disparities and improving the quality of care, not just intermediate outcomes such as improved knowledge or skills.

Although reducing and eliminating disparities is an important priority, improving the care of seriously ill older adults requires that we not only examine differences in utilization and quality between racial and ethnic groups but that we also examine outcomes within groups. Even in the absence

of disparities, interventions are needed to improve care when outcomes are similarly poor for whites and minorities, such as similarly low rates of hospice enrollment for whites and African Americans in a common geographic area. Models of care that demonstrate favorable outcomes across racial and ethnic groups should be tapped for their ability to serve as best practices. Where outcomes are poor for one group and not another, interventions should target that group.⁶¹ Finally, work to eliminate disparities cannot end with developing and testing interventions in the context of rigorous research designs, but must move to implementing interventions in real-life settings and communities, evaluating their effectiveness, and refining them to meet the needs of their target group.

Conclusions

Existing research documents disparities in palliative care for minorities living with serious illness; however, there are significant gaps in content and methodological limitations in the current body of work. Additional research is needed to examine differences in utilization and quality of palliative care, understand the determinants of disparities, and develop and test interventions to reduce disparities and improve the care of seriously ill minorities. This work should consider the full spectrum of racial and ethnic groups, across diagnoses and settings of care. Efforts to reduce disparities should target patients, providers, health systems, communities, and health policy and ensure that new models of care accommodate the range of needs and preferences of a rapidly growing racially and ethnically diverse population of older adults.

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