

# Disparities in Palliative Care in Patients With Cancer

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In the United States, racial and ethnic minorities and people with lower socioeconomic status (SES) face structural, health system, and interpersonal barriers to optimal health care, including palliative care. Much of the available data on palliative care in racial and ethnic minorities and people with lower SES have identified disparities according to race, ethnicity, and SES. Limitations to understanding disparities in palliative care include the fact that much of the available data are cross-sectional, drawn from administrative or claims data, or based on qualitative work in limited geographic areas. To advance our knowledge and achieve health equity with respect to palliative care in patient groups that have been understudied or that are known to receive disparate care, gaining a deeper understanding of the barriers to palliative care is necessary from patients, families, referring providers, and communities. In addition, cultural competency training for all members of the palliative care team and referring providers needs to be changed from being obligatory to being intentional and assessed continuously. Finally, concerted changes in coordination of care, payment structures, and policy are needed.

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## INTRODUCTION

Disparities in palliative care according to race, ethnicity, and socioeconomic status (SES), as well as other categories of people at risk for disparate care, have received little attention in the literature. Nonetheless, there is emerging evidence that there are differences in care for black, Hispanic, and Native American patients and people with lower SES compared with non-Hispanic white patients and those with higher SES. Data are lacking regarding disparities in palliative care in other marginalized people, such as people with disabilities, including mental illness, immigrants, people with low English proficiency, and sexual and gender minorities. However, it is important to consider that these groups face the same structural, social, and economic barriers and need to overcome unique difficulties with navigating an increasingly complex medical system with respect to palliative care.

Different terms have been used to describe people and populations who face barriers to optimal care. The term *vulnerable* is often used to describe people who are at risk for worse health outcomes and often refers to a person's characteristics, such as advanced age, geographic region, or chronic health conditions. The term structural vulnerability refers to the environmental, social, economic, and political forces that render people vulnerable. Although the term *underserved* is often used, disparities persist even when services are available. Disparities are attributable to

more than just provision of services; rather, they are the result of discrimination, stigma, differences in the quality of education to patients provided by clinicians, differences in beliefs between clinicians and patients and their families, and a host of other factors. *Marginalized* is another word used to accurately describe people who live on the edges of society with little voice or power to change the systems in which they have lived for most or all of their lives.

Although groups of people are often talked about in aggregate with statements such as, "Black people prefer more aggressive treatment at the end of life," it is critical that observational data about patient groups not be applied to individuals. It is essential to acknowledge the marked heterogeneity within groups to avoid reinforcing stereotypes and to provide individualized care. In addition, although they may not

## DEFINITION OF DISPARITIES

The definition of disparities used throughout this article is the one used by the Department of Health and Human Services, which defines health disparities as differences in health outcomes that are closely linked with social, economic, and environmental disadvantage and are often driven by the social conditions in which individuals live, learn, work, and play.<sup>1</sup>

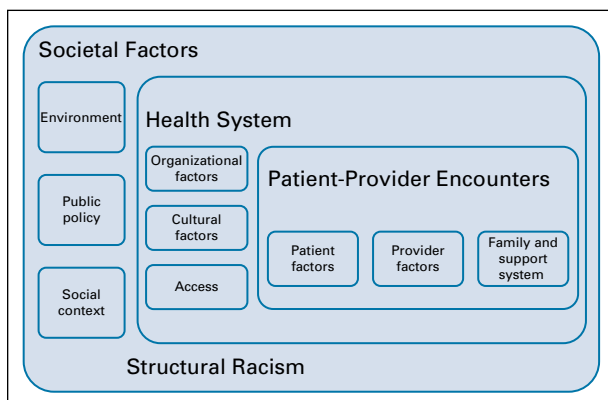
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be aware of it, clinicians practice within the culture of medicine and from their own individual culture, both of which influence their beliefs about their patients and their behavior toward patients.<sup>2-4</sup>

Figure 1, based on Kilbourne et al,<sup>5</sup> illustrates how environmental factors, policies, and the social environment have an impact on health and on health care disparities. Each of the domains offers both opportunities for or barriers to optimal palliative care. Briefly, societal factors include the physical environment, public policy, and the social context. The social context includes the degree of social cohesion, residential segregation, and other neighborhood factors that will promote or impede the safety of its residents and home health care workers providing palliative care. It also includes structural racism, which refers to the ways in which society has developed to favor and improve the well-being of white people.<sup>6-8</sup> The health care system within that society has its own organizational, cultural, and access factors. Examples of health system factors include availability of transportation and translators, payment policies for people with lower SES, and availability of social workers for patients in need of palliative care. Finally, the patient-clinician relationship is ideally characterized by trust, cultural competence on the part of the clinician, strategies to improve patients' health literacy, and the ability to build rapport. Any of the societal, health system, or patient-clinician factors can pose barriers to receipt of palliative care. More often than not, marginalized groups face multiple barriers.

This article will give an overview of the literature regarding disparities in receipt of palliative care and symptom management, identify gaps in knowledge with respect to this area, and suggest future directions for practice and research. When available, data regarding palliative care among other marginalized groups will be included.



**FIG 1.** How environmental factors, policies, and the social environment affect health and health care disparities. Based on Kilbourne et al.<sup>4</sup>

## DISPARITIES IN RECEIPT OF PALLIATIVE CARE

### Outpatient Palliative Care

Patients who are members of racial and ethnic minority groups and those of lower SES receive outpatient palliative care services less often than do non-Hispanic white patients. The available literature on outpatient palliative care consultations suggests that black patients<sup>9</sup> and Native American/Alaskan Native patients<sup>10,11</sup> are less likely to receive outpatient palliative care. Little is known about referral patterns and uptake of outpatient palliative care among Hispanic or Asian populations in the United States.<sup>12</sup>

SES, whether measured via individual or area-level measures, is also associated with greater symptom burden.<sup>9</sup> In a sample of 482 patients with advanced disease seen at an academic cancer center over 5 years, the association between insurance status and several palliative care outcomes was studied. Outcomes included the timing of referral to the supportive care clinic relative to the diagnosis, pain and opioid use at the time of consultation, and the number of visits to the clinic. Pain scores, total opioid use, and number of visits to the clinic were significantly higher among the uninsured and patients with Medicaid compared with those with private insurance. There was no difference in time to referral.<sup>9</sup> The higher level of pain suggests that, despite more visits to the clinic, patients with lower SES were not receiving relief of their symptoms. It is possible that less effective communication between clinician and patient, uninsured patients' inability to afford medications other than opioids, and unmeasured factors unrelated to the cancer diagnosis, such as perceived discrimination,<sup>13</sup> may contribute to the differences in pain scores.

Among those with lower SES, homeless people have unique challenges.<sup>14-16</sup> In addition to the stigma associated with homelessness, qualitative work has identified specific barriers to accessing palliative care, including lack of a permanent address, lack of a usual source of care, lack of family and social support, and fears of dying anonymously and alone.<sup>16</sup>

### Inpatient Palliative Care Consultation

Several studies have indicated that inpatient palliative care consultations are more common among black than white patients.<sup>17-19</sup> For example, in a study of nearly 68,000 women with gynecologic cancer in the National (Nationwide) Inpatient Sample (NIS), several factors were associated with receipt of inpatient palliative care. After controlling for clinical and nonclinical factors, black patients had 22% higher odds of having a palliative care consultation compared with white patients.<sup>17</sup>

In a study of > 4 million hospitalizations in the NIS from 2005 to 2014, the likelihood of adult black patients with advanced cancer having a palliative care consultation was

20% higher than for white patients.<sup>18</sup> In addition, among those who died in the hospital, more minority patients had received palliative care consults. The odds were 30% higher for black, 13% higher for Hispanic, and 20% higher for Asian or Pacific Islander patients compared with non-Hispanic white patients.<sup>18</sup>

In a single-institution report of > 6,000 patients with cancer treated in an urban hospital, investigators identified patients who were eligible for inpatient palliative care consultations. The investigators found that 16% of white patients, 22% of black patients, and 20% of Hispanic patients had an inpatient consultation. The adjusted odds of black patients receiving an inpatient palliative care consultation were 20% higher than for whites.<sup>19</sup> In addition, the time between the consultation and death was longer for black patients than for white patients by a week, suggesting that consults were requested earlier in the hospital stay for black patients than they were for whites.<sup>19</sup>

Inpatient palliative care consultation may increase the likelihood that advance directives are completed among black and Hispanic patients.<sup>13,20</sup> In a retrospective palliative care database study of 1,999 patients from 1 institution, the proportion of patients who had completed do not resuscitate (DNR) paperwork increased from 20% at admission to 65% at discharge in black patients and increased from 16% on admission to 70% at discharge in Hispanic patients.<sup>13,20</sup> The study did not include non-Hispanic white patients, however, so it is not possible to identify the difference that would have occurred in white patients. In addition, only 35% of the patients had a cancer diagnosis. Nonetheless, the marked increase in the proportion of patients who had completed DNR orders suggests that end-of-life and advanced care planning discussions by palliative care specialists could narrow the racial and ethnic gap in use of extreme measures at the end of life.<sup>13</sup>

In summary, hospitalized minority patients with advanced cancer, particularly black patients, are more likely to have inpatient palliative care consultations and, in one study, were more likely to have a consult earlier in the course of their hospitalization. Such consultations appear to be effective in end-of-life planning in patients who are seriously ill, and it is possible that palliative care consultations may reduce overuse of futile measures. Observational studies using large databases are prone to bias because of unmeasured confounding factors, and exclusion and other factors may likewise introduce selection bias. Such studies are generally considered hypothesis generating. There is no research available to explain the higher consultation rates in racial and ethnic minorities, but one might speculate that specialty-trained palliative care experts are asked to help with what are often referred to as difficult conversations when the patient and clinicians are discordant in terms of race and ethnicity. Research to test this and alternative

hypotheses will be important in informing interventions to introduce palliative care in the inpatient setting.

It is likely that access to palliative care in the inpatient setting is greater than in the outpatient setting because patients are already admitted into the health system and have access to multiple health care providers. This is in contrast to outpatients, who face multiple barriers to accessing care, sometimes even being unable to find a primary care clinician.

## DISPARITIES IN SYMPTOM MANAGEMENT

The available research on disparities in symptom management and overall symptom burden is limited. Many of the symptoms that palliative care specialists manage and treat have not been systematically studied in other marginalized groups.

### Pain and Overall Symptom Burden

In a cross-sectional study of nearly 600 patients admitted to home health care, non-Hispanic black patients and Hispanic patients had greater pain, including more sites of pain and greater pain intensity, and pain-related disability than did non-Hispanic white patients.<sup>21</sup> In this same study, depression, which was more prevalent among Hispanic and black patients, was associated with higher levels of pain-related disability.<sup>21</sup>

A cohort study of 980 patients seen at a supportive care center of a major academic cancer center identified a higher symptom burden among non-Hispanic black patients and Hispanic patients at their first visit compared with non-Hispanic white patients. Equally concerning, although white patients had improvement in their symptom burden when seen during their first follow-up visit, minority patients did not.<sup>22</sup>

Native Americans are underrepresented in the cancer literature in terms of pain and symptom management, and there is no information regarding the symptom burden among Native Americans compared with other groups. Symptom management in Native Americans may be complicated by poor patient-provider communication, language barriers, low health literacy, poor care coordination, and lack of self-efficacy, which in turn leads to poor uptake of self-management strategies for pain and other symptoms.<sup>23</sup> As with Native Americans, there are few data regarding symptom management in Asians and Pacific Islanders, people of different faith traditions, and other marginalized groups.

### Depression, Anxiety, and Sleep Disturbance

Depression, anxiety, and sleep disturbance are common among patients with cancer. The SEER-Medicare database was used to investigate racial differences in the use of supportive medications for the treatment of these symptoms in a large sample of patients with advanced cancer.<sup>24</sup> Supportive medications included opioids and nonopioid

psychotropic medications, such as antidepressants, anxiolytics, and nonbenzodiazepine sleep aids, used in the 90 days after diagnosis. Black women were equally likely to receive opioids but significantly less likely to receive non-opioid psychotropic medications after controlling for clinical and nonclinical factors.<sup>24</sup> Because the data on prescriptions came from claims data, it is not possible to know whether clinician prescribing behavior or information support given to patients regarding new medications, patients' prescription fill rates, or structural problems, such as transportation and high copayments, accounted for the differences in prescription medication use.

In another analysis of supportive medication use in the SEER-Medicare database, patterns of use were investigated in the 3 months after diagnosis according to Hispanic ethnicity and nativity. Four groups of women with stage I-IV breast cancer were compared: US-born/non-Hispanic, US-born/Hispanic, foreign-born/Hispanic, and foreign-born/non-Hispanic. Supportive medications included opioids and nonopioid psychotropic medications, such as antidepressants, anxiolytics, and nonbenzodiazepine sleep aids. For nearly every type of medication, foreign-born/non-Hispanic women were least likely to have claims for these supportive care medications than the other groups. Compared with the other groups, US-born/Hispanic women were most likely to fill prescriptions for supportive medications. The findings did not change after adjustment for SES or after repeated analysis without patients with stage IV disease.<sup>25</sup> As with the database study described earlier, physician behavior, patient behavior, or structural barriers, or all three, could explain the differences in prescription claims.

### Nausea and Vomiting

Prevention of nausea and vomiting is a priority for clinicians and patients alike. A study evaluated use of oral NK1 receptor antagonists for the prevention of nausea and vomiting among 1,130 Medicare beneficiaries with breast cancer receiving adjuvant chemotherapy with high emetic risk.<sup>26</sup> Black women filled prescriptions for oral NK1 receptor antagonists at a significantly lower rate. After adjusting for individual and area-level SES, however, the racial differences were no longer significant.<sup>26</sup> The same limitations of claims-based databases described earlier apply to this study, but this study demonstrates how the intersection of race and lower SES plays out in the palliative medications that poorer black women receive.

Two qualitative studies, one involving Hispanic patients and non-Hispanic black patients<sup>27</sup> and the other involving Hispanic patients,<sup>28</sup> have identified patient and family beliefs that may make collaborative management of pain and other symptoms unique in some minority populations. For example, the community participants had concerns about revealing suffering to others,<sup>27,28</sup> including their health care providers, becoming addicted to prescription

medication, and developing tolerance to pain medication.<sup>27</sup> In addition, in a pilot study designed to understand the impact of culture on pain management in Hispanic patients with cancer, the investigators identified a preference for nonpharmacologic strategies, such as relaxation, distraction, massage, heat or cold, and home remedies.<sup>28</sup> In symptom palliation, exploring patient and family beliefs when prescribing medication is likely to increase acceptance.

In summary, in the palliation of symptoms in patients with cancer, disparities appear to be present according to race and ethnicity in overall symptom burden and the degree to which symptoms are effectively treated. Qualitative work suggests that culture plays a role in how people interpret and manage symptoms. An awareness of and respect for peoples' beliefs, as well as an understanding of barriers to care, including costs of care, are critical in addressing disparities in palliative care. This applies not just to racial and ethnic minorities, but also to other marginalized groups.

### LIMITATIONS AND FUTURE DIRECTIONS

Limitations in understanding disparities in palliative care are the result of small sample sizes, particularly samples of minority groups. In addition, as described earlier, administrative databases have limitations. Much of what we know about disparities in palliative care referral patterns is based on cross-sectional studies using observational or retrospective databases. The lack of longitudinal data and the inability to control for unobservable confounding factors decrease the ability to draw causal inferences from these studies. In those studies that do address disparities in palliative medication use, it is not possible to determine the mechanism for disparities.

Finally, the body of work that addresses culture-specific beliefs, experiences, and preferences to inform culturally tailored palliative care is, for the most part, based on small sample sizes in a limited geographic region or a single health system. With few exceptions, the findings have not been confirmed in larger samples, nor have the interventions been adapted for other groups of people.<sup>29</sup>

Addressing disparities through the development of robust quality measures in palliative care, particularly patient- and caregiver-reported measures, may help identify specific areas for improvement.<sup>30</sup> Involvement of diverse populations in the selection, development, and testing of quality measures will be essential to avoid further marginalization of those who have been left out of decision making in health care. Organizations and payment mechanisms that support practices that provide care for minority and poorer patients with quality improvement and resources will increase engagement of these often overwhelmed and under-resourced practices.

Widespread differences in experiences among racial and ethnic minorities and those of different cultures and faith traditions, including obstacles to care, social stressors, and stigma, clearly require that providers acquire what has been called “cultural competence.” One-time cultural competency programs that address bias against racial minorities are available (or mandated) through many workplaces although there is no evidence that they have been effective in improving health equity.

In addition to addressing race and culture, cultural competence is required in caring for all marginalized patients, particularly with respect to those conversations that happen when providing palliative care. There are multiple calls in the literature for specific training in cultural competence to

understand the roles that culture and faith traditions play in how patients think about symptom management, advance care planning, and end-of-life care.<sup>27,28,31-34</sup> Developing a deep understanding of these factors for people in a particular region or service area may increase the likelihood that patients’ needs are met and suffering is relieved. Cultural competence includes an understanding of structural racism.<sup>6-8</sup>

Other steps that will address disparities in palliative care include increasing racial and ethnic diversity among palliative care specialists. Finally, inclusion, rather than omission, of community members in community-based participatory research is more likely to lead to long-standing change.

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## AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

Disclosures provided by the author and data availability statement (if applicable) are available with this article at DOI <https://doi.org/10.1200/JCO.19.02108>.

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#### **AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**

##### **Disparities in Palliative Care in Patients with Cancer**

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