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Inequitable Access to Palliative Care

Palliative care enhances the quality of life for patients, their families, and caregivers dealing with challenges associated with life-threatening diseases. It is a bedrock of the American healthcare system, as its structure is built on a holistic, multidisciplinary approach to provide relief of physical, psychological, and social suffering. There has been a steady growth in palliative care in the United States from 25% to 75% of hospitals with over 50 beds from 2000-2005. Despite this growth, there are still inequities seen with ethnic minorities and individuals with lower socioeconomic status systematically having the least palliative care infrastructure, while also receiving lower-quality palliative care even when services are available.

Ethnic, racial, and socioeconomic disparities create significant and continuous multifaceted barriers to palliative care. Namely, racial and ethnic disparities extend through multiple dimensions, whether it's pain management, palliative care encounters, advance directive completion, or opioid prescribing near the end of life. These factors are even further compounded by historical medical mistrust, cultural perceptions, socioeconomic status, and education, which create additional layers of disadvantage.

Therefore, effective interventions to tackle the inequitable access to palliative care will rely simultaneously across structural, institutional, and individual levels, which include expanding primary as well as community-based palliative care models and initiating policy and payment reform.

Unfortunately, palliative care continues to have significant racial and ethnic disparities that impact patients' quality of care. Black and Hispanic/Latino patients commonly experience increased symptom severity but have a decreased likelihood of having their pain properly assessed and managed. These individuals frequently report having a lower quality of life throughout their illness. Similarly, inequities persist within the management of chemotherapy-related side effects. This emphasizes the notion of gaps in symptom control and access to supportive care.

These disparities are present in advance care planning. When compared to White patients, Black, Hispanic/Latino, Asian American, and Pacific Islander patients are less likely to complete advance care directives, discuss end-of-life wishes, and identify a healthcare proxy. These differences are often affected by cultural and religious beliefs, limited/lack of culturally sensitive communication, discomfort in discussing these topics, and mistrust of the healthcare system. Alone, written directives do not always lead to improvements in end-of-life outcomes, but these discussions focus on the patient's goals, values, beliefs, and preferences, which have been shown to support patient-centered care and reduce unnecessary aggressive interventions.

Understanding the racial and ethnic disparities of palliative care requires one to account for a multitude of different factors. These disparities are multi-leveled, including the patient (social determinants of health, language, spiritual and religious beliefs, culture, health literacy, and illness severity), the healthcare provider (communication skills, biases, attitudes, and knowledge), and the healthcare system/organization (diversity, equity, and inclusion of the staff, staff education, and community outreach). Future research should focus on developing and implementing interventions to alleviate these inequities, ensuring that high-quality palliative care is available and accessible to all patients.

Social determinants of health play an important role in accessibility to palliative care, patient preferences, the family decision-making process, and patients' values. Factors such as socioeconomic status, health literacy, education, insurance coverage, language proficiency, geographic location, religion, and social support influence not only access to palliative care services but also the quality and timing of care received. Evidence suggests that patients from historically marginalized communities are less likely to receive timely palliative care referrals, despite experiencing similar or greater symptom burden than other populations. Structural barriers, including limited specialist availability in rural and underserved areas, financial hardship, transportation challenges, and language discordance, further widen these disparities. Additionally, cultural beliefs, previous experiences with the healthcare system, and mistrust stemming from historical inequities may influence patients' willingness to engage in palliative care or advance care planning. Importantly, disparities in palliative care are driven by inequities within healthcare systems rather than differences in patient need. Ethical palliative care therefore requires clinicians to recognize how social determinants shape decision-making and to individualize care in ways that respect each patient's cultural background, values, and goals.

Incorporating culturally responsive communication, addressing barriers to health literacy, and partnering with community resources can improve patient engagement and support shared decision-making. Advancing health equity in palliative care also requires system-level interventions, including equitable referral practices, workforce diversity, and policies that address structural inequities. By integrating social determinants of health into clinical practice, healthcare professionals can better uphold the ethical principles of justice, beneficence, and respect for patient autonomy.

Palliative care provides essential, holistic care for patients with serious illnesses by addressing their physical, spiritual, and emotional needs while also supporting their caregivers and family members. Physicians must incorporate discussions on pain management and end-of-life care early when speaking with patients with serious, life-limiting illnesses. Early discussion helps deter misconceptions about palliative care being a total withdrawal of curative treatments for patients. Speaking with patients and their loved ones improves understanding of palliative care's function to improve patients' quality of life while continuing targeted disease treatments. As well as offers providers the opportunity to learn about a patient's treatment goals, spiritual beliefs, and designation of surrogate decision makers. It is vital that physicians recognize patients who may benefit from palliative care services early on to limit frequent hospitalizations and high symptom burden on patients and their caregivers. Learning about the local community palliative / hospice organizations and healthcare systems' home-based, inpatient, and outpatient palliative care services is vital in ensuring patients are provided the most accurate resources available to them. Beyond the referral to palliative care services, providers have the responsibility to routinely screen for barriers in patients receiving healthcare services. Discussion with patients and their caregivers about language interpretation services, housing stability, transportation accommodations, and financial concerns to ensure that patients can access or continue to access palliative care services.

Reflection Questions

- What ethical responsibilities do healthcare systems have to reduce disparities in access to palliative care for historically marginalized and underserved populations?
- How can clinicians balance respect for patients' cultural values and beliefs to ensure equitable access to high-quality palliative care?
- In what ways can clinicians engage their patients to discuss palliative care using culturally sensitive communication?
- Given that disparities in palliative care access arise simultaneously from structural inequities, how should interventions be designed to address these interconnected dimensions?
- How can physicians ensure that conversations about palliative care occur early enough for patients to make informed decisions about their treatment goals and quality of life?

Helpful Links

- Get Palliative Care | Resources
- APA | Culturally Diverse Communities and Palliative and End-of-Life Care
- Compassion and Choices | Resources
- National Coalition for Hospice and Palliative Care

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