

Chapter 15

Health Disparities in End-of-Life Care

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Key Points

- High-quality end-of-life care should be available to all individuals faced with terminal illness.
- Differences in end-of-life care that are not driven by informed patient or family preferences may represent disparities in healthcare.
- Disparities in end-of-life care exist across race/ethnicity, socioeconomic status, sexuality, and underlying illness.
- Existing racial/ethnic disparities may be addressed by improving cultural competence among healthcare providers and enhancing communication about end-of-life care for nonwhite patients and their family members.
- Access to care is a major barrier to the delivery of quality end-of-life care to patients of lower socioeconomic status.
- Advance care planning is essential for members of the LGBT community and efforts to ensure equal rights for LGBT surrogate decision-makers must continue.
- Individuals with noncancer diagnoses are at risk for suboptimal palliative and end-of-life care.
- Future research is needed to elucidate mechanisms underlying disparities in end-of-life care and evaluate interventions targeted at improving both patient and family outcomes.

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Introduction

Achieving excellence in end-of-life care requires a multifaceted approach involving high-quality communication, emotional support for patients and family members, and adequate control of patient symptoms during the dying process [1]. Accomplishing these goals is often challenging given the complex nature of medical decision-making at the end of life and the multitude of factors related to providers, patients, and healthcare systems that have the potential to affect delivery of care. For patients and family members, difficult decisions surrounding death and dying are made within a framework that incorporates characteristics unique to each individual. When well-informed patients and family members assert preferences about end-of-life care, differences are to be expected across a heterogeneous population. Thus, the exploration for disparity in end-of-life care often revolves around identifying differences that are not the result of an informed patient's preferences. End-of-life care that involves fewer elements of palliative care, more aggressive life-sustaining treatments, and limited symptom control may not represent preference-driven differences, but may instead represent healthcare disparity. Differences in informed preferences for end-of-life care should be respected, but differences in end-of-life care that are not driven by informed patient or family preferences must be addressed and intervened upon. In the following chapter, we examine differences in end-of-life care relative to gender, race/ethnicity, socioeconomic status (SES), sexuality, and underlying illness and consider explanations for identified differences.

Gender

Many of the described gender differences in end-of-life care relate to the intensity and aggressiveness of life-sustaining treatments provided prior to death and suggest that, compared to men, women are less likely to receive aggressive life-sustaining treatments at the end of life. This has been demonstrated in elderly patients with poor-prognosis malignancies, where women were less likely to receive chemotherapy in the last 14 days of life and had lower rates of in-hospital death [2]. In addition, hospice use appears to differ significantly between men and women, with timelier enrollment [2] and higher utilization among women [3–6]. One potential explanation for these gender differences relates to observed life expectancies of men and women. In general, men live shorter life spans than women [7]. Advanced age is associated with a higher prevalence of both chronic medical conditions and functional limitation [8]. Therefore women, dying at older ages than men, may be more likely to experience a progressive decline in health during their last years of life. Also, elderly women survive longer than men following the onset of significant disability, another factor influencing gender differences in the prevalence of chronic illness [9, 10]. Additional years spent in the setting of severe disability may

influence medical decision-making for elderly women and their family members, potentially prompting a shift away from aggressive life-sustaining treatments at the end of life. However, many of these observed gender differences in end-of-life care remain after adjustment for age, suggesting that differences in life expectancy do not completely explain these associations. Other factors are likely to be influential and thus must be examined when considering the potential for disparity.

Gender Differences in Social Support at the End of Life

Social support for patients and their family members is an important factor influencing quality of care at the end of life, and variation in levels of social support among men and women offers another potential explanation for observed gender differences in end-of-life care. Spousal support is a common source of informal caregiving for terminally ill patients, and marital status has been posited as an important mediator of the relationship between gender and many facets of end-of-life care [11]. Men frequently rely on female spouses for care at the end of life [12]. In contrast, elderly women are more likely than men to be widowed and often rely on other avenues of support [13]. Among lung cancer decedents, women were more likely to use social supportive services than men in the last year of life, potentially reflecting less robust informal caregiver support [14]. These differences in support systems may influence location of death [15] and this in turn may affect the characteristics of care provided to men and women at the end of life. The presence of gender differences in social support among elderly adults should prompt healthcare providers to ask specific questions regarding the availability of both formal and informal caregivers for patients with chronic illness and limited life expectancy. Furthermore, support should not only be assessed for the patient but also for the primary caregiver. The role of primary caregiver is often assumed by women, and evaluations of caregiver experiences suggest that women are more likely to report caregiver strain [16, 17]. Understanding the interplay between gender and social support may assist in addressing caregiver burden while also ensuring that adequate networks are in place to help achieve end-of-life care goals for dying patients and their family members.

Gender Differences in Preferences for End-of-Life Care

It is important to consider the possibility that men and women have differing attitudes about end-of-life care. Men report more favorable views of life-sustaining measures compared to women [18] and among young adults, men are less likely to report a positive opinion about hospice than women [19]. Whereas women seem more likely to have a higher level of trust in the healthcare system, men are more likely to express concern about incurring harm within the system [20], a sentiment

that may translate into reluctance to utilize hospice and palliative care services and distrust of offers related to limited intervention. In addition to gender differences in attitudes and knowledge about end-of-life care, men and women also demonstrate different understandings of terminal illness. In a study of patients with advanced cancer, when compared with men, women improved the accuracy of their medical knowledge with progression of time and were also more likely to report having conversations about life expectancy with their oncologists [21]. Some of these differences may relate to variability in the styles of communication and emotional support that men and women prefer, but more information is needed to assist in development of a clear understanding of the nature of gender differences in values, beliefs, and knowledge surrounding end-of-life care.

Summary: Gender

Gender differences in end-of-life care are influenced by a complex interplay of age, chronic illness and disability, social support networks, and values and beliefs. It is difficult to know if any of the aforementioned differences represent disparities, but they do represent elements of end-of-life care that may require special attention from providers. Women live longer than men and often face significant functional limitation at the time of death without the support of a spouse. Women also frequently serve as the primary caregivers for their male spouses and may have unrecognized caregiver strain. Concerted efforts to evaluate social support networks for elderly patients and those with chronic illness should be universal, but may require different approaches based upon gender differences. In an ideal setting the achievement of end-of-life care goals would be directed by informed patient preferences and not by life circumstances that affect the social support available to dying patients and their family members. Finally, additional research is required in order to explain observed discrepancies between men and women regarding perceptions of hospice and preferences for aggressive life-sustaining treatments. A better understanding may allow healthcare providers to tailor communication about the nature of palliative and end-of-life care to meet the differing needs of men and women.

Race and Ethnicity

There is significant evidence of racial and ethnic differences in end-of-life care, including differences in communication practices, advance care planning, and the characteristics of care provided prior to death. In addition, attitudes about end-of-life care and patient preferences related to receipt of life-sustaining treatments also differ significantly across race/ethnicity. In general, individuals of nonwhite race/ethnicity receive more aggressive life-sustaining treatments at the end of life. Among patients age 65 and older, African-Americans, Asians, and Hispanic patients

are less likely than whites to have do not attempt resuscitation (DNAR) orders in place within the first 24 h after hospital admission [22], and compared to whites, African-Americans are more likely to be “full code” at the end of life [23] and die in the setting of full support [24]. Observed differences in hospice utilization suggest lower use among patients of nonwhite race/ethnicity [25, 26], and African-Americans who do enroll in hospice are more likely than whites to revoke hospice in pursuit of aggressive care [27] and less likely to return to hospice after leaving [28]. Much of the excess cost of end-of-life care observed for African-American and Hispanic patients has been attributed to ICU admissions and receipt of life-sustaining interventions at the end of life [29]. To understand the observed associations between race/ethnicity and end-of-life care, it is helpful to begin by exploring the relationship between race/ethnicity and communication about end-of-life care.

Differences in Communication about End-of-Life Care by Race/Ethnicity

A fundamental component of quality end-of-life care includes clear communication with patients and their family members about a patient’s medical illness, overall prognosis, and goals of care. In order to make an informed decision about treatment preferences, patients and their family members must be provided with information that facilitates an appreciation of the issues at hand. If this task cannot be accomplished for patients with life-limiting illnesses, the likelihood that they will make informed decisions is low. Active communication between physicians and patients is essential but the quality of this communication may differ by race/ethnicity. In general healthcare settings, African-American patients rate their visits with physicians as less participatory [30], and patients experiencing racially discordant physician interactions engage less with physicians and receive less information during visits [31]. Similar communication disparities have been identified in end-of-life care. Family members of African-American decedents are more likely than those of white decedents to express concerns about being informed or cite absent or problematic communication with physicians [32], and hospitalized African-American patients are less likely than patients of other races to have communication about cardiopulmonary resuscitation (CPR) preferences [33].

Racial/ethnic differences in advance care planning may also be related to inadequate communication with healthcare providers. Compared to whites, African-American and Korean Americans are less likely to have knowledge about advance directives, including living wills and the concept of a durable power of attorney [34]. Though sociocultural differences may play a role in shaping the characteristics of conversations that patients and their family members have with healthcare providers, it is difficult to imagine that individuals of nonwhite race/ethnicity prefer less participatory conversations about end-of-life care or wish to be less informed. A lack of information sharing that leaves patients and family members with limited knowledge about options for treatment and results in decision-making about end-of-life care that is not fully informed would represent disparities in care.

Differences in Preferences for and Attitudes about End-of-Life Care by Race/Ethnicity

Poor quality communication is unlikely to reflect patient preference, but it could be argued that some other observed racial/ethnic differences in end-of-life care do reflect patient choice. Patients of nonwhite race/ethnicity have been consistently demonstrated to prefer more aggressive life-sustaining treatments at the end of life [35–37], and numerous potential explanations have been provided for this observation. Spirituality and religion may factor prominently into end-of-life decisions for many nonwhite patients and their family members, where the concept of miracles and potential intervention from a higher power may promote requests for ongoing aggressive measures and where efforts to limit therapies at the end of life may be viewed as conflicting with deeply held spiritual beliefs [38–40]. Cultural norms regarding the decision-making role of family members may also affect choices made about life-sustaining interventions. For example, among Korean-American decisions regarding life-sustaining measures might be deferred to family members in order to respect the notion of filial piety, even if the patient or family member has their own personal preferences regarding aggressive care at the end of life [39]. Importantly, patient preferences may also be shaped by mistrust in a healthcare system that has participated in mistreatment of individuals of nonwhite race/ethnicity [40, 41].

In addition, negative attitudes about advance care planning have been identified among African-Americans [42], and these attitudes may influence the likelihood that patients complete such planning. Compared to whites, African-American patients are less likely to have completed a living will prior to death or to have appointed a durable power of attorney for health [43–45], and among nursing home residents nonwhite patients are less likely than non-Hispanic whites to have living wills, DNAR orders, or surrogate decision-makers [46–49]. However, there is evidence to suggest that limited participation in advance care planning may not simply be a reflection of patient preference. African-American patients who have conversations about end-of-life care with their physicians are more likely to have DNAR orders in place than those who do not [50]. This would suggest that the failure to actively engage nonwhite patients in communication about end-of-life care might shape the characteristics of the care they receive.

Summary: Race/Ethnicity

Race/ethnicity and culture do play a significant role in shaping preferences for end-of-life care [37, 51], and it is important for healthcare providers to understand these factors in order to provide the best quality end-of-life care for patients and their family members. However, patient preferences alone are unlikely to fully account for racial/ethnic differences in end-of-life care. As previously noted,

communication about end-of-life care plays a significant role in the decision-making process for patients and families, and a lack of information affects the ability to make informed decisions. Mistrust in the healthcare system, coupled with a poor understanding of available palliative care services [52, 53], could potentially be addressed by enhanced communication with patients of nonwhite race/ethnicity. Indeed, interventions to enhance patient understanding of treatment options may attenuate differences in choices about end-of-life care that might otherwise be reflexively attributed to patient preferences [54]. Healthcare providers must make a concerted effort to acknowledge the influence and importance of culture on end-of-life care decision-making, while simultaneously ensuring that the treatment decisions of nonwhite patients and their family members are made in the context of appropriate communication. Given a historical background of racial discrimination and exploitation within the healthcare system, expressed preferences that might result in poor quality of life or limited control of pain and suffering at the end of life should be thoroughly scrutinized before being attributed to sociocultural norms.

Socioeconomic Status

In the study of healthcare outcomes, SES (often measured as income, and/or education level) and race/ethnicity are often related, with similar associations seen between outcomes of interest and these different predictors. However, conflation of SES and race/ethnicity can diminish the importance of each and hinder efforts to improve outcomes for patients and family members. Associations between race/ethnicity and end-of-life care are often found to be independent of SES, and vice versa. Though individuals with lower levels of income and education may experience end-of-life care that shares similarities with the end-of-life care described for individuals of nonwhite race/ethnicity, healthcare providers should take care not to assume that the mechanisms underlying associations between race/ethnicity and end-of-life care are identical to those observed for SES.

Differences in Delivery End-of-Life Care by Socioeconomic Status

Poverty has long been associated with poor quality health and worse healthcare outcomes, and inadequate education and limited access to care may serve as underlying determinants of these outcomes among the poor [55]. In addition to limited access to general healthcare services, evidence suggests that individuals of lower SES also face similar barriers to care at the end of life [56]. Assessments of sociodemographic factors suggest that those of lower SES [26] and those with no or limited insurance [57, 58] underutilize hospice care at the end of life. Although a lack of

financial resources does not preclude enrollment in hospice or utilization of palliative care services, the poor may face challenges not experienced by those with higher SES, including limited access due to out-of-pocket costs associated with hospice care or absence of the social support necessary for hospice care. Similarly, death at home may be difficult for those with few financial resources or limited support systems. Patients with higher SES are more likely to die at home [59], and individuals with lower income who do receive home hospice services are more likely to transfer to another location prior to death [60]. Many individuals with terminal illness would prefer to spend their last days of life at home [61], but this may not be possible for those who lack financial and social support.

Planning and Preferences for End-of-Life Care by Socioeconomic Status

Advance care planning and patient preferences for end-of-life care also differ by SES. Those of higher SES are more likely to participate in advance care planning than those with lower SES [62, 63], an association that may be explained in part by financial planning among individuals with more material assets [62]. Language used in advance care planning documents is another important factor to consider. Lower SES has been associated with inadequate health literacy among older adults [64], and poor literacy may be a significant barrier to completion of legal documents that are often written above a 12th-grade reading level [65]. Health literacy has also been identified as an independent predictor of patient preferences regarding end-of-life care, with individuals of lower health literacy preferring more aggressive life-sustaining treatments [66]. Low health literacy may impair a patient's ability to comprehend information about diagnosis and prognosis, and thus lead to uncertainty in decision-making about end-of-life care [67]. Importantly, efforts to enhance patient understanding through nonverbal approaches may attenuate differences in end-of-life preferences related to low health literacy [66, 67].

Summary: Socioeconomic Status

SES has a wide range of influences on end-of-life care, and those of lower SES represent a vulnerable patient population. The ability to have treatment preferences honored and to achieve a satisfactory quality of dying should not be predicated upon a patient's social status, but differences in end-of-life care across levels of income and education suggest that this is not the reality for many patients and their family members. Improvements in resource allocation will require a broader commitment to equitable end-of-life care from healthcare organizations and financial stakeholders. From the standpoint of healthcare providers, targeted approaches to addressing end-of-life care needs for patients with limited income and education are necessary, and further research is needed to better understand the mechanisms underlying the

observed socioeconomic disparities in end-of-life care. Currently available information regarding the importance of health literacy in the process of informed decision-making supports ongoing investigation into methods aimed at improving the quality of communication about end-of-life care for individuals at a socioeconomic disadvantage.

Lesbian, Gay, Bisexual, and Transgender

Many challenges exist for members of the lesbian, gay, bisexual, and transgender (LGBT) community at the end of life [68]. Despite efforts to affect social and political change, legal restrictions continue to significantly influence end-of-life care for members of the LGBT community, as do social stigmatization and discrimination. For married heterosexual couples, the right of surrogate decision-making may be automatically afforded to either member of a partnership if one member becomes unable to make medical decisions. However, same-sex marriage is not legal in many regions nor are domestic partnerships uniformly recognized, and LGBT individuals may not be identified as surrogate decision-makers for a same-sex partner who is incapacitated by illness or injury [65]. In addition to the fear of being marginalized during and after the deaths of their partners, LGBT individuals in some regions also have to contest with the significant potential for loss of shared financial and property interests, interests that would be recognized for married heterosexual couples. Thus, advance care planning may be necessary both to maintain decision-making authority over the care of a dying loved one and to ensure shared finances and property are not lost at the time of death [69].

In recent years, political action by LGBT individuals affected by legal restrictions on surrogate decision-making has spurred legislation to extend rights for visitation and end-of-life decisions on behalf of same-sex partners [70]. However, significant barriers to quality end-of-life care for the LGBT community remain [71]. In addition to ongoing legal battles to ensure equal care for all, a vested interest in research endeavors directed at LGBT issues in end-of-life care is important. Literature addressing the palliative and end-of-life care preferences of sexual minorities is limited [72], and a better understanding is necessary to improve outcomes for this patient population. When communicating with terminally ill patients and their loved ones, healthcare providers should make a concerted effort to avoid assumptions of heterosexuality in order to support LGBT patients and their family members as they navigate these disparities in end-of-life care.

Underlying Illness

Despite differences in underlying illness, patients with limited life expectancy share a similar need for high-quality palliative care at the end of life. Although the trajectory of terminal illness varies from patient to patient, in many cases overall

prognosis may be similarly poor across a spectrum of disease processes. However, quality of end-of-life care may differ significantly by underlying illness [73]. Specialist palliative care is more commonly utilized for patients with cancer, compared to patients with other life-limiting illnesses such as chronic obstructive pulmonary disease (COPD), heart failure, or dementia [74–77]. Prognostic uncertainty for noncancer patients, particularly those with COPD or heart failure, may serve as a significant barrier to initiation of palliative care [78] yet the failure to discuss treatment preferences may result in more aggressive care at the end of life for patients with noncancer diagnoses. Patient communication needs and concerns may differ according to underlying illness [79], but provision of palliative care or end-of-life care consistent with patient preferences should occur regardless of disease process. A concerted effort is needed to improve the quality of palliative and end-of-life care provided to patients with noncancer diagnoses.

Conclusion

As the population ages and the burden of chronic illness increases, the need for end-of-life care services is only expected to grow. The failure to address existing disparities in end-of-life care will allow continued delivery of suboptimal care and result in poor quality of dying and death for patients with terminal illness. It is important, then, to consider which of the identified differences in end-of-life care across gender, race/ethnicity, SES, sexuality, and underlying illness truly represent disparity (Fig. 15.1). Many of the differences observed across gender may reflect variation in

	Differences in End-of-Life care	Disparities in End-of-Life care
Definitions	Variations in care that reflect informed patient preferences and that cannot be linked to poor clinical outcomes or cannot be evaluated in terms of appropriateness of care	Differences in care that are not attributable to informed patient preferences and can be associated with poorer clinical outcomes
Examples	<p>Gender: use of life-sustaining measures related to longer life expectancies of women compared to men</p> <p>Race/ethnicity: choices about life-sustaining interventions related to religion, spirituality, or cultural perspectives</p>	<p>Race/ethnicity, Underlying illness: less communication about goals of care and treatment preferences</p> <p>Socioeconomic status: reduced access to hospice/palliative care due to insurance status</p> <p>Sexuality: limits placed on ability to act as surrogate decision-makers for partners</p>
Solutions	<ul style="list-style-type: none"> Assess social support for terminally ill patients and their caregivers Advance cultural competence in palliative and end-of-life care Evaluate mechanisms underlying differences to ensure variations in care are simple differences and not disparities 	<ul style="list-style-type: none"> Ensure high quality communication about goals of care and treatment preferences regardless of race/ethnicity or disease process Improve access to hospice and palliative care services for the socioeconomically disadvantaged Establish equal rights for same-sex partners of incapacitated patients

Definitions of differences and disparities adapted from: Rathore SS, Krumholz HM. Differences, disparities, and biases: clarifying racial variations in health care use. *Ann Intern Med.* Oct 2004;141(8):635-8.

Fig. 15.1 Differences and disparities in end-of-life care: definitions, examples, and potential solutions

life expectancy and comorbidity among women and men, though evidence of gender differences in social support systems and caregiver roles should prompt specific focus on addressing how these factors influence the quality of end-of-life care for women and men. Racial and ethnic differences in end-of-life care present a more complicated issue, with evidence of poor communication for nonwhite patients and family members and end-of-life decisions that may be influenced by mistrust in the healthcare system. However, there are also important differences in preferences for end-of-life care by race/ethnicity and culture that must be honored and supported. Cultural competence in end-of-life care must be a priority for healthcare providers in order to improve communication for nonwhite patients and their family members and ensure respect for informed decisions that reflect patient and family preferences. Just as poverty affects many other healthcare outcomes, low SES also influences the quality of care that patients receive at the end of life. Underutilization of hospice and palliative care services by poor individuals and those without adequate insurance raises concerns for significant disparity in end-of-life care across levels of income. Similarly, limited education and poor health literacy represent barriers to receipt of high-quality end-of-life care. Addressing socioeconomic disparities in end-of-life care will require commitments from insurance agencies and health systems to attenuate differences related to financial constraints, and additional efforts to tailor communication about end-of-life care to patients with limited education or health literacy will be necessary. Disparity in end-of-life care for sexual minorities is prevalent. As efforts continue to secure equal rights for the LGBT community, healthcare providers should play an active role in sharing the importance of advance care planning for their LGBT patients and providing communication that is not biased by assumptions of heterosexuality. Finally, evidence of less frequent institution of palliative care for patients with noncancer diagnoses should promote efforts to improve communication and planning for these patients. Future research is needed to better understand the mechanisms underlying differences in end-of-life care across gender, race/ethnicity, SES, sexuality, and underlying illness, and additional study is necessary to more clearly define the relationship between these factors and patient and family outcomes.

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