



2022 Hospice Information Gathering Report

Health Equity in the Hospice Setting



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Table of Acronyms

AIDS	Acquired Immunodeficiency Syndrome
AMA	American Medical Association
BIPOC	Black, Indigenous, and People of Color
CAHPS®	Hospice Consumer Assessment of Healthcare Providers and Systems
CMS	Centers for Medicare and Medicaid Services
COPD	Chronic Obstructive Pulmonary Disease
FR	Final Rule
FY	Fiscal Year
HDAH	Healthy Days at Home
HOPE	Hospice Outcomes and Patient Evaluation
HQRP	Hospice Quality Reporting Program
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning and other sexual orientations and identities
NHATS	National Health and Aging Trends Survey
NHPCO	National Hospice and Palliative Care Organization
RFI	Request for Information
SDOH	Social Determinants of Health
SOGI	Sexual Orientation and Gender Identity
SVI	Social Vulnerability Index
TEP	Technical Expert Panel

Executive Summary

Background

Many Americans rely on hospice care for end-of-life support. In 2019, more than 1.6 million Medicare beneficiaries received hospice care, with Medicare spending \$20.9 billion on hospice services (MedPAC, 2021). High quality hospice services are critical to terminally ill patients. CMS anticipates expanding its Hospice Quality Reporting Program (HQRP) over the next several years to include additional meaningful quality measures to help consumers make informed decisions when selecting a hospice for end-of-life support.

Since the release of Abt's 2021 Information Gathering Report, the agency released its [Framework for Health Equity](#) which considers addressing health disparities in all of its programs, including the HQRP. Additionally, CMS requested information on a potential structural measure to address health equity in the hospice setting.¹ After discussion with federal stakeholders and the hospice quality measure development team, Abt staff identified health-equity as a key area where additional information could support HQRP expansion.

This 2022 Information Gathering Report reflects four main information gathering activities:

1. Updating Abt's 2020 social determinants of health (SDOH) literature review
2. Conducting interviews with experts on health equity in the hospice setting
3. Conducting a literature review focused on health equity in the hospice setting
4. Conducting a literature review for recent quality-related hospice activities

And presents these findings using the following five themes:

1. Discussing health equity
2. Access to and enrollment in hospice
3. Receipt of hospice care
4. Addressing hospice inequities
5. Other recent hospice literature

Discussing Health Equity

CMS defines health equity as “the attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes”². While this definition is widely accepted, linguistic choices that contribute to marginalizing some subpopulations remain prominent. Deficit-based language focuses on the absence of certain characteristics (e.g., non-white) or defining others by their least desirable characteristics (e.g., lacking trust). Reframing language in ways that do not “blame” the patient for such

¹ See [87 FR 19422](#)

² <https://www.cms.gov/pillar/health-equity>

disparities may aid in dismantling implicit bias that can create barriers to equitable hospice care. Sometimes overly inclusive terms, even if well-intentioned, can reinforce marginalization by serving as “catch all” phrases that either substitute for deficit-based language, or further obscure the groups they intend to represent – masking important variations in sub-group hospice experiences and outcomes. Examples include “minority” and Black, Indigenous, and People of Color (BIPOC), which are often used as synonyms for non-white.

Access to and Enrollment in Hospice

Historically excluded populations, including Black, Hispanic, Asian, and Indigenous Americans, are less likely to use hospice care than their white counterparts. Differences in referral patterns do not seem to be a contributing factor. In fact, recent literature suggests that Black patients are more likely to receive hospice or palliative care referrals, though this finding was not consistent across all studies and differences appear to be more common across facilities than within facilities. Overall, white patients are more likely to be aware of hospice and its benefits, but the reasons historically excluded populations are less likely to use hospice are more nuanced and complex. Other sociodemographic factors associated with the likelihood of hospice use include gender, education levels, how disenfranchised a patient’s neighborhood is, income levels, rurality, primary language, hospice-specific characteristics, and patient preferences.

With respect to timing and type of enrollment, among patients that enroll in hospice, Black and Hispanic patients tend to enroll earlier than their white counterparts, though they may stay in the hospital longer before transitioning to hospice. Findings regarding factors associated with type of enrollment (i.e., home-based vs. facility-based hospice) are mixed. One study³ found that hospice providers in neighborhoods with higher proportions of women or Hispanic beneficiaries were less likely to provide home hospice care than facility-based hospice care; similarly, another study⁴ found that white patients were more likely to receive continuous home care than patients of other races. In contrast, a third study⁵ found that Black, Hispanic, and female patients were more likely to receive home hospice care as compared to white patients, and an additional small qualitative study⁶ found that Animist and Christian Hmong elders prefer at-home care.

Receipt of Hospice Care

Several studies have considered the patient experience for those enrolled in hospice care, though they reflect inconsistent findings. While Black and Hispanic patients and caregivers seem to experience lower-quality care, they report overall better satisfaction and caregiver confidence than white patients and caregivers. This suggests that even when patients and caregivers experience lesser patient care, individuals do not always recognize that their care could have been better. This may be because differences are more likely to be between hospices than within a given hospice. Furthermore, Black, Hispanic, and Asian hospice patients are more likely to experience adverse outcomes, such as emergency department admission, hospitalization, and live discharge, though these differences may be related to patient preferences or other patient-specific circumstances. Studies consistently reported Asian and

³ Osakwe, Z. T., Arora, B. K., Peterson, M. L., Obioha, C. U., & Fleur-Calixte, R. S. (2021). Factors Associated with Home-Hospice Utilization. *Home Healthc Now*, 39(1), 39-47.

⁴ Wang, S. Y., Aldridge, M. D., Canavan, M., Cherlin, E., & Bradley, E. (2016). Continuous Home Care Reduces Hospice Disenrollment and Hospitalization After Hospice Enrollment. *J Pain Symptom Manage*, 52(6), 813-821. doi:10.1016/j.jpainsymman.2016.05.031

⁵ Mendieta, M., & Miller, A. (2018). Sociodemographic Characteristics and Lengths of Stay Associated with Acute Palliative Care: A 10-Year National Perspective. *Am J Hosp Palliat Care*, 35(12), 1512-1517.

⁶ Her-Xiong, Y., & Schroepfer, T. (2018). Walking in Two Worlds: Hmong End of Life Beliefs & Rituals. *J Soc Work End Life Palliat Care*, 14(4), 291-314. doi:10.1080/15524256.2018.1522288

Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, and other sexual orientation and identity (LGBTQ+) populations having poorer care experiences. A few small studies indicate that women, either as patients or caretakers, may have poorer experiences of care.

Pain management, a critical component of hospice care, may also have inequities in the hospice setting. Men and Black patients may have less access to pain medication, though other studies have found no difference. Some studies that focused on Hispanic and South Asian patients reported a cultural reluctance to acknowledge pain. In studies focused on caregivers, even though knowledge of or perceived barriers to pain management varied for different populations, the caregiver experience often did not.

Addressing Hospice Inequities

Studies consistently cited community engagement as essential to increasing hospice enrollment for historically excluded populations. However, effective engagement strategies vary for different populations. For example, studies suggested partnering with churches to reach Black patients, hiring Spanish-speaking staff for Hispanic patients whose primary language is Spanish, and increasing availability of local hospice providers for Indigenous Americans. For LGBTQ+ patients, studies recommended discussing gender identity and familial preferences rather than making assumptions. At the organizational level, hospices face both challenges and opportunities with respect to staffing and data collection. Hospices often struggle to recruit and retain diverse talent, and sometimes staff themselves may be subject to inequitable treatment by those for whom they care. This is particularly true for Black and LGBTQ+ staff. Diversifying leadership may provide additional support to those facing discrimination from patients. Several studies suggested that use of non-traditional care staff, such as community health workers, patient navigators, and social work students, can alleviate recruitment challenges. Use of these roles, for example, in helping patients understand hospice services, can be particularly advantageous for lower-resourced organizations.

Both studies and our experts noted insufficient data to effectively understand health inequities. This is particularly acute in LGBTQ+ communities and historically excluded racial and ethnic groups. Hospices do not collect sexual orientation or gender identity (SOGI) data, and if staff collect these data, they often do so through inference rather than a conversation with the patient to understand how they identify. Data beyond demographics, such as community-level demographic data and patient preferences, can facilitate an understanding of populations currently excluded from or receiving poorer quality hospice care. Qualitative data can help inform health equity in hospice, but experts cautioned against selection bias. Furthermore, for any data collection, validated tools may not be validated with historically excluded populations.

Few studies suggested specific measures or constructs related to health equity, though CMS asked for feedback on a health equity focused structural measure in their Fiscal Year (FY) 2023 Hospice Rule ([87 FR 19442](#)). In the months following this report, CMS will convene Technical Expert Panels (TEPs) that will reflect on the role CMS can play within its quality reporting programs to improve health equity in hospice and home health settings.

Other Recent Hospice Literature

To identify any emerging trends outside of our specific research questions, we conducted an environmental scan to identify literature related to the general quality of care in the hospice setting published in the last one to two years. Our results fell into three main categories: hospice care for dementia patients, use of new technologies in hospice, and approaches to staffing and services. One additional study explores a Health Days at Home (HDAH) measure.

Conclusion

Many studies have explored differential use of hospice care over the past seven years, with many focused on race and ethnicity. Historically excluded populations are less likely to use hospice, and often less likely

to be aware of hospice care and its benefits. This is despite some evidence suggesting that Black patients are referred to hospice more often than their white counterparts. Studies consistently reported Asian and LGBTQ+ populations having poorer care experiences. Addressing equity in hospice involves community engagement, recruiting and retaining diverse staff, and expanding available data. Few studies suggested specific measures or constructs related to health equity. In the months following this report, Abt Associates will convene TEPs that will reflect on the role CMS can play within its quality reporting programs to improve health equity in the hospice and home health settings. As for other emerging trends in hospice, in the past year the literature has focused on dementia patients, technology, hospice structures, and the novel HDAH measure.

Background and Significance

Many Americans rely on hospice care for end-of-life support. In 2019, more than 1.6 million Medicare beneficiaries received hospice care, with Medicare spending \$20.9 billion on hospice services (MedPAC, 2021). These services are critical to terminally ill patients. CMS continually strives to improve hospice quality and the experience of care for beneficiaries within the context of the [Meaningful Measures Framework](#), which prioritizes high-impact quality measure areas that are meaningful to patients, their families and caregivers.

CMS anticipates expanding the Hospice Quality Reporting Program (HQRP) over the next several years to include additional meaningful quality measures that assess the quality of care provided to hospice patients. The Abt team, under contract to CMS, supports this work. The HQRP currently includes a Hospice Item Set (HIS) quality measure, claims-based quality measures, and Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey measures. The Abt team is also developing and testing the Hospice Outcomes and Patient Evaluation (HOPE), a draft patient assessment instrument that, when finalized in rulemaking, will support assessment-based quality measure.

The Hospice Information Gathering Reports support these efforts by reviewing available resources to inform HOPE development and related quality measures. The [2019 Information Gathering Report](#) used stakeholder input, environmental scans, literature reviews, and focus groups to establish a candidate list of domains for HOPE inclusion. The [2020 Information Gathering Report](#) used similar methods to explore specific areas where additional information was needed to support HOPE and quality measure development. Specifically, it addressed potential adaptation of the Integrated Palliative Outcome Scale (IPOS) for HOPE, the most clinically up-to-date signs and symptoms of a patient who is actively dying, and additional information on pain and dyspnea management to support related quality measures. The [2021 Information Gathering Report](#) narrowly focused on hospice-specific quality measurement and data collection research related to current HOPE activities. Topics included treatment of moderate to severe pain, patient preferences, spiritual and psychosocial assessment and care, medication management, and any recent quality measurement and reporting activities in the hospice setting.

Since CMS released the last Information Gathering Report, the agency released its [Framework for Health Equity](#) which considers addressing health disparities in all of its programs, including the HQRP. In its FY 2023 Proposed Rule ([87 FR 19442](#)), CMS requested information on a structural measure intended to make hospice care more equitable. In support of CMS' health equity work, the 2022 Information Gathering Report reflects four main information gathering activities:

- **Updating our 2020 SDOH literature review:** In the [2020 Information Gathering Report](#), we completed a brief literature review focused on the social determinant of health that may be most applicable to the hospice setting. Those findings suggested that there are differences in pain treatment by both race and gender, that lived experience influences patient preferences, and that there is widespread geographic access to hospice services. We repeated this literature review to more narrowly focus on the hospice setting and to account for both improvements in our methods and any new material published since 2020.
- **Conducting expert interviews:** In the spring of 2022, the Information Gathering Team spoke with several experts familiar with health equity in the hospice setting. Our discussions focused on understanding how these experts are thinking about and addressing health equity in the hospice setting and informing future health equity-related information gathering activities, including our health equity literature review. Additional information on our experts and our methods, refer to Appendix I: Methods.

- **Conducting a health equity focused literature review:** As this is the first major exploration of health equity undertaken by the HQRP to date, the Abt team was broadly inclusive of items related to hospice. We categorized our results into three main themes:
 - Access to and enrollment in hospice
 - Receipt of hospice care
 - Addressing hospice inequities
- **Conducting a literature review for recent quality-related hospice activities:** To better inform HQRP measurement and reporting activities, the Abt Team gathered information on recent quality measurement and reporting activities in the hospice setting.

Given that the content of these activities overlapped significantly, the report presents integrated findings rather than summarizing results by activity. The sections of this report are as follows, largely aligning with the aforementioned themes of our health equity literature review:

- **Discussing health equity:** Here we summarize conversations with our experts in which they reflected upon how health equity should be discussed and the importance of specific language in these discussions.
- **Access to and enrollment in hospice:** Here we present findings from our literature searches and our experts about how hospice use varies among different populations. We further present information on what might contribute to that variance, including referral patterns, knowledge of hospice, and cultural, historical and environmental influences. For those who elect hospice, we also report on findings related to differences in the timing of hospice enrollment and the type of hospice in which patients enroll.
- **Receipt of hospice care:** Here we present findings from our literature searches and our experts on the experiences of those in hospice and their families and caregivers, including a dedicated section about differences in pain management.
- **Addressing hospice inequities:** Here we present findings from our literature searches and our experts on how hospice providers can address the disparities identified in earlier sections. This section includes a discussion of community engagement, organizational improvement efforts such as staffing and data collection, and next steps.
- **Other Recent Hospice Literature:** Here were present findings from our literature review focused on recent hospice publications and reports.

Methods

To address this year's information gathering topics, we searched for and reviewed both peer-reviewed and grey literature. We also conducted a limited set of expert interviews that included representatives of diversity, equity, and inclusion initiatives from hospice provider associations as well as health services researchers with relevant expertise.

For our literature reviews, we used MEDLINE/PubMed® database, supplemented with searches in Google Scholar, using pre-developed search terms (e.g., MeSH) specific to the topic. For grey literature, we established a list of well-known resources and applied key words from our topics to find relevant information. We limited our results to US articles published within the past seven years, except for the general hospice activities topic, where we used a shorter period of one year.

For our expert interviews, we created a brief, semi-structured interview guide to facilitate our discussion that included health equity focused questions on both receipt of and access to hospice care. We probed on topics such as key health equity terms and concepts, use of data, cultural gaps, hospice referral and enrollment, and increasing representative hospice staff.

Throughout the process we consulted key stakeholders to clarify the purpose or intent of the research questions and confirm expected sources of information, as needed. For more details on our methods refer to **Appendix I**. We present a summary of search results for each section in **Appendix II**, and complete literature review tables for each section in **Appendix III**.

Discussing Health Equity

CMS defines health equity as “the attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes”⁷. A main topic area for expert interviews was how to think about and discuss health equity in the hospice setting. This both supported our development of a robust set of search terms for our literature review, and improved awareness of the importance of language as CMS works to address health inequities. Here we summarize this portion of our expert interviews.

Though not specific to the hospice setting, linguistic choices that contribute to the marginalization of some subpopulations remains prominent. Deficit-based language focuses on the absence of certain characteristics or defining others by their least desirable characteristics. Examples include “non-white” and “non-Hispanic” which implicitly reflects what the specific group or person is not, rather than what they are, which would be a strength-based approach to identifying diverse attributes. Certain phrases like “underserved” and “lack of trust in the medical system” also convey deficiency on the part of the patient, family and/or community. Often, describing a patient as “underserved” rather than “historically excluded” suggests the patient had access to services, but did not use the service or care. Reframing language in ways that do not “blame” the patient for such disparities may aid in dismantling implicit bias that can create barriers to equitable care. Similarly, describing a group of people as “lacking trust” implies that the onus is on the patient, rather than the medical system, to develop that trust and fails to recognize that for historically marginalized and excluded patient populations a lack of trust is rational and justified.

Sometimes overly inclusive terms, even if well-intentioned, can reinforce marginalization by serving as “catch all” phrases that either become proxy terms that substitute for deficit-based language, or further obscure the groups they intend to represent. An example of the former is “minority,” which is mostly, if not exclusively, used to refer to race or as a replacement for non-white. Minority is rarely, if ever, used to describe white people—even when white people are the minority (e.g., in Detroit or the District of Columbia)⁸. Moreover, terms like BIPOC, though intended to be a more inclusive term, poses their own challenges. BIPOC is used so generally that often those who use it do not recognize its intent to represent racial groups. One interviewee described an encounter with a conference presenter who, when asked who she was referring to with the term BIPOC, struggled to answer the question and ultimately replied “biracial people.” In this example, BIPOC has substituted for minority, which itself has substituted for non-white. Even labels such as African American can be too broad. Not all Black people identify as African American. As one expert noted: “My grandmother who was born in the 1800s was

“Minority is not a race, it’s a status. We should not be referring to people as minorities.” – Interviewed Expert

“Equity has to do with being more inclusive, and yet that’s not always the case with these acronyms.” – Interviewed Expert

one step removed from enslavement, as a sharecropper, in the rural south. Her lived experiences, in the U.S. were very different experiences from my Black colleague who emigrated from the Continent of Africa by choice with an abundance of resources and formal education. My colleague also reminds me that she identifies as Nigerian American, not as African American. The cultural

differences and healthcare decision-making preferences can vary widely.”

While we recognize the significance of language and its role in health equity, much of this report compiles research conducted by others. We believe that in some cases the researchers we cite here,

⁷ <https://www.cms.gov/pillar/health-equity>

⁸ <https://www.census.gov/quickfacts/fact/table/DC,detroitcitymichigan/RHI725221>

particularly those conducting interviews with their subjects, took care to represent their participants in a way that respected participant identities. However, other research, particularly research which uses aggregate data from which researchers cannot ascertain patient preferences, was not sensitive to or aware of some of the potentially stigmatizing or marginalizing language we discuss above. Where the content of this report is that of its authors we have conformed with the American Medical Association's (AMA) [Advancing Health Equity: A Guide to Language Narrative and Concepts](#) wherever possible. The AMA guidelines include, for example, white not being capitalized as other races are and using terms such as "historically excluded" rather than "underserved." However, for our descriptions of other's research we have used the terms its authors used, both to be sure we accurately represent their work and to respect instances where the authors likely accurately reflected their participants' identities. For this reason, the reader may see the same or similar populations referred to differently throughout this document (e.g., both Black and African American, or Indigenous American and American Indian), or use of language that may reinforce marginalization of certain communities.

Access to and Enrollment in Hospice

Hospice Use

Several studies reported that certain populations are less likely to use hospice care than other populations. Most of these focused on historically excluded races and ethnicities relative to white populations, though some looked at factors such as gender, education level, neighborhood characteristics, income, and region. Some of these studies have specifically explored why certain populations are less likely to use hospice care. For example, some have studied differences in awareness of hospice and its benefits among various populations. Several additional qualitative studies provided further insight into perceptions of hospice for different populations. For example, evidence suggests those who receive a palliative consultation are more likely to use hospice care. Patients who received an inpatient palliative care consultation are up to four times more likely to enroll in hospice than those who did not receive this consultation (Starr et al., 2020; Johnson et al., 2020). Some studies found no significant associations between race and hospice enrollment among patients who received a palliative care consultation (Worster et al., 2018; Starr et al., 2021). Here we discuss findings related to hospice use among different populations, and why their use patterns may differ.

Our experts also reflected on reasons why patients may not be referred to or enrolled in hospice. Many interviewees noted that clinicians typically lack training on hospice and are often uncomfortable discussing end-of-life care with patients. This is especially true if the clinician does not perceive the patient to have a caregiver. As one expert noted, many clinicians assume people of color won't be interested in hospice care, and do not have that conversation. End-of-life conversations take time and require cultural training that facilitates talking about topics that may be taboo. For example, one expert noted that patients may believe hospice is just for AIDS or cancer patients, or be hesitant to have people in their home, and overcoming these misconceptions and concerns takes time. However, these conversations about hospice are crucial for earlier referrals to hospice. Doctors that share a cultural background with their patients may find these conversations easier and may be more likely to make a hospice referral.

“If we went to a doctor for a pain or a lump, they would not hesitate to refer you to an oncologist. However, there’s a lot of hesitation around hospice referrals because the clinician doesn’t understand everything that hospice entails.” – Interviewed Expert

Racial and Ethnic Differences in Hospice Use

Studies that addressed hospice use by different races and ethnicities primarily reported differences between Black patients and white patients. Often, they looked at specific diagnoses or groups of diagnoses, largely cancer related. In almost all cases, Black, Hispanic, Asian, and Indigenous American patients were less likely to use hospice care than their white counterparts. Differences in referral patterns did not seem to be a contributing factor. In fact, some studies suggested that Black patients were more likely to be referred to hospice than non-Black patients even though they seem to use hospice less. Differences in referrals were more likely across facilities than within facilities. Overall, white patients were more likely to be aware of hospice and its benefits, but the reasons patients of other races and ethnicities were less likely to use hospice were more nuanced and complex.

Hospice Use among Black Patients

Several studies reported on hospice use among patients with cancer. Two studies of Medicare patients looked at cancer generally, with one finding that Non-Hispanic Black patients who died from cancer were less likely to enroll in hospice than white patients (Koroukian et al., 2017). The other found no racial difference in hospice use for cancer patients but did find that Black patients without cancer were less likely to enroll in hospice than white patients (Samuel-Ryals et al., 2021).

Eleven additional studies looked at specific types of cancer. Black patients were less likely to enroll in or die in hospice than their white counterparts for brain metastasis (Mehanna et al., 2020; Shenker et al., 2022); ovarian cancer (Mullins et al., 2021; Taylor et al., 2017); pancreatic cancer (Paredes et al., 2021); small cell lung-cancer (Du et al., 2015), malignant glioma (Forst et al., 2018); breast cancer (Check et al., 2016); and head and neck cancer (Stephens et al., 2020). Two studies reported no racial difference in hospice use. A study of patients with cervical cancer found that place of death (hospice or hospital) did not vary between Black and white patients (Sheu et al., 2019). Another study of New Jersey Medicaid patients with breast or colorectal cancer found no racial differences in hospice use, but also found that Black patients had almost twice the odds of receiving aggressive end-of-life care than white patients (Yang et al., 2020).

All identified studies that focused on non-cancer diagnoses reported Black patients were less likely to use hospice care than their white counterparts. These included Black patients with severe acute brain injury (Jones et al., 2021), dementia (Lin et al., 2022; Oud et al., 2017), chronic obstructive pulmonary disorder (COPD) (Yaqoob et al., 2017), and those on dialysis (Foley et al., 2018). Additionally, a Florida survey of older adults found that for African American patients, an increasing number of functional disabilities was associated with decreased willingness to use hospice (Park et al., 2016).

Additional research explored potential reasons why Black patients are less likely to use hospice. Some research suggests that Black patients are more likely to want aggressive end-of-life treatment. A 2017 Kaiser Family Foundation and Economist survey found that while few Americans viewed living as long as possible as “extremely important,” the share of Black respondents who felt this way (45%) was higher than that of white respondents (18%) (Hamel et al., 2017). Another survey of Black American older adults in North Carolina found they were less likely to prefer or request hospice support than their white counterparts (Cagle et al., 2016). African American decision makers for dementia patients elected life-sustaining treatments more than comfort-focused care (Hart et al., 2022). Additionally, advance directives increase the odds of a discharge to hospice, and African American patients are less likely to complete advance directives (Haines et al., 2021). One of our experts noted that in her Black American community, there may be more collective decision-making preferences. She described her mother not understanding why she would need a written advanced directive if her daughter was there to advocate on her behalf.

Other research suggests the Black patients may be unaware of hospice care and its benefits. For example, African American decision makers for dementia patients often did not use hospice fully due to a lack of information and preparedness (Hart et al., 2022), and a California-based study found Black people were less likely than non-Hispanic white peoples to be aware of hospice (Bazargan et al., 2021). Qualitative research among African American church members indicated that lack of knowledge of hospice services and spiritual beliefs were the top two contributing factors to underutilization of hospice care (Townsend et al., 2017). Further, additional interviews with African American church leaders found their congregants were unfamiliar with the terms “hospice” and “palliative care,” while also harboring beliefs, perceptions, and feelings about death and dying that they had not communicated to their family members or providers. Those who had positive perceptions of hospice care were uncertain how to approach their health care providers about it (Johnson et al., 2016). A study of African American adults in Alabama’s “Black belt” region found that those who were worried about stable housing or were more socially isolated were less likely to be aware of hospice care (Noh et al., 2021). Meanwhile, adults with better perceived health and higher levels of physical and social activity were more likely to have accurate knowledge of hospice. This was true for both Black adults and white adults, except for the physical activity finding which the author did not find for white patients (Noh et al., 2018).

Interestingly, recent literature suggests that Black patients are more likely to receive hospice or palliative care referrals, though this finding was not consistent across all studies and differences appear to be more common across facilities than within facilities. For example, Johnson and colleagues looked across four urban hospitals and found African American patients received more palliative care consultation referrals

than both white and Hispanic patients, though there was no difference within hospitals (Johnson et al., 2020). A Chicago hospital-based study also found African American patients more likely to be referred to hospice than white patients (Sharma et al., 2015). However, a study of patients with metastatic cancer in New Jersey hospitals found Black patients were less likely to receive hospice referrals than white patients (Nicholson et al., 2022). A study of cancer centers found that minority patients were less likely to receive a hospice referral than their white counterparts, but there were no significant differences within hospitals (Wasp et al., 2020).

In a series of interviews, Rhodes and colleagues found that though African American respondents perceived hospice to be beneficial to patients and family, they also perceived cultural differences, a lack of knowledge about hospice, spiritual or religious conflicts with hospice, and mistrust in the medical system as barriers (Rhodes et al., 2017). Similarly, Dillon and Basu found that African American people's experience of discrimination or mistreatment by the healthcare system has led to a mistrust of hospice, in addition to the perception of hospice as incongruent with their cultural values and practices. Dillon and Basu also noted that African American people experience inconsistent access to medical care. This, combined with some avoiding the medical system, can lead to late diagnosis of terminal illness, thereby limiting the opportunity to receive hospice care (Dillon and Basu, 2016).

Our experts provided particularly illustrative details on why Black patients may elect not to participate in hospice even when referred. One expert illuminated how the collective experience of Black Americans has shaped their attitudes towards hospice. In addition to a medical system that has fostered distrust (e.g., the [USPHS Syphilis Study at Tuskegee](#) and [J. Marion Sims' gynecological experiments](#) on enslaved women), other cultural attitudes and beliefs affect participation. She recounted her own research on end-of-life care at an urban hospital and her inability to find a sufficient sample of Black patients to match the number of white patients who had died at that hospital, to conduct a retrospective study of the end-of-life experiences in a hospital setting. She realized that the Black American patients in that community were seeking their care at a hospital across town—a legacy that remained after decades of having been legally denied access to hospitals where only white patients received care during segregation. This translates to primary care as well. She noted that Black people may prefer aggressive treatment for illness, as they distrust the motives of those providing primary care. She further described Black Americans, particularly of older generations, relying on home remedies rather than pharmacological interventions and care, reflecting the practices they used before they had access to primary care settings. The mistrust of the medical system, influenced by historical racism, structural and systemic, makes it difficult for Black Americans to choose hospice as a culturally acceptable care option. The benefit of having a stranger provide care in the home is culturally incongruent for many Black people in the U.S. The lack of hospice enrollment and hospice utilization compounds the challenge of achieving equity, as few Black Americans elect hospice care this means there are fewer lived examples for others in the community to share, affirm and reinforce its benefits.

“The whole philosophy of hospice care is challenging for Black older adults” – Interviewed Expert

Hospice Use among Hispanic Patients

As with Black patients, research suggests that Hispanic patients are less likely to use hospice than non-Hispanic white patients. Hispanic patients with brain cancer, ovarian cancer, and malignant glioma were less likely to use hospice than white patients (Mehanna et al., 2020; Mullins et al., 2021; Taylor et al., 2017; Forst et al., 2018). However, as with Black patients, Sheu and colleagues found no variance in place of death (hospice or hospital) for Hispanic patients (Sheu et al., 2019). Non-cancer related diagnoses exhibit the same pattern. Hispanic patients with severe acute brain injury (Jones et al., 2021), dementia (Lin et al., 2022), and those on dialysis (Foley et al., 2018) were all less likely to use hospice care than their non-Hispanic white counterparts.

As with Black patients, the 2017 Kaiser Family Foundation and Economist survey found a higher share of Hispanic patients (28%) viewing living as long as possible as “extremely important,” compared to 18% of white respondents (Hamel et al., 2017). As in other populations, Latino caregivers who held a strong belief that hospice care means giving up on life were less likely to consider using hospice care for their loved ones (Ko, et al., 2017). Other research finds more nuanced reasons for Hispanic patients not using hospice care. The two identified studies focused specifically on Mexican identities, and neither supported cultural barriers as the main reason these populations are less likely to use hospice care. Rising and colleagues interviewed US Mexicans with terminal cancer and found that they perceived referral to hospice as coercive in nature, unless they had an existing paternalistic view of healthcare that defers to the physician (Rising et al., 2021). Shepard and colleagues looked at Hispanic Estimate Population for Epidemiological Study of the Elderly (H-EPESE), H-EPESE Survey data, and CMS data, to determine what characteristics were associated with hospice use for Mexican Americans and found no association between hospice use and marital status, high-depressive symptoms, disability, church attendance, or seeing a physician in the last year of life. This led the authors to conclude that health system factors, rather than individual patient factors or community factors, were driving hospice use and referral variation (Shepard et al., 2022).

For referral to hospice, as with Black patients, studies were mixed. Nicholson and colleagues’ study of New Jersey hospital patients with metastatic breast cancer found Hispanic patients were less likely receive hospice or palliative care referrals than white patients, while Sharma and colleague’s work with Chicago hospitals found no difference in referral to hospice between Hispanic patients and white patients (Sharma et al., 2015). As mentioned previously, some studies have found no significant associations between race and hospice referral, with Worster and colleagues assessing the association between Hispanic patients and hospice referral specifically (Starr et al., 2021; Worster et al., 2018).

Qualitative studies suggest that providers are not adequately discussing end-of-life care options with Hispanic patients. A small number of interviews with caregivers of those enrolled in home hospice in rural US/Mexico border towns found that while most caregivers were informed about the patient’s terminal condition, only half had a discussion with a provider about hospice (Ko and Fuentes, 2020). A small survey found Hispanic people had less knowledge of about hospice than their non-Hispanic counterparts, such as believing that only those over 65 were eligible for hospice and not knowing that hospice helps family members as well as the dying person (Carrion et al., 2015). Additional work showed Hispanic people were less likely to be aware of hospice than non-Hispanic white people (Bazargan et al., 2021).

Hospice Use among Asian Patients

Several of the studies that reported hospice use among Black and Hispanic patients also presented findings for Asian patients. Here too, white patients were more likely to use hospice than their Asian counterparts. Asian patients with brain metastasis (Mehanna et al., 2020), malignant glioma (Forst et al., 2018), severe acute brain injury (Jones et al., 2021), and those on dialysis were less like to use hospice than white patients (Foley et al., 2018). Three additional studies specified inclusion of both Asian and Pacific Islander patients in their analysis, finding for brain cancer patients, head and neck cancer patients, and cervical cancer patients these populations were less likely to die at home or in hospice than white patients (Shenker et al., 2022; Stephens et al., 2020; Sheu et al., 2019, respectively). Notably, the Asian and Pacific islander population was the only population Sheu and colleagues identified as less likely to die at home or in hospice rather than a hospital. They found no variation in place of death for Black patients, Hispanic patients, or Native American patients relative to their white counterparts (Sheu et al., 2019).

Though most studies considered Asian patients a single population, Haines and colleagues disaggregated the Asian population to provide insights within different Asian identities. This work reported that Chinese

trauma patients were more likely to die in hospice than Japanese patients, Filipino patients, Indian patients, and Vietnamese patients. Korean patients were more likely to die in hospice than their Chinese counterparts (Haines et al., 2021).

As for referral to and knowledge of hospice, Shirsat and colleagues conducted a small survey of Indian Americans in Northern California to discern their knowledge of hospice. Ten percent of respondents knew someone in hospice care and ten percent were able to answer either four or five out of five questions that assessed their knowledge of hospice care. Once educated about hospice care, almost 70 percent agreed that they would consider enrolling an extremely ill family member in hospice, though 44 percent would not allow a stranger in their home, even if the stranger was with hospice (Shirsat et al., 2021). Additionally, advance directives increase the odds of a discharge to hospice, and Asian patients were less likely to complete advance directives (Haines et al., 2021). An expert we interviewed noted that for the Chinese community, older people, particularly those who do not speak English, may not have their decisions respected. For example, the patient's child may "talk over" them (intending to protect their senior patients) and older people may find it difficult to advocate for themselves in a medical setting even if the children's wishes are different than their own. Our expert described how advance care plans when an individual is still capable of talking and expressing their medical wishes can be of value, as they help clarify what the patient prefers while alleviating the decision-making burden on the children.

Hospice Use among Native American Patients

Native American populations were also less likely to use or die in hospice care than white patients in our identified studies. Studies reported this for American Indian patients and Alaska Native patients with metastatic cancer (Shiovitz et al., 2015), Native American patients with brain cancer (Shenker et al., 2022), and Native American patients on dialysis (Foley et al., 2018). Sheu and colleagues, when looking at cervical cancer patients, did not find variation in place of death between Native American patients and white patients, consistent with their findings for Black and Hispanic patients referenced in the previous section (Sheu et al., 2019).

Some qualitative studies explored potential barriers to use of hospice in Native American populations. For Great Plains Native Americans, there is not sufficient availability of hospice, resulting in long travel distances services; meanwhile, the workforce does not have adequate cultural familiarity with the Great Plains Native Americans. Historical racism and trauma further limit Great Plains Native Americans willingness to use hospice (Soltoff et al., 2022). Interviews with Elders of the Blackfeet Nations revealed that while some found "sickness should not be mentioned when it is bringing death," others felt end-of-life care was not against tradition (Colclough et al., 2019).

Hospice Use among Non-specific Patient Populations

Wherever possible, we have presented results with respect to specific racial and ethnic populations. However, many studies reported results without such specificity. These studies yielded similar results—white patients were more likely to use hospice than patients of other races or ethnicities. This held true for Medicare populations both in managed care plans and in fee-for-service Medicare (Ornstein et al., 2016; Elting et al., 2020). One study found race to be the strongest predictor of one's opinion about hospice, with white people having the most positive opinion (Lee and Cagle, 2017).

The differences are present across multiple diagnoses. White patients were more likely to use hospice than other races or ethnicities for hepatocellular carcinoma (Rice et al., 2021), gynecologic oncology (Taylor et al., 2016), and lung, esophageal, pancreatic, colon, and rectal cancers (Abbas et al., 2021). A study focused on cancer centers in the deep south found non-white cancer patients less likely to use hospice than whites (Turkman et al., 2019). Haines and colleagues found similar results for trauma patients (Haines et al., 2018).

Two studies explored reasons why some racial and ethnic groups may not use hospice. A small survey of hospice employees reported that they perceive cultural beliefs of racial and ethnic groups as barriers to their use of hospice care (Hughes and Vernon, 2020). Another study that surveyed hospice directors found that diverse populations may prefer to associate with their own cultural group, return to their home country as death approaches, or perceive hospice as “divergent to their cultural and religious beliefs or thinking” (Reese and Beckwith, 2015).

Other Sociodemographic Differences in Hospice Use

Gender

Overall, female patients were more likely than male patients to use hospice. Again, this was true for brain cancer (Mehanna et al, 2020), malignant glioma (Forst et al., 2018), COPD (Yaqoob et al., 2017), and females with cancer in the deep south (Turkman et al., 2019). A small study of female patients with metastatic breast cancer at a Boston hospital found that only one third were referred to hospice after their last hospitalization (Shin et al., 2016).

Education

Those with higher levels of education were more likely to use hospice than those with lower levels of education. Cancer patients and non-cancer patients alike were more likely to use hospice if they have higher levels of education (Ornstein et al., 2016; Koroukian et al., 2017; Forst et al., 2018). Cagle and colleagues found college education, as well as race and working in the medical industry, were predictors of hospice knowledge (Cagle et al., 2016). Higher health literacy was associated with awareness of hospice and hospice use (Noh et al., 2021; Ornstein et al., 2016). However, Ornstein and colleagues found that Medicare patients with a higher education level than their spouse were less likely to use hospice (Ornstein et al., 2016).

Socially Vulnerable Communities and Lower Income Patients

Some studies used zip-codes, the [Social Vulnerability Index](#) (SVI), or other means to determine whether place of residence was associated with hospice use. Others looked at income and its relationship with hospice use. Most studies supported higher SVI communities and patients with lower incomes being less likely to use hospice care.

Abbas and colleagues looked at patients with specific cancers (lung, esophageal, pancreatic, colon, or rectal cancers) and found that those in high SVI areas (especially non-white residents) were less likely to enroll in hospice (Abbas et al., 2021). Similarly, for patients with hepatocellular carcinoma, the probability of hospice use declined for those in areas with higher social vulnerability (Rice et al., 2021). Riggs and colleagues focused on New York patients, finding that patients who received community-based palliative care and live in a zip code with a lower share of residents living in poverty were more likely to enroll in hospice (Riggs et al., 2016). Patients in areas with low health literacy were also less likely to use hospice (Luo et al., 2021).

As for income, its influence on hospice use was mixed. While Koroukian and colleagues found higher income patients who died of cancer were more likely to enroll in hospice than those with higher incomes (Koroukian et al., 2017), Forst and colleagues found that for patients with malignant glioma, lower income predicted hospice use (Forst et al., 2018). Similarly, Dhingra and colleagues, who compared New York to the nation, found that New York’s higher socioeconomic status was an independent predictor of their lower hospice use (Dhingra et al., 2022). Ornstein and colleagues also cited socioeconomic status as related to hospice use (Ornstein et al., 2016).

Region

Several of studies we have referenced previously throughout this section also found regional differences in hospice use, particularly between urban and rural areas. Rural patients were less like to enroll or die in

hospice than their urban counterparts for cervical cancer (Sheu et al., 2019), malignant glioma (Forst et al., 2018), non-small cell lung cancer (Du et al., 2015), and cancer generally (Wang et al., 2016).

Fornehed and colleagues interviewed informants in rural Appalachia to better understand their attitudes towards palliative care and found that they make end of life decisions with family. The communication that encompasses family decision making for this population was both essential and complex, with education and economics influencing end-of-life decision making (Fornehed et al., 2020).

Other studies made more specific regional comparisons. Yaqoob and colleagues found that for patients with COPD, the likelihood of dying in hospice is highest in the south, at eight percent, and lowest in the Northeast, at four percent (Yaqoob et al., 2017). A Massachusetts report identified county level variation in hospice use, with particular inequities in the western part of the state, which is more rural (Massachusetts State Hospice Report, 2021).

Language

Two of our studies found that patients who spoke a primary language other than English were less likely to receive hospice referrals than their primarily English-speaking counterparts. One focused on patients with metastatic cancer in New Jersey hospitals, and the other focused on New York patients who received community-based palliative care (Nicholson et al., 2022; Riggs et al., 2016, respectively). Another study, based in Florida, generally found that non-Cuban Hispanic Floridians who were proficient in English were more willing to use hospice, but this was not true for Cuban Americans. The authors believe this may be because Cuban Americans have access to information about hospice in their native language in their communities (Park et al., 2016). Dressler and colleagues interviewed care end-of-life care providers in an Rhode Island community with a high proportion of non-English speakers and identified three key themes that contributed to language barriers in end-of-life care: structural barriers inhibiting access to interpreters, variability in how accurately end of life concepts can be translated, and the style and manner of the interpreter influencing efficacy during complex conversations. The latter two appear critical for hospice enrollment and care (Dressler et al., 2021).

Other

Additional works cited other factors related to hospice use, including facility characteristics. A higher proportion of for-profit hospices was positively associated with racial and ethnic minorities using hospice (Hughes and Vernon, 2019), and in the deep south, cancer patients seen at hospitals with inpatient palliative care beds were less likely to receive hospice care (Turkman et al., 2019). When investigating why New York State has low hospice utilization, Dhingra and colleagues found that, in addition to socioeconomic status, New York's higher number of physicians seen in the last years of life, larger number of skilled nursing facility beds, smaller number of for-profit skilled nursing facilities, and smaller number hospices relative to the nation overall independently accounted for differences in hospice utilization (Dhingra et al., 2022).

Additional factors that predicted a positive opinion of hospice include better health, greater familiarity with hospice, a high importance of pain control, the importance of fulfilling personal goals, a desire to have health-care professionals involved in one's care, and having engaged in advance care planning (Lee and Cagle, 2017). Expectations about death are also associated with hospice use (Ornstein et al, 2016).

Timing of Hospice Enrollment and Hospice Type

For patients that enroll in hospice, the time at which they enroll and the specific type of hospice services they received can vary for different populations. With respect to enrollment timing, white patients are enrolling later than other patient populations (Rice et al., 2021; Taylor et al., 2016; Turkman et al., 2019; Wallace, 2017; Ornstein et al., 2020). Rice and colleagues, who focused on patients with hepatocellular carcinoma, further found that as social vulnerability of an area increases, the likelihood of early hospice use among white patients decreases. Meanwhile, in this scenario, the likelihood of early hospice use

among non-white patients increases—suggesting that though they may have less access to hospice services, Black and Latino patients may be referred to or decide to enroll earlier in hospice when it is available (Rice et al., 2021). For American Indian and Alaska Native patients, the likelihood of late hospice use was not found to be significantly different than that of their non-Hispanic counterparts (Shiovitz et al., 2015). Wallace identified other factors associated with enrollment in the Southern US. Those receiving curative treatment, referred to hospice by a family rather than a physician, and with incomes over \$50,000 all took longer to enroll in hospice (Wallace, 2017). However, Haines and colleagues found that African American patients and Hispanic patients both stayed in the hospital longer than Caucasian patients when discharged to hospice—two and half days longer for Hispanic patients and nearly four days longer for African American patients (Haines et al., 2018).

A few studies examined the hospice types that different populations were likely to receive. Osakwe and colleagues used Medicare and American Community Survey data in a cross-sectional study focused on factors associated with home hospice use relative to facility-based hospice use. Hospice providers with higher proportions of women or dually eligible beneficiaries⁹ were less likely to provide home hospice. For the dually eligible population, the authors believe this may reflect an institutional setting's ability to meet the higher care needs of dually enrolled patients more easily (Osakwe et al., 2021). They also analyzed the racial and ethnic makeup of a hospice's neighborhood. Specifically, higher proportions of Black patients in a hospice's neighborhood were not associated with provision of home hospice, while higher proportions of Hispanic patients in a hospice's neighborhood decreased the likelihood of the hospice providing home services (Osakwe et al., 2021). Two additional Medicare studies looked at the type of hospice care provided. One found that white patients were more likely to receive continuous home care than other races or ethnicities, and that receipt of continuous home care was associated with decreased hospice disenrollment (Wang et al., 2016). The other Medicare study found that African American patients, Hispanic patients, and female patients were more likely to receive home hospice care; white patients were more likely to receive facility-based hospice care; and for Asian patients there was no difference (Mendieta and Miller, 2018). However, a small qualitative study found that Animist and Christian Hmong elders prefer at-home care, when possible, as they felt out-of-home care facilities could not meet the spiritual and cultural needs they see as centrally integral to end-of-life care (Her-Xiong and Schroepfer, 2018).

⁹ Dually eligible beneficiaries are eligible for both Medicare and Medicaid

Receipt of Hospice Care

Racial and Ethnic Differences in Patient Care

Several studies have considered the patient experience for those enrolled in hospice care, though they reflect inconsistent findings. A Southwest caregiver survey found that racial minorities experience less satisfaction with the information and education they received, the patient care provided, and the emotional and spiritual support provided to families and caregivers during the hospice stay; however, race did not show a significant effect on overall satisfaction or caregiver confidence (Holland et al., 2015). This finding suggests that even when patients and caregivers experience lesser patient care, individuals do not always recognize that their care could have been better. Price and colleagues analyzed CAHPS® Hospice Survey data and found that Black and Hispanic patients were more likely than white patients to receive care from hospices that offered significantly poorer care experiences, though racial differences were mostly attributed to between-hospice differences rather than within-hospice differences (Price et al., 2017). However, within a given hospice, caregivers of Black and Hispanic hospice patients reported significantly better care experiences than those of white patients, except that caregivers of Black patients were less likely to recommend hospice and Hispanic patients were less likely to report receiving the right amount of emotional and religious support as compared to white counterparts (Price et al., 2017). Another study focused on the experience of Black and white caregivers in the Northeast and Midwest and found that, though there were social, demographic, and socioeconomic differences between the Black and white caregivers, they experienced similarly high levels of anxiety, depression, and burden, and had similar perceptions of hospice communication (Starr et al., 2022). Black hospice patients were also more likely to disenroll from hospice even when controlling for hospice level factors (Rizzuto et al., 2018). Collectively, these studies suggest that even when patients and caregivers experience poorer quality care, individuals do not always recognize that their care could have been better.

Asian patients seem to have poorer experiences of care than non-Hispanic white patients. Another study based on CAHPS® Hospice Survey for San Francisco caregivers found that Asian family members more often experienced a lack of respect for their cultural traditions and their religious and spiritual beliefs, did not receive as much information as they would have liked about what to expect in the last months of life, and did not receive the right amount of emotional support after their family member's passing (Kim et al., 2021).

A few qualitative studies explored the Hispanic experience of care. Beltran and colleagues conducted interviews with older Latinos enrolled in hospice, finding they often did not have a lot of experience with the US healthcare system (likely because of insufficient healthcare due to geographic or financial reasons); did not communicate directly with their health care providers because of low health literacy and language barriers, instead relying on family members to translate; and expected nursing care and medical supplies from hospice, but were not aware of other services provided (Beltran, 2022). Nuñez and colleagues interviewed family members of hospice patients, finding that cultural norms influence interactions between families, and that the family members considered the hospice-provided social supports helpful, but they often did not have health literacy around hospice care (Nuñez et al., 2019). Nuñez et al. also reported that family members of Hispanic hospice patients preferred religious and spiritual support that fit within their cultural values (Nuñez et al., 2019). These studies—combined with the studies cited earlier in this section that noted Hispanic patients and caregivers were less likely to be satisfied with the information, education, and spiritual and emotional support they receive—suggest that there is an unmet need in this population (Holland et al., 2015; Price et al., 2017).

The likelihood of adverse outcomes, such as emergency department admission, hospitalization, and live discharge, is also greater for several historically excluded groups. Black and Hispanic hospice patients are both more likely to be admitted to the emergency department than white hospice patients, even when controlling for hospice level factors (Lin et al., 2022; Rizzuto et al., 2018). Several hospice patient populations were more likely to be hospitalized than their white counterparts: Black patients (Phongtankuel

et al., 2017; Rizzuto et al., 2018), non-white and non-Black patients (Phongtankuel et al., 2017), Asian patients, and Hispanic patients (Russell et al., 2017). The results of Phongtankuel and colleagues' study held even after adjusting for patient and hospice level factors (Phongtankuel et al., 2017). Russell and colleagues analyzed electronic medical records at an urban New York hospice, finding that Black patients, Hispanic patients, and Medicaid patients were all disproportionately being discharged alive due to hospitalization (Russell et al., 2020). The disparity between Hispanic and non-Hispanic white patients was found in affluent communities rather than economically disadvantaged neighborhoods, whereas neighborhood characteristics did not affect the odds of live discharge for Black patients. Black hospice patients were also more likely to disenroll from hospice compared to white patients even when controlling for hospice level factors (Rizzuto et al., 2018). A small study by Taylor and colleagues also found Black patients more likely to disenroll from hospice prior to death than their white counterparts, though they found no difference for other racial or ethnic groups (Taylor et al., 2019). Another smaller based in New York found that Asian patients receiving home hospice care were more likely to revoke hospice care than their non-Hispanic white counterparts (Russell et al., 2017).

Most of these studies did not address whether increased likelihood of aggressive treatment reflected patient preferences. Russell and colleagues conducted supplemental interviews with caregivers of home hospice patients, finding that medical events, uncontrolled symptoms, imminent death, or inability to provide care safely at home all influenced decisions to pursue hospitalization (Russell et al., 2017).

LGBTQ+ Differences in Patient Care

Recent studies indicate that LGBTQ+ patients are experiencing discriminatory hospice care that does not respect their identities. A cross-sectional survey of hospice and palliative care providers found that 54 percent of providers believed that LGB patients were more likely than non-LGB patients to experience discrimination, with 24 percent having observed such discriminatory care. Sixty-four percent of respondents believed transgender patients were more likely than non-transgender patients to experience discrimination, with 21 percent having observed such discrimination. Additionally, 15 percent of respondents observed the spouse or partner of an LGBT patient have their treatment decisions disregarded or minimized, be denied or have limited access to the patient, and be denied private time with the patient, with 14 percent having observed the spouse or partner being treated disrespectfully (Stein et al., 2020). A qualitative study that interviewed older lesbian adults confirmed that discriminatory behavior exists, finding that patients who disclosed their sexual orientation or gender identity did not receive patient centered care, and that their loved ones may have experienced disenfranchised grief, which is grief that is not publicly acknowledged or viewed as legitimate (Candrian and Cloyes, 2021). Another set of interviews with older LGBTQ patients found that all participants reported a connection between their sexuality and their spiritual lives, yet few resources for hospice and palliative care explicitly outline the direct connection for LGBTQ patients (Fair, 2021).

Gender Differences in Patient Care

Gender also contributes to how patients and caregivers experience care. A small qualitative study examining gender dynamics in home hospice care found that, in some cases, nurses in resource-constrained settings shifted care responsibilities to female (but not male) caretakers and pushed back more against female caretakers' boundaries than against male caretakers' boundaries; female nurses and caregivers focused care efforts on female over male clients (Sutherland et al., 2016). In a small New York study women receiving home hospice care were more likely to be disqualified from hospice care than their male counterparts (Russell et al., 2017).

Differences in Pain Management

Pain management is a critical component of hospice care for both patients and caregivers. A study of Medicare patients found inequities in access to pain medication for hospice patients, with men less likely

to receive psychotropic and opioid medication prescriptions, and non-Hispanic Black patients less likely to receive nearly any class of medication (Gerlach et al., 2021). However, another study found no difference in pain management between African American patients and Caucasian American patients in hospice (Booker et al., 2020).

Two studies reported on caregiver experience with respect to pain management. One study analyzed family caregiver knowledge and experience of cancer pain management, finding rural caregivers had worse knowledge of pain management principles than their urban counterparts, but the caregiver experiences when managing cancer pain were not significantly different (Washington et al., 2019). Another study of cancer patients and their caregivers receiving home hospice analyzed their perceived barriers to pain management using the [Barrier Questionnaire 13](#). There was no difference in perceived pain management barriers between African American patients and caregivers and white patients and caregivers, or between male and female patients and caregivers. Hispanic patients did perceive more pain management barriers than non-Hispanic patients, though there was no difference among caregivers (Wilkie et al., 2017). A separate study found Hispanic patients were more likely to believe that admitting pain is a sign of weakness and that a “good” patient doesn’t talk about pain (Carrion et al., 2015). Untreated pain may have a disproportionate impact on Hispanic patients, as Hispanic hospice patients who experience pain have nearly four times the odds of experiencing restlessness at the end of life relative to non-Hispanic patients or Hispanic patients without pain (Beltran, 2018).

Like Hispanic patients, South Asian patients may be reluctant to address pain at the end-of-life. A small qualitative study of health care providers found that they perceived South Asian patients and families as reluctant to report or treat pain at the end of life. They suggested that patients may wish to avoid burdening others, have concerns about side effects or potential addiction to pain medication, find pain management medication inconsistent with their spiritual beliefs, or not be made aware of medication benefits (Khosla et al., 2016).

Addressing Hospice Inequities

Increasing Enrollment in and Engagement with Hospice

To increase hospice enrollment, studies consistently recommended conducting community outreach to different racial and ethnic populations as well as low-income communities and creating educational materials that are clear and available in multiple languages (Hughes and Vernon, 2019). Hughes and Vernon also suggested that successful enrollment requires hospices with an inclusive culture and with a diverse staff (Hughes and Vernon, 2020). While these recommendations are broadly applicable, organizations should tailor community outreach and education to specific populations. Hospice leaders from varied organizations considered community outreach, when specifically tailored to its community, the most successful approach to increasing hospice use in minority populations and believed that the benefits of these programs outweigh the costs (Hughes et al., 2021). Having an advanced illness management program may also increase overall transition to hospice and increased length of hospice stays (Hostetter et al., 2018).

In addition to the research we cite below, our experts noted that hospices themselves may be able to increase referrals by talking with providers to understand what they find difficult about making hospice referrals. Hospice organizations could identify providers with low-referral rates and offer education and resources, such as prognostic indicator training, informational hospice training, and providing scripts to help physicians discuss hospice with their patients. Hospices can further monitor whether they see a corresponding increase in appropriate referrals, and any differences in the communities being served. Such differences reflect not only demographic or cultural groups, but the types of diagnoses that may have been previously under-referred and could benefit from more timely hospice care.

Our experts noted that hospices should use the demographic data of their communities to better understand who may benefit from increased access to or enrollment in hospice. Addressing that gap involves understanding why certain communities do not feel welcome, why they may hesitate to elect hospice, and how to establish trust among patient populations that have historically experienced structural and systemic racism.

However, one expert warned that hospice should not fixate on reaching certain percentages of the community, but rather should make sure that it treats the people they serve with dignity and respect. Cultural organizations can help fill the gaps by educating hospices and providing them a better understanding of cultural differences that can build awareness and knowledge necessary for staff to engage more effectively with diverse patients and families.

“Treating patients well will spread by word of mouth around the community, which will encourage more people to come to hospice.” – Interviewed Expert

Experts described efforts to increase community engagement that go beyond encouraging clinical referrals. This includes developing partnerships with faith-based organizations, fraternities, sororities, and other institutions to educate the community about hospice.

“Go to the community. Do not wait for the community to contact you. Continue to educate the community while they are still healthy instead of waiting until they are dying” – Interviewed Expert

Using these partners also provides the hospice an opportunity to hear first-hand what the community members need, rather than assuming what they need. Community partnerships can also help hospices better meet the social needs of their patients.

Engaging with the Black Community

Most work on engaging Black patients in hospice advocated reaching patients through churches. Older adults who belong to African American churches, as well as their families and caregivers, often rely on their spirituality and church community to help them cope with illness (Siler et al., 2016). Churches are

considered trusted spaces for health resources and social supports (Siler et al., 2016), with members being receptive to information about hospice even if the educator does not understand the church's specific religious construct (Townsend et al., 2017). Hospices can partner with African American churches to provide education, for example, by arranging regular information sessions at the church (Townsend et al., 2017). Specific content areas that may help to overcome African American patient barriers to hospice care include reframing hospice care in a way that prioritizes cultural values and practices, creating alternative goals for hospice care, and using information from outside the formal medical system (Dillon and Basu, 2016). Other approaches include counteracting the perception that hospice means giving up on faith, for example, by emphasizing the continued support patients can receive from their spiritual leaders and peers and that prayer can remain powerful in hospice (Rhodes et al., 2017).

A recent position paper from the National Hospice and Palliative Care Organization (NHPCO), which does not specifically reference engaging churches, suggests that organizations can support Black communities at the end-of-life by conducting an analysis of the education system within redlined communities, investing in a community health education campaign, advocating for equitable health laws, being innovative about multi-generational engagement and who can be community health equity stakeholders, identifying implicit biases and reflecting on the impacts of their decisions, having a clear and precise dialogue with both physician and patient about available options, and scheduling time for relationship building (NHPCO, 2020). NHPCO also cautions that organizations should engage minorities in ways “add genuine value to communities rather than investing in ‘Diversity, Inclusion and Equity’ solely for capitalization and incentivization.” Hospice and palliative care providers should also “educate themselves on the psyche of BIPOC that has been shaped by systemic racism, socioeconomic inequities, and disparities in health care education” (NHPCO, 2020).

Regardless of the engagement approach used, hospices that set specific goals to increase the number African American patients they serve engage in their outreach activities more frequently than organizations without specific goals (Johnson et al., 2016). Additionally, evidence suggests that being more clinically inclusive can improve hospice use for both Black patients and white patients. One study found that that less restrictive hospice admission practices, such as being more likely to enroll patients receiving expensive palliative therapies or patients with less robust home support systems, were associated with a greater proportion of both Black Medicare beneficiaries and white Medicare beneficiaries using hospice. Other characteristics associated with increased use of hospice by both African American Medicare beneficiaries and white Medicare beneficiaries include hospices having nonprofit status or larger budgets and being in a service area with a larger proportion of generalists, less market competition, and fewer physicians available for those age 65 years or older (Johnson, 2016).

Engaging with the Hispanic Community

In addition to some of the strategies already discussed, for Hispanic patients, language plays a role in overcoming barriers. In rural US-Mexico border towns, while most family caregivers of Latino patients were likely to use hospice for their loved ones, they preferred hospice providers that were able to speak their primary language and where they trusted the physician to “make the right decision” (Ko, et al., 2017). Yet, hospice staff volunteers and patients were almost entirely white and rarely spoke Spanish (Reese and Beckwith, 2015). Education about hospice should reflect how cultural values impact hospice placement, and should clearly explain hospice's purpose, function, and benefits (Ko and Fuentes, 2020). However, Rising and colleagues believe that efforts to increase engagement are most effective for those that already have a paternalistic, or deferential, relationship with their physicians, and that “cultural accommodation may do little to mitigate hospice avoidance that is rooted in mistrust” (Rising et al., 2021).

Engaging with the Indigenous American community and the Asian Community

We identified limited work addressing how to increase enrollment for Indigenous American populations and Asian populations. For Great Plains American Indians, Soltoff and colleagues recommended

increasing the availability of hospice at the reservation or in local Indian Health Service Facilities, helping families navigate the health care system, and improving the “trustworthiness of the system” by giving clinicians access to cultural training and engaging Tribal Nations in health system changes. (Soltoff et al., 2022). Interviews with Elders of the Blackfeet Nation revealed that while many members of the Blackfeet Nation fear death, they would not feel that their beliefs were being violated if a culturally competent provider was caring for them (Colclough et al., 2019). As with all patients, providers should work with Native Americans on an individual level to establish how much care a Native American patient would like to receive (Colclough, 2017). For Asian populations, interviews with Hmong family members, shamans, and funeral officiants found that Hmong patients prefer to die at home and that providing families and patients information about hospice helps families see hospice as a viable care option within their deeply held cultural beliefs (Helsel et al., 2020).

Engaging with the LGBTQ+ community

For LGBTQ+ populations, a few case studies illuminated the ways hospice care can be more inclusive of these populations. One case study of a male with metastatic breast cancer who was assigned female at birth (Stevens and Abraham, 2019) and another of a lesbian woman receiving hospice care from Veteran’s Affairs (Hinrichs and Christie, 2019) both advocated for building the trust of the LGBTQ+ community by being overtly welcoming and inclusive. This includes using inclusive language and images in outreach materials. For those in hospice, organizations should update the wording on intakes form to be more inclusive and ask patients who they want to be involved in decision making—then including partners and chosen families in decision making when the patient wishes (Hinrichs and Christie, 2019). LGBT adults often have a “chosen family” over a biological one. Providers should not make assumptions about family dynamics but instead ask questions (Acquaviva, 2017). For transgender patients, additional considerations include recognizing the lack of specific guidelines and standards for transgender patients in hospice settings, understanding patient preferences for discontinuation of hormone therapy, understanding insurance billing guidelines to avoid gender mismatch, and reflecting their SOGI disclosure preferences in their plan of care (Stevens and Abraham, 2019). Despite the unique considerations applicable caring for the LGBTQ+ community, a small survey found that providers generally felt that LGBT adults do not require different treatment than other adults (Cloyes et al., 2022).

One the most significant barriers to improving patient care in the LGBTQ+ community is insufficient data. A survey of hospice care team members found that most hospices did not collect any SOGI data, and a third of them were unsure whether collecting data was mandatory. Providers generally felt that the patient should disclose SOGI data instead of asking them for it (Cloyes et al., 2022). Because of their unique needs, researchers believe that collection of collection of SOGI data should be mandatory (Candrian and Cloyes, 2021), and providers should ask the patient how they identify rather than assuming. A patient’s assigned gender and the gender they identify with may differ, and the best way to determine both gender identity and sexual orientation is to ask (Acquaviva, 2017). A study by Kemery and colleagues suggested that in some cases available data that might illuminate the LGBTQ+ experience of care can be flawed. The family members they interviewed reported lower quality of life than their non-LGBT counterparts, yet there was no difference between the two groups in responses to the individual [Quality of Death and Dying](#) questions. This suggests the instrument may not be valid in the LGBTQ community (Kemery et al., 2021)

Organizational Efforts to Improve Hospice Care and Engagement

Organizations may face barriers in their efforts to provide cultural humility. Reese and Beckwith surveyed hospice directors to identify the main barriers hospices face when trying to provide culturally competent care identified barriers at the community, organizational, and health system level. Organizations had difficulty diversifying their staff because they lacked diverse and bilingual volunteers, funding, community outreach programs, and an organizational culture that recognizes and values cultural differences. Hospice directors cited geography, severe poverty, and a lack of diversity within their

communities as community-level barriers to culturally competent care. Finally, health system factors included government regulations that reduce the hospice's ability to meet diverse needs (Reese and Beckwith, 2015). Boucher and Johnson surveyed hospices about the cultural competence trainings, finding 73% of surveyed hospices offering training and larger hospices (i.e., with an average daily census greater than 100) more likely to offer such training. Trainings were typically one hour included content on cross-cultural communication, beliefs about death, spirituality and religion, and health disparities. (Boucher and Johnson, 2021)

Staffing Challenges and Opportunities

One factor that seems to be essential to providing equitable care in the hospice setting is having staff that understand different cultural preferences and beliefs, as well as staff that is itself diverse. As an American Academy of Hospice and Palliative Medicine piece highlighted recently, there is an enduring lack of diversity in the field of hospice and palliative medicine and more time and effort should be spent gaining an understanding of how underrepresented people who are medical students make their career choices and how they can be influenced to choose hospice (Beresford, 2020). Those who provided comment to CMS' Request for Information (RFI) echoed those concerns, noting things like a limited pool of applicants, and needing additional resources to support recruitment and retention efforts (87 FR 45669).

Challenges to hiring and maintaining diverse staff

Sometimes staff themselves may be subject to inequitable care by those they care for. For example, male caretakers may discount the professional status of a nurse relative to a physician (Sutherland et al., 2016). Our experts reflected on these challenges for Black patients and LGBTQ+ patients. Providing adequate staff that understand Black cultural values presents different challenges. As one interviewee described it, African American hospice providers often face discrimination from the patients they serve, which, as one expert noted, is making many Black hospice staff consider leaving the industry. For example, patients may say they "don't want the Black nurse" and some organizations, to be patient-centered, will accommodate those requests. Yet, they may not accommodate a Black person's request to be placed with a Black clinician. The LGBTQ+ community also experiences a dearth of culturally competent care. Not only do staff often fail to treat for LGBTQ+ patients with dignity and respect, but hospice itself may attract a workforce more prone to biases against the LGBTQ+ community. Hospice providers may feel a "calling" to end-of-life care that connects to their personal religious beliefs, which can be imposed upon the patients and families. One expert described hearing of nurses and nursing assistants attempting "death bed conversions" with their LGBTQ+ patients. She further noted that hospice patients may be more vulnerable to this kind of behavior than patients in other settings because hospice care is often provided at home, and rarely are there multiple staff members in the home simultaneously. While LGBTQ+ individuals work in hospices, they may not feel comfortable being "out" at work because of the organizational culture.

Different challenges exist for the Chinese-speaking patients. According to our experts, staff who speak Chinese or Chinese interpreters can be difficult to find. Even when interpreters are available, patients may be unable to comprehend what is happening to them because there is often not a direct translation for medical issues. Finding bilingual Chinese-speaking staff is particularly difficult, as cultural taboos about hospice and end-of-life care in the Chinese community limit the number who choose hospice nursing and social work.

Use of non-traditional roles

Several studies found that hospices employing students or others in the community through non-traditional roles were better equipped to hire diverse staff and serve patients of diverse backgrounds. Two studies looked specifically at community health workers. A Chicago study found that racial and ethnic minorities from low-income neighborhoods who were newly diagnosed with cancer and assigned a community health worker were more likely to use hospice care than those in without a community health worker. Participants felt more comfortable discussing their care goal and advance directives with

members of their community than with health care professionals (Patel et al., 2021). Soltoff and colleagues also suggested engaging community health workers in their work with Great Plains American Indians. Community health workers can help families navigate the health care system, increase the American Indian workforce, and improve cultural understanding (Soltoff et al., 2022).

For Hispanic patients who were provided patient navigators, the results were mixed. One study provided culturally and linguistically tailored materials describing advance care planning, pain management, and hospice care to a control group of Hispanic patients with advanced cancer and their family caregivers. They provided an intervention group with the same materials, as well as home visits by a Hispanic lay navigator who helped patients understand hospice by, for example, addressing misconceptions about hospice care. The navigators successfully facilitated advance care plan discussions, motivated patients to talk with providers about their pain needs, and helped patients and family caregivers learn more about hospice more so than written materials alone (Fink et al., 2020). However, in a prior study of Latino adults being treated for advanced cancer who worked with a culturally tailored patient navigator, the intervention increased advance care planning and improved physical symptoms, but had no effect on pain management, hospice use, or overall quality of life (Fischer, et al., 2018).

An additional study evaluated the effectiveness of hospice placement of student social workers in a rural community. The students helped address several of the organization staffing barriers by providing public information sessions, cultural competence training for staff, and a needs assessment to identify groups not served by the hospice—all services for which the hospice originally lacked resources (Reese et al., 2017).

Diversity in leadership

Our expert interviewees emphasized the importance of diversifying the hospice workforce at all levels to better reflect the communities they serve, while noting the particular importance of doing so at more senior levels. Some hospices are diversifying their board members, which helps to hold senior leadership accountable. However, board members are typically not involved in day-to-day decision making. Having representation at the organization’s senior leadership levels can have a “trickle-down” effect, by making those who work at those institutions feel more supported. For example, if a patient refuses the services of a Black hospice clinician because of the color of her skin or her sexual orientation, a leader that has lived experience with discrimination may be more willing or able to address the issue in a way that is supportive of the clinician. Further, leadership may be where diversity is lacking. The most diverse staff often are typically at the bedside with patients and families. Preferably, representation would reflect not only the organization’s patient population, but those in the community they aim to reach.

“How would it [more representation] work against you? Diversity helps us to be more creative in our thinking.” – Interviewed Expert

Supporting the findings of our experts, Boucher and Johnson found that of hospices that provided cultural competency training, 90% of the nursing, social work, and chaplain staff participated. 60 to 70% of leaders participated. Only 26% of board members participated (Boucher and Johnson, 2021)

Data Collection Challenges and Opportunities

Our expert interviews reflected a unanimous concern that the available data are simply insufficient to understand the complexity of inequities that exist in healthcare systems and settings, beyond what we discussed previously with respect to the LGBTQ+ community. For example, hospices often do not collect any SOGI data. Even with data hospices routinely collect, the quality of that data can be poor. Often, hospices will complete forms based on their perception of the patient, rather than a discussion with the patient—if they collect the data at all. As one expert noted, when a patient goes to a primary care physician, the patient completes paperwork that includes

“When collecting this demographic data, clinicians often click the easiest thing in the EMR rather than asking the patient directly.” – Interviewed Expert

demographic information independently. In hospice, the patient often does not complete those forms on their own, and instead depends on whoever is at the bedside. Hospice providers should be trained on how to collect patient data, including why collecting these data is important. One expert opined that hospice providers, who are comfortable asking about bowel movements, should not be worried they will offend a patient by asking questions about their gender identity.

Absent robust data on subpopulations, researchers, policymakers, and hospice providers are limited in their understanding of the quality of care in different subpopulations and how they might differ from each other. Multiple interviewees supported mandating more extensive data collection. For example, requiring the addition of questions about race, ethnicity, sex assigned at birth, gender identity, and sexual orientation in the CAHPS® Hospice Surveys, and requiring hospices to collect race, ethnicity, sex assigned at birth, gender identity, and sexual orientation data. Most interviewees explicitly requested mandatory data collection and reporting, with one interviewee warning that organizations can skew voluntary data collection and reporting, as they often want to demonstrate improvement or “show that they are doing a good job.” Experts noted that using standard question construction and standard validated instruments can support both comparisons of different subpopulations and lend credibility to the results. One interviewee put mandatory data collection in more stark terms, noting: *“The largest barrier to care is [organizational] prioritization. Health equity is currently viewed as a nice-to-have rather than a must-have. There should be a financial disincentive to provide inequitable and non-inclusive care.”* Those who responded to CMS’ RFI also commented on the need for more data, particularly a standardized on sociodemographic and SDOH data (87 FR 45669)

Our experts also suggested data collection beyond patient demographics—specifically, community-level demographic data and patient preferences data. Understanding community level data is a precursor to hospices understanding the subpopulations they may not be engaging in services. One expert advocated for collecting data on end-of-life preferences, such as preferences for invasive treatment, whether the patient or their caregiver stated those preferences, and whether a patient has an advanced care plan. They also recommended that hospice staff ask SDOH questions of all patients, noting that hospice staff cannot make assumptions about a patient’s needs.

All our experts supported qualitative data collection to inform health equity in hospice. Qualitative research offers an opportunity to collect more personalized details about hospice care, including understanding what is most important to patients and the caregivers, and what barriers they may face. However, interviewees warned that such research can be subject to selection bias, particularly if hospices select the participants. Of particular concern is that certain standardized data collection tools have not been validated with people of color. Though standardized research is important, it may need to be balanced with more creative or ethnographic research to accurately reflect the experiences of certain subpopulations.

Two identified studies focused on telehealth illustrate the need for caution with validated instruments. Hughes and Vernon believe that the COVID-19 public health emergency presents an opportunity to increase equity in hospice care. With the expansion of telehealth, hospices have an opportunity to provide their services in a more inclusive way, with approaches that may lead to greater hospice inclusion beyond the public health emergency. For example, health care providers can make their content and health services mobile friendly, work with patients to obtain affordable internet services, and lend electronic devices to patients (Hughes and Vernon, 2021). However, a meta-analysis focused on telehealth in the hospice setting found that validation and utilization of telehealth assessment measures underrepresented adolescents, geriatric populations, non-white or low-income populations, and those without a post-secondary education (Weaver et al., 2021).

Measurement Approaches

A few studies suggested specific approaches to considering for measuring conditions relevant to health equity. Mendola and colleagues suggest introducing the term “social determinants of comfort” to describe structural conditions that influence to what degree hospices offer and patients and their families accept comfort measures. This framework would recognize factors such as safety of the built environment, access to nourishing food, a steady income source, among others as structural conditions that influence the health outcomes of individuals and populations (Mendola et al., 2021). A survey by AbuDagga and colleagues asked home health and hospice agencies about cultural competency training and awareness and found that they could reliably calculate two measure constructs based on their survey questions: 1) whether the hospice provides mandatory cultural competency training, and 2) whether the hospice effectively communicate in culturally competent ways (AbuDagga et al., 2018).

Lastly, CMS requested information on a multi-domain structural composite measure in their FY 2023 proposed hospice rule, which includes domains related to health equity and community engagement in strategic planning; diversity, equity, and inclusion training; and organizational inclusion and capacity to promote health equity (87 FR 45669). Commenters were generally supportive of a health equity structural measure, but noted that having adequate resources and accurate, actionable data related to the measure are important. As this report has suggested, there are several opportunities to improve access to hospice and the experience of care for hospice patients and their caregivers.

In the months following this report, Abt Associates will convene two TEPs that will engage in work to incorporate health equity into quality measure development. The first is a newly recruited TEP of health equity experts in both hospice and home health that will further reflect on the role CMS can play within its quality reporting programs to improve equity in these settings. The second is the existing HQRP TEP (which has provided input for the HQRP since 2019), which will consider this report and reflect upon the available opportunities to promote health equity within the HQRP.

Other Recent Hospice Literature

To identify any emerging trends outside of our research questions, we conducted an environmental scan to identify literature related to quality of care in the hospice setting that was published in the last year. Our results fell into three main categories: hospice care for dementia patients, use of new technologies in hospice, and approaches to staffing and services. One additional study explores a Health Days at Home measure.

Two recent studies using National Health and Retirement Study data linked to Medicare claims considered hospice care for patients with dementia. The first considered patients with both primary and co-morbid dementia, which combined represented approximately 45 percent of hospice patients. Patients with either co-morbid or primary dementia had longer lengths of stay and were more likely to disenroll from hospice after six months than those without dementia (Aldridge et al., 2022). The second study considered caregiver experience and found that, for dementia patients enrolled in hospice, proxies were more likely to report excellent care, that the patient's anxiety and sadness was managed, and that the patient changed care settings in the last 3 days of life less frequently than those not enrolled in hospice. For those receiving hospice, proxy ratings did not differ between patients with dementia and those without (Harrison et al., 2022).

Two studies pertained to use of technology at end of life: one focused on telehealth and the other on machine learning. A recent study using both caregiver surveys and hospice leader interviews explored telehealth use. Telehealth reportedly enhanced usual care activities such as addressing patient and family concerns, explaining lab results, and basic diagnostic activities as well as bereavement support; however, perceptions of telehealth for social workers and spiritual counselors were mixed. Some felt social workers and spiritual counselors could reach more people using telehealth and did not have to visit patient homes, but others felt these services “are more difficult to do well without in-person connection.” Providers also expressed continued confusion over telehealth policies and concerns about abuse, such as some hospices doing phone calls instead of true audio-visual visits or family drug diversion becoming more prevalent. From a patient perspective, those with better internet, better access to video, and under 65 were more satisfied with telehealth (Hughes et al., 2022). With respect to machine learning, a recent analysis of therapy sessions for family caregivers of hospice patients found that machine learning techniques that use automated speech-to-text transcription and acoustic features can reasonably indicate improvements in anxiety and quality of life measures in older adults with a reasonable degree of accuracy relative to assessment with a validated instrument. The authors reported this may have implications for the use of chatbots to provide therapy. They further noted that the use of machine learning could minimize the need to repeatedly administer instruments such as the Generalized Anxiety Disorder-7 and the Caregiver Quality of Life Index-Revised, and increases the ability of these instruments to be administered outside of clinical settings. (Demiris et al., 2022)

Two studies addressed hospice staffing and services. The first, an Italian study, analyzed the predictive power of staffing on controlling clinically significant symptoms in residential hospices. They found a ratio of approximately 20% physicians, 20% nurse assistants, and 60% registered nurses was associated with the greatest likelihood of symptom control (including pain, nausea, shortness of breath, feeling sad, feeling nervous), and that physicians and nurses trained in palliative care were associated with improved patient outcomes (Artico et al., 2022). Another study looked at how the provision of inpatient services can impact a hospice's total operating margin (i.e., income/revenue) and their return on assets (i.e., income/assets). Hospices that had staff provide inpatient services had shorter lengths of stay and lower total operating margins than hospices that did not offer inpatient services. Hospices that offered a combination of inpatient services provided by staff and by a third-party arrangement had a lower return on assets than hospices that do not provide inpatient services. The authors conclude that many hospices

increasingly look to provide inpatient services by arrangement to maintain financial sustainability (He et al., 2021).

Lastly, one study used a novel quality measure in the last 180 days of life for cancer patients. The HDAH measure considers the last 180 days of life and subtracts days the patient spends in an acute inpatient setting or emergency department (including observation), skilled nursing facility, inpatient psychiatric setting, inpatient rehabilitation facility, long-term hospital, or inpatient hospice. Days at home with home hospice or home health are considered HDAHs and not subtracted. Skilled nursing facility days and inpatient facility days resulted in the most substantial HDAH reductions, and males and Medicaid patients had fewer HDAH's than their female and male counterpart, respectively. (Lam et al., 2021)

Conclusion

Many studies have explored differential use of hospice care over the past seven years, with many focused on race and ethnicity. Historically excluded populations are less likely to use hospice, and often less likely to be aware of hospice care and its benefits. However, there is some evidence that historically excluded populations are not referred to services less. In fact, some evidence suggests that Black patients are more likely referred to hospice more often than their white counterparts. Indigenous American populations face limited access, and Hispanic patients and Asian patients face language barriers. There are also myriad complex cultural values and lived experiences unique to each population that influence willingness to use hospice care. Of those that choose to enroll in hospice, historically excluded races and ethnicities are more likely to enroll early. Though most of the health equity research focuses on race and ethnicity, other influencers of likelihood to receive hospice care include gender, education, income, and location.

Studies consistently reported Asian and LGBTQ+ populations having poorer care experiences. Asian patients seem to face particular cultural and language barriers to receiving high quality hospice care. For LGBTQ+ patients, there are no incentives for hospice providers to discuss SOGI with patients and discounting of chosen family and spouses persists. Pain management, a bedrock of hospice care, also reflects inequities of gender and race.

Addressing equity in hospice involves community engagement, recruiting and retaining diverse staff, and expanded available data. Many studies offered specific approaches to engage communities to increase enrollment, though strategies will vary depending on the specific community. Recruiting and maintaining diverse staff can be a particular challenge for hospice providers, especially when bedside employees may face discrimination from patients. Increasing diversity in senior roles may help staff feel more supported. Use of non-traditional staff and students has also shown promise for both increasing staff diversity and engaging the community. Currently available data are insufficient to effectively understand health equity in hospice care. Additional patient demographic data (e.g., SOGI), community-level demographic information, SDOH data, and qualitative data can all help to better illuminate how equitable hospice care is.

Few studies suggested specific measures or constructs related to health equity, though CMS asked for feedback on a health equity focused structural measure in its FY 2023 Hospice Rule (87 FR 45669). Over the next few months CMS will convene two TEPs focused on health equity to reflect on the role CMS can play within its quality reporting programs to improve equity in these settings.

As for other emerging trends in hospice, in the past year the literature has focused on dementia patients, technology, hospice structures, and the novel HDAH measure. Almost half of hospice patients have dementia and benefit from hospice care. Technology advancements in hospice in telehealth and machine learning have potential to improve care, but telehealth works better for certain medical interventions than for social and spiritual care, and there remains confusion and concern over potential abuse. Structural elements also impact hospice care, with a higher ratio of nurses to physicians associated with better symptom management, and hospice perhaps deciding to offer inpatient services by arrangement rather than their own staff to maintain financial stability. A novel HDAH measure looks at quality of life in the last 180 days of life and can help users understand where patients are going when not at home and who is more likely to have HDAHs.

Appendix I: Methods

Literature Reviews

The Information Gathering Team used a stepwise process to identify information relevant to our research questions. Those steps are outlined here.

Determine search terms. We determined a specific set of search terms to both identify the hospice setting and to identify work relevant to each specific research question using the following steps:

- Determine MeSH terms using [MeSH on Demand](#),
- Determine additional non-MeSH terms,
- Discuss identified search terms as a group and solicit expert review where needed,
- Finalize search terms.

The following search terms to identify the hospice setting were consistent across all searches:

- MeSH terms included: Hospices, Hospice Care, Hospice and Palliative Care Nursing, Terminal Care.
- Non-MeSH terms included: end-of-life care.

Determine search parameters and identify articles. We conducted our literature searches in PubMed, which include MEDLINE indexed journals, journal and manuscripts deposited in PubMed Central, and the National Center for Biotechnology Information Bookshelf. We used the following steps to conduct the search and ensure the most relevant results.

1. Determine Boolean phrase using predetermined search terms (i.e., how terms will connect using and/or)
2. Set results filters to adult, human, and English language results in the past 5 years.
3. Use the Advanced Search option to search in the Title and Abstract fields

If this yielded fewer than ten results, we updated the parameters to search in all Text Word fields. If this still yielded fewer than ten results, we searched in All Fields and reviewed the search terms with subject matter expert to see if the terms should be revised. If a search yielded greater than 500 results, we revised our search terms to narrow the results and consulted with a subject matter expert. We exported all results to an EndNote library.

Review identified articles. To facilitate our review, we designated folders within each EndNote Library for relevant articles, somewhat relevant articles, and insufficiently relevant articles that we rejected from our results. We further sorted rejected articles based on how detailed our review of each article was. Some were rejected based on the relevance of their title or abstract. Remaining articles were either kept or rejected based on a review of the full text. Potential reasons for rejection include incorrect setting, incorrect population, or lack of specificity to target questions. If fewer than five articles remained after the review process, we consulted with a subject matter expert and conducted a supplementary Google Scholar search.

Supplement results using Google Scholar. For searches with fewer than five relevant articles remaining after review, we conducted a search in Google Scholar using the same search terms and review criteria outlined for our PubMed searches.

Identify and review grey literature. The Information Gathering lead identified relevant grey literature by using the hospice search terms identified above in the [Harvard Kennedy School Think Tank](#) site as well as the following individual sites with a focus on healthcare or hospice:

- Center to Advance Palliative Care
- Institute for Healthcare Improvement
- Joint Commission
- Robert Wood Johnson Foundation
- The Commonwealth Fund
- Kaiser Family Foundation
- National Academy of Medicine
- National Coalition for Hospice and Palliative Care (NCHPC) (trade group membership)
- Hospice and Palliative Care Nurses Association
- American Academy of Hospice and Palliative Care
- National Hospice and Palliative Care Organization (NHPCO) (membership required)
- Visiting Nurse Associations of America

The Information Gathering lead reviewed the search results within each site and compiled links relevant to hospice or our topics. The larger Information Gathering team searched these compiled links using the previously determined search terms for each of their research questions. For the Center to Advance Palliative Care site, staff searched the overall site with their research question specific search terms.

Most of the sites did not yield any recent, accessible, and relevant content apart from: Kaiser Family Foundation, NHPCO, the Commonwealth Fund and the American Academy of Hospice and Palliative Care.

Review additional supplemental information. We compiled information provided by the TEP, subject matter experts, and other stakeholders over the course of the year. Information Gathering staff reviewed these materials and incorporated findings relevant into their research questions.

Expert Interviews

We identified nine experts, including representatives of diversity, equity, and inclusion initiatives and provider associations as well as health services researchers with relevant expertise. After CMS approved this list of experts, we emailed each of these experts and invited them to speak with us. Four agreed, one declined, and the remainder did not respond after three outreach attempts. Our four interviewed experts were:

- Kimberly Acquaviva, Betty Norman Norris Endowed Professor at the University of Virginia School of Nursing and end-of-life advocate for the lesbian, gay, bisexual, transgender, gender-non-conforming, queer, and/or questioning (LGBTQ+) community.

- Karen Bullock, former Professor and Head of the School of Social Work at North Carolina State University
- Sandy Chen Stokes, Founder and Executive Director of the Chinese American Coalition for Compassionate Care and Member of NHPCO's Diversity Advisory Council
- Nicole McCann Davis, former Associate Vice President of Health Equity and Access at Seasons Hospice and Palliative Care and Chair of NHPCO's Diversity Advisory Council

We created a brief, semi-structured interview guide to facilitate our discussion that included health equity focused questions on both receipt of and access to hospice care. We probed on topics such as key health equity terms and concepts, use of data, cultural gaps, hospice referral and enrollment, and increasing representative hospice staff.

Appendix II: Search Results

Social Determinants of Health	
Search Terms	("social determinant*" AND ("hospice" OR "hospice care" OR "end of life care" OR "terminal care" OR "hospice and palliative care nursing")) [All Fields]
Search Date	March 2022
Total Peer-Reviewed Articles	43
Total Google Scholar Results	N/A
Total Grey Literature Articles	0
Title/Abstract Rejection	15
Article Rejections	21
Final Articles	7
Health Equity in the Hospice Setting	
Search Terms	(Hospice OR Hospice Care OR Hospice and Palliative Care Nursing OR terminal care OR end-of-life care) AND (ident* OR disparit* OR equity OR underrepresent* OR inclus* OR cultur* OR diversity OR underserve OR minori*) [Title Abstract = 3,300] (Hospice OR "terminal care" OR "end-of-life care") AND (identity OR disparit* OR equity OR underrepresent* OR inclus* OR cultur* OR diversity OR underserve OR minori*) [title/Abstract = 1,961] (Hospice) AND (identity OR disparit* OR equity OR underrepresent* OR inclus* OR cultur* OR diversity OR underserve OR minori*) [title/abstract = 805] (Hospice) AND (identity OR disparit* OR equity OR underrepresent* OR inclusive OR cultur* OR diversity OR underserve OR minori*) [title/abstract = 619]
Search Date	June 2022
Total Peer-Reviewed Articles	619
Total Google Scholar Results	N/A
Total Grey Literature Articles	5
Title/Abstract Rejection	409
Article Rejections	105
Final Articles	111
Other Recent Hospice Literature	
Search Terms	("hospice") AND ("quality")
Search Date	August 8, 2022
Total Peer-Reviewed Articles	71
Total Google Scholar Results	NA
Total Grey Literature Articles	0
Title/Abstract Rejection	60
Article Rejections	4
Final Articles	7

Appendix III: Literature Review Tables

Health Equity and Social Determinants of Health

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
2021 Massachusetts State Hospice Report: 2019 Medicare Information with 2018 Comparisons Using Annual Files. (2021, 02/23/2021). State Hospice Organization.	Massachusetts, Hospice	NA	Hospice utilization data for the country in comparison to the United States	Presentation presents nice data visualizations for county-level variation in hospice utilization as percent of Medicare deaths (slide 7 and 8). This visualization particularly shows inequities of hospice utilization in the West.
Abbas, A., Madison Hyer, J., & Pawlik, T. M. (2021). Race/Ethnicity and County-Level Social Vulnerability Impact Hospice Utilization Among Patients Undergoing Cancer Surgery. <i>Ann Surg Oncol</i> , 28(4), 1918-1926. https://doi.org/10.1245/s10434-020-09227-6	United States	54, 256 patients 65 years of age or older with a diagnosis of lung, esophageal, pancreatic, colon, or rectal cancer who underwent a resection for cancer between 2013 and 2017.	Patients were identified through CMS Standard Analytical Files, which contain de-identified data on Medicare beneficiaries. They used the CDC Social Vulnerability Index to understand the socioeconomic qualities of a patient's area of residence. SVI = higher is more vulnerable.	White patients were more likely to utilize hospice care than minority patients (OR 1.24, 1.17-1.31). As the Social Vulnerability Index (SVI) increases for minority patients, hospice utilization and early hospice initiation decrease (OR 0.97, 0.96-0.99). Ultimately, patients in high SVI areas were less likely to be enroll in hospice, especially if they are not white.
AbuDagga, A., Mara, C. A., Carle, A. C., & Weech-Maldonado, R. (2018). Factor Structure of the Cultural Competence Items in the National Home and Hospice Care Survey. <i>Med Care</i> , 56(4), e21-e25. https://doi.org/10.1097/mlr.0000000000000714	United States	1,036 home health and hospice agencies.	Data were collected from the 2007 National Home and Hospice Care Survey, which consisted of interviews with agency directors and designated staff. The NHHCS asks 9 questions about cultural competency, and all were included in this study. Analysis was then performed to understand what combination of questions can be measured to provide a decent measure of cultural competency.	The study found two constructs that can be measured using the 9 survey questions. The first is mandatory cultural competency training (questions 1-3), and the second is cultural competency communication practices (questions 7-9). These constructs were analyzed with the questions for correlation and found to have a p value of <0.01.
Acquaviva, Kimberly D. <i>LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice</i> . Harrington Park Press, 2017.	United States	Book – guide to practical changes	N/A	Chapter 2: It is important to recognize that gender identity occurs on a spectrum and that assigned sex does not always show what gender a person identifies as. The only way to determine gender identity and sexual orientation is to ask.

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				<p>Chapter 3: To provide LGBT-inclusive care, providers must understand oppression faced by LGBT adults. Furthermore, hospice providers must address barriers (perceptual, financial, and institutional) in both an outward facing (outreach, education) and inward facing (staff education) fashion.</p> <p>Chapter 5: When discussing family dynamics with LGBT patients, do not assume anything about the relationship with their family. Asking questions is the easiest way to understand these dynamics and will help determine who is the legal decisionmaker and who should be excluded from decisions. It should also be noted that LGBT adults often have a “chosen family” over a biological one.</p> <p>Chapter 6: It is important to remember that LGBT adults are more often smokers, so oxygen usually becomes more of an issue at end of life. It's important to understand differences between LGBT and cis/hetero adults when planning care.</p> <p>Chapter 10: Health code of ethics compels a person to advocate for changes to ensure equal treatment of LGBT adults. This can be achieved through four main planks:</p> <p>Plank 1: Nondiscrimination statement Plank 2: Employee benefits, orientation, and training Plank 3: Intake forms and processes Plank 4: Marketing and community engagement</p> <p>For LGBT patients to feel safe, LGBT employees should also feel safe.</p>

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Citation	Setting	Population	Design	Main Findings
Bazargan, M., Cobb, S., Assari, S., & Kibe, L. W. (2021). Awareness of Palliative Care, Hospice Care, and Advance Directives in a Racially and Ethnically Diverse Sample of California Adults. <i>Am J Hosp Palliat Care</i> , 38(6), 601-609. https://doi.org/10.1177/1049909121991522	California	2,328 people. Hispanic (31%), Black (30%), and non-Hispanic White (39%)	Cross-sectional study from the Survey of California Adults on Serious Illness and End of Life 2019. The goal of the study was to examine socioeconomic, racial, and medical factors to understand the awareness of palliative and hospice care.	Adjusted for socioeconomic and demographic characteristics, as well as chronic conditions, Whites are more likely to be aware of hospice than Black people (OR 0.44) or Hispanics (OR 0.23). Primary caregivers were more likely to be aware of palliative care (OR 1.71) or advanced care planning (OR 1.48) than hospice care (OR 0.99). Having a primary care provider was associated with a higher likelihood of being aware of hospice care.
Beltran, S. J. (2018). Hispanic Hospice Patients' Experiences of End-Stage Restlessness. <i>J Soc Work End Life Palliat Care</i> , 14(1), 93-109. https://doi.org/10.1080/15524256.2018.1437589	United States	143 Hispanic patients, 285 non-Hispanic patients who were discharged due to death	Analyzed the patients to understand whether they had restlessness prior to death or present at death (NHHCS question 77). Binary yes/no. Then they performed bivariate analyses to determine the statistical significance of race on this question.	Being Hispanic (OR: 1.67), having trouble breathing (OR: 2.13), pain (OR: 2.38), and sedation (OR: 3.06) were all factors that were significantly associated with end stage restlessness. Furthermore, the odds of experiencing end-stage restlessness were 3.77 times higher for Hispanics experiencing pain ($p < .01$) than for non-Hispanic whites and Hispanics not in pain.
Beltran, S. J. (2022). Latino Families' Decisions to Accept Hospice Care. <i>Am J Hosp Palliat Care</i> , 39(2), 152-159. https://doi.org/10.1177/10499091211042336	United States	13 Latinos 65+ age, who are enrolled in hospice (or their proxies) who scored 8+ on the Brief Interview for Mental Status	Descriptive, cross-sectional study that conducted semi-structured interviews in English and Spanish regarding factors that guide decisions regarding end-of-life care.	The interviews shed light on several subjects specific to Latino experiences in hospice care. Latino people generally do not have a lot of experience with the US healthcare system – reporting a lack of healthcare due to location or finances. Limited health literacy and language barriers mean that patients often rely on family members for translation and can lose the fundamental understanding of their prognosis during the process. Most patients learned about hospice at the time of referral.

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				In terms of expectations, Latinos expect nursing care and medical supplies from hospice. Often, they are confused about what services can exactly be provided.
Beresford, L. (2020). Programs Have Stepped Up to New Roles--Where They've Had Sufficient Staffing. American Academy of Palliative and Hospice Medicine. http://aahpm.org/quarterly/fall-20-feature . Accessed August 26, 2022	American Academy of Hospice and Palliative Medicine Fall Feature 2020	N/A	Reporting on staff experience in care in COVID	"Another important issue raised by the COVID pandemic, with its disproportional impact on people of color, is the enduring lack of diversity in the field of hospice and palliative medicine. "We need to spend more time and effort reaching out to underrepresented people among our medical students and to gain better understanding of how they make their career choices and how to influence them to choose us," [Robert Arnold, MD FACP FAAHPM, chief of the section of palliative care and medical ethics at the University of Pittsburgh Medical Center in Pennsylvania] said."
Booker, S. Q., Herr, K. A., & Wilson Garvan, C. (2020). Racial Differences in Pain Management for Patients Receiving Hospice Care. <i>Oncol Nurs Forum</i> , 47(2), 228-240. https://doi.org/10.1188/20.Onf.228-240	Midwestern United States	32 African Americans and 32 Caucasian Americans 65+ age who are receiving hospice care at home for cancer.	Secondary analysis of a completed cluster randomized controlled trial 2007-2010. Patients were measured using the Cancer Pain Practice Index (CPPI)	There was no statistically significant difference in CPPI scores between races.
Boucher, N. A., & Johnson, K. S. (2021). Cultivating Cultural Competence: How Are Hospice Staff Being Educated to Engage Racially and Ethnically Diverse Patients? <i>Am J Hosp Palliat Care</i> , 38(2), 169-174. https://doi.org/10.1177/1049909120946729	United States	197 hospices	Data obtained from a cross-sectional national survey of a convenience sample of hospices from 2014-2015. Telephone interview with hospice leaders. Additionally, a web-based survey with questions about CCT.	Hospices with a >100 average daily census were more likely to offer CCT (80% vs. 64%) 73% of surveyed hospices offered cultural competency training, although there was no statistical significance in characteristics between hospices that do and do not offer CCT. Most of these trainings are 1 hour in length. Of the hospices that participated, 90% of the nursing, social work, and chaplain staff participated. 60-

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				70% of leaders participated. Only 26% of board members participated. Main themes covered in CCT include cross-cultural communication, death beliefs, spirituality/religion, and health disparities.
Cagle, J. G., LaMantia, M. A., Williams, S. W., Pek, J., & Edwards, L. J. (2016). Predictors of Preference for Hospice Care Among Diverse Older Adults. <i>Am J Hosp Palliat Care</i> , 33(6), 574-584. https://doi.org/10.1177/1049909115593936	United States	2487 people	Analysis of North Carolina AARP End of Life Survey in 2002. Socioeconomic and demographic information was collected, as well as questions regarding attitudes about hospice, dying, and healthcare.	Black Americans are less likely to prefer or request hospice support (63.8% vs. 79.2%, $P < 0.0001$). Black Americans were more likely to not know their preference for hospice as well (31.5% vs. 16.8%). Furthermore, gender, age, income, insurance coverage, importance of physical comfort, religiosity, and importance of being on/off machines to extend life were able to predict hospice preference. Generally, Black Americans are much more uncertain about receiving hospice than their white counterparts.
Cagle, J. G., Van Dussen, D. J., Culler, K. L., Carrion, I., Hong, S., Guralnik, J., & Zimmerman, S. (2016). Knowledge About Hospice: Exploring Misconceptions, Attitudes, and Preferences for Care. <i>Am J Hosp Palliat Care</i> , 33(1), 27-33. https://doi.org/10.1177/1049909114546885	United States	123 adults living in the contiguous US	Telephone numbers were randomly selected, and minority groups were over-sampled. A small telephone survey was conducted to ask questions regarding awareness and knowledge about hospice.	86% of respondents had heard of hospice, and 54% had already had a personal experience with hospice. Greater knowledge of hospice was associated with better attitudes toward hospice. Respondents who were college-educated, worked in the medical field, or were non-Hispanic white, are more likely to be aware of and be knowledgeable of hospice.
Candrian, C., & Cloyes, K. G. (2021). "She's Dying and I Can't Say We're Married?": End-of-Life Care for LGBT Older Adults. <i>Gerontologist</i> , 61(8), 1197-1201.	United States	31 older lesbian adults	Qualitative interviews conducted with lesbian adults to understand their perspectives about end-of-life care. Interviews lasted 1-2 hours and were conducted in-home or on video.	Hospices do not routinely collect SOGI data. In a 2018 survey, 43% of hospice professionals reported that they had observed directly discriminatory behavior against LGBT people and their spouses.

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https://doi.org/10.1093/geront/gnaa186				<p>The interviews elaborated the fact that LGBT people, even if asked about SOGI, can receive discrimination from hospice staff. One story of a wife dying from leukemia involved a nurse providing less and less care once he realized the patient and the visitor were a couple.</p> <p>As a result, LGBT people are often forced to hide their identities as they receive healthcare to receive the best quality care. However, developing LGBT-approved SOGI guidelines and mandating SOGI collection in hospice can help normalize the process, which may not stop personal discrimination, but can help shift the system towards inclusivity.</p>
<p>Carrion, I. V., Cagle, J. G., Van Dussen, D. J., Culler, K. L., & Hong, S. (2015). Knowledge About Hospice Care and Beliefs About Pain Management: Exploring Differences Between Hispanics and Non-Hispanics. <i>Am J Hosp Palliat Care</i>, 32(6), 647-653.</p> <p>https://doi.org/10.1177/1049909114536023</p>	United States	123 individuals, 13% of whom were Hispanic	Cross-sectional phone survey of adults living in the contiguous US. Phone numbers were randomly selected. Participants were measured on knowledge, attitudes, experiences, and preferences related to hospice and pain management.	<p>Hispanic people generally have less knowledge and understanding of hospice, as well as more difficult views on pain.</p> <p>Hispanic people were less likely to have heard of hospice and more likely to have incorrect information about it ($p < 0.001$, $p = 0.05$). 56% of Hispanic respondents thought that hospice was only for people 65+ years old (versus 7% for non-Hispanic respondents).</p> <p>Hispanic people were also more likely to say pain is a sign of weakness and that a good patient does not talk about pain.</p>
<p>Check, D. K., Samuel, C. A., Rosenstein, D. L., & Dusetzina, S. B. (2016). Investigation of Racial Disparities in Early Supportive Medication Use and End-of-Life Care Among Medicare Beneficiaries with Stage IV Breast Cancer. <i>J Clin Oncol</i>, 34(19), 2265-2270.</p>	United States	752 white and 131 Black women who had stage IV breast cancer	SEER-Medicare data collected from 2007 – 2012, analyzed for the relationship between race and hospice admission (among other factors).	Disparity in hospice use: Black women were 14% less likely to be enrolled in hospice than their white counterparts (OR: 0.86).

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https://doi.org/10.1200/jco.2015.64.8162				
Cloyes, K. G., Jones, M., Gettens, C., Wawrzynski, S. E., Bybee, S., Tay, D. L., Reblin, M., & Ellington, L. (2022). Providing home hospice care for LGBTQ+ patients and caregivers: Perceptions and opinions of hospice interdisciplinary care team providers. <i>Palliat Support Care</i> , 1-9. https://doi.org/10.1017/s1478951522000657	United States	48 hospice care team members	Six focus groups from three hospice sites were convened with hospice care team members. HCT members were asked about their knowledge and experience related to EOL care for LGBT adults.	<p>Two sites said they do not collect any SOGI data. The third site believed it was collected but was unsure. In the absence of SOGI, providers used terms like “partner” or “significant other” to indicate an LGBT relationship.</p> <p>Providers felt that it was the patient’s job to disclose their SOGI to the provider. Many providers felt that LGBT people do not need specialized care and used death as the “great equalizer” to justify this. They view equal treatment as a positive as opposed to lacking specialized care for a marginalized group.</p> <p>Only one site had received any competency training on LGBT services.</p> <p>Providers emphasized a need for further education surrounding the needs of transgender patients.</p> <p>The best practice for care and communication with LGBT adults is to establish trust and ensure the patient that they are in a safe space.</p>
Colclough, Y. Y. (2017). Native American Death Taboo: Implications for Health Care Providers. <i>Am J Hosp Palliat Care</i> , 34(6), 584-591. https://doi.org/10.1177/1049909116638839	United States	N/A	N/A – paper that discusses Native American beliefs on death, no formal methods section	<p>Native Americans have a different perspective on death. They believe that death is the Creator’s job to determine, and that human control is not required. They believe that silence reduced evil spirits and therefore harm. They also believe that death may trigger more deaths.</p> <p>Healthcare providers must be sensitive to these beliefs, as they can determine how much care a Native American patient wants to receive. Providers should establish comfort level with</p>

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				<p>advanced medication and provide many reassurances to the patient that this care is not against the Creator.</p> <p>Involving family members in the decision is also important, although it may vary family to family.</p>
Colclough, Y. Y., & Brown, G. M. (2019). Moving Toward Openness: Blackfeet Indians' Perception Changes Regarding Talking About End of Life. <i>Am J Hosp Palliat Care</i> , 36(4), 282-289. https://doi.org/10.1177/1049909118818255	United States	10 Elders, 102 tribal members. All the Blackfeet Nation.	Interviews conducted with Elders and members of the Blackfeet Nation. Questions were asked based on a modified Duke End of Life Care Survey.	<p>Elders among the Blackfeet people were divided in their beliefs about end-of-life. Some felt that discussing end-of-life care was not against tradition, while others felt that sickness breaks the living spirit and should not be mentioned.</p> <p>Researchers concluded that fear of death primarily drove the Blackfeet to avoid discussing end-of-life. They found that, as long as a culturally comfortable environment is available, the Blackfeet people will not feel that end-of-life care is violating their beliefs.</p>
Dhingra, L., et al. (2022). "Low Hospice Utilization in New York State: Comparisons Using National Data." <i>J Pain Symptom Manage</i> 63(4): 522-529.	All hospices in New York.	All patients in the U.S. insured by traditional Medicare who died in 2018.	Analysis of national data to evaluate the differences between New York State and the rest of the country by exploring associations between patient and state characteristics and a group of hospice utilization outcome variables.	This study identified eight factors that independently accounted for differences in hospice utilization— in enrollment or length of stay, or both outcomes—when comparing New York State to all other states. In addition to the relatively higher socioeconomic status of the New York State population, these factors included the higher number of physicians seen in the last two years of life; the greater number of SNF beds and lower number of for-profit SNF facilities; and the smaller number of hospice agencies (both for-profit and not-for-profit).
Dillon, P. J. and A. Basu (2016). "African Americans and Hospice Care: A Culture-Centered Exploration of Enrollment Disparities." <i>Health Commun</i> 31(11): 1385-1394.	Quest Hospice, a comprehensive hospice organization that serves four counties surrounding a large metropolitan	26 African American hospice patients (n = 10) and lay caregivers (n = 16) receiving hospice or bereavement services from Quest Hospice. Patients'	39 total semi-structured in-depth interviews (with a mean length of 37 minutes) that were conducted in participants' homes (n = 37) and in a private office at the hospice organization's headquarters (n = 2).	Interviewees identified several barriers to hospice enrollment and reported how they were able to overcome these barriers by reframing/prioritizing cultural values and practices, creating alternative

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	area in the southeastern United States. The hospice is part of a larger non-profit, post-acute care system that also provides palliative care and senior services. In 2013, 9.8% of the hospice's patients self-identified as African American.	mean age was 69.8 years, with a range of 29–81 years. The 16 caregivers who took part in the study ranged in age from 34 to 76 years (M = 46).	The research questions were: 1) How do African American patients and lay caregivers overcome potential barriers to hospice enrollment? And 2) How do African American patients and lay caregivers make sense of hospice enrollment disparities?	goals for hospice care, and relying on information obtained outside the formal health system. Barriers include: 1) inconsistent access and/or active avoidance of medical care leads, which means that some African Americans learn of a terminal diagnosis (relatively) late in the disease trajectory; 2) a history of discrimination and/or mistreatment within the health care system, causing mistrust in hospice; and 3) the perception of hospice policies and procedures to be incongruent with cultural values and practices associated with death. These interviews demonstrate how disparities are intertwined with structural patterns of financial insecurity, differentiated health care access, and racial prejudice that perpetuate a marginal position for African Americans with the medical system. This perspective shifts the conception of hospice enrollment disparities from a matter of knowledge-based or motivational deficiencies to an issue of equity.
Dressler, G., Cicoello, K., & Anandarajah, G. (2021). "Are They Saying It How I'm Saying It?" A Qualitative Study of Language Barriers and Disparities in Hospice Enrollment. <i>J Pain Symptom Manage</i> , 61(3), 504-512. doi:10.1016/j.jpainsymman.2020.08.019	End-of-life care (EOL) clinicians in the state of Rhode Island, where around 22% of the population speaks a language other than English at home, and 8.6% speak English less than very well. Spanish is the most commonly spoken language after English. About 6.9% of the population	Twenty-two participants included six nurses/certified nursing assistants, five physicians, three administrators, three social workers, three patient caregivers, and two chaplains, self-identifying from a variety of racial/ethnic backgrounds. All participants lived or worked in RI.	A secondary qualitative analysis of semi structured individual interviews that were audio recorded and transcribed verbatim. Data were coded using NVivo 11. Three researchers analyzed all data related to language barriers, first individually, then in group meetings, using a grounded theory approach, until they reached consensus regarding themes. Institutional review board approval was obtained.	Disparities in quality EOL care and hospice enrollment persist for patients with low English proficiency, despite attempts to improve access to trained medical interpreters via implementation of Culturally and Linguistically Appropriate Services standards, increased training for medical interpreters, and access to phone and video interpretation services. Three themes emerged regarding language barriers: 1) structural barriers inhibit access to interpreters; 2) variability in accuracy of translation of EOL concepts exacerbates language barriers; and 3) interpreters' style and manner influence

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	speaks other Indo-European languages, and 2.3% speaks Asian or Pacific Islander languages.			communication efficacy during complex conversations about prognosis, goals of care, and hospice. The theoretical model derived from the data suggests that Theme 1 is foundational and common to other medical settings. However, Theme 2 and particularly Theme 3 appear especially critical for hospice enrollment and care.
Du, X. L., Parikh, R. C., & Lairson, D. R. (2015). Racial and geographic disparities in the patterns of care and costs at the end of life for patients with lung cancer in 2007-2010 after the 2006 introduction of bevacizumab. <i>Lung Cancer</i> , 90(3), 442-450. doi:10.1016/j.lungcan.2015.09.017	End-of-life care settings in Detroit, Seattle, Atlanta, rural Georgia, California, Connecticut, Iowa, New Mexico, Utah, Hawaii, Kentucky, Louisiana, and New Jersey.	37,393 patients (ages 65+) who were diagnosed with non-small cell lung cancer of all stages in 1991–2009 and died between July 2007 and December 2010.	A retrospective cohort study of The National Cancer Institute’s Surveillance, Epidemiology and End Results (SEER) cancer registries and Medicare linked databases.	<p>Overall, Black people or other ethnic populations were significantly less likely to receive hospice care and more likely to be hospitalized in the last 6 months of life. Patients from urban areas were significantly more likely to receive hospice care than those from rural or less urban areas.</p> <p>There are no standard or clear-cut guidelines about what should not be used in the last few months of life for cases with terminal cancer, which is likely leading to substantial variations in choices of types of cancer care by the providers or patients/family members.</p> <p>Additionally, religious and cultural beliefs played a major role in the end-of-life care, which may vary significantly in the same area or same ethnic population. For example, African Americans preferred more aggressive treatment at the end-of-life care than other racial/ethnic populations and desired to provide all possible care to prolong life, whereas the treatment decisions for whites were more likely to withhold treatment before death.</p>
Elting, L. S., Liao, K. P., Giordano, S. H., & Guadagnolo, B. A. (2020). Hospice enrollment among cancer patients in Texas covered by Medicare managed care and	Hospice – Texas.	40,184 elderly Texas Medicare beneficiaries who died from primary breast, colorectal, lung, pancreas, or prostate cancer between	We studied the use of hospice care in the final 30 days of life using statewide Medicare claims linked to the Texas Cancer Registry. Rates of hospice use were computed by	Rates of hospice use increased significantly over time, from 68.9% in 2007 to 76.1% in 2013. By 2013, differences in hospice use rates between MC and FFS plans had been reduced from 10% to < 5%.

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traditional fee-for-service plans: a statewide population-based study. <i>Support Care Cancer</i> , 28(7), 3351-3359. doi:10.1007/s00520-019-05142-z		January 1, 2007, and December 31, 2013.	race/ethnicity and insurance plan (managed care (MC) or fee-for-service (FFS)). We used logistic regression to account for the impact of confounding factors.	However, after accounting for insurance plan and confounding factors, racial/ethnic minority beneficiaries' hospice use was significantly lower than non-Hispanic white beneficiaries' (p < 0.0001). This disparity was observed among both FFS and MC beneficiaries. In conclusion, hospice use among elderly patients with cancer has increased over time, particularly among dually eligible and fee-for-service beneficiaries. Despite these positive trends, racial/ethnic-based disparities persist.
Fair, T. M. (2021). Lessons on Older LGBTQ Individuals' Sexuality and Spirituality for Hospice and Palliative Care. <i>Am J Hosp Palliat Care</i> , 38(6), 590-595. doi:10.1177/1049909120978742	Colorado Front Range	16 total LGBTQ participants born prior to 1964. The majority (n = 14) were cisgender; of those, women (n = 8) and men (n = 6). There was also a transgender woman (n = 1) and one gender queer transgender participant (n = 1). To qualify as a participant, the individual had to identify as LGBTQ and be born before 1964 (the cut-off year for the Baby Boomer generation).	Semi-structured interviews were conducted following a pre-established interview guide. First, the participant was asked demographic questions. Next, they were asked to share their spiritual or religious background as a child or earliest spiritual memory. When adequate trust and familiarity were established, the researcher asked the central sexuality/ spirituality questions of focus.	Hospice and palliative care are in the beginning stages of providing inclusive care to older lesbian, gay, bisexual, transgender, queer (LGBTQ) patients. This inclusivity is exceedingly more pressing given the growing population of out and aging LGBTQ individuals. Hospice and palliative care literature recognizes that spirituality and religion can be fraught topics for LGBTQ patients. A few resources are available to help providers give more inclusive care. Few in hospice and palliative care, however, explicitly outline the direct connection for LGBTQ elders between their sexuality and their spiritual lives. All 16 participants responded that there was a connection for them. The participants expanded on this connection using five themes in their answers: the sexual act itself is spiritual; their authentic LGBTQ journey as spiritual; love/attraction is spiritual; spirituality and sexuality are inseparable; and finally, noting the ineffability of the sexuality-spirituality connection.

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Fink, R. M., Kline, D. M., Siler, S., & Fischer, S. M. (2020). Apoyo con Cariño: A Qualitative Analysis of a Palliative Care-Focused Lay Patient Navigation Intervention for Hispanics With Advanced Cancer. <i>J Hosp Palliat Nurs</i> , 22(4), 335-346. doi:10.1097/njh.0000000000000666	3 urban and 5 rural cancer center clinics across Colorado.	223 self-identified Hispanic patients, 18 years or older, with stage III/IV advanced cancer. Participants received either a culturally and linguistically tailored educational material packet describing ACP, pain management, and hospice care (control group [n = 111]) or the same educational materials and at least 5 home visits over 3 months from a Hispanic lay patient navigator (intervention group [n = 112]).	As part of a qualitative analysis, research team members analyzed field notes comprising 499 visits to 112 intervention patients and family caregivers (if available).	Part of the navigators' role was raising awareness about hospice by asking patients about their understanding of hospice, if they know anyone who has been under hospice care, addressed misconceptions about hospice care, and confirmed hospice care choice. Findings demonstrate that navigators facilitated ACP discussions, advocated for and motivated patients to talk with their provider about pain needs with the intent to receive optimal pain management, and helped patients/family caregivers learn more about hospice. Findings helped further understanding of how lay patient navigators may be effective in reducing barriers to palliative care and improving palliative care health literacy for underserved populations.
Fischer, S. M., Kline, D. M., Min, S. J., Okuyama-Sasaki, S., & Fink, R. M. (2018). Effect of Apoyo con Cariño (Support With Caring) Trial of a Patient Navigator Intervention to Improve Palliative Care Outcomes for Latino Adults With Advanced Cancer: A Randomized Clinical Trial. <i>JAMA Oncol</i> , 4(12), 1736-1741. doi:10.1001/jamaoncol.2018.4014	Clinics across the state of Colorado, including an academic National Cancer Institute–designated cancer center, community cancer clinics (urban and rural), and a safety-net cancer center.	Participants were adults who self-identified as Latino and were being treated for advanced cancer. In total, 223 Latino adults enrolled (mean [SD] age, 58.1 [13.6] years; 55.6% female) and were randomized to control (n = 111) or intervention (n = 112) groups.	A randomized clinical trial of a culturally tailored patient navigator intervention was conducted from July 2012 to March 2016. Primary outcome measures included hospice use. Secondary outcome measures included the McGill Quality of Life Questionnaire (MQQL), hospice length of stay, and aggressiveness of care at the end of life. This study used an intent-to-treat design.	The intervention had mixed results. The intervention increased advance care planning and improved physical symptoms; however, it had no effect on pain management and hospice use or overall quality of life. Further research is needed to determine the role and scope of lay navigators in palliative care. In this overall sample, 81.7% (98 of 120) of the patients enrolled in hospice, which is well above previously reported national averages of a 40% Hispanic enrollment. The National Hospice and Palliative Care Organization reports that, over the past decade, 6% to 8% of hospice patients have been Hispanic. However, the US Hispanic population is young, and accounting for crude death rates among Hispanics, the hospice enrollment rate for Hispanic deaths is 38%.

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Citation	Setting	Population	Design	Main Findings
Foley, R. N., Sexton, D. J., Drawz, P., Ishani, A., & Reule, S. (2018). Race, Ethnicity, and End-of-Life Care in Dialysis Patients in the United States. <i>J Am Soc Nephrol</i> , 29(9), 2387-2399. doi:10.1681/asn.2017121297	End-of-life care, United States.	1,098,384 patients on dialysis dying between 2000 and 2014.	We performed a retrospective national study using United States Renal Data System files to determine whether end-of-life care among patients on dialysis is subject to racial or ethnic disparity. The primary outcome was a composite of discontinuation of dialysis and death in a nonhospital or hospice setting.	<p>Patients of a minority race or ethnicity were likely to discontinue dialysis, less likely to receive hospice care, and more likely to die in hospital than their non-Hispanic white counterparts.</p> <p>Across the breadth of end-of-life outcomes studied here, patterns were broadly similar for patients of non-Hispanic Black and Asian race-ethnicity, and broadly similar for patients of non-Hispanic Native American race ethnicity and Hispanic ethnicity.</p> <p>These disparities could not be explained by differences in age, demography, local income dispersion, urban-rural configuration, dialysis facility type, mode of insurance coverage, and recent illness profiles, and were evident in a wide range of subgroups.</p> <p>These data suggest the existence of substantial, graded, and unexplained racial and ethnic disparities in end-of-life care practices in United States patients on dialysis.</p>
Fornehed, M. L. C., Mixer, S. J., & Lindley, L. C. (2020). Families' Decision Making at End of Life in Rural Appalachia. <i>J Hosp Palliat Nurs</i> , 22(3), 188-195. doi:10.1097/njh.0000000000000642	End-of-life care – east Tennessee region of rural Appalachia.	10 key informants consented to participate in this study. Four were family members with a loved one (spouse or parent) who had already died when their interview took place. Six had a parent hospitalized in an acute care setting with a life-limiting illness and were actively making EOLC decisions.	Unstructured interviews were conducted in homes, hospital rooms, and private conference rooms. Observations before and during the interviews about the environmental context, artifacts, nonverbal informant expressions, interview time and location, and researcher thoughts, feelings, and hunches were recorded in a field journal. The interviews were digitally audiotaped, transcribed verbatim, and deidentified through coding.	<p>Four themes provide insights that could help improve this underserved population's access to palliative and hospice care:</p> <p><i>Rural Appalachians make EOL decisions with family.</i> Rural Appalachian families' awareness of the illness trajectory moves at different rates and influences EOL decision making. Accepting death as a part of life influences Rural Appalachian family decision making (FDM) at EOL.</p> <p><i>Communication Encompassing EOL FDM Is Essential and Complex.</i> Rural Appalachians describe that EOL FDM communication is a burden on someone (either in the family or</p>

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				<p>interdisciplinary team). Interdisciplinary team members plant seeds for families to consider when making decisions at EOL. The concept of “lay it on the line” characterizes effective communication among family and interdisciplinary team members.</p> <p><i>Education and Economics Influence Decision Making at EOL.</i> Rural Appalachian EOL FDM is influenced by a lack of knowledge about the illness trajectory and EOL care. Rural Appalachian FDM at EOL is influenced by economics and the need to choose “the lesser of two evils.”</p> <p><i>Comfort—Living While Dying.</i> Folk care for rural Appalachian families making decisions at EOL meant experiencing “a sense of normalcy.” Some rural Appalachian families felt hospice care was helpful and some did not.</p>
<p>Forst, D., Adams, E., Nipp, R., Martin, A., El-Jawahri, A., Aizer, A., & Jordan, J. T. (2018). Hospice utilization in patients with malignant gliomas. <i>Neuro Oncol</i>, 20(4), 538-545. doi:10.1093/neuonc/nox196</p>	<p>The SEER database includes information about incident cancer cases from 17 affiliated cancer registries, covering approximately 26% of the US population. These data include information for patients between January 1, 1973, and December 31, 2012.</p>	<p>We used the SEER-Medicare database to retrospectively identify patients 18 years of age or older who were diagnosed with malignant glioma (MG) and subsequently passed away between January 1, 2002, and December 31, 2012. We excluded the 13.7% of patients who did not have fee-for-service Medicare insurance, as well as those who were diagnosed with MG after</p>	<p>We extracted sociodemographic and clinical data and used univariate logistic regression analyses to compare characteristics of hospice recipients versus nonrecipients. We performed multivariable logistic regression analyses to examine predictors of hospice enrollment >3 or >7 days prior to death.</p>	<p>We identified important disparities in hospice utilization among patients with malignant glioma, with differences by race, sex, age, level of education, and rural versus urban residence.</p> <p>12,437 eligible patients (46% female), of whom 7849 (63%) were enrolled in hospice before death.</p> <p>On multivariable regression analysis, older age, female sex, higher level of education, white race, and lower median household income predicted hospice enrollment.</p> <p>Of those enrolled in hospice, 6996 (89%) were enrolled for >3 days, and 6047 (77%) were enrolled for >7 days.</p>

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		entering hospice or during autopsy.		<p>Older age, female sex, and urban residence were predictors of longer LOS (3- or 7-day minimum) on multivariable analysis. Median LOS on hospice for all enrolled patients was 21 days.</p> <p>Our study highlights important disparities in hospice utilization among patients with MG. We found differences by race, sex, age, level of education, and rural versus urban residence.</p> <p>We also describe important predictors of a suboptimal short stay in hospice (≤ 3 days or ≤ 7 days), including younger age, male sex, and rural place of residence.</p>
Gerlach, L. B., Kales, H. C., Kim, H. M., Zhang, L., Strominger, J., Covinsky, K., . . . Maust, D. T. (2021). Prevalence of psychotropic and opioid prescribing among hospice beneficiaries in the United States, 2014-2016. <i>J Am Geriatr Soc</i> , 69(6), 1479-1489. doi:10.1111/jgs.17085	Hospice – United States	554,022 older Medicare beneficiaries with an index hospice enrollment period between July 1, 2014, and December 31, 2016. Most hospice enrollees were female (58.3%), non-Hispanic white (87.5%), and the average age was 83.2.	Cross-sectional analysis of a 20% sample of traditional and managed Medicare with Part D enrolled in hospice, 2014–2016.	<p>The prevalence of any psychotropic or opioid medication prescription fill was highest among beneficiaries who were female (76.7%), younger (76.5%), lived in rural areas (76.6%), non-Hispanic white (76.6%), and those with cancer (78.9%). Male beneficiaries were slightly less likely to receive psychotropic and opioid medication prescriptions.</p> <p>Non-Hispanic whites were more likely to receive prescriptions for most medication classes. Compared to non-Hispanic white beneficiaries, non-Hispanic Black beneficiaries were less likely to receive nearly every class of medication, with significantly lower odds of receiving opioids and benzodiazepines.</p> <p>Psychotropic and opioid medications are frequently prescribed in hospice. Observed variations in prescribing across race and ethnicity may reflect disparities in prescribing as well as patient preferences for care. Further work is important to understand factors driving prescribing</p>

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				given limited studies surrounding medication prescribing in hospice.
Haines, K. L., Jung, H. S., Zens, T., Turner, S., Warner-Hillard, C., & Agarwal, S. (2018). Barriers to Hospice Care in Trauma Patients: The Disparities in End-of-Life Care. <i>Am J Hosp Palliat Care</i> , 35(8), 1081-1084. doi:10.1177/1049909117753377	Hospice – United States	Critically ill trauma patients. Sample is trauma patients older than 15 from 2012 to 2015 logged into the National Trauma Databank. N= 2,966,444	Two methodological approaches: (1) For disposition to hospice, chi-square and multivariate logistic regression were used (2) Negative binomial regression was used to explore the length of stay in hospice	<p>“Race and ethnicity are independent predictors of a trauma patient’s transition to hospice care and significantly affect [length of stay]. Our data demonstrate prominent racial and socioeconomic disparities exist, with uninsured and minority patients being less likely to receive hospice services and having a delay in transition to hospice care when compared to their insured Caucasian counterparts.”</p> <p>“Asian, African Americans, and Hispanic patients were less likely to patients (P < .001). than Caucasians (P < .0001).”</p> <p>“Additionally, socioeconomic status affected total hospital LOS. An analysis of 23 612 patients revealed that Medicare patients were transferred to hospice 1.2 days sooner than privately insured patients (P < .001), and uninsured patients remained in the hospital 1.6 days longer than privately insured patients (P < .001).”</p> <p>“When evaluating racial disparities, African American patients who were discharged to hospice stayed in the hospital 3.7 days longer and Hispanic patients stayed 2.4 days longer than Caucasian patients (P < .0001). A secondary analysis for the more severely injured trauma patients (ISS > 15) showed that African Americans stayed inpatient 4.9 days longer and Hispanics 2.3 days longer than their equivalent Caucasians counterparts (P < .0001).”</p> <p>“This analysis shows that despite efforts to promote and improve access for end-of-life referrals, enormous racial disparities are prevalent</p>

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				<p>in the trauma system separate from significant socioeconomic inequalities.”</p> <p>“Additionally, this analysis demonstrates that for those uninsured and minority population who do receive hospice care, there is a delay in transfer to hospice when compared to their insured, Caucasian counterparts.”</p> <p>“...a project exploring end-of-life barriers in lower income, African Americans, and Hispanics found that when focus groups were conducted, they were highly receptive to care that would provide relief for patients. This study found that improving awareness of hospice services would increase utilization in minority populations. These analyses combined with the knowledge that minority trauma patients are transferred to hospice less often than Caucasians portend to the success of workgroups developed for minority trauma populations.”</p>
Haines, K. L., Kawano, B. A., & Agarwal, S. K. (2021). Disparities in Asians' Hospice Utilization and Location of Death. <i>Am Surg</i> , 31348211034756. doi:10.1177/00031348211034756	See next row	Disaggregates the Asian category to look at place of death based on ethnicity.	This is a letter to the editor that disaggregates the category of “Asian” based on the below study	<p>“There are differences in place of death among Asian subgroups. Japanese and Korean patients were less likely than Chinese patients to die in a hospital and more likely to die at home (OR = .53, OR = .78/OR = 1.39, OR = 1.18, P < .001).</p> <p>Japanese patients were likewise more likely than Chinese patients to die in a nursing facility/long-term care (OR = 1.24, P < .001) but less likely to die in hospice (OR = .87, P < .001).</p> <p>Koreans were slightly more likely than Chinese patients to die in hospice (OR = 1.09, P < .05).</p> <p>In comparison, Filipinos and Indians were more likely than Chinese patients to die in hospitals or at home (OR = 1.05, P < .001, OR = 1.04, P < .05; OR = 1.21, P < .001; OR = 1.10, P < .001), and</p>

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				<p>less likely to die to in a nursing facility/long-term care (OR = .62, P < .001; OR = .42, P < .001) or hospice (OR = .78, P < .001; OR=.82, P < .001).</p> <p>Similarly, Vietnamese patients were more likely than Chinese patients to die at home (OR = 1.28, P < .001) and less likely to die in a nursing facility/long-term care (OR = .63, P < .001) or hospice (OR = .90, P < .05).</p> <p>There are clear disparities in hospice utilization and location of death amongst varying [Asian] subgroups.”</p>
Haines, K. L., Nguyen, B. P., Antonescu, I., Freeman, J., Cox, C., Krishnamoorthy, V., . . . Agarwal, S. (2021). Insurance Status and Ethnicity Impact Health Disparities in Rates of Advance Directives in Trauma. <i>Am Surg</i> , 31348211011115. doi:10.1177/00031348211011115	United States, inpatient trauma	Adult trauma patients. Sample is American College of Surgeons Trauma Quality Improvement Program from 2013-2015. N= 44,705	Multivariable logistic regression was used on the data to measure the primary outcome, advance directive (AD) presence. Other outcomes include mortality, length of stay (LOS), mechanical ventilation, ICU admission/LOS, withdrawal of life-sustaining measures, and discharge disposition	<p>Authors are primarily leveraging large-N data and running naïve regressions on them to see what pop up. There are some leaps in logic to get at health equity outcomes in hospice as hospice is not a primary outcome in this study.</p> <p>“Nationally, over one-third of US adults have ADs; however, disparities in AD completion are commonly seen depending on race, ethnicity, and socioeconomic status. African American and Asian patients are less likely to complete ADs.”</p> <p>“Presence of ADs was associated with increased odds of discharge to hospice and a decreased odds of discharge to inpatient rehabilitation, a skilled care facility, or home.”</p>
Hamel, L., Wu, B., & Brodie M. 2017. Views and Experiences with End-of-Life Medical Care in Japan, Italy, the United States, and Brazil: A Cross-Country Survey. KFF. https://www.kff.org/other/report/views-and-experiences-with-end-of-life-medical-care-in-japan-italy-the-united-	end-of-life care in the U.S. and three other nations	Americans’ experiences and opinions about aging and end-of-life care and how this compares with the views and experiences of residents of Italy, Japan and Brazil	The poll was conducted by telephone from March through November 2016 among random digit dial telephone (landline and cell phone) samples of adults in the U.S. (1,006), Italy (1,000), Japan (1,000) and Brazil (1,233). The margin of sampling error for results from each country is plus	<p>When asked to think about their own death, most Americans (54%) say it is “extremely important” to make sure their family is not burdened financially by their care.</p> <p>Large shares also cite other factors as “extremely important,” including having loved ones around</p>

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states-and-brazil-a-cross-country-survey/			or minus 4 percentage points. For results based on subgroups, the margin of sampling error may be higher.	<p>them (48%), being at peace spiritually (46%) and being comfortable and without pain (42%).</p> <p>Fewer (23%) say living as long as possible is “extremely important,” though the share who do is higher among Blacks (45%) and Hispanics (28%) than among whites (18%).</p> <p>Black and Hispanic people are also more likely than whites to say the health care system in the U.S. places too little emphasis on preventing death and extending life as long as possible.</p>
Hart, A. S., Matthews, A. K., Arslanian-Engoren, C., Patil, C. L., Krassa, T. J., & Bonner, G. J. (2022). Experience of African American Surrogate Decision Makers of Patients With Dementia. <i>J Hosp Palliat Nurs</i> , 24(1), 84-94. doi:10.1097/njh.0000000000000822	Surrogate end-of-life decision makers for dementia patients in the United States	African American surrogate decision makers. Sample n=8	African American decisions makers were interviewed about their experiences with the decision-making process	<p>The most important takeaway here is that interview data indicates that African American surrogates often did not utilize hospice to its full extent due to a lack of information and preparedness with this option and they often expressed regret in not prioritizing comfort-focused care like hospice over life-sustaining treatments after the fact.</p> <p>“Surrogates lacked a general understanding of EOL options resulting in underutilization of hospice and palliative care and subsequent regret, and few interventions exist to improve the uptake of EOL care services.”</p> <p>“Of [African American] surrogates who implemented DNR orders, few elected for comfort-focused care. In addition to the limited use of hospice, patients often did not receive the full benefit of hospice services: both patients who used hospice spent less than a week on the service before they died.”</p> <p>“In contrast [to electing for comfort-based solutions like hospice], some [African American] surrogates who opted for life-sustaining</p>

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				treatments experienced regret, perceiving the decision as out of alignment with personal or patient values, preferences, and priorities. These findings may result from unpreparedness in the acceptance phase, reinforcing the need for patient-surrogate-provider discussion about EOL options early in the dementia trajectory."
Helsel, D., Thao, K. S., & Whitney, R. (2020). Their Last Breath: Death and Dying in a Hmong American Community. <i>J Hosp Palliat Nurs</i> , 22(1), 68-74. doi:10.1097/njh.0000000000000616	End-of-life care decision making in the United States	Hmong Americans. Sample is 15 family care and 5 shamans and Hmong funeral officiants.	Semi-structured interviews with sample to explore the beliefs that ultimately determine end-of-life care goals and strategies for Hmong patients.	Providing information to Hmong patients and families about hospice helps to inform strategies that incorporate hospice as a viable care option. "All of the caregiver-respondents explained that Hmong people would rather die in their homes, although most acknowledged an awareness of circumstances in which that is not possible. One respondent noted, "They would be homesick and uncomfortable anywhere else. In their own home they can see their family. And if they die in their home, they leave their family a good life; they leave good luck for you. The person who sees your last breath gets your leftover luck. You want that to be your family.""
Her-Xiong, Y., & Schroepfer, T. (2018). Walking in Two Worlds: Hmong End of Life Beliefs & Rituals. <i>J Soc Work End Life Palliat Care</i> , 14(4), 291-314. doi:10.1080/15524256.2018.1522288	End of life beliefs and care in the United States	Hmong American immigrants. Sample is 12 Animist and 8 Christian Hmong elders born in Southeast Asia	In-depth face-to-face interviews	Both Animists and Christians strongly felt that family should provide care at end of life vs. hospice/palliative care. Both samples felt that out-of-home care facilities could not meet their spiritual and cultural needs which they see as centrally integral to end-of-life care and thus generally prefer at-home care if at all possible.
Hinrichs, K. L. and K. M. Christie (2019). "Focus on the family: A case example of end-of-life care for an older LGBT veteran." <i>Clin Gerontol</i> 42(2): 204-211.	Veterans Affairs hospice unit	Older LGBT veterans and their families. Case study of an older, Caucasian, lesbian veteran and her Caucasian wife	In-depth exploration into how the research team could care for the veteran and meet the wife's emotional and psychological needs in the process.	The case study provides specific interventions that are helpful in terms of thinking through inequities LGBT patients face in hospice and how they can be overcome. "In order to effectively work with Diane, the hospice team had to take a two-pronged approach

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				<p>to address both the emotional and financial needs of the wife as the veteran medically declined. To support her emotionally, the entire hospice team was encouraged to stop by and check in on Diane when she was visiting. This helped her feel less alone and decreased her feelings of dread while sitting with her dying wife. The mental health provider recommended referral to an LGBT Bereavement group and other LGBT-specific support services, but Diane was not open to this idea since she had never been connected with the larger LGBT community before.”</p> <p>“Throughout their time on the unit, the hospice team was able to identify several areas of need and assist Diane with some of her psychosocial and financial concerns. After building trust with the team Diane was able to accept information about social services and government programs to help with paying taxes, applying for disability, etc. She allowed the team to help her apply for supplemental nutrition assistance and fuel assistance to heat her home. The hospice social worker was able to partner with community agencies to arrange a funeral for Susan free of charge so Diane would not have to worry about this.”</p> <p>“After Susan’s death, the hospice team reached out to Diane a few times to provide bereavement support and case management.”</p> <p>“Health care institutions that provide end-of-life care must be more overtly inclusive and welcoming to build the trust of LGBT older adults. This can be accomplished by altering the wording on intake forms, updating policies, and assessing</p>

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				<p>outreach materials for inclusive language and images.”</p> <p>“Inclusion of partners and families of choice is essential to the provision of patient-centered end-of-life care for marginalized populations. This is best accomplished by encouraging LGBT patients to engage in advance care planning (e.g., completing advance directives and DPOAs), and by simply asking patients who they would like to be involved in their decision-making at end-of-life and documenting the conversations.”</p> <p>“Mental health providers should familiarize themselves with Affirmative Therapy approaches, which are used to validate and advocate for the needs of sexual and gender minority patients.”</p> <p>“All health care professions should consider formally adopting and disseminating competencies for practice with this diverse population.”</p>
Holland, J. M., Keene, J. R., Kirkendall, A., & Luna, N. (2015). Family evaluation of hospice care: Examining direct and indirect associations with overall satisfaction and caregiver confidence. <i>Palliat Support Care</i> , 13(4), 901-908. doi:10.1017/s1478951514000595	Hospice in the United States	Primary caregiver or health representative for hospice patients. Sample is taken between 2008 to 2013 “at a large hospice in an urban area of the Southwest United States” n=3226.	Participants were asked to complete the Family Experience of Hospice Care (FEHC) survey. Survey responses were then used to measure the impact of a broad suite of variables on two major outcomes: (1) overall satisfaction and (2) caregiver confidence using structural equation modeling	<p>“Our results suggest that the most important factors that influence caregivers’ perceptions of hospice care are patient race, patient symptoms, and their appraisal of the timing of hospice referral. Specifically, caregivers of racial minority patients, patients with a more complex symptom profile, and patients perceived to be referred too late or too early tended to express less contentment with the information/education and patient care received from the hospice staff.”</p> <p>“Racial minority status and late/early referral were also associated with less positive perceptions of caregiver/family emotional and spiritual support.”</p>

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				<p>“As can be seen from Figure 1, participants completing the FEHC with regard to a racial minority patient were more likely to report lower levels of contentment with the information/education received, provision of care to the patient, and caregiver/family support. Patient race did not show statistically significant direct effects on overall satisfaction or caregiver confidence. However, patient race was indirectly associated with lower levels of caregiver confidence through education/information (see Table 3). Stated differently, participants reporting on a racial minority patient were more likely to express some discontent with the education/information they received, which in turn put them at greater risk for feeling less confident as a caregiver.”</p> <p>“This pattern of results suggests that efforts directed toward informing/educating patients’ family members may be most potent in terms of promoting a sense of self-efficacy and confidence.”</p>
Hostetter, M., Klein, S., & McCarthy, D. (2018). Supporting Patients Through Serious Illness and the End of Life: Sutter Health’s AIM Model. https://www.commonwealthfund.org/publications/case-study/2018/jan/supporting-patients-through-serious-illness-and-end-life-sutter . Accessed August 29, 2022	Palliative care in the US	AIM program	Case study of an Advanced Illness Management program (AIM)	An examination of how AIM can improve end-of-life care via planning. It also discusses how AIM increases transitions to hospice and the length of hospice stays which reduce costs.
Hughes, M. C. and E. Vernon (2019). “Closing the Gap in Hospice Utilization for the Minority Medicare	Hospice in all 50 states and	Medicare hospices in all 50 states and Washington,	Quantitative analysis (multivariate logistic regression) of CMS’s Chronic Conditions Data Warehouse (CCW), US Census data, and data from the	Multivariate logistic regression found a positive association between the prevalence of for-profit hospices in a state and hospice utilization by

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Population." Gerontol Geriatr Med 5: 2333721419855667.	Washington, D.C., United States	D.C. (N = 51) and Medicare beneficiaries	Pew Research Center, the Bureau of Economic Analysis, the Kaiser Family Foundation, and Hospice Analytics	<p>racial/ethnic minorities, $\chi^2 (6, N = 51) = 17.76, p = .007$.</p> <p>There was no significant association between hospice utilization by racial/ethnic minorities and religiosity, racial/ethnic diversity, income, or education.</p> <p>The economic analysis found if racial/ethnic minority Medicare hospice utilization were to equal that of the white Medicare users, it would result in an estimated savings of nearly \$270 million per year.</p> <p>To increase equity in hospice utilization, authors recommend hospices conduct community outreach to both racial/ethnic minorities and low-income communities, offer short bouts of increased emotional and physical support for the patient and/or caregiver(s) during times of crisis, create materials that comply with the NIH's Clear Communication initiative, and develop materials in multiple languages and employ bilingual staff.</p>
Hughes, M. C. and E. Vernon (2020). "We Are Here to Assist All Individuals Who Need Hospice Services": Hospices' Perspectives on Improving Access and Inclusion for Racial/Ethnic Minorities." Gerontol Geriatr Med 6: 2333721420920414.	Hospice across the United States	Administrators at 41 unique hospices (n = 41)	Qualitative surveys were conducted. Survey data was analyzed through content analysis including theme and quote identification.	<p>This study surveyed hospice employees to determine outreach strategies to improve minority hospice utilization.</p> <p>Commonly reported barriers to hospice care for racial/ethnic minorities included culture/beliefs (mentioned by 46% of respondents) that hospice is "giving up" or that families are responsible for care, mistrust of the medical system (20%), and language barriers (25%).</p> <p>A major theme pertaining to successful minority hospice enrollment was an inclusive culture that provided language services (mentioned by 70% of</p>

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				<p>survey respondents), staff cultural training (33%), and a diverse staff (33%).</p> <p>Another major theme was the importance of community outreach activities (over 60%) that extended beyond the medical community and forming relationships with churches, racial/ethnic minority community leaders, and Native American reservations.</p> <p>Over 30% of hospices indicated inclusionary policies, though most did not mention formal committees/policies.</p>
Hughes, M. C. and E. Vernon (2021). "Hospice Response to COVID-19: Promoting Sustainable Inclusion Strategies for Racial and Ethnic Minorities." <i>J Gerontol Soc Work</i> 64(2): 101-105.	Hospice in the United States	Hospice patients in the US during the COVID-19 pandemic	Letter to the editor	The author indicates that the COVID-19 crisis disproportionately affects racial/ethnic minorities in the US but presents an opportunity to increase equity in hospice care. Inclusion strategies include supporting advanced care planning through information-sharing in multiple languages by hospices, social workers, community groups, and religious institutions; the expansion of telehealth services and content, including technical support and broadband access; and expansion of hospice services/staff such as hiring from diverse backgrounds.
Hughes, M. C., Vernon, E., Kowalczyk, M., & Basco-Rodillas, M. (2021). US hospices' approach to racial/ethnic minority inclusion: a qualitative study. <i>BMJ Support Palliat Care</i> . doi:10.1136/bmjspcare-2020-002680 ¹⁰	Hospice in the United States	Hospice leaders in the US (n = 22)	Qualitative in-depth, semi structured interviews	Interviews with hospice leaders found racial/ethnic minority inclusion strategies for hospices include language translation services (22 interviewees mentioned), cultural competence training (21), outreach beyond the medical community, and diversity, equity, and inclusion committees (7).

¹⁰ Abt Staff identified this article in both the SDOH and Health Equity literature reviews.

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				The authors found that tailoring strategies to the local population and helping the community meet needs that extend beyond end-of-life care may be especially effective approaches in establishing trust. Another key finding of the study was that hospices were not that focused on the costs of inclusionary strategies and usually believed the benefits resulting from these strategies outweighed the costs.
Johnson, J., Hayden, T., True, J., Simkin, D., Colbert, L., Thompson, B., . . . Martin, L. (2016). The Impact of Faith Beliefs on Perceptions of End-of-Life Care and Decision Making among African American Church Members. <i>J Palliat Med</i> , 19(2), 143-148. doi:10.1089/jpm.2015.0238	Hospice/palliative care in the United States	51 churchgoers at 2 African American churches, including 27 deacons or deaconesses, 17 members of health or bereavement ministries, and 7 other congregation members	Qualitative focus groups (7 focus groups) to understand perceptions, beliefs, and attitudes about: (1) the relation between faith beliefs and EOL care; (2) emotional and family influences on EOL decision making; (3) palliative care and hospice resources; and (4) opportunities to improve communication among lay persons and health professionals and within families	<p>The study found that faith beliefs of African Americans can support discussions about palliative care and hospice.</p> <p>Participants perceived that many of their congregants harbor beliefs, perceptions, and feelings about death and dying that were often not communicated to family members or to health providers.</p> <p>Participants also voiced a consensus that patients, caregivers, and family members of their churches need more knowledge about EOL care – many were unsure what hospice meant and unfamiliar with the term palliative care.</p> <p>Supportive views about hospice were often expressed by persons with prior experience with hospice, but participants expressed uncertainty as to how to approach health care providers and what questions to ask.</p>
Johnson, K. S., Payne, R., & Kuchibhatla, M. N. (2016). What are Hospice Providers in the Carolinas Doing to Reach African Americans in Their Service Area? <i>J Palliat Med</i> , 19(2), 183-189. doi:10.1089/jpm.2015.0438	Hospice in North and South Carolina, United States	Staff (including directors, social workers, chief medical officers, clinical managers, and administrators) at hospices in North and South Carolina	Qualitative cross-sectional surveys used scales to measure the frequency of community outreach, marketing efforts, efforts to recruit African American staff, cultural sensitivity training, and goals to increase service for African Americans, and	A cross sectional survey completed by 79 hospices in the Carolinas found that over 80% were at least somewhat concerned about the low proportion of African Americans they served, and 78.5% had set goals to increase service to African Americans.

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Citation	Setting	Population	Design	Main Findings
		operating for at least 3 years (n = 79)	nonparametric Wilcoxon tests compared mean scores on these scales	<p>Most were engaged in community education/outreach, with 92.4% reporting outreach to churches, 76.0% to social services organizations, 40.5% to businesses, 35.4% to civic groups, and over half to health care providers; 48.0% reported directed marketing via newspaper and 40.5% via radio.</p> <p>The vast majority reported efforts to recruit African American staff, most often registered nurses (63.75%). Nearly 90% offered cultural sensitivity training to staff.</p> <p>The frequency of strategies to increase service to African Americans did not vary by hospice characteristics, such as profit status, size, or vertical integration, but was greater among hospices that had set goals to increase service to African Americans.</p>
Johnson, K. S., Payne, R., Kuchibhatla, M. N., & Tulsy, J. A. (2016). Are Hospice Admission Practices Associated With Hospice Enrollment for Older African Americans and Whites? <i>J Pain Symptom Manage</i> , 51(4), 697-705. doi:10.1016/j.jpainsymman.2015.11.010	Hospice in North and South Carolina, United States	61 hospices in North and South Carolina (n = 61)	Cross-sectional study that developed a hospice admission practices scale to rate the restrictiveness of admissions and conducted multivariate analyses to assess the association between admission practices and proportion of decedents in the hospice service area by racial group	<p>This study explored the relationship of hospice admission practices (e.g., restriction of patients who desire high-cost palliative therapies or without a primary caregiver) and the use of hospice by older African Americans.</p> <p>In the bivariate analyses, less restrictive admission practices were associated with a greater proportion of both African American (r=0.44, P<0.0001) and white Medicare beneficiaries (r=0.47, P<0.0001) served by a hospice in the service areas.</p> <p>Other characteristics associated with serving a larger proportion of decedents in both racial groups include, nonprofit status, larger budgets, larger proportion of generalists in the service areas, less market competition, and fewer</p>

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Citation	Setting	Population	Design	Main Findings
				physicians per population of those age 65 years or older.
Johnson, T., Walton, S., Jr., Levine, S., Fister, E., Baron, A., & O'Mahony, S. (2020). Racial and ethnic disparity in palliative care and hospice use. <i>Am J Manag Care</i> , 26(2), e36-e40. doi:10.37765/ajmc.2020.42399	Hospital in the Chicago metropolitan area, United States	5613 patients who were discharged to hospice or died during their hospital stay between 2012 and 2014 in 4 urban hospitals with an inpatient palliative care service	Retrospective, cross-sectional study	<p>After adjusting for patient characteristics and hospital site, race/ethnicity was not significantly associated with receipt of inpatient palliative care consultation.</p> <p>A larger proportion of African American patients received an inpatient palliative care consultation than white or Hispanic patients, but there was no significant association between race/ethnicity and receipt of inpatient palliative consultation when hospital site was included in the model, and there was no significant difference in location of death by race/ethnicity.</p> <p>Hispanic race/ethnicity was associated with a higher likelihood of discharge to hospice (odds ratio, 1.22; P = .036), and inpatient palliative care consultation was associated with 4 times higher likelihood of discharge to hospice (P <.001). Hospital site was also associated with both receipt of inpatient palliative care consultation and discharge to hospice.</p>
Jones, R. C., Creutzfeldt, C. J., Cox, C. E., Haines, K. L., Hough, C. L., Vavilala, M. S., . . . Krishnamoorthy, V. (2021). Racial and Ethnic Differences in Health Care Utilization Following Severe Acute Brain Injury in the United States. <i>J Intensive Care Med</i> , 36(11), 1258-1263. doi:10.1177/0885066620945911	Hospital/Hospice across the United States	Adult patients with a primary diagnosis of severe acute brain injury (stroke, traumatic brain injury, or post-cardiac arrest) who received greater than 96 hours of mechanical ventilation between 2002 and 2012 (n = 86 246)	Retrospective cohort study of including multivariable analysis of data from the National Inpatient Sample	<p>Minority race (Black, Hispanic, Asian, and other) was associated with decreased hospice utilization compared to white race among patients with severe acute brain injury. In multivariable analysis, compared to white patients,</p> <p>Black patients had a 25% decreased risk of hospice discharge (RR: 0.75, 95% CI: 0.67-0.85, P < .001), Hispanic patients had a 20% decreased risk (RR: 0.80, 95% CI: 0.69-0.94, P < .01), and Asian patients had a 47% decreased risk (RR: 0.53, 95% CI: 0.39-0.73, P < .001).</p>

Health Equity and Social Determinants of Health Literature Review Table				
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Kemery, S. A. (2021). "Family perceptions of quality of end of life in LGBTQ+ individuals: a comparative study." <i>Palliat Care Soc Pract</i> 15: 2632352421997153.	Hospice in the United States	122 family members of individuals who have died while under hospice care in the past 5 years. n=56 family members of LGBTQ and n =66 family members of non-LGBTQ individuals.	Quantitative comparative descriptive design using the Quality of Dying and Death Version 3.2a Family Member/Friend After-Death Self-Administered Questionnaire	Comparison of the experiences of the lesbian, gay, bisexual, transgender, and queer (LGBTQ) cohort (n = 56) and non-LGBTQ cohort (n = 66) yielded varying results, with the LGBTQ cohort experiencing lower quality end of life in some Quality of Dying and Death measures and no statistically significant difference from the non-LGBTQ cohort in others.
Khosla, N., Washington, K. T., & Regunath, H. (2016). Perspectives of Health Care Providers on US South Asians' Attitudes Toward Pain Management at End of Life. <i>Am J Hosp Palliat Care</i> , 33(9), 849-857. doi:10.1177/1049909115593063	End-of-life care in the United States	57 healthcare and end-of-life care providers in the US	Qualitative descriptive study of interviews (23) and focus groups (35 participants) with thematic analysis of interview and focus group data	<p>Thematic analysis of interviews and focus group discussions with 57 health care providers indicated that providers perceive South Asian patients and families to be generally reluctant to use medications to treat pain experienced at end of life.</p> <p>Patient-related factors contributing to the reluctance include: reluctance to report pain (participants explained that this stoicism may be rooted in a desire to avoid burdening others, fear of embarrassment and showing weakness); concerns about pain medications (including side effects such as drowsiness and confusion and the potential for addiction); spiritual beliefs (particularly those rooted in Hinduism, Buddhism, and Islam); and lack of awareness of medication benefits.</p> <p>Factors Related to the Culture of Health Care in South Asia include minimalistic attitude towards medication (including doctors not routinely asking about pain, less prescribing and lower doses of pain medications, and non-medication alternatives); and limited access to pain medications</p>

Health Equity and Social Determinants of Health Literature Review Table				
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Kim, H., Anhang Price, R., Bunker, J. N., Bradley, M., Schlang, D., Bandini, J. I., & Teno, J. M. (2021). Racial Differences in End-of-Life Care Quality between Asian Americans and Non-Hispanic Whites in San Francisco Bay Area. <i>Journal of palliative medicine</i> , 24(8), 1147–1153. https://doi.org/10.1089/jpm.2020.0627	San Francisco, Hospice	108 Asian and 414 non-Hispanic white bereaved family members	A San Francisco mortality survey based on the CAHPS® Hospice Survey that asked about how their family member was treated by hospice care staff members during end-of-life found that, compared with their white counterparts and adjusted for cause of death, site of death, type of health insurance, respondent's relationship to decedent, decedent age, and respondent education	<p>Asian decedents more often experienced:</p> <p>Lack of respect for their cultural traditions (Adjusted Odds Ratio [AOR] 3.59; 95% Confidence Interval [CI] 1.88 – 6.86)</p> <p>Lack of respect for their religious and spiritual beliefs (AOR 2.85; CI 1.45 – 5.62)</p> <p>Not receiving as much information as they had wanted about what to expect during the last months of life (AOR 2.15; CI 1.10 – 4.19)</p> <p>Not receiving the right amount of emotional support after the decedent's passing (AOR 2.39; CI 1.23-4.63)</p>
Ko, E. and D. Fuentes (2020). "End-of-Life Communication Between Providers and Family Caregivers of Home Hospice Patients in a Rural US-Mexico Border Community: Caregivers' Retrospective Perspectives." <i>Am J Hosp Palliat Care</i> 37(5): 329-335.	US, Southwest US/Mexico border towns, Home Hospice	Informal caregivers of Latino patients who are enrolled in home hospice in US/Mexico border towns (n = 28)	In-depth interviews using qualitative methods were conducted and thematic analysis was used	<p>Thematic analysis revealed themes including (1) lack of/insufficient EOL communication and (2) informational needs, including (a) signs of symptom changes, (b) EOL treatment options and goals of care, and (c) hospice care and its benefits.</p> <p>Limited caregiver-provider EOL communication was observed, in which most of the caregivers (n = 22, 78.6%) were informed of the patient's terminal condition, but only half (n = 15, 53.6%) had a discussion with the providers about hospice care.</p> <p>Authors recommend timely EOL communication between caregivers and the providers. Providers need to be aware of the caregivers' informational needs relating to patient symptoms and health condition as well as hospice care.</p>

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				It is important to be aware of the impact of cultural values on hospice care placement. A clear explanation about the purpose and functions of hospice care and its benefit can better guide the family caregivers in making hospice care decisions.
Ko, E., Lee, J., Ramirez, C., Lopez, D., & Martinez, S. (2018). Patient-family EoL communication and its predictors: Reports from caregivers of Latino patients in the rural U.S.-Mexico border region. <i>Palliat Support Care</i> , 16(5), 520-527. doi:10.1017/s147895151700092x	US, Southwest rural US/Mexico border towns, Home Health	Caregivers of Latino patients enrolled in a home health agency (n = 189)	Data analysis (data from a hospice needs assessment collected from family caregivers of Latino patients) included Bivariate tests and logistic regression	<p>About half of the family caregivers of Latino patients at a home health agency (n = 96, 50.8%) reported to have ever engaged in EoL discussion with patients.</p> <p>Significant predictors of EoL discussion included life-sustaining treatment preference (odds ratio [OR] = 0.44, p < 0.05); knowledge of an advance directive (AD) (OR = 5.50, p < 0.01); and distrust of physicians (OR = 0.29, p < 0.01).</p> <p>Caregivers who preferred extending the life of their loved one even if he/she had to rely on life supports were less likely to engage in EoL communication.</p> <p>Also, caregivers who worried that physicians might want to stop treatments (i.e., "pull the plug") too soon were less likely to do so.</p> <p>Conversely, caregivers who had knowledge about ADs were more likely to engage in EoL communication.</p>
Ko, E., Lee, J., Ramirez, C., Martinez, S., & Lopez, D. (2017). Willingness to use hospice care among caregivers of Latino patients in the United States-Mexico border region. <i>Palliat Support Care</i> , 15(3), 279-287. doi:10.1017/s1478951516000687	Southern California US/Mexico border towns, Home Hospice	Caregivers of Latino patients enrolled in a home health agency (n = 189)	Data analysis (secondary data from a home health agency and primary data from caregiver interviews) included Bivariate tests and logistic regression	<p>The majority (83%) of family caregivers of Latino patients were willing to use hospice services for their loved ones.</p> <p>The factors impacting willingness to use hospice services included the primary language of the caregiver (OR = 6.30, CI 95% = 1.68, 23.58); trust in doctors to make the right decisions (OR = 3.77,</p>

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				<p>CI 95% = 1.05, 13.57); and the belief that using hospice care means giving up on life (OR = 0.52, CI 95% = 0.30; 0.88).</p> <p>Caregivers who trusted doctors to make the best decisions for their loved ones and English-speaking caregivers were more willing to utilize hospice services, while caregivers who held a strong belief that hospice care means giving up on life were less likely to consider using hospice care for their loved ones.</p>
Koroukian, S. M., Schiltz, N. K., Warner, D. F., Given, C. W., Schluchter, M., Owusu, C., & Berger, N. A. (2017). Social determinants, multimorbidity, and patterns of end-of-life care in older adults dying from cancer. <i>J Geriatr Oncol</i> , 8(2), 117-124. doi:10.1016/j.jgo.2016.10.001	Home, hospice, hospital	Cancer patients, U.S., N=835	Post-mortem multivariable logistic regression (of linked data from 1991-2008 Health and Retirement Study, Medicare, and National Death Index)	<p>The majority (61.2%) of patients enrolled in hospice, but non-Hispanic Black patients and patients with lower incomes were significantly less likely to enroll in hospice.</p> <p>There was a non-linear relationship between income and in-hospital death (U-shaped), and income and cancer-directed treatment (J-shaped).</p> <p>Non- Hispanic Black patients were less likely to enroll in hospice than white patients (p < 0.05)</p> <p>Patients with less than a high school education were less likely to enroll in hospice than patients with a high diploma or some college (p < 0.05)</p> <p>Patients in the lowest income quartile were less likely to enroll in hospice than patients with higher incomes (p < 0.05)</p>
Lee, J. and J. G. Cagle (2017). "Factors Associated with Opinions About Hospice Among Older Adults: Race, Familiarity with Hospice, and	US, Florida, Hospice	2,714 older adults	Analysis of survey data from the American Association of Retired Persons in Florida	<p>Results showed race of the respondent was the strongest predictor of one's opinion about hospice.</p> <p>Predictors of positive opinions of hospice included being of Caucasian race and non-Hispanic</p>

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Attitudes Matter." J Palliat Care 32(3-4): 101-107.				ethnicity, in addition to better health, greater familiarity with hospice, a high importance of pain control, the importance of fulfilling personal goals, a desire to have health-care professionals involved in one's care and having engaged in advance care planning.
Lin, P. J., Zhu, Y., Olchanski, N., Cohen, J. T., Neumann, P. J., Faul, J. D., . . . Freund, K. M. (2022). Racial and Ethnic Differences in Hospice Use and Hospitalizations at End-of-Life Among Medicare Beneficiaries With Dementia. <i>JAMA Netw Open</i> , 5(6), e2216260. doi:10.1001/jamanetworkopen.2022.16260	Hospice/hospital across the United States	Medicare fee-for-service beneficiaries (continuously enrolled for at least 6 months prior to death) aged 65 years or older diagnosed with dementia who died between 2000 and 2016 (n = 5058)	Cohort study (data from national surveys from the Health and Retirement Study linked with Medicare and Medicaid claims) using 2-part models (logistic regression and generalized linear model)	<p>This cohort study found that non-Hispanic Black and Hispanic decedents with dementia used less hospice but more emergency department and inpatient services and incurred roughly 60% higher Medicare inpatient expenditures at the end of life, compared with non-Hispanic white decedents.</p> <p>A higher proportion of Black and Hispanic than white beneficiaries with dementia who were enrolled in hospice were subsequently admitted to the ED.</p> <p>The proportion of dementia beneficiaries completing advance care planning was significantly lower among non-Hispanic Black and Hispanic decedents compared with non-Hispanic white decedents, and a higher proportion of Black and Hispanic decedents with dementia had written instructions choosing all care possible to prolong life.</p> <p>Predictors of hospice use include older age, female gender, higher education levels, more severe cognitive impairment, and more instrumental activities of daily living impairment.</p>
Mehanna, E. K., Catalano, P. J., Cagney, D. N., Haas-Kogan, D. A., Alexander, B. M., Tulskey, J. A., & Aizer, A. A. (2020). Hospice Utilization in Elderly Patients with		Medicare patients (n=50,148) aged 66 years and older diagnosed with brain metastasis.	Retrospective cohort study using data from the Surveillance, Epidemiology and End Results (SEER)– Medicare database for the period 2005-2016.	The overall incidence of hospice enrollment among elderly patients with brain metastases between 2005 and 2016 was 71.4%, with a sustained increase in incidence over the study

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Brain Metastases. J Natl Cancer Inst, 112(12), 1251-1258.				<p>period. This suggests underutilization of hospice in a high-need group (28.6% do not enroll).</p> <p>The investigators identified statistically significant racial and ethnic disparities in hospice utilization with lower rates of hospice enrollment among Asian, Black, and Hispanic patients, as compared to white.</p> <p>The mechanisms for these disparities cannot be identified through this study, but the authors assert that they may include structural inequality in access to hospice care, cultural and religious preferences, lack of knowledge about the benefits of palliative care and hospice services, and stigma against hospice use or beliefs that palliative services hasten death.</p> <p>This study also identified that male patients and patients with greater comorbidities had lower odds of enrolling in hospice.</p> <p>Lastly, patients living in areas with higher household income were also found to be less likely to enroll in hospice, however this was not a clinically significant finding.</p>
Mendieta, M., & Miller, A. (2018). Sociodemographic Characteristics and Lengths of Stay Associated with Acute Palliative Care: A 10-Year National Perspective. Am J Hosp Palliat Care, 35(12), 1512-1517.	Home-based and facility-based hospice care and acute palliative care settings across the U.S.	Medicare beneficiaries in-hospice care, accessing and deceased while in acute palliative care (n=94,557).	Retrospective cohort study using data from the University of Michigan Institute for Healthcare Policy and Innovation (contains data from private insurers and CMS and is nationally representative sample of Medicare population) for the period 2006-2014. The study is designed to examine how various patient characteristics were associated with length of stay in acute palliative care.	<p>Lengths of stay in hospice and acute palliative care are recommended to be longer to allow for patient-provider relationship building and for patients to take full advantage of services.</p> <p>African American and Hispanic patients were more likely to receive home-based hospice care services (12.2% and 8.8%, respectively), as compared to facility-based hospice (10.2% and 6.6%, respectively).</p>

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				<p>In contrast, there was no observed difference in proportion of Asian patients between home-based and facility-based hospice (1.5% and 1.3%, respectively).</p> <p>White patients comprised a greater proportion of facility-based hospice patients (73%) as compared to home-based hospice patients (69%).</p> <p>Nevertheless, this study did not find that home-based hospice was associated with shorter length of stay in acute palliative care across groups.</p> <p>Despite being more likely to use home-based hospice care, African American patients had longer lengths of stay in acute palliative care (10 days), compared to white and Asian patients (9 days).</p> <p>Hispanic patients, who were also more likely to use home-based care, had the shortest lengths of stay (8 days).</p>
Mendola, A., Naumann, W. C., Mooney-Doyle, K., & Lindley, L. C. (2021). Social Determinants of Comfort: A New Term for End-of-Life Care. <i>J Palliat Med</i> , 24(8), 1130-1131. doi:10.1089/jpm.2021.0209	US, end-of-life care	Not applicable	Letter to the editor	<p>This letter to the editor proposes the term “social determinants of comfort” to describe structural conditions that influence to what degree comfort measures are offered to and accepted by patients and their families.</p> <p>Social determinants of comfort include structural conditions that influence the health outcomes of individuals and populations, such as safety of the built environment, access to nourishing food, and steady income source.</p>
Mullins, M. A., Ruterbusch, J. J., Clarke, P., Uppal, S., Wallner, L. P., & Cote, M. L. (2021). Trends and racial disparities in aggressive end-of-life		Medicaid beneficiaries aged >66 years diagnosed with ovarian cancer in the between 2000 and 2015	Retrospective cohort study designed to assess trends in the aggressiveness of end-of-life care for women with ovarian cancer and	The proportion of women who do not enroll in hospice declined over time since 2007 (P < .01);

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Citation	Setting	Population	Design	Main Findings
care for a national sample of women with ovarian cancer. Cancer, 127(13), 2229-2237.		and who died between 2007 and 2016 (n=7,756)	evaluate whether racial disparities in aggressive end-of-life care exist at a national level.	<p>but the proportion enrolling late did not improved over the study period (P = .17).</p> <p>Compared with non-Hispanic white (NHW) women, approximately 10% more non-NHW women did not enroll in hospice (P < .01).</p> <p>Compared with NHW women: Non-Hispanic Black (NHB) women had 38% greater odds of no hospice enrollment, Hispanic women had 36% greater odds of no hospice enrollment, and women in the other races group had 76% greater odds of no hospice enrollment.</p> <p>There were no statistically significant differences in late enrollment in hospice by race/ethnicity.</p>
NHPCO. (2020). Position Paper: COVID-19 and Supporting Black Communities at the End of Life. 1-11. Retrieved from https://www.nhpc.org/dac-position-paper/ . Accessed: August 29, 2022	National Hospice and Palliative Care Organization' Diversity Advisory Council	Ethnic communities	<p>The Diversity Advisory Council in this Position Paper endeavors</p> <p>to help communities at all levels better understand the situation, with emphasis on building trust with the diverse populations</p> <p>relative to patient care and the pain, misery, grief and sorrow caused by this horrible virus.</p>	<p>"Ultimately, organizations should entertain innovative minority engagement initiatives that add genuine value to communities rather than investing in "Diversity, Inclusion and Equity" solely for capitalization and incentivization. Hospice and palliative care providers would do well to educate themselves on the psyche of Black, Indigenous, and People of Color (BIPOC) that has been shaped by systemic racism, socioeconomic inequities, and disparities in health care education." Organizations can overcome these barriers and build trust by:</p> <ul style="list-style-type: none"> • Having a health and health care advocate, someone who is in a neutral place but has the influence and authority to see things through. • Building a framework around treatment and quality of life for elders. • Identifying implicit biases and reflect on the impact they have on decisions made related to patient care.

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				<ul style="list-style-type: none"> • Having a clear and precise plan of care and dialog with physician and patient about all options. • Scheduling time for relationship building. If there are patients who are traditionally underserved, plan to spend more time discussing options, providing education, and building trust. Doing this on the front end will prove to be beneficial to both the patient and clinician later. • Advocating for equitable laws related to health care. The Hospice Action Network and NHPCO advocate annually for policies that impact the Medicare Hospice Benefit and all are welcome to join.” <p>Hospice and palliative care providers are encouraged to position themselves in the gap between these redlined delivery systems by addressing disparities in health care education.</p> <p>Organizations can conduct an analysis of the education system within redlined communities, identify age group(s) that may benefit from early chronic disease education, consider investing in a community health education campaign, be innovative about multi-generational engagement, and collaborate with unlikely community health equity stakeholders</p>
Nicholson, B. L., Flynn, L., Savage, B., Zha, P., & Kozlov, E. (2022). Hospice Referral in Advanced Cancer in New Jersey. J Hosp Palliat Nurs, 24(3), 167-174.	Inpatient hospital facilities in New Jersey	Patients hospitalized with metastatic cancer in New Jersey in 2018 (n=28,697)	Retrospective cohort study using Health Care Utilization Project (HCUP) New Jersey state inpatient database to examine the relationship	<p>This study revealed racial disparities in hospice referral (either home hospice or hospice facility) patterns in New Jersey.</p> <p>After adjusting for pain and depression, Black patients were 15% less likely and Hispanic patients were 16% less likely to receive hospice</p>

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
			among demographics, symptoms of pain and depression, and hospice referral.	referrals in New Jersey hospitals compared with whites. Patients with a primary language other than English, there were 15% less likely to receive a hospice referral as compared to those with English a primary language.
Noh, H., Kim, J., Sims, O. T., Ji, S., & Sawyer, P. (2018). Racial Differences in Associations of Perceived Health and Social and Physical Activities with Advance Care Planning, End-of-Life Concerns, and Hospice Knowledge. <i>Am J Hosp Palliat Care</i> , 35(1), 34-40.	Alabama communities	Community-dwelling older adults (aged 55+ years) in Alabama (n= 1,044)	Cross-sectional study using survey data from the Comprehensive Center for Healthy Aging at the University of Alabama at Birmingham	Adjusting for sex, age marital status, education, and income, whites were more likely than Black people to have knowledge of hospice care (P < .01). Both whites and Black people with better perceived health (P < .05; P < .05) and a higher level of social activity (P < .001; P < .05) were likely to have more accurate knowledge of hospice than those with poorer perceived health and a lower social activity level. However, Black older adults generally reported poorer general perceived health. Higher levels of physical activity were associated with higher levels of knowledge of hospice for Black people (P < .05) but not for whites.
Noh, H., Lee, H. Y., Lee, L. H., & Luo, Y. (2021). Awareness of Hospice Care Among Rural African-Americans: Findings From Social Determinants of Health Framework. <i>Am J Hosp Palliat Care</i> , 10499091211057847. doi:10.1177/10499091211057847	US, Alabama's "black belt," hospice	179 African Americans living in Alabama's "black belt" region	A US cross-sectional survey that examined the association between social determinants of health (operationalized as financial resource strain, food insecurity, housing instability, education/health literacy, social isolation, and threats to interpersonal safety) and hospice awareness and use They also performed binary logistic regression that estimated the	82.1% of participants had heard of hospice care Participants over 50 were more likely to report awareness of hospice care (Odds Ratio [OR] = 7.29; CI 1.21 – 43.08) Participants with higher health literacy were more likely to report awareness of hospice care (OR =2.59; CI 1.27 = 5.31) Participants reporting worries about stable housing and higher social isolation were less likely

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Citation	Setting	Population	Design	Main Findings
			association between SDOH and hospice awareness	to have heard of hospice care. (OR= 0.05; CI 0.004 – 0.76) More socially isolated participants were less likely to be aware of hospice (OR 0.53; CI 0.31 – 0.90)
Núñez, A., Holland, J. M., Beckman, L., Kirkendall, A., & Luna, N. (2019). A qualitative study of the emotional and spiritual needs of Hispanic families in hospice. <i>Palliat Support Care</i> , 17(2), 150-158.	Hospices in Southwestern United States	Hispanic family members (aged <18 years) of former patients at large and well-established hospices in the Southwestern U.S. (n=29)	Qualitative semi-structured key informant interviews to examine the emotional and spiritual needs of Hispanic patients' families while in hospice.	<p>This study revealed five overarching themes that reflect the experiences of Hispanic family members when receiving hospice-based emotional and spiritual support services.</p> <ul style="list-style-type: none"> • The influence of Hispanic cultures in the hospice care relationship, which included ways in which Hispanic cultural norms and values influenced the interactions between patients' families and hospice care providers. • Types of social support (i.e., instrumental, informational) from hospice, which captured helpful types of social support participants received from hospice care providers. • Barriers to receiving support, which included both psychological and practical impediments to receiving support. • Lack of health literacy regarding hospice care, which consisted of participant responses describing difficulties they had in understanding hospice care information and a desire for education for caregivers. • Cultural preferences for religious/spiritual support in hospice, which included participants' responses that pertained to religious/spiritual support and the extent to which it fit with their cultural values. <p>The authors assert that their findings highlight the need for hospice staff training in culturally sensitivity, integrating members of the Hispanic community into the healthcare team to provide</p>

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Citation	Setting	Population	Design	Main Findings
				health education, and provision of care that is consistent with the religious/spiritual beliefs of patient families - or at least not contradictory.
Ornstein, K. A., Aldridge, M. D., Mair, C. A., Gorges, R., Siu, A. L., & Kelley, A. S. (2016). Spousal Characteristics and Older Adults' Hospice Use: Understanding Disparities in End-of-Life Care. <i>J Palliat Med</i> , 19(5), 509-515.	United States	Adults over the age of 55 who died between 2000 and 2011, participated in fee-for-service Medicare for at least 6 months, married/partnered, and with at least one chronic condition	Prospective cohort study using Health and Retirement Study and linked Medicare claims data to determine association between spousal characteristics and hospice use.	<p>Bivariate analyses revealed that hospice users were more likely than those who did not use hospice to have a high school degree or higher (70.3% versus 65.1%, $p = 0.03$) and be white (85.7% versus 79.1%, $p = 0.003$).</p> <p>Additionally, the spouse having lower educational attainment than the decedent was associated with no hospice use ($p = 0.015$).</p> <p>After controlling for patient and regional factors associated with hospice use, the spouse having lower educational attainment than the decedent resulted in 42% decreased odds of using hospice (OR = 0.58; 95% CI = 0.40–0.82).</p> <p>The authors assert that the association found between educational attainment discordance of spouse and hospice use may be reflective of socioeconomic status, health literacy, realistic expectations about death, or knowledge about hospice.</p> <p>They suggest that a better understanding of barriers to hospice enrollment, such as the concerns of the patient's spouse or partner, is needed.</p>
Ornstein, K. A., Roth, D. L., Huang, J., Levitan, E. B., Rhodes, J. D., Fabius, C. D., Safford, M. M., & Sheehan, O. C. (2020). Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the	United States	Adults 45 years or older who died between 2013 and 2015	Prospective cohort study using Reasons for Geographic and Racial Differences in Stroke and linked Medicare claims data	Authors point out that extant research has shown that use of hospice care is on the rise in the United State in the last decade and that the fastest-growing segment of the population receiving hospice care includes individuals with noncancer diagnoses.

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Citation	Setting	Population	Design	Main Findings
REGARDS Cohort. JAMA Netw Open, 3(8), e2014639.				<p>Despite the recent increase in the use of hospice care, this study revealed that racial disparities in the use of hospice remain, especially for noncancer deaths.</p> <p>The investigators found that Black decedents were less likely than white decedents to use hospice for 3 or more days (34.9% vs 46.2%; $P < .001$).</p> <p>After stratification by cause of death, racial differences in hospice use were found among persons who died of other deaths not attributed to cancer, dementia, or CVD cardiovascular disease.</p>
Osakwe, Z. T., Arora, B. K., Peterson, M. L., Obioha, C. U., & Fleur-Calixte, R. S. (2021). Factors Associated with Home-Hospice Utilization. Home Healthc Now, 39(1), 39-47.	Medicare-certified hospices across the U.S. including home-based hospice providers and institutional settings (i.e., assisted living, skilled nursing facility, inpatient hospice, inpatient hospital hospice, long-term care or non-skilled nursing facility, and other facility hospice).	Medicare-certified hospice providers in 2016 (n=2,148)	Cross-sectional study using Medicare Provider Utilization and Payment Data: Hospice Public Use File (2016) and American Community Survey data linked by hospice provider ZIP code to identify which characteristics are associated with home-hospice use (as compared to institutional hospice use).	<p>The authors point out that home hospice is recognized as an important patient-centered goal in EoL care.</p> <p>Provision of home-hospice was reduced by 2% for each percentage increase in proportion of female patients of the hospice (OR = 0.97, 95% CI = 0.97–0.98).</p> <p>Among community-level factors, hospice location in a ZIP-code with higher proportion of Black residents was not significantly associated with home-hospice provision (OR = 1.00, 95% CI = 1.00–1.01). For each unit increase in the proportion of Hispanic residents in a hospice ZIP-code, there was a decrease in the odds of providing home hospice (OR = 1.00, 95% CI = 0.99–0.99).</p> <p>Hospices with a proportion of dually enrolled beneficiaries in the lower 80th percentile had 42% increased odds of providing home hospice as compared with their counterparts in the upper 20th percentile. The authors suggest that this</p>

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				<p>finding may reflect higher care needs of the dually enrolled population that may be more easily met in institutional settings.</p> <p>Hospices in the Midwest were 36% less likely to provide home-hospice compared with those in the Northeast (the reference group; OR = 0.64, 95% CI = 0.56–0.72).</p>
Oud, L. (2017). Predictors of Transition to Hospice Care Among Hospitalized Older Adults with a Diagnosis of Dementia in Texas: A Population-Based Study. <i>J Clin Med Res</i> , 9(1), 23-29.	Inpatient hospital settings in Texas	Hospitalized adults aged 65 years and older with a diagnosis of dementia in Texas between 2001 and 2010 (n=889,008).	Retrospective cohort study using the Texas Inpatient Public Use Data file to identify factors associated with hospice utilization in the inpatient setting, and to quantify temporal patterns of escalation of care to ICU setting preceding discharge to hospice.	<p>Discharge to hospice was reported in 40,669 (4.6%) hospitalizations.</p> <p>Dementia hospitalizations discharged to hospice increased from 908 (1.5%) in 2001 to 7,398 (6.3%) in 2010. Insurance other than commercial predicted lower transition to hospice care, being lowest among hospitalizations with Medicaid insurance (aOR (95% CI): 0.41 (0.37 - 0.46); P < 0.0001).</p> <p>Non-white race groups had lower odds of hospice utilization, being lowest among Black patients (aOR (95% CI): 0.67 (0.65 - 0.70); P < 0.0001).</p> <p>This contrasts with other studies which have revealed higher odds of hospice use among non-white patients with dementia, though the authors point out that this may be due to the population sampled in this study which is more likely to be experiencing severe disease as they have already been hospitalized.</p> <p>Discharge to hospice was reported in 16,111 (5.8%) hospitalizations among ICU admissions during study period; this proportion increased significantly from 1.7% in 2001 to 7.7% in 2010, accounting for nearly one in two hospice discharges by the end of the decade.</p>

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				<p>This finding suggests that increasing proportion of key discussions by clinicians about goals of care and options of palliative care likely took place following admission to ICU and possibly after institution of invasive life support interventions.</p> <p>This underscores the need to effectively incorporate discussions on ICU admission and related interventions vs. alternative care options (such as hospice) earlier in the hospital course.</p>
Paredes, A. Z., Hyer, J. M., Palmer, E., Lustberg, M. B., & Pawlik, T. M. (2021). Racial/Ethnic Disparities in Hospice Utilization Among Medicare Beneficiaries Dying from Pancreatic Cancer. <i>J Gastrointest Surg</i> , 25(1), 155-161.	United States, various settings (inpatient, outpatient)	Medicare beneficiaries older than 65 years of age with pancreatic cancer who underwent a pancreatectomy between 2013-2017 and lived at least 30 days following surgery	Retrospective cohort study using CMS Inpatient, Outpatient, and Hospice Standard Analytic files designed to define the incidence and characterize the timing of hospice utilization among racial/ethnic minority patients following pancreatectomy for pancreatic cancer.	<p>Although there were no significant racial/ethnic disparities in mortality rate following pancreatectomy nor in time until death, racial/ethnic minorities (Black or Hispanic) were more likely to have experienced a complication after surgery and to have had a longer length of stay, and less likely to have used hospice services at time of death, compared to their white counterparts.</p> <p>Even after controlling for relevant clinical covariates, racial/ethnic minorities were 22% less likely to use hospice services as compared to white patients.</p> <p>Although hospice utilization among pancreatic patients declined overall between 2013 and 2017, the decrease is more pronounced among racial/ethnic minorities (-11.1% vs. -5.6% among white patients).</p> <p>There was no significant difference between white and minority patients in odds of late hospice use, however.</p>
Park, N. S., Jang, Y., Ko, J. E., & Chiriboga, D. A. (2016). Factors Affecting Willingness to Use Hospice	Florida, community setting	Floridian adults aged 65 years or older cognitively capable in understanding	Retrospective cohort study using Survey of Older Floridians administered between 2004-2005 and	Among non-Hispanic white participants, younger individuals were more willing to use hospice (odds

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in Racially/Ethnically Diverse Older Men and Women. Am J Hosp Palliat Care, 33(8), 770-776.		and answering survey questions (n=1,433)	designed to explore the predictors of the willingness to use hospice services in racially/ethnically diverse older men and women.	<p>ratio [OR]=0.93, 95% confidence interval [CI]: 0.87-0.98).</p> <p>Among African American participants, an increasing number of functional disabilities was associated with decreased willingness to use hospice (OR= 0.77, 95% CI: 0.62-0.95).</p> <p>A similar trend was observed in Cuban Americans and non-Cuban Hispanics, though not statistically significant.</p> <p>No observed factor was significantly associated with willingness to use hospice services among Cuban Americans.</p> <p>In the non-Cuban Hispanic sample, English proficiency increased the willingness by 3.1 times (95% CI: 1.26-7.58).</p> <p>Notably this was not the case for Cuban American participants and authors suggest that this is due to unique geographic clustering of this community with significant access to information and services in their native language.</p> <p>These results support the notion that willingness to use hospice may be influenced by different sets of factors that vary by race/ethnicity.</p>
Patel, M. I., Khateeb, S., & Coker, T. (2021). Association of a Lay Health Worker-Led Intervention on Goals of Care, Quality of Life, and Clinical Trial Participation Among Low-Income and Minority Adults with Cancer. JCO Oncol Pract, 17(11), e1753-e1762.	Chicago, community setting	Racial and ethnic minority union members >18 years old from low-income households newly diagnosed with cancer	Prospective cohort evaluation, comparison with historical cohort designed to assess a community health worker-led supportive cancer care intervention impact on variety of outcomes (including hospice use) among racial/ethnic minorities,	<p>Union members (all low-income and racial/ethnic minorities) in the community health worker intervention group were more likely to receive hospice care, as compared with the control group (44% v 7%; P < .001).</p> <p>This study suggests there are associated benefits of using lay health workers to connect low-income</p>

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			including hospice use. (n=66, vs n=72 in historical control group)	<p>and minority hourly wage workers with cancer to hospice care in an urban setting.</p> <p>In focus groups with the participants, many acknowledged that they felt more comfortable openly discussing their concerns about their goals of care and advance directives with peers from their community than with health care professionals such lay workers would more readily enable trust in health systems.</p> <p>The authors therefore suggest it is possible that the interpersonal relationships between the lay health workers and participants might have promoted the high uptake of these important cancer care services, such as hospice use.</p>
Phongtankuel, V., Johnson, P., Reid, M. C., Adelman, R. D., Grinspan, Z., Unruh, M. A., & Abramson, E. (2017). Risk Factors for Hospitalization of Home Hospice Enrollees Development and Validation of a Predictive Tool. <i>Am J Hosp Palliat Care</i> , 34(9), 806-813.	Home-based hospices in the United States	Medicare beneficiaries enrolled in home hospice between April and June 2012 (n=384,484)	Retrospective cohort study using Medicare fee-for-service claims from CMS designed to analyze pre-hospice admission risk factors associated with hospitalization to develop and validate a predictive tool aimed at identifying home hospice patients at risk for hospitalization.	<p>Non-Black minorities (OR = 1.40; 95% CI: 1.21-1.62), and Black individuals (OR = 2.68; 95% CI: 2.45-2.92) were associated with greater odds of hospitalization compared to whites (Table 2).</p> <p>These associations persisted even after adjusting for other patient and hospice level factors (Black: OR=2.13; 95% CI: 1.93-2.34; non-Black: OR=1.41; 95% CI: 1.22-1.65).</p>
Price, R. A., Parast, L., Haas, A., Teno, J. M., & Elliott, M. N. (2017). Black And Hispanic Patients Receive Hospice Care Similar to That of White Patients When in The Same Hospices. <i>Health Aff (Millwood)</i> , 36(7), 1283-1290.	Hospice settings across the United States	Hospice primary caregivers (n= 292,516) whose family member or friend died in the period of April 2015 – March 2016	Retrospective cohort study using Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey data. The study was designed to assess whether caregivers' reports of hospice care experiences differ by patients' race/ethnicity and to what degree are observed differences due to racial/ethnic minorities' concentration in certain hospices versus differences	<p>The study revealed that racial/ethnic differences are mostly attributed to between-hospice differences.</p> <p>For all seven CAHPS® Hospice Survey quality measures, Black and Hispanic patients were found to be more likely than white patients to receive care from hospices that offered significantly poorer care experiences (the between-hospice differences).</p>

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			in care delivered to racial/ethnic subgroups within the same hospice.	<p>Within a given hospice, however caregivers of Black and Hispanic hospice patients reported significantly better within-hospice care experiences than did caregivers of white patients on five of seven outcomes.</p> <p>The two exceptions to this were that within a given hospice, 1) caregivers of Black patients were less likely to recommend hospice compared to caregivers of white patients, and 2) Hispanic patients were less likely to report receiving the right amount of emotional and religious support (notably, they are more likely to receive “too much” support) as compared to caregivers of white patients.</p> <p>The results of this study highlight that to address racial/ethnic inequities in hospice experience, it will be critical to improve awareness of and access to high quality hospices that currently serve Black and Hispanic patients and their families.</p>
Reese, D. J., & Beckwith, S. K. (2015). Organizational Barriers to Cultural Competence in Hospice. <i>Am J Hosp Palliat Care</i> , 32(7), 685-694.	U.S. hospices	Hospice directors (n=207)	Mixed-methods study utilizing web-based cross-sectional survey including closed (quantitative) and open-ended (qualitative) items	<p>Results from quantitative data indicated that hospice staff, volunteers, and patients across these hospices were almost entirely white and very rarely spoke Spanish. Qualitative results identified organizational, community, healthcare system, and other barriers to cultural competence in hospice settings, as well as organizational strengths that promote cultural competence.</p> <p>Organizational barriers included lack of diverse or bilingual job applicants and volunteers, knowledge barriers. In this case, staff were unaware of any barriers or that anyone was underserved, lack of knowledge about how to access resources, including written materials and videos for patients,</p>

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				<p>lack of funding (e.g., DEI or cultural sensitivity training, interpretation services, additional staff for community outreach), lack of a focused, concentrated community outreach program (e.g., community referral network, collaborations), organizational culture that does not recognize or want to recognize cultural differences, staff unconcerned or uncomfortable with diversity</p> <p>Community barriers included lack of diversity in the community (e.g., rural communities), geographic barriers, and severe poverty. Healthcare system issues included government regulations that reduce ability to meet diverse needs.</p> <p>Other issues with diverse populations included preferences to associate with their own cultural group, in some cases return to their own country, perception of hospice as divergent to their cultural and religious beliefs or thinking.</p> <p>Organizational strengths identified were staff diversity, hiring of interpreters and provision of funding for cultural competence training, access to tools needed for serving diverse populations, community outreach (e.g., speaking at local churches and functions, collaborations with local university), organizational culture in which staff are excited to learn about the culture and providing best possible care, knowledge of underserved populations and inequity.</p>
Reese, D. J., Buila, S., Cox, S., Davis, J., Olsen, M., & Jurkowski, E. (2017). University-Community-Hospice Partnership to Address Organizational Barriers to Cultural	Hospice in a rural community	Staff and patients at one rurally located hospice	Participatory action research project using mixed methods designed to evaluate the effectiveness of a social work student field placement intervention in one rural hospice.	Through the intervention social work students completed clinical field work by providing services and 3 public information sessions and cultural competence training for staff at no cost to the hospice, addressing a reported lack of funding for

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Competence. Am J Hosp Palliat Care, 34(1), 64-78.				<p>community outreach and training needs and a lack of knowledge about diverse cultures.</p> <p>The intervention addressed lack of applications from cultural backgrounds by having a social worker hired from the intervention, as well as increasing the number of Black volunteers.</p> <p>The social work students also conducted a needs assessment of the community to identify groups not being served which addressed the reported barrier of lacking awareness of which cultural groups are not being served.</p>
Rhodes, R. L., Elwood, B., Lee, S. C., Tiro, J. A., Halm, E. A., & Skinner, C. S. (2017). The Desires of Their Hearts: The Multidisciplinary Perspectives of African Americans on End-of-Life Care in the African American Community. Am J Hosp Palliat Care, 34(6), 510-517.	Various/Unclear	African American hospice providers, caregivers, and patients	Qualitative study using semi-structured interviews and focus groups with African American hospice and palliative care providers, ministers, caregivers, patients	<p>Respondents reported hospice was beneficial to patients and family (e.g., helpful, comforting). Perceived barriers among African Americans included cultural differences, conflicts with spirituality and religious preferences, overall lack of knowledge about what hospice entails, and mistrust in the medical system.</p> <p>Strategies to overcome perceived barriers included counteracting the believe that hospice means giving up on faith (e.g., emphasizing the power of prayer in hospice, continuation of support and comfort from spiritual leaders/peers in the community and in hospice, integrating religious and cultural beliefs into individual care plan) more provision of education about the purpose of hospice, taking time to build rapport and respecting and meeting people where they are in the EOL decision-making process, learning about each individual patient (i.e., patient-centered care).</p>
Rice, D. R., Hyer, J. M., Diaz, A., & Pawlik, T. M. (2021). End-of-Life Hospice Use and Medicare	United States, various settings	Medicare beneficiaries with hepatocellular carcinoma	Retrospective cohort study using Surveillance, Epidemiology,	Whereas hospice use was not associated with sex, racial/ethnic minority patients less often used hospice services during the last year of life

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Expenditures Among Patients Dying of Hepatocellular Carcinoma. Ann Surg Oncol, 28(9), 5414-5422.		(HCC) diagnosed between 2004 and 2016 (n= 14,369)	and End Results (SEER)-Medicare-linked database and designed to define health care expenditures and hospice use among patients with HCC.	<p>compared with white patients (no hospice [44.3 %] vs. hospice [31.1 %]; P<0.001).</p> <p>Social vulnerability of the patient's county of residence was also associated with hospice use; in specific, the probability of hospice use declined as social vulnerability increased (P<0.001).</p> <p>Among patients who did use hospice, both race and SVI of county were associated with early vs. late hospice use. Notably, white patients were less likely than minority patients to initiate hospice use early (OR, 0.76; 95 % CI, 0.60–0.96), this held true even when holding SVI constant.</p> <p>Furthermore, as SVI of an area increased, the adjusted probability of early hospice use increased among minority patients yet decreased among white patients.</p> <p>These findings suggest that although minority patients may have less access to hospice services, when hospice is available, Black and Latino patients may be referred or decide to enroll earlier.</p> <p>Hospice use was associated with an approximate \$10,000 decrease in inpatient expenditures (hospice, US \$7900 vs. no hospice, US \$18,000; P<0.001) and a \$1,300 decrease in outpatient expenditures (hospice, US \$900 vs. non-hospice, US \$2200; P<0.001) compared with expenditures of patients who did not use hospice.</p> <p>This suggests that, in addition to benefiting patient care, hospice use may reduce overall health care costs, and reduce risk of financial detriment for patients and their families.</p>

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Riggs, A., Breuer, B., Dhingra, L., Chen, J., Hiney, B., McCarthy, M., Portenoy, R. K., & Knotkova, H. (2016). Hospice Enrollment After Referral to Community-Based, Specialist-Level Palliative Care: Incidence, Timing, and Predictors. <i>J Pain Symptom Manage</i> , 52(2), 170-177.	MJHS Hospice and Palliative Care is a not-for-profit company that maintains a certified hospice agency and a multifaceted palliative care program and provides care in all the boroughs of New York (except Staten Island) and Nassau County.	Patients who received community-based specialist-level palliative care services in a large program in New York (n=1,505)	Retrospective cohort study using data from electronic medical records and designed to evaluate the incidence, timing, and predictors of hospice enrollment after referral to a community-based palliative care program.	<p>Bivariate analyses revealed that white patients were more likely to receive hospice after palliative care, whereas Black and Hispanic patients were less likely to receive hospice after palliative care. (Asian patients were also more likely to receive hospice, however the numbers were very small).</p> <p>Poverty status was also associated with hospice use among the palliative care cohort, with patients from zip codes with a smaller share of residents living in poverty being more likely to enroll in hospice.</p> <p>Patients whose primary language was not English were less likely to enroll in hospice.</p> <p>Multivariate analyses indicated that poverty status of neighborhood continued to be significantly associated with hospice use and demonstrated that as the length of palliative care stay increased, the odds of hospice admission decreased.</p> <p>Among the patients who did enroll in hospice, mean length of palliative care stay was greater among Black and Hispanic patients as compared to white and Asian patients, and greater among patients whose primary language was Spanish as compared to English speakers.</p> <p>The findings highlight the need for ensuring access to hospice for those in economically and medically underserved communities.</p>
Rising, M. L., Hassouneh, D., Berry, P., & Lutz, K. (2021). Mistrust Reported by US Mexicans With Cancer at End of Life and Hospice	United States, various settings	US Mexican family members exposed to hospice (n=26)	Qualitative study using critical grounded in a postcolonial theory framework and semi structured interviews to develop a grounded	This study revealed that hospice avoidance among US Mexicans is driven more so by patients' mistrust of the healthcare system and providers rather than cultural barriers. This

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Citation	Setting	Population	Design	Main Findings
Enrollment. ANS Adv Nurs Sci, 44(1), E14-e31.			theory of hospice decision-making in U.S. Mexicans with terminal cancer	<p>mistrust was found to result in a perception of referral to hospice as coercive in nature.</p> <p>Among those US Mexicans who did enroll in hospice, they were US Mexicans who demonstrated a sense of belonging in the Eurocentric health care system, thereby precluding feelings of mistrust. Other instances of US Mexican use of and satisfaction with enrollment resulted from paternalistic relationship with the Eurocentric health care and provider.</p> <p>Among some older US Mexicans, there was a preference for traditional Mexican paternalistic relationship with physicians and among these patients, a sense of a belonging through identification with Eurocentric views and through trusting their physicians.</p> <p>The authors conclude that these findings suggest that cultural accommodation may do little to mitigate hospice avoidance that is rooted in mistrust.</p>
Rizzuto, J., & Aldridge, M. D. (2018). Racial Disparities in Hospice Outcomes: A Race or Hospice-Level Effect? J Am Geriatr Soc, 66(2), 407-413.	U.S. hospices, various types	Medicare beneficiaries in hospice who died between 2009-2010.	Longitudinal cohort study designed to determine whether there is racial variation in hospice enrollees' rates of hospitalization and hospice disenrollment	<p>In unadjusted models, Black hospice enrollees were significantly more likely than white enrollees to be admitted to the hospital (14.9% vs 8.7%, respectively), visit the ED (19.8% vs 13.5%, respectively), and disenroll from hospice (18.1% vs 13.0%, respectively).</p> <p>These results remained after accounting for participant clinical and demographic covariates and hospice-level random effects. In adjusted models, Black people were at higher risk of hospital admission (OR = 1.75, 95% CI = 1.64–1.86), ED visits (OR = 1.61, 95% CI = 1.52–1.70),</p>

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				<p>and hospice disenrollment (OR = 1.54, 95% CI = 1.45–1.63).</p> <p>This indicates holding clinical and demographic characteristics constant and within the same hospice – Black enrollees have greater odds of poor hospice outcomes as compared to their white counterparts.</p> <p>The authors suggest that these differences in outcomes may be due to Black patients tending to prefer life-sustaining therapies and spiritual beliefs that conflict with goals of hospice – a preference that is rooted in distrust in healthcare system based on the history of racism in medical research and persistent health disparities.</p> <p>They also suggest that racial differences in outcomes may reflect differences in the patterns of communications between providers and patients of different races.</p>
Russell, D., Diamond, E. L., Lauder, B., Dignam, R. R., Dowding, D. W., Peng, T. R., Prigerson, H. G., & Bowles, K. H. (2017). Frequency and Risk Factors for Live Discharge from Hospice. <i>J Am Geriatr Soc</i> , 65(8), 1726-1732.	New York City, large non-profit hospice agency; focus on home hospice service for this study	Home hospice patients who received care from a large urban not-for-profit hospice agency in New York City during a 3-year period between 2013 and 2015 (n = 9,190).	Retrospective cohort study using electronic medical records of hospice patients designed to calculate frequencies and identify associated risk factors for 4 distinct causes of live discharge from hospice.	<p>The risk for acute hospitalization was higher among racial/ethnic minorities (Hispanic AOR = 2.23 [CI = 1.82–2.73] P < .001; African American AOR = 2.46 [CI = 2.00–3.03] P < .001; Asian/other AOR = 1.63 [CI = 1.25–2.11] P < .001) and for patients with Medicaid (AOR =1.53; CI =1.20 -2.25) and Managed Medicaid (AOR=1.54; CI= 1.06–2.25).</p> <p>Odds of acute hospitalization were also higher for patients with primary diagnosis of dementia, (AOR=1.48; CI=1.07-2.05), heart failure (AOR=2.42, CI=1.84-3.20), pulmonary disease (AOR=1.97; CI=1.34-2.90), or any other non-cancerous disease (AOR=1.45; CI-1.13-1.85), as compared to those with cancer diagnosis.</p>

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				<p>Supplemental interviews with caregivers of home hospice revealed that decisions to pursue hospitalization were influenced by medical events, uncontrolled symptoms, imminent death, or inability to provide care safely at home.</p> <p>Asians/Others had greater odds of elective revocation (AOR = 1.43; CI = 1.01–2.00), as compared to white non-Hispanic patients.</p> <p>The odds of disqualification were higher among women compared to men (AOR = 1.34; CI = 1.03–1.87). Additionally, patients with non-cancerous primary diagnoses had greater odds of disqualification, as compared to those with cancer as a primary diagnosis.</p> <p>The odds of transferring to another hospice setting or moving out of the area were greater among Hispanics compared to white non-Hispanic patients (AOR = 1.56; CI = 1.45–2.34).</p>
Russell, D., Luth, E. A., Ryvicker, M., Bowles, K. H., & Prigerson, H. G. (2020). Live Discharge from Hospice Due to Acute Hospitalization: The Role of Neighborhood Socioeconomic Characteristics and Race/Ethnicity. <i>Med Care</i> , 58(4), 320-328.	Nonprofit hospice agency in New York City (NYC) between 2013 and 2017	Hospice patients (N=17,290) in NYC between 2013 and 2017	Retrospective cohort study using electronic medical records of hospice patients (N=17,290) linked with neighborhood-level socioeconomic data (N=55 neighborhoods) designed to examine associations between neighborhood socioeconomic characteristics and risk for live discharge from hospice because of acute hospitalization	<p>Notable differences were observed in sociodemographic, clinical, and neighborhood characteristics between patients who died in hospice versus those who experienced live discharge.</p> <p>Greater percentages of Black and Hispanic hospice patients experienced live discharge compared with white patients.</p> <p>Despite Black and Hispanic patients representing 17.3% and 20.1% of the study population, these groups represented 27.4% and 28.4% of hospice patients who were discharged alive because of hospitalization, respectively.</p>

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Citation	Setting	Population	Design	Main Findings
				<p>Patients who experienced live discharge also tended to have Medicaid insurance.</p> <p>Compared with patients who died in hospice, patients who experienced live discharge lived in neighborhoods with greater proportions of residents that lacked a high school diploma, fewer residents that held a college degree, greater proportions of residents that lived below the poverty line, and where median household incomes were lower.</p> <p>In adjusted models, factors associated with higher odds of live discharge included patients from underrepresented racial/ethnic groups, patients with Medicaid insurance, patients residing in neighborhood with lower proportion of college graduates, and patients living in neighborhoods with lower median household incomes.</p> <p>Interaction models demonstrated that disparity between Hispanic and non-Hispanic white patients in odds of live discharge was greatest in most affluent neighborhoods rather than more economically disadvantaged neighborhoods; notably there was no such differential effect of neighborhood characteristics on odds of live discharge among Black patients.</p>
Samuel-Ryals, C. A., Mbah, O. M., Hinton, S. P., Cross, S. H., Reeve, B. B., & Dusetzina, S. B. (2021). Evaluating the Contribution of Patient-Provider Communication and Cancer Diagnosis to Racial Disparities in End-of-Life Care Among Medicare Beneficiaries. <i>J Gen Intern Med</i> , 36(11), 3311-3320.	United States, various settings	Black and white Medicare beneficiaries 65 years or older with cancer (N=2000) and without cancer (N=11,524).	Retrospective cohort study using the population-based SEER-CAHPS linked dataset, which combines Consumer Assessment of Healthcare Providers and Systems (CAHPS) patient experience surveys (2001–2005, 2007–2015), Medicare enrollment and claims data (2003–2015), and Surveillance,	<p>Black beneficiaries were 26% less likely than their white counterparts to enroll in hospice (ARR: 0.74, 95%CI: 0.66–0.83).</p> <p>Notably these racial disparities in enrollment use varied by primary diagnosis. Among beneficiaries without cancer, Black beneficiaries had a 32% lower likelihood of enrolling in hospice (ARR: 0.68, 95%CI: 0.59–0.79); however, there was no</p>

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
			Epidemiology, and End Results (SEER) cancer registry data (2003–2015). This study was designed to examine racial disparities in hospice use overall and by disease group (cancer vs. non-cancer) and to assess whether racial differences in patient-provider communication accounted for observed disparities.	<p>significant difference in hospice enrollment between Black and white patients with cancer.</p> <p>This indicates that overall hospice use disparities between Black and white patients are largely driven by non-cancer patients.</p> <p>Patient-provider communication did not explain racial disparities in hospice use.</p> <p>Condition-specific differences in palliative care integration at the end-of-life may partly account for variations in hospice use disparities across disease groups.</p>
Sharma, R. K., Cameron, K. A., Chmiel, J. S., Von Roenn, J. H., Szmuiłowicz, E., Prigerson, H. G., & Penedo, F. J. (2015). Racial/Ethnic Differences in Inpatient Palliative Care Consultation for Patients with Advanced Cancer. <i>J Clin Oncol</i> , 33(32), 3802-3808. doi:10.1200/jco.2015.61.6458	US, Chicago, inpatient hospital	6,288 Patients with advanced cancer admitted to a Chicago hospital	Retrospective medical record review that evaluated the association between race/ethnicity and rates of inpatient palliative care consultation (IPCC).	<p>African Americans were more likely than whites to be referred to hospice (15.9 v 11.0 p < 0.001).</p> <p>There was no difference between Hispanics and whites, or Hispanics and African Americans.</p> <p>Of those who received IPCC, there was no difference in referrals to hospice.</p>
Shenker, R. F., Elizabeth McLaughlin, M., Chino, F., & Chino, J. (2022). Disparities in place of death for patients with primary brain tumors and brain metastases in the USA. <i>Support Care Cancer</i> , 30(8), 6795-6805. doi:10.1007/s00520-022-07120-4	US, multiple	7,255,693 patients who died between 2003 and 2016 and has solid cancer (primary brain, brain metastases, or solid non-brain tumors) as their primary cause of death.	Retrospective cohort study using WONDER death certificate data to examine place of death.	<p>For all solid cancers, multivariate analysis:</p> <p>Black patients were less likely to die at home or in hospice than white patients (OR 0.71; CI 0.70, 0.71; P < 0.001)</p> <p>Native American patients were less likely to die at home or in hospice than white patients (OR 0.85; CI 0.82, 0.87; P < 0.001)</p> <p>Asian/Pacific Islander patients were less likely than whites to die at home in a hospice facility (OR 0.66; 0.64, 0.65; p < 0.001)</p>

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Shepard, V., Al Snih, S., Burke, R., Downer, B., Kuo, Y. F., Malagaris, I., & Raji, M. (2022). Characteristics Associated with Mexican American Hospice Use: Retrospective Cohort Study Using the Hispanic Established Population for the Epidemiologic Study of the Elderly (H-EPESE). <i>Am J Hosp Palliat Care</i> , 10499091221110125. doi:10.1177/10499091221110125	US, Southwest, Hospice	Cohort 1: 970 Mexican Americans who died between 2004 and 2016 Cohort 2: 403 decedents of Cohort 1	Retrospective cohort study using the Hispanic Estimate Population for the Epidemiological Study of the Elderly (H-EPESE) and CMS data. A second cohort added H-EPESE Survey data.	Mexican American are more likely to use hospice in 2016 than in 2008 (OR 1.88; 1.19=2.97; p<0.001) 38% of patients died within the first week of hospice care. In the second cohort, no significant relationship was found between hospice use, marital status, high depressive symptoms, ADL disability, church attendance or seeing a doctor in the last year. They concluded that health system factors were most likely driving the variation in hospice use and referral.
Sheu, J., Palileo, A., Chen, M. Y., Hoepner, L., Abulafia, O., Kanis, M. J., & Lee, Y. C. (2019). Hospice utilization in advanced cervical malignancies: An analysis of the National Inpatient Sample. <i>Gynecol Oncol</i> , 152(3), 594-598. doi:10.1016/j.ygyno.2018.12.016	US, Hospital	2073 admissions with a cervical cancer diagnosis that were discharged to hospice or died the hospital	Retrospective cohort study	Asian/Pacific Islander were more likely to die in the hospital than white patients (OR 2.24; 1.11-4.49; p 0.02) There is no difference in place of death any other race (Black, Hispanic, Native American, Other) in likelihood of dying in the hospital rather than in hospice. There are also regional differences in hospice use. Rural patients are more like to die in the hospital than urban patients (OR 1.62; 1.12-2.36; p = 0.01)
Shin, J. A., Parkes, A., El-Jawahri, A., Traeger, L., Knight, H., Gallagher, E. R., & Temel, J. S. (2016). Retrospective evaluation of palliative care and hospice utilization in hospitalized patients with metastatic breast cancer. <i>Palliat Med</i> , 30(9),	US, Boston, inpatient hospital	123 patients hospitalized for the first time with a diagnosis of metastatic breast cancer at one tertiary care center.	Retrospective chart review	Less than one-third of patients (29%) were referred to hospice after their last hospitalization.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
854-861. doi:10.1177/0269216316637238				
Shiovitz, S., Bansal, A., Burnett-Hartman, A. N., Karnopp, A., Adams, S. V., Warren-Mears, V., & Ramsey, S. D. (2015). Cancer-Directed Therapy and Hospice Care for Metastatic Cancer in American Indians and Alaska Natives. <i>Cancer Epidemiol Biomarkers Prev</i> , 24(7), 1138-1143. doi:10.1158/1055-9965.Epi-15-0251	US, non-specific	388 American Indian/Alaska Native (AI/AN) and 85,871 non-Hispanic whites (NHW) metastatic cancer cases that were identified in Medicare enrollment files or Indian Health Service Care System records and linked to SEER Medicare data	Retrospective cohort study that used regression model to estimate odds ratios and hazard ratios for receipt of care.	Of those who died within two years, AI/ANs were less likely to enroll in hospice before death (OR 0.78; 95% CI; 0.61 – 0.99; P = 0.04) than NHWs. AN/AIs showed less hospice use across cancer types. Late hospice utilization was not significantly lower for AI/ANs than NHWs.
Shirsat, N., Hoe, D., & Enguidanos, S. (2021). Understanding Asian Indian Americans' Knowledge and Attitudes Toward Hospice Care. <i>Am J Hosp Palliat Care</i> , 38(6), 566-571. doi:10.1177/1049909120969128	US, Northern California, Hospice	82 Indian Americans aged 60 and over recruited from Indian cultural centers	Cross-sectional survey assessing attitudes towards hospice care and advance care planning.	10% of respondents know someone in hospice care. 10.4% answered 4 to 5 knowledge questions. After being educated about hospice 69.6% of participants agreed that if a family member was extremely ill, they would consider enrolling them in hospice. 44% would not want strangers in their home, even if the stranger was with hospice.
Siler, S., Arora, K., Doyon, K., & Fischer, S. M. (2021). Spirituality and the Illness Experience: Perspectives of African American Older Adults. <i>Am J Hosp Palliat Care</i> , 38(6), 618-625. doi:10.1177/1049909120988280	US, Colorado, non-specific	Church members who identified as African Americans living with at least one chronic condition, and their family caregivers.	Qualitative analysis of 5 churches with African American older adults living with chronic health conditions.	Participants relied on their spirituality and church community to help them cope with illness. Social struggles include mistrust of the health system and not being connected to adequate resources. Churches were referred to as a trusted space for health resources as well as spiritual and social supports.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Soltoff, A., Purvis, S., Ravicz, M., Isaacson, M. J., Duran, T., Johnson, G., . . . Daubman, B. R. (2022). Factors Influencing Palliative Care Access and Delivery for Great Plains American Indians. <i>J Pain Symptom Manage</i> . doi:10.1016/j.jpainsymman.2022.05.011	US, Great Plains reservation land, end-of-life care	21 specialty and 17 primary care clinicians caring for American Indians in the Great Plains.	Qualitative analysis of interview data that identified themes associated with palliative care delivery and access	Themes identified were health care system operations (e.g., insufficient availability of hospice), geography (e.g., travel distances), workforce elements (e.g., cultural familiarity), and historical trauma and racism The authors suggest increasing availability of hospice that can be provided on the reservation or in local Indian Health Service facilities; engaging community health workers to help families navigate the health care system, visit the home, increase AI/AN workforce, and improve cultural understanding; improving the “trustworthiness of the system” by investing in the workforce and giving clinicians access to cultural training and engaging Tribal Nations in health system changes.
Starr, L. T., Bullock, K., Washington, K., Aryal, S., Parker Oliver, D., & Demiris, G. (2022). Anxiety, Depression, Quality of Life, Caregiver Burden, and Perceptions of Caregiver-Centered Communication among Black and White Hospice Family Caregivers. <i>J Palliat Med</i> , 25(4), 596-605. doi:10.1089/jpm.2021.0302	US, Northeast and Midwest, hospice	722 Black and white hospice family caregivers that were over 18	Secondary analysis of baseline data from two randomized clinical trials to compare caregiver experience between Black and white caregivers	There were demographic and socioeconomic differences between the Black and white caregivers, but they experience similarly high levels of anxiety, depression, burden, and perception of hospice communication.
Starr, L. T., Ulrich, C. M., Junker, P., Appel, S. M., O'Connor, N. R., & Meghani, S. H. (2020). Goals-of-Care Consultation Associated with Increased Hospice Enrollment Among Propensity-Matched Cohorts of Seriously Ill African American and White Patients. <i>J Pain Symptom Manage</i> , 60(4), 801-810.	US, Northeast, Hospital	11,158 African American or 23,994 white propensity-score matched patients over 18 not admitted for conditions other than childbirth or rehabilitation, who weren't hospitalized at the end of the study, and	Secondary analysis of a retrospective cohort study that used stratified propensity-score matching to compare enrollment in hospice at discharge between African American and white patients with and without palliative care consultations (PCCs)	Both whites and African Americans who received a PCC were more likely to be discharged to hospice. African Americans were 15% more likely (2.4% vs 36%; p < 0.0001) and whites were 14% more likely (3.0% v 42.7%, p < 0.0001)

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
doi:10.1016/j.jpainsymman.2020.05.020		who did not die during index hospitalization.		
Starr, L. T., Ulrich, C. M., Perez, G. A., Aryal, S., Junker, P., O'Connor, N. R., & Meghani, S. H. (2021). Hospice Enrollment, Future Hospitalization, and Future Costs Among Racially and Ethnically Diverse Patients Who Received Palliative Care Consultation. <i>Am J Hosp Palliat Care</i> , 39(6), 619-632. doi:10.1177/10499091211034383 ¹¹	US, Northeast, Hospital	1,306 patients who received a palliative care consultation at an academic hospital	Secondary analysis of a retrospective cohort study	Medicaid patients were 42% less likely to than non-Medicaid patients to be discharged to hospice (AOR=0.59 95% CI 0.37 -0.90; P=0.02). Race and ethnicity did not predict hospice enrollment among patients who received a palliative care consultation.
Stein, G. L., Berkman, C., O'Mahony, S., Godfrey, D., Javier, N. M., & Maingi, S. (2020). Experiences of Lesbian, Gay, Bisexual, and Transgender Patients and Families in Hospice and Palliative Care: Perspectives of the Palliative Care Team. <i>J Palliat Med</i> , 23(6), 817-824. doi:10.1089/jpm.2019.0542	US, multiple	865 hospice and palliative care providers.	Mixed-methods Cross-sectional study with data collected via an online survey	53.6% of respondents believed that lesbian, gay, or bisexual (LGB) patients were more likely than non-LGB patients to experience discrimination. 23.7% observed discriminatory care. 64.3% believed transgender patients were more likely than non-transgender patients to experience discrimination. 21.3% observed discrimination to transgender patients. 15% observed the spouse/partner of LGBT patients have their treatment decisions disregarded or minimized, be denied or have limited access to the patient, and be denied private time. 14.3% observed the spouse or partner being treated disrespectfully.

¹¹ Abt Staff identified this article in both the SDOH and Health Equity literature reviews.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Stephens, S. J., Chino, F., Williamson, H., Niedzwiecki, D., Chino, J., & Mowery, Y. M. (2020). Evaluating for disparities in place of death for head and neck cancer patients in the United States utilizing the CDC WONDER database. <i>Oral Oncol</i> , 102, 104555. doi:10.1016/j.oraloncology.2019.104555	US, non-specific	101,963 patients who died of head and neck cancers	Retrospective study using CDC WONDER Underlying Cause of Death database with using sample proportions and multivariate logistic regression.	Caucasian patients were more likely to die at home or in hospice than patients of other races [59.5% v 50.8%; mean difference 8.7%; 95% CI 6.3%, 11.0%) African Americans and Asian/Pacific Islander were less likely to die at home or in hospice than Caucasians. [African Americans OR 0.73; CI 0.65 – 0.82; Asian/Pacific Islander OR 0.66; CI 0.54-0.81)
Stevens, E. E., & Abrahm, J. L. (2019). Adding Silver to the Rainbow: Palliative and End-of-Life Care for the Geriatric LGBTQ Patient. <i>J Palliat Med</i> , 22(5), 602-606. doi:10.1089/jpm.2018.0382	US, Hospice and Palliative Care	67-year-old male with metastatic ovarian cancer who was assigned female at birth.	Case study	The patient did not want to disclose his gender identity to friends or family. His spouse and he were legally married, but the current state of residence did not recognize the marriage, and his spouse was unable to take FMLA. Medical teams were vigilant in using inclusive language and his preferred terms. The cancer was referred to as a “germ cell tumor” Home hospice care was not possible due to insurance barriers (he did not have Medicare coverage) and his spouse inability to take FMLA he was unable to received hospice. They compiled a list of clinical recommendations for sexual and gender minorities in the hospice and palliative care settings (see Table 1)
Sutherland, N., Ward-Griffin, C., McWilliam, C., & Stajduhar, K. (2016). Gendered Processes in Hospice Palliative Home Care for Seniors With Cancer and Their Family Caregivers.	US, home hospice	25 patients with terminal cancer	A qualitative study with in-depth interviews, 9 observed agency home visits, and 12 institutional documents qualitative study comprised of 25 in-depth interviews, 9 observed agency home visits, and 12 institutional documents found that gendered	They found that gendered power dynamics are present among patients, caregivers, and providers. For example, in some cases, nurses in resource-constrained settings shifted care responsibilities to female (but not male) caretakers and pushed back more

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<p><i>Qual Health Res</i>, 26(7), 907-920. doi:10.1177/1049732315609571</p>			<p>power dynamics are present among patients, caregivers, and providers. For example:</p>	<p>against female caretakers' boundaries than male caretakers.</p> <p>Male caretakers discounted the professional status of nurses as compared to physicians.</p> <p>Female nurses and caregivers focused care efforts on female over male clients.</p> <p>To promote equity, the authors suggest providers and policymakers recognize gender as a prevalent social determinant of health.</p>
<p>Taylor, J. S., Brown, A. J., Prescott, L. S., Sun, C. C., Ramondetta, L. M., & Bodurka, D. C. (2016). Dying well: How equal is end of life care among gynecologic oncology patients? <i>Gynecol Oncol</i>, 140(2), 295-300. doi:10.1016/j.ygyno.2015.12.012</p>	US, Texas, hospital	189 gynecologic oncology patients	Retrospective analysis of medical records using	<p>Non-white race increased the odds of dying without hospice (OR 3.07, 95% CI 1.27,2.46).</p> <p>Non-white patients who did enroll, did so earlier than white patients (42 vs 47 days before death, p=0.054).</p> <p>Most patients, regardless of race, preferred to die at home (74% of white patients; 61% of Black patients; 61% of Hispanic patients, 57% of Asian patients).</p> <p>Black patients had the highest percentage of inpatient hospice deaths (23%) and Asian patients and had the highest percentage of hospital deaths (29%).</p> <p>There were no racial differences in other medical outcomes (admissions, receipt of chemo, ER visits, aggressive medical care, use of supportive care).</p> <p>Non-white patients were less likely to have medical power of attorney or living will documentation (24% v 76%, p=0.09) even if enrolled in hospice (12% v 31%; p=0.07)</p>

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Taylor, J. S., Rajan, S. S., Zhang, N., Meyer, L. A., Ramondetta, L. M., Bodurka, D. C., . . . Giordano, S. H. (2017). End-of-Life Racial and Ethnic Disparities Among Patients with Ovarian Cancer. <i>J Clin Oncol</i> , 35(16), 1829-1835. doi:10.1200/jco.2016.70.2894	US, Texas, hospital	3,666 patients with ovarian cancer	Retrospective study using the Cancer Texas Registry-Medicare data	Those of Hispanic ethnicity were less likely to enroll in hospice than white people (OR 0.78; CI 0.62, 0.97). Those of Black race were less likely to enroll in hospice than white patients (OR 0.74; CI 0.55, 0.98). No racial or ethnic groups were more likely to have multiple hospice enrollments. Those who did not die while enrolled in hospice were similar in terms on race/ethnicity.
Taylor, J. S., Zhang, N., Rajan, S. S., Chavez-MacGregor, M., Zhao, H., Niu, J., . . . Giordano, S. H. (2019). How we use hospice: Hospice enrollment patterns and costs in elderly ovarian cancer patients. <i>Gynecol Oncol</i> , 152(3), 452-458. doi:10.1016/j.ygyno.2018.10.041	US, Texas, Hospital	2,331 patients with ovarian cancer	Retrospective study using the Cancer Texas Registry-Medicare data	Black patients were more likely to unenroll from hospice prior to death than white patients (OR 2.07; CI 1.15-3.73; p=0.02). There was no difference in disenrollment for other racial/ethnic groups and whites.
Townsend, A., March, A. L., & Kimball, J. (2017). Can Faith and Hospice Coexist: Is the African American Church the Key to Increased Hospice Utilization for African Americans? <i>J Transcult Nurs</i> , 28(1), 32-39. doi:10.1177/1043659615600764	US, hospice	34 members of African American churches	Focus group to elicit beliefs about hospice care	Lack of knowledge of hospice services and spiritual beliefs were the top two contributing factors to underutilization of hospice care. Findings support partnerships between hospices and African American churches to provide hospice education to the African America community. Participants either believed that the hospice provider needed to understand and support their spiritual beliefs, or that it was necessary for their hospice provider to share their specific religious beliefs.

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Citation	Setting	Population	Design	Main Findings
				<p>While some participants felt cultural competence was necessary, others felt it was unrelated to the delivery of hospice care.</p> <p>Participants would be receptive to information about hospice even if the educator did not understand African American based religious constructs.</p> <p>The authors recommend that local hospices arrange regular information sessions at African American churches.</p>
Turkman, Y. E., Williams, C. P., Jackson, B. E., Dionne-Odom, J. N., Taylor, R., Ejem, D., . . . Rocque, G. B. (2019). Disparities in Hospice Utilization for Older Cancer Patients Living in the Deep South. <i>J Pain Symptom Manage</i> , 58(1), 86-91. doi:10.1016/j.jpainsymman.2019.04.006	US, Deep South, Cancer Hospital	12,725 University of Alabama Cancer Center Network who were Medicare decedents	Retrospective cohort study	<p>Non-white patients had a 24% increased risk of no hospice utilization compared to whites (Unadjusted Relative Risk [URR] 1.24; 95% CI 1.17 – 1.32).</p> <p>Males has a 15% increased risk of no hospital utilization compared to females (URR 1.1595% CI 1.09 – 1.21).</p> <p>Patients seen at hospitals with inpatient palliative care beds has a 15% increased risk for no hospice utilization compared to those without (URR 1.15; 95% CI 1.10 – 1.21).</p> <p>Non-white patients had a 16% decreased risk of receiving late hospice compared to white patients (URR 0.84; 95% CI 0.73 – 0.97).</p>
Wallace, C. L. (2017). Examining hospice enrollment through a novel lens: Decision time. <i>Palliat Support Care</i> , 15(2), 168-175. doi:10.1017/s1478951516000493	US, South, hospice	90 hospice patients or their primary decision maker	Cross-sectional study exploring the time between initial referral to hospice and enrollment in hospice	<p>White patients took longer to enroll in hospice than nonwhites (60 days vs 8 days (t -2.75; df 88; p = 0.01).</p> <p>Those with higher incomes (> \$50,000) took longer to enroll in hospice than those with lower</p>

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				<p>incomes (114 days vs 25 days; $t = -283$; $df = 85$; $p = 0.007$).</p> <p>Those receiving treatment took longer to enroll than those not in treatment (166 days vs 23 days).</p> <p>Those who were referred by a family member took longer to enroll than those referred by a physician (89 days vs 39 days; $t = -2.39$; $df = 88$; $p = 0.019$).</p>
<p>Wang, H., Qiu, F., Boilesen, E., Nayar, P., Lander, L., Watkins, K., & Watanabe-Galloway, S. (2016). Rural-Urban Differences in Costs of End-of-Life Care for Elderly Cancer Patients in the United States. <i>J Rural Health, 32</i>(4), 353-362. doi:10.1111/jrh.12160</p>	US, multiple end-of-life	175,181 elderly adults with lung, colorectal, breast, or prostate cancer who died in 2008	Retrospective cohort study using Medicare claims data	Rural cancer patients were less likely to use hospice for all cancer types (coefficient range 0.1 to 0.08; $p \leq 0.01$).
<p>Wang, S. Y., Aldridge, M. D., Canavan, M., Cherlin, E., & Bradley, E. (2016). Continuous Home Care Reduces Hospice Disenrollment and Hospitalization After Hospice Enrollment. <i>J Pain Symptom Manage, 52</i>(6), 813-821. doi:10.1016/j.jpainsymman.2016.05.031</p>	US, hospice	All fee-for-service Medicare beneficiaries older than 66 who died in 2011; 3592 hospices	Retrospective cohort analysis	<p>White patients are much more likely to receive continuous home care (CHC) than other races/ethnicities (85.4% vs 6.1% [Black], 6.7% [Hispanic], 1.8% [other]; $p < 0.001$).</p> <p>CHC care use was associated with a decreased likelihood of hospice disenrollment (CHC 10.6% vs 3.7% $p < 0.001$).</p>
<p>Washington, K. T., Oliver, D. P., Smith, J. B., Kruse, R. L., Meghani, S. H., & Demiris, G. (2019). A Comparison of Rural and Urban Hospice Family Caregivers' Cancer Pain Knowledge and Experience. <i>J Pain Symptom Manage, 58</i>(4), 685-689.</p>	US, Midwest, hospice	196 Adult Family Caregivers (FCGs) from one of 6 hospices	Substudy of an ongoing National Cancer Institute cluster randomized crossover pragmatic trial. Substudy compares rural and urban hospice FCGs cancer pain knowledge and experience using the Family Pain Questionnaire	Rural FCGs knowledge of pain management principles was worse than their urban counterparts (Multiple Regression Model [MRM] estimate -4.95; CI -8.91 – 1.01; $p = 0.01$) however rural FCGs experiences when managing cancer pain were not statistically significantly different.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
doi:10.1016/j.jpainsymman.2019.07.010				
Wasp, G. T., Alam, S. S., Brooks, G. A., Khayal, I. S., Kapadia, N. S., Carmichael, D. Q., . . . Barnato, A. E. (2020). End-of-life quality metrics among Medicare decedents at minority-serving cancer centers: A retrospective study. <i>Cancer Med</i> , 9(5), 1911-1921. doi:10.1002/cam4.2752	US, cancer centers	110,119 Medicare beneficiaries who received treatment at one of 54 cancer centers and had poor prognosis cancers	Retrospective study cohort study	Minority patients were more likely to receive no referral to hospice (39.5% v 37%; CI 0.03) when looking across hospitals. Within hospitals, there was no significant differences within hospitals.
Weaver, M. S., Lukowski, J., Wichman, B., Navaneethan, H., Fisher, A. L., & Neumann, M. L. (2021). Human Connection and Technology Connectivity: A Systematic Review of Available Telehealth Survey Instruments. <i>J Pain Symptom Manage</i> , 61(5), 1042-1051.e1042. doi:10.1016/j.jpainsymman.2020.10.010	US, hospice	3,100 articles focused on available survey instruments that assess telehealth interactions, the constructs covered, and the patient populations surveyed.	Meta-analysis conforming to PRISMA guidelines	Studies focused on validation and utilization of telehealth assessment measures found that they underrepresented adolescents, geriatric populations, non-white or low-income populations, and those without a postsecondary education.
Wilkie, D. J., Ezenwa, M. O., Yao, Y., Gill, A., Hipp, T., Shea, R., . . . Wang, Z. W. (2017). Pain Intensity and Misconceptions Among Hospice Patients with Cancer and Their Caregivers: Status After 2 Decades. <i>Am J Hosp Palliat Care</i> , 34(4), 318-324. doi:10.1177/1049909116639612	US, Chicago, home hospice	161 patients who received home hospice, had cancer, had their worst pain in the past 24 hours (≥ 3 out of 10), were 18 or older, were English or Spanish literate, had caregiver willing to participate, and had a Palliative performance scale $> = 30$.	Cross-sectional study using baseline data from an ongoing RCT or patient and lay caregiver dyads receiving hospice care.	Hispanic patients had higher scores on the Barrier Questionnaire 13, which determines perceived barriers to pain management, than non-Hispanic patients (mean score on 3.09 v 2.56 $p=0.05$. For caregivers, there was no difference. Minority caregivers scored higher on the BQ 13 than their non-Hispanic white counterparts (2.86 v 2.55; $p = 0.03$). For patients, there was no difference. There was no difference between Caucasians and African Americans, or males and females.

Health Equity and Social Determinants of Health Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Worster, B., Bell, D. K., Roy, V., Cunningham, A., LaNoue, M., & Parks, S. (2018). Race as a Predictor of Palliative Care Referral Time, Hospice Utilization, and Hospital Length of Stay: A Retrospective Noncomparative Analysis. <i>Am J Hosp Palliat Care</i> , 35(1), 110-116. doi:10.1177/1049909116686733	US, Philadelphia,	3207 patients from referred to the palliative care service inpatient team between 2006 and 2015 a single, large, urban medical center.	Retrospective non-comparative analysis assessing if race predicts time to palliative care consult, hospice, or overall length of hospital stay for inpatient palliative care patients using archival data	Race was not significantly associated with hospice enrollment. They analyzed Black and Asian patients relative to white patients and Hispanic patients relative to white patients.
Yaqoob, Z. J., Al-Kindi, S. G., & Zein, J. G. (2017). Trends and Disparities in Hospice Use Among Patients Dying of COPD in the United States. <i>Chest</i> , 151(5), 1183-1184. doi:10.1016/j.chest.2017.02.030	US, hospice	1,242,350 patients who died of COPD, were aged 50 or older, and were in the US mortality files	Retrospective cohort study	Female patients are more likely to die in hospice (6.1% v 5.7%; p < 0.001). Whites were more likely to die in hospice than were African American (6.1% v 4.2%; p < 0.001). Dying in hospice had regional variation: Northeast 4.1%, Midwest 4.7%, South 8.1%, West 4.7% (p < 0.001).

Other Recent Hospice Literature

Other Recent Hospice Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Aldridge, M. D., Hunt, L., Husain, M., Li, L., & Kelley, A. (2022). Impact of Comorbid Dementia on Patterns of Hospice Use. <i>J Palliat Med</i> , 25(3), 396-404. doi:10.1089/jpm.2021.0055	US, hospice, unspecified	3,123 Medicare beneficiaries who died in hospice	Pooled cross-section analysis of Health and Retirement Study data linked with Medicare claims	Approximately 45% of hospice patients have primary or co-morbid dementia. Co-morbid dementia was associated with hospice stays longer than 6 months (AOR 1.52; 95% CI 1.11 – 2.09) and hospice disenrollment after 6 months (AOR 2.55; 95% CI 1.43 – 4.55)
Artico, M., Piredda, M., D'Angelo, D., Di Nitto, M., Giannarelli, D., Marchetti, A., . . . De Marinis, M. G. (2022). Palliative care organization and staffing models in residential hospices: Which makes the difference? <i>Int J Nurs Stud</i> , 126, 104135. doi:10.1016/j.ijnurstu.2021.104135	Italy, residential hospice	Adult patients enrolled in one of 13 residential hospices.	Secondary analysis of a multicenter prospective longitudinal observational study to analyze the predictive power of staffing, structure, and process indicators on optimal control of clinically significant symptoms	A staffing ratio of 19% physicians, 23% nurse assistants, and 58% registered nurses was most likely to control patient symptoms (pain, nausea, shortness of breath, feeling sad, feel nervous, and overall feeling). Physicians and nurses with palliative care qualifications were associated with improved patient outcomes.
Demiris, G., Oliver, D. P., Washington, K. T., Chadwick, C., Voigt, J. D., Brotherton, S., & Naylor, M. D. (2022). Examining spoken words and acoustic features of therapy sessions to understand family caregivers' anxiety and quality of life. <i>Int J Med Inform</i> , 160, 104716. doi:10.1016/j.ijmedinf.2022.104716	US, hospice	124 audio files of discussion between family caregivers of hospice patients	Assessment of how well a machine learning algorithm using an automated speech recognition system and trained to use both spoken word and acoustic features correlates to anxiety and quality of life assessed by validated instruments.	Machine learning that uses automated speech-to-text transcription and acoustic features improved accuracy. Incorporating acoustic features in machine learning improved precision (86% to 92%) accuracy (81% - 89%), and recall (78% - 88%). Machine learning techniques can indicate improvements in anxiety and quality of life measures with a reasonable degree of accuracy and can be used to inform the design of tailored therapy chatbots.

Other Recent Hospice Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Harrison, K. L., Cenzer, I., Ankuda, C. K., Hunt, L. J., & Aldridge, M. D. (2022). Hospice Improves Care Quality for Older Adults with Dementia in Their Last Month of Life. <i>Health Aff (Millwood)</i> , 41(6), 821-830. doi:10.1377/hlthaff.2021.01985	US, hospice	2,059 National Health and Aging Trends (NHATS) participants aged 70 or older	NHATS study and Medicare claims to determine the impact of hospice enrollment on caregiver on proxy perceptions of care quality in the last month of life using predicted probability.	Proxies of people with dementia enrolled in hospice (compared to proxies of patients with dementia not enrolled in hospice) were more likely to report the care to be excellent (predicted probability 52% v 41.4%; p=0.012), more often reported having anxiety and sadness managed (67% v 46%), and less often reported changes in care settings in the last 3 days of life (10% v 25%). There we no differences between proxy ratings for hospice for patients with and without dementia.
He, M., O'Connor, S. J., Qu, H., Menachemi, N., & Shewchuk, R. M. (2021). Hospice inpatient services provision, utilization, and financial performance. <i>Health Care Manage Rev</i> , 46(4), E68-e76. doi:10.1097/hmr.0000000000000303	US, inpatient hospice	9,929 hospices (537 did not provide inpatient services, 1,197 offered inpatient services by staff, 7,811 offered inpatient services by arrangement	Longitudinal retrospective analysis of CMS hospice cost reports, provider of service files, and areas resource health files to explore the relationship between inpatient hospice, hospice use, and financial performance.	Hospice with staff offering inpatient services had shorter lengths of staff and lower total operating margins (TOM) (b = -0.063, p < 0.05; b = -0.022, p < 0.05). Hospices that offer inpatient services both by staff and under arrangement had a lower return on assets (ROA) than hospices that don't offer inpatient services (b = -0.073; p < 0.05).

Other Recent Hospice Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Hughes, M. C., Vernon, E., Kowalczyk, M., & Zhou, H. (2022). Experiences of caregivers and hospice leaders with telehealth for palliative care: a mixed methods study. <i>Ann Palliat Med</i> , 11(7), 2302-2313. doi:10.21037/apm-21-3899	US, Hospice unspecified	595 caregivers of seriously ill patients and 25 hospice leaders	Cross-sectional survey (caregivers) and interviews (hospice leaders)	<p>Those with good internet, better access to video, and under 65 were more satisfied with their telehealth. The general outlook from hospice leaders is that telehealth is positive and hopeful</p> <p>Patients mentioned that having training or instructions helped, as did having a family member present and customer service available.</p> <p>There is still confusion over telehealth policies and concern about abuse. For example, a hospice may only do telephone calls instead of true audio-visual telehealth visits, or family drug diversion may become more prevalent if informal caregivers are given more control over medication.</p> <p>Telehealth was reported to have enhanced usual care for activities such as addressing patient/family concerns, explaining lab results, and basic diagnostic activities. Interviewees also reported positive experiences with bereavement support, enhancing connections with out-of-town family members.</p> <p>Thoughts on virtual social workers or spiritual counselor services was more mixed, with some noting they could reach more patients and fewer people would need to visit the patient's home, but other felt these areas are difficult to do well within an in-person connection.</p>

Other Recent Hospice Literature Review Table				
Citation	Setting	Population	Design	Main Findings
Lam, M. B., Riley, K. E., Zheng, J., Orav, E. J., Jha, A. K., & Burke, L. G. (2021). Healthy days at home: A population-based quality measure for cancer patients at the end of life. <i>Cancer</i> , 127(22), 4249-4257. doi:10.1002/cncr.33817	US, multiple	284,751 Medicare patients with who died of cancer	Calculation and analysis of a novel population-based measure called Health Days at Home	<p>The measure calculates Healthy Days at Home (HDAH) in the last 180 days before death. It subtracts days spent in inpatient or outpatient emergency departments (including observations stays), skilled nursing facilities, inpatient psychiatry, inpatient rehabilitation, long-term hospitals, and inpatient hospice.</p> <p>Days on home hospice and home health were considered HDAH.</p> <p>Time spent in inpatient and at skilled nursing facilities resulted in the most substantial HDAH reductions.</p> <p>Males had fewer HDAHs than females (153 v 156; $p < 0.001$), Medicaid patients had fewer HDAH than non-Medicaid (152 v 155; $p < 0.001$).</p>

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