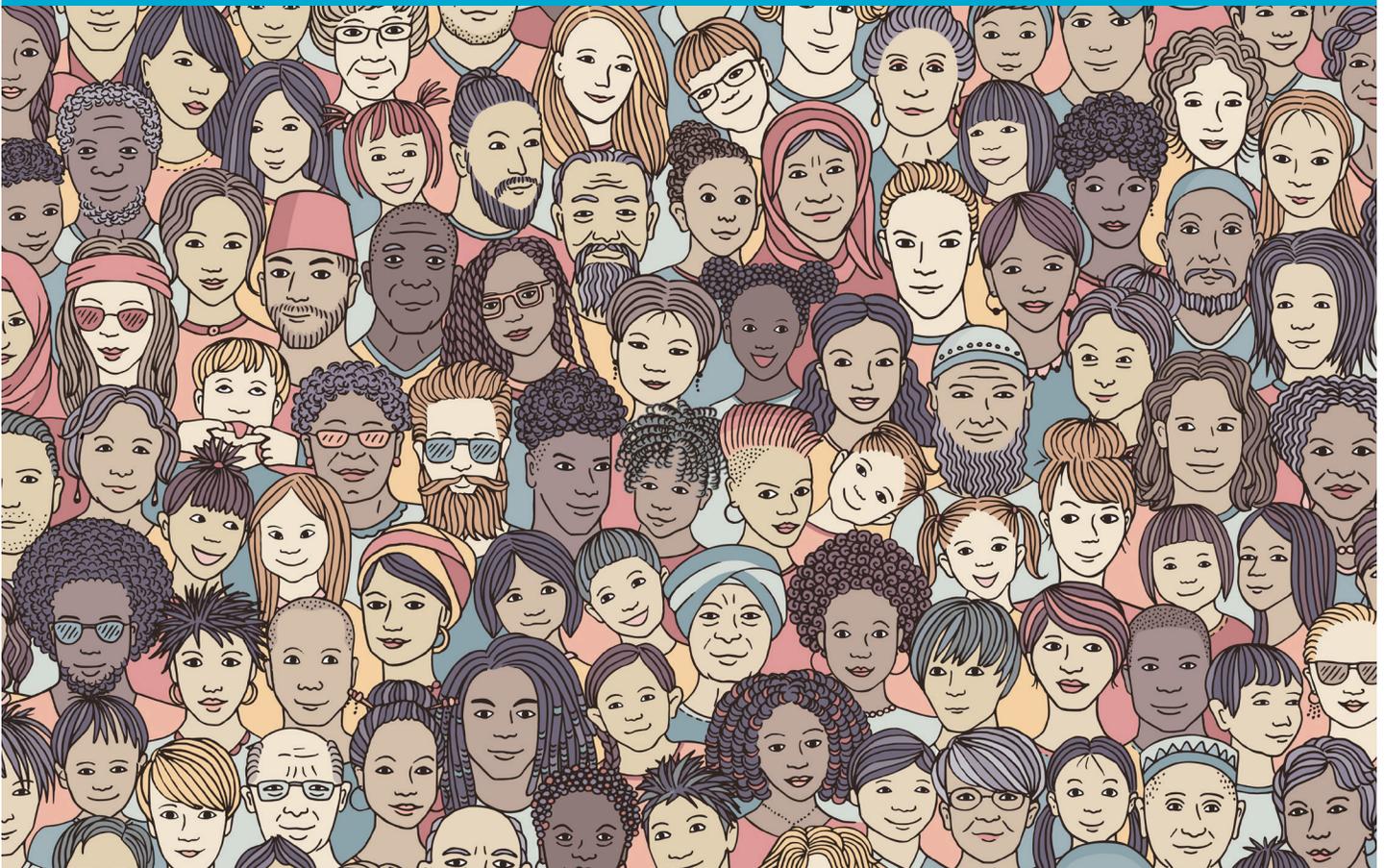


Addressing Inequities in End-of-Life Planning and Care: Advancing Equity at Life's End

Research Scan



November 4, 2021

Executive Summary

Compassion & Choices seeks to understand inequities associated with end-of-life care and used this scan to inform its summit, *Addressing Inequities in End-of-Life Planning and Care: Advancing Equity at Life's End*. This scan was conducted to help the organization develop a more informed understanding of current research, including gaps in the research, as it relates to end-of-life care and planning.¹

The research scan identified 58 articles addressing disparities around end-of-life care and end-of-life planning related to the following demographic groups and populations, identified as the focus for this initial work:

- » Black Americans and African Americans
- » Hispanics/Latinos/Latinx
- » Asian American, Native Hawaiian and other Pacific Islanders
- » American Indians/Native Americans
- » LGBTQ+²

Nearly all of the articles were published between 2018 – 2021, although many rely on data that was collected before 2018.

For the purposes of this research, “end-of-life healthcare” means healthcare services including palliative care and hospice. Advance care planning and other end-of-life planning may inform the services offered or received, and are thus included in the research scan.

The research confirms severe disparities in end-of-life planning and care. The disparities occur at every stage and level of care, including education about available care, access to care and provision of care. The research describes patient distrust in the healthcare system based on a lifetime of experience with provider bias, discrimination and hindered access, which creates additional challenges at the end of life.

Some key findings include:

- » Disparities in end-of-life healthcare are systemic and persistent for all groups included in this research. For example, the groups included in the reviewed research are less likely to receive palliative care and hospice care, and are more likely to receive aggressive end-of-life care.³
- » These differences were found among decedents of Chinese or South Asian ethnicity, as well as Hispanic/Latino and Black/African American individuals. Although each group faces multiple unique underlying contributing factors leading to these findings, the research suggests that provider–patient race and ethnicity discordance, inaccessible socioeconomic resources, and discrimination may be common among end-of-life care inequity drivers for people identifying from these groups.⁴ Any of these factors or all of them together may lead to inequities in end-of-life care.

- » Understanding disparities in access to palliative care, including pain management, requires close attention to patient communication needs, the meaning of suffering for a patient and the cultural implications of decision making.⁵
- » Disparities in access to palliative care have been identified in relation to geography and race and ethnicity.⁶ Factors that may be considered barriers to palliative care include discrimination and mistrust of healthcare providers.⁷
- » Individuals can simultaneously have multiple identities (e.g., based on age, race, gender, sexuality, socioeconomic factors), which may compound the impacts of discrimination experienced when trying to access end-of-life care.⁸ This theoretical framework is known as “intersectionality” and must be considered in efforts to address inequities.
- » There are also significant disparities across racial groups in regard to advance care planning and other end-of-life planning.
- » Overall, there is a tremendous lack of culturally competent communication (including communication in a patient’s preferred language) — or sometimes any communication — about end-of-life issues with patients and their loved ones. Providers either do not raise the issues sufficiently with patients and their loved ones or, when they are raised, may do so in a way that does not reflect the individual’s religious beliefs or cultural values. For example, in a survey of 108 caregivers of Asian American decedents, almost half indicated that their cultural traditions and religious and spiritual beliefs were not respected.⁹
- » A longstanding history of mistrusting the healthcare system exacerbates the inequities as some individuals — particularly Black Americans and people who identify as LGBTQ+ — may lack confidence in their healthcare provider or the healthcare system.¹⁰ The research describes a rational “lack of trust” due to decades of discrimination, and as a movement, we understand that trust between patients and providers requires relationship and must be engendered.

Recommendations

In the aggregate, the research demonstrates disparities in care for every demographic group examined in this scan. While many articles provide data documenting the disparities, the research rarely identifies the reasons for these differences — whether the immediate cause or the larger historical context of discrimination and historic marginalization experienced by different populations.

However, some of the articles provide recommendations to reduce inequities in end-of-life care and planning. Specific recommendations include:

- » Education for clinicians providing care and individuals seeking care to ensure that end-of-life care is provided in a culturally competent manner that acknowledges and respects a person’s beliefs and values. As one article noted, what matters most to individuals at the end-of-life differs depending on their cultural background.¹¹
- » Training all physicians and staff involved with end-of-life care on skills of cultural competency, recognizing implicit bias, and practicing patient-centeredness and how

to effectively implement these skills in order to engage in higher quality and more respectful communication with patients of different racial identities.¹²

- » More high-quality intervention studies that address racial and ethnic-related health disparities in palliative care, particularly those that address systemic racism and other complex multilevel factors that influence disparities in health.¹³

Of course, providing care in a culturally competent manner will look different to different populations. For example, one article noted that African Americans mistrust a healthcare system in which they have been historically marginalized or not fully considered. As one focus group participant stated:

*Before doctors start throwing out pills [...], I want to know if they have a cultural sensitivity and how they've helped our community to live before they could tell me about what my options are in dying.*¹⁴

Similarly, research suggests that LGBTQ+ individuals may have an understandable or warranted mistrust of the healthcare system. One article surveying LGBTQ+ individuals found that in a healthcare setting, individuals want to be heard, feel safe and value competency in their relationship with their provider, suggesting trust and strong patient-provider relationships are particularly important to improve care in the LGBTQ+ community at the end of life.¹⁵

For many populations, improving end-of-life care involves an awareness and recognition of how such populations are systematically marginalized within the healthcare system. One article regarding the LGBTQ+ community noted that cultural competency may be insufficient and instead recommended training regarding cultural humility, with a focus on (1) individuals instead of their cultural groups, (2) self-reflection and (3) active listening. Training on cultural humility could theoretically benefit all populations.

Nearly all authors found that either additional research is needed on a specific topic or call attention to how little research has been conducted on a particular demographic group (e.g., older LGBTQ+ women, older Mexican Americans). According to these authors, additional research is needed to provide: (1) more current information — particularly after the onset of the COVID-19 pandemic, (2) information on different sub-populations and (3) data related to larger numbers of individuals.

Much of the existing research is qualitative, including focus groups or interviews with patients, relatives or caregivers. While the qualitative data is rich, it may not be generalizable. A question for Compassion & Choices is whether additional research is necessary to drive a successful policy agenda. While research frequently helps to drive policy, for policy regarding end-of-life care and planning, individual stories can be sufficiently powerful to propel legislation without large, peer-reviewed studies. Therefore, extensive research may not be needed in all areas to drive policy change.

To better treat a diverse patient population, medical schools must do a better job of recruiting and retaining diverse candidates. Some articles noted that patients seek a provider who is the same race, ethnicity or gender.

Ultimately, every person should have access to the end-of-life care options that align with their values. Individuals with different beliefs may choose different levels of care. However, the healthcare system and individual providers should improve access to end-of-life options for everyone.

Introduction

Before the COVID-19 pandemic, individuals from all communities included in this research and other historically underserved groups faced longstanding disparities in health. As of 2018, life expectancy among Black Americans was four years lower than white Americans, with the lowest expectancy among Black men. Research also documents disparities across other factors. For example, people reporting low-incomes also describe worse health status than individuals reporting higher income. Lesbian, gay, bisexual and transgender (LGBT) individuals experience certain health challenges at increased rates.

These and other inequalities continue to be exacerbated during COVID-19. The pandemic has highlighted that health equity through the life course and end of life is not a reality as COVID-19 has unequally affected many racial and ethnic groups, putting them more at risk of getting sick and dying from COVID-19.¹⁶ According to the Centers for Disease Control and Prevention, African American, Black, Hispanic and Latino persons are nearly three times as likely as white individuals to be hospitalized and are at least twice as likely to die of COVID-19¹⁷ (See Table 1).

Table 1: Hospitalization and Death by Race/Ethnicity¹⁸

Rate ratios compared to White, Non-Hispanic persons	American Indian or Alaska Native, Non-Hispanic persons	Asian, Non-Hispanic persons	Black or African American, Non-Hispanic persons	Hispanic or Latino persons
Cases	1.7x	0.7x	1.1x	1.9x
Hospitalization	3.5x	1.0x	2.8x	2.8x
Death	2.4x	1.0x	2.0x	2.3x

The results of this research scan document that the health disparities experienced throughout life persist during end-of-life care and advance care planning.

Key Terms

Compassion & Choices supports advancing equity in end-of-life care and planning. “Equity” in this context is not standardized in the literature, and there are many definitions for “health equity” focused on upstream interventions that are preventive in nature.

With this scan, the Centers for Disease Control description of “inequities” is informative:

- » the differences in obtaining full (health) potential which “are reflected in differences in length of life; quality of life; rates of disease, disability, and death; severity of disease; and access to treatment.”¹⁹

Compassion & Choices is considering “**inequities**” as reflected in inequitable access to quality end-of-life care.

For the purposes of this research and the related end-of-life healthcare policy development, Compassion & Choices is focused on end-of-life healthcare inequities. In addition, and to clarify Compassion & Choices’ anchor in end-of-life care, rather than refer to “health disparities,” Compassion & Choices uses the term “disparities.” It is beyond the scope of this research scan and the related efforts to develop policy recommendations that include preventative measures earlier in the life course. It is also challenging and sometimes confusing to talk about “health” alongside “dying” and “death.”

When describing “**disparities**,” the U.S. Department of Health and Human Services notes:

- » Disparities “adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.”²⁰

For this work, Compassion & Choices is considering “disparities” as the differences in access to quality end-of-life care that are systematically experienced in relation to an individual’s racial or ethnic group or identity; religion or spiritual preference; socioeconomic status; gender; mental health; cognitive, sensory or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.

Note that research about disparities in end-of-life healthcare for people with disabilities, people who live in institutions and other demographic groups will be addressed in a future research project.

Methodology

The research scan includes peer-reviewed articles generally published in 2018 or later regarding disparities in both end-of-life care and end-of-life planning for the specified demographic groups: (1) Black Americans/African Americans; (2) Hispanics/Latinos/Latinx; (3) Asian American, Native Hawaiian and other Pacific Islanders; (4) American Indians/Native Americans; and (5) LGBTQ+. The search was conducted using PubMed, Google Scholar and SSRN. See the Annotated Bibliography for summaries of each article as well as a full list of search terms.

After the research results were reviewed with Compassion & Choices staff, eight articles were added to include additional research related to disparities in the provision of and access to palliative care (including three articles published prior to 2018). Additionally, a small number of articles were deleted that focus on specific diseases where the findings did not differ from larger, more generalizable studies: e.g., discontinuation of dialysis and death in a nonhospital or hospice setting was less in minority patients than in non-Hispanic white patients.²¹

Limitations

There are several limitations to the research results. First, although most of the articles were published in 2018 or later, some are literature reviews which rely on research published earlier. Similarly, primary research that was published in 2018 or later may rely on data that was collected earlier (e.g., deaths between 2005-2009) but analyzed later. At the time this paper was written, there was little published research analyzing disparities in end-of-life care after the onset of the COVID-19 pandemic.

Additionally, many of the articles are based on a small sample size. For some subpopulations, it may be challenging to find sufficient data. While some of the research is objective and quantitative (e.g., hospice admissions, receipt of invasive treatments), much of the research is qualitative (e.g., surveys, focus groups, interviews). The qualitative data provides a richness that is lacking in the larger analyses but may not be generalizable. Almost every article highlights the lack of research about particular demographic groups or populations.

The research uses different and inconsistent terms to describe populations that identify with certain demographic groups, e.g. African American, Black, Black American, non-Hispanic Black. (See footnote 2 for additional examples.) This paper and the annotated bibliography use the terms provided by authors, which are inconsistent and may not reflect how individuals would self-identify.

Discussion

The research scan confirms known disparities among end-of-life care and end-of-life planning. This section first highlights the research on disparities for patients receiving palliative care, including hospice. Policies specific to palliative care are likely most promising for Compassion & Choices' policy agenda development. Following the section on palliative care and hospice are summaries of the identified research about end-of-life care options and individuals who identify with the various demographic groups.

1. Palliative Care

Research has shown unequal access to palliative care by race, ethnicity, geography and other factors.²² For purposes of this discussion, palliative care begins at the time of diagnosis of a serious illness and continues along the entire continuum of care, to hospice and end-of-life care, and finally to family bereavement after death.²³

Immense regional disparities have been identified in the delivery of palliative care, with certain regions and states having low access to the service.²⁴ Another study found both geographic and racial and ethnic disparities in the types of cancer care and associated costs regardless of hospice care status.²⁵ For example, Black cancer patients had lower rates of hospice care and higher rates of hospitalization than white cancer patients in the last six months of life.²⁶ For patients who died in the ICU, patient and family member minority race/ethnicity was consistently associated with lower ratings of quality of dying.²⁷

One study audiotaped conversations between hospitalized patients and palliative care clinicians. The research results showed that communication about prognosis was less than half as likely to occur during conversations with Black and Latino patients and that these conversations included fewer optimistic cues than conversations with other patients.²⁸ The authors hypothesize that less optimistic cueing may reflect clinicians' tacit efforts to address perceived unrealistic optimism on the part of Black and Latino patients.²⁹

For individuals with limited English proficiency, communication with providers is even more challenging. For example, patients with limited English proficiency had worse quality discussions about end-of-life care and goals of care when professional interpreters were not used.³⁰

Using data to manage the patient population and demonstrate program outcomes is essential as reimbursement shifts from traditional fee-for-service to value-based. However, a survey conducted by the National Hospice and Palliative Care Organization (NHPCO) found that 34% of respondents do not participate in any public reporting or data sharing.³¹ Survey participants were also asked about how NHPCO can assist them in development and sustainability of palliative care services. The top area for assistance was engaging and contracting with payers, followed by data collection, analysis, metrics and benchmarking. Other top areas of need include sample documents, advocacy at the federal level and state levels,

referring provider outreach and marketing, staff training and competencies, patient education resources, and metrics and measurement resources.³²

Recommendations

In order to address disparities in palliative care, the research makes a number of recommendations, including:

- » To reduce, or potentially eliminate, geographic and racial and ethnic disparities in end-of-life care, policies should minimize the overuse of ineffective but costly types of cancer care and to promote more effective palliative care services to patients and families.³³
- » The substantial geographic variation in the use of palliative care suggests a need for additional research on geographic disparities in palliative care and strategies that might improve state-level palliative care delivery.³⁴
- » A better rapport between clinicians and Black and Latino patients is necessary to improve prognosis communication.³⁵
- » Healthcare professionals should learn about the cultural groups with whom they work, including consulting community members and interfaith chaplains to enable them to integrate the patient's personal and cultural perspectives into their therapeutic plans.³⁶
- » More advocacy, legislation and programming is necessary to expand access to palliative care.³⁷

2. Black Americans/African Americans

Fourteen articles were identified related to disparities in end-of-life care and end-of-life planning for Black Americans and African Americans. This research confirms disparities in end-of-life care, including access to palliative care and hospice among African Americans. For example:

- » Black individuals were more likely than white individuals to be hospitalized or admitted to the emergency department during their last month of life.³⁸
- » Black residents of nursing homes were consistently less likely to use hospice before death; Hispanic and Black residents were more likely to experience an end-of-life hospitalization compared with non-Hispanic white residents; and racial/ethnic minority residents experienced worse pain and symptom management at the end of life.³⁹
- » Black individuals are less likely to use hospice and are more likely to have multiple emergency department visits, intensive treatment and hospitalizations than white individuals, notably in noncancer deaths.⁴⁰
- » African American cancer patients receiving hospice care had a lower likelihood of receiving a pain assessment, received more nonopioid and nonpharmacological interventions, and received lower levels of management of opioid-induced constipation than Caucasian Americans.⁴¹

The reasons for these disparities are not fully explained by the research. In fact, some articles call for more research to better understand racial disparities in access to and quality of end-of-life care,⁴² especially in regions with a history of racial discrimination.⁴³

A compelling 2020 essay by Alan Elbaum argues that structural racism and mistrust of the medical system must be addressed to overcome the barriers. As the essay notes, if different choices about end-of-life care are attributable to knowledge and access gaps, these disparities in knowledge and access should be addressed in their own right.⁴⁴

However, to the extent that these differences result from unjust conditions in medical systems as in society at large, more structural, systemic changes may be necessary.⁴⁵ The U.S. medical institution has a long legacy of discriminating against and exploiting Black Americans and using people's bodies without consent.⁴⁶

An ethnographic study of African American adults in the San Francisco Bay Area spoke of their "struggle" against unjust conditions, such as experienced clinicians acting on racial biases, making decisions on their behalf so that the patients were not given "a say" in their own end-of-life care.⁴⁷ As one African American focus group respondent said in another study: "Before doctors start throwing out pills [...], I want to know if they have a cultural sensitivity and how they've helped our community to live before they could tell me about what my options are in dying."⁴⁸

The Elbaum essay argues that the United States must implement systems that protect African American communities from the effects of systemic racism and the healthcare provider's subjective judgments about whether they "deserve" care.⁴⁹

Recommendations

In order to address these disparities, the research makes a number of recommendations, including:

- » Culturally targeted end-of-life interventions, such as psycho-educational approaches and interactive discussion and interviews, which have yielded significant improvements in psychological and behavioral outcomes including self-efficacy; anxiety, depression and/or well-being; and advance care planning among African Americans experiencing serious illness.⁵⁰
- » Language services and cultural competency training for staff in nursing homes with higher proportions of racial/ethnic minorities.⁵¹
- » More frequent, culturally sensitive advance care planning discussions (recommended in the context of African Americans with end-stage renal disease). The article notes that, despite a preference for aggressive life-sustaining treatments, individuals with prior advance care planning discussions were significantly less likely to support aggressive end-of-life care.⁵²
- » National and community-based, multifaceted, multidisciplinary, theoretical-based, resourceful, culturally sensitive interventions.⁵³
- » An increase in diverse communities' inclusion within healthcare institutions and research.⁵⁴

- » Because it will not be possible for every patient to see a physician who shares their race or ethnicity, training all physicians on skills of cultural competency, recognizing implicit bias and practicing patient-centeredness and how to effectively implement these skills in order to engage in higher quality communication with racially discordant patients.⁵⁵
- » Addressing the general mistrust from Black Americans of healthcare systems and clinicians, essential to moving forward in the wake of the COVID-19 pandemic and addressing the large impact of COVID-19 in Black communities.

Regarding advance care planning, research shows that conversations with healthcare providers or family members significantly decreased their likelihood of opting for aggressive life-extending care. However, some research points to shockingly low rates of conversations with providers related to advance care planning. For example, among 101 African American patients receiving haemodialysis, 69% report no advance care planning discussions with providers.⁵⁶

However, other research suggests high rates of end-of-life planning. In data from 65 African American family caregivers of older adults with dementia, 74% had obtained agency forms (e.g., power of attorney) and 63% had a formal end-of-life care planning document.⁵⁷ One study showed that verbal plans for the end of life are of particular importance to African American people and may help us understand why there is a perception that African Americans are less likely to possess a formal end-of-life care planning document.⁵⁸

Recommendations regarding advance care planning include:

- » Faith-based health promotion models, which may be applicable to advance care planning and end-of-life care literacy for African American people.⁵⁹
- » Integration of religious beliefs and practices into advance care planning and end-of-life care educational programs, which may enhance the efficacy of these efforts in promoting advance care planning, advance directive completion and hospice use.⁶⁰
- » Building trust, creating community partnerships and involving church leadership in advance care planning and end-of-life care literacy promotion efforts to serve as important elements to inform future initiatives.⁶¹

3. Hispanics/Latinos/Latinx

Four articles were identified regarding end-of-life care and end-of-life planning for Hispanics, Latinos and Latinx communities. Overall, the articles found the same categories of disparities in end-of-life care as with other demographic groups. For example, one article noted that Mexican Americans are the largest, fastest growing Latino subgroup in the United States, yet their use of hospice is limited.⁶² Another study found that Hispanic (and Asian American) patients were likely to die without receiving any services or to die in the hospital, suggesting that they might use hospital services (as opposed to hospice) at the very end of life.⁶³

One important factor identified in the research is the immigrant status of the individual. For example, one article found that among study participants, Latino immigrants were 9.4 times more likely to prefer life-extending care than U.S.-born Latinos.⁶⁴

One study found that Latino patients respect doctors' medical advice, prefer the involvement of family members in advance care planning discussions with doctors, hold optimistic religious beliefs (e.g., belief in miracles) that impact advance care planning discussions, and prefer culturally competent approaches such as using their native language for learning how to discuss end-of-life care preferences.⁶⁵

Focus groups in another study identified common themes among all participants (African American, Latino and white) regarding end-of-life care preferences: (1) clear, comprehensive and culturally relevant provider-patient communication regarding serious illness; (2) the impact of provider characteristics and competency on patient satisfaction; and (3) supports and barriers to care within health systems.⁶⁶ Additionally, Latino and African American focus group participants in one study wanted to match characteristics with providers (e.g., similar race/ethnicity).⁶⁷

Recommendations

Recommendations for achieving equitable care for people identifying as Hispanic, Latino or Latinx include:

- » More high-quality intervention studies that address racial and ethnic health disparities in palliative care, particularly those that address systemic racism and other complex multilevel factors that influence disparities in health.⁶⁸
- » Acknowledging diversity within groups, provider demonstration of comfort and competence, more effective care coordination and recruitment of providers who share similar characteristics with the communities they serve.⁶⁹
- » Randomized controlled trials and educational interventions focused on the most impacted groups, which can have significant and positive effects on advance directives and/or advance care planning-related outcomes.⁷⁰
- » Regarding advance care planning, an intervention that involves culturally competent communication, considers the patient's family dynamic, and incorporates cultural and religious beliefs.⁷¹

4. Asian American, Native Hawaiian and Other Pacific Islanders

Nine articles were identified regarding end-of-life care and end-of-life planning for Asian American, Native Hawaiian and other Pacific Islanders. The research confirms disparities in care. For example, in a large Canadian study, individuals of Chinese or South Asian ethnicity were more likely to receive aggressive end-of-life care — including more ICU and hospital, ventilation, dialysis, feeding tube placement, tracheostomy and cardiopulmonary resuscitation and deaths in the ICU — than others in the general public.⁷²

One shocking article found that, in a survey of 108 caregivers of Asian American decedents, almost half indicated that their cultural traditions and religious and spiritual beliefs were not respected.⁷³ Additionally, caregivers of Asian (American) decedents more often reported unmet needs for support/lack of respect than the white decedents' caregivers.⁷⁴

Although the research does not specifically identify a cause for these inequities, one article hypothesizes that the findings regarding more aggressive care may be due to communication difficulties between patients and clinicians, differences in preferences about end-of-life care or differences in access to palliative care services.⁷⁵

A literature review of research specifically on Korean Americans found an avoidance related to end-of-life communication and hopes that their families would know about their wishes, without discussing them directly. Some Korean Americans consider advance directives unnecessary, and only a few Korean Americans use advance directives to lessen the burden of their family's decision-making. The article states that many Korean Americans are unaware of what end-of-life care provides, which may explain less frequent use.⁷⁶

Recommendations

A number of the articles highlight the importance of cultural competency in end-of-life care. For example, focus groups with 60 Chinese Americans emphasized that cultural considerations must be incorporated into end-of-life care discussions. Specifically with Chinese Americans in the focus groups, the following were identified as priorities of "a good death": to be free from pain, to trust their doctor, to not be a burden to their family, to have their family with them, to maintain their dignity, and to pray.⁷⁷ The same article noted that, when caring for Chinese Americans, a comprehensive end-of-life care plan should include cultural considerations in addition to physical, psychosocial and spiritual needs.⁷⁸

The literature review on Korean Americans recommends that providers discuss end-of-life care with Korean Americans and tell them what it entails. However, the discussion should be culturally tailored and involve family members whenever possible.⁷⁹

Another article recommended that in order to improve equitable access to advance care planning, such planning should be framed as a tool to help families reduce stress while fulfilling filial obligations.⁸⁰

5. American Indians/Native Americans

The search revealed almost no published literature regarding disparities in end-of-life care or end-of-life planning among American Indians/Native Americans. The one article found on end-of-life care focused on access to care issues within tribal communities. The article stated that although life-limiting illness plagues Native Americans, access to palliative and end-of-life care, including hospice care, is severely limited.⁸¹ The article identified major challenges for Native Americans in terms of palliative and end-of-life care needs, relation to access, infrastructure and the systems established by tribal government and the Indian Health Service.⁸²

Regarding advance care planning, the one article identified on the topic noted that American Indian older adults were significantly less likely than non-Hispanic whites to have an end-of-life care plan or to have a durable power of attorney for healthcare or a living will.⁸³

Recommendations

Both articles recommend culturally sensitive approaches to working with Native American communities on end-of-life issues, including:

- » community-based participatory research (e.g., talking circles);
- » embracing cultural differences, seeking to learn from the culture itself how to best meet its people's needs;⁸⁴ and
- » targeted culturally sensitive approaches to promote advance care planning, grounded in indigenous cultures' health beliefs and practices.⁸⁵

6. LGBTQ+

Seventeen articles were identified regarding end-of-life care and end-of-life planning for lesbian, gay, bisexual, transgender or queer/questioning (LGBTQ+) individuals.⁸⁶ The research finds that lesbian, gay and bisexual older adults are more likely than their heterosexual peers to experience health disparities, discrimination from healthcare providers based on sexual orientation and rejection from their family of origin, all of which can complicate medical care and decision making, as well as end-of-life arrangements.⁸⁷

Other challenges experienced by LGBTQ+ individuals receiving quality care at the end of life include lack of confidence in the healthcare system to address their needs, homophobia and transphobia from medical staff, and forced outing.⁸⁸ One article describes a litany of barriers to palliative care for LGBT patients, including discrimination, criminalization, persecution, fear, distress, social isolation, disenfranchised grief, bereavement, tacit acknowledgment, homophobia and mistrust of healthcare providers.⁸⁹ As a result of these barriers, the article posits that palliative care is likely to be provided for LGBT patients with cancer in a deficient manner, perpetuating marginalization and healthcare inequities.⁹⁰

Additionally, one article found insufficient information for LGBTQ+ individuals about advance care planning,⁹¹ while another noted there is a dearth of knowledge regarding end-of-life preparation and perceptions of LGBT older adults.⁹² One article found common themes regarding end-of-life preparations for LGBT adults were the need for respect of "their family of choice," the ability to present their "true selves," not wanting to be a burden, and not wanting to rely on long-term care communities because of fear.

Recommendations

In response to these challenges, the research recommends:

- » Training for healthcare providers on culturally competent care to help clinicians address the unique care needs of this population and further decrease health inequities;⁹³

- » Hospice providers must take concrete steps to ensure that professional caregivers and office staff are qualified to meet the needs of LGBTQ+ people;⁹⁴
- » Clinics should strive toward person-centered care in a sensitive way, promote social support that alleviates distress, and ensure dignity is maintained;⁹⁵
- » Providers should learn and practice LGBT-inclusive communication skills, create opportunity and space for patients to disclose their orientation and gender identity, allow the patient to define who is family and the role of family in care, extend bereavement and grief support services to chosen family and close others, create and maintain a nondiscriminatory and inclusive practice setting, and promote continuity of care;⁹⁶
- » For LGBTQ+ women, address the vulnerability associated with isolation and poverty, women's social needs and support networks, and preferences for complementary care;⁹⁷
- » Conduct research on transgender and bisexual persons and providers of end-of-life care and studies that address the impact of policy changes such as marriage equality;⁹⁸ and
- » When considering end-of-life wishes for this population, understanding past experiences with the end of life, ensuring practical considerations are taken into account, including spiritual beliefs as a coping mechanism, while recognizing the uncertainty of life.⁹⁹

One article discussing health disparities among LGBTQ+ populations recommended cultural “humility” training rather than cultural competency training.¹⁰⁰ The authors posit that the strengths of cultural humility training include focus on (1) individuals instead of their cultural groups, (2) self-reflection and (3) active listening. The authors suggest practical components of successful cultural humility trainings including leadership buy-in, appropriate outcome measurements, multiple training sessions and fostering a safe reflection space.¹⁰¹ The approach of “cultural humility” could theoretically be an effective tool with individuals of many different backgrounds.

Conclusion

The results of the research scan confirm that inequities in care related to all groups included in this scan persist in end-of-life care and planning. Additional research may be needed to provide greater clarity about the reasons for such inequities and best practices to remedy them.

One of Compassion & Choice's core values is to be “respectful of the autonomy of individuals to decide which end-of-life options are best for them and their family.”¹⁰² It is clear that much of the research demonstrates that individuals' values, beliefs and wishes are not honored. All too often, the healthcare system is not making adequate effort to understand.

Additional work is necessary to achieve equity at the end of life. As stated by the CDC, “achieving ... equity [at the end of life] requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities.”¹⁰³

Endnotes

- 1 The research scan was produced for Compassion and Choices by Leslie Zellers, JD, and ThinkForward Strategies for the Summit hosted on November 4, 2021.
- 2 The research uses varied terms to refer to people who identify with certain demographic groups, depending on the individuals involved in the research. The terms used in specific articles are used in this scan. For example, (1) African American, Black, Black American, non-Hispanic Black; (2) Latino, Hispanic, Latino/Hispanic, Mexican American; (3) Asian Pacific Islander, Asian American, Asian, Chinese, Chinese Americans, Korean Americans, South Asian, Native Hawaiian, Pacific Islander; (4) Native Americans, American Indian; (5) LGBTQ+, LGBTQ, LGBT, lesbian, gay and bisexual, sexual and gender minority, transgender and gender-non-conforming; (6) White, non-Hispanic white, Caucasian, Caucasian American.
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