Addressing Inequities in End-of-Life Planning and Care:

Advancing Equity at Life's End

Summit Report

November 4, 2021

Summit
Organizational
Partners

Latinos
For Healthcare Equity

NATIONAL ORGANIZATION OF BLACK
ELECTED LEGISLATIVE WOMEN

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Services for
LGBT Elders
**We refuse to be invisible**

VITAS
Healthcare

Introduction

Experts convened at Compassion & Choices' *Addressing Inequities in End-of-Life Planning & Care* summit on November 4, 2021. The summit included 14 experts who responded to research about inequities in end-of-life care and planning. Experts included palliative care, hospice, primary care and emergency department practitioners and advocates focused on addressing healthcare-related inequities, ending systemic racism and discrimination, and providing end-of-life support for LGBTQ+ communities.

To frame the discussion, Compassion & Choices commissioned a peer-reviewed research scan about disparities related to end-of-life care and planning. The research scan explored disparities based on demographic data including race, ethnicity, immigrant status, and sexual orientation and gender identity.

Current research reveals tremendous barriers in access to palliative care, hospice and end-of-life planning for Black Americans, Asian Americans, Native Hawaiians and Pacific Islanders; those identifying as Hispanic or Latino; Indigenous communities; and LGBTQ+ communities. These barriers frequently lead to a lower likelihood of completing an advance directive or identifying a healthcare proxy, inadequate pain management during the dying process, and higher likelihood of in-hospital, invasive end-of-life treatments.

As the participants talked with Compassion & Choices senior leadership and staff about inequities within the communities they serve, they identified promising policy approaches to address the inequities. The summit conversations and ongoing collaboration will help Compassion & Choices develop a federal policy agenda to further address inequities in end-of-life care and planning.
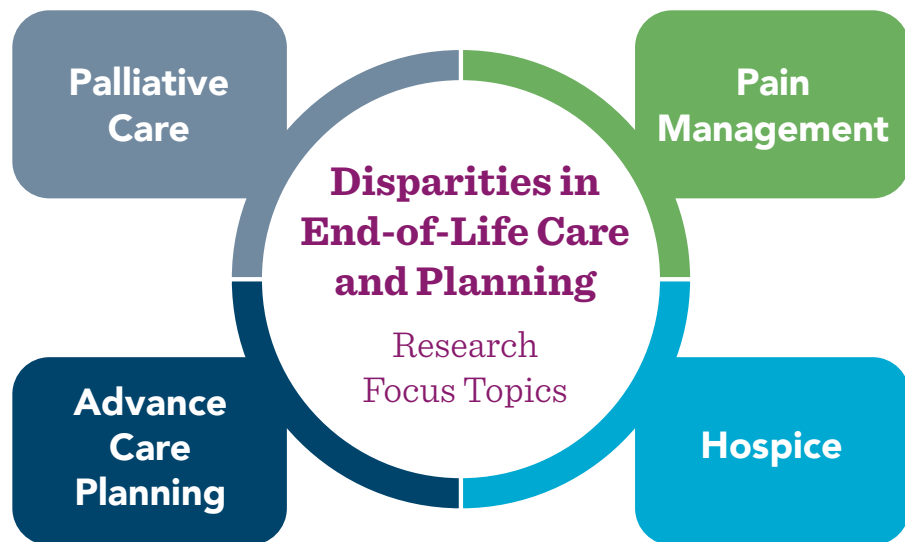
Summary of the Research

Disparities in end-of-life care and planning persist for many historically underserved communities. To focus this initial summit, we identified research addressing disparities in end-of-life care and end-of-life planning related to the following demographic groups and populations:

- » Black Americans and African Americans
- » Hispanic/Latino/Latinx Americans
- » Asian American, Native Hawaiian and Other Pacific Islanders
- » American Indians/Native Americans
- » LGBTQ+[1]

Find a PDF of the reseach scan at
CandC.org/research-scan-eol

The research confirmed that disparities in end-of-life care and planning are systemic and persistent for all groups included. While 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.[2] Any of these factors or all of them together may lead to inequities in end-of-life healthcare and planning.

With this data in mind, participants were invited to reflect on how the research affirms or confirms their experience when serving individuals and families from these communities. Experts also offered insight into potential policy solutions to address the inequities in end-of-life care and planning.
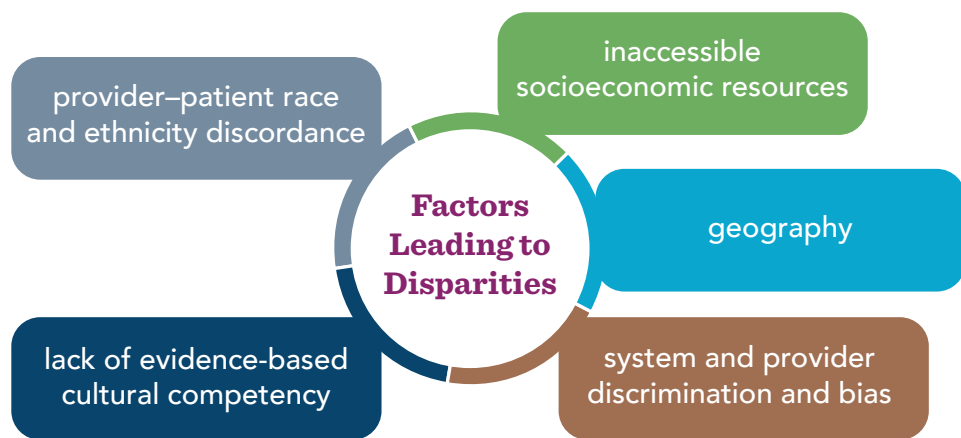
Any of these drivers or all of them together may lead to inequities in end-of-life care and planning.

As a first step, we defined terms related to the end of life to ensure a common foundation from which to identify factors related to disparities in end-of-life care and discuss potential solutions. Terms and their definitions for the purposes of the Summit include the following:

Important Terms

Advance care planning: Process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care. Common advance care planning tools include a living will or advance directive, which take effect when a person is unable to make healthcare decisions and is either permanently unconscious or terminally ill. Living wills and advance directives often name a healthcare proxy or other adult to make decisions on an individual's behalf. Other end-of-life legal documents include physician or medical orders for life-sustaining treatment and do not resuscitate orders.

Disparities: Differences in access to quality end-of-life planning and care that are systematically experienced in relation to an individual's racial or ethnic group or identity, religion or spiritual preference; marital status; socioeconomic status; gender; mental health; cognitive, sensory or physical disability; sexual orientation; gender identity; geographic location; national origin; or other characteristics historically linked to discrimination or exclusion.

End of life: Transition to death to the last breath

End-of-life care and planning: Palliative care, hospice, pain management, advance care planning

Hospice: Access to a compassionate team when diagnosed with a terminal illness. The team focuses on relief from physical, emotional and spiritual suffering. It prioritizes caring for, not curing, the individual at the end of life.

Inequities: Avoidable, systemic barriers in access to quality end-of-life planning and care

Palliative care: Specialized care for people living with a chronic, advanced or serious illness that is focused on providing patient-centered care and relief from symptoms and stress.

Reflections and Recommendations

The discussion resulted in examining factors centered on six key challenges, outlined below.

Inequities at the end of life are a preventable continuation from the life course

Perhaps it goes without saying that the inequities historically underserved communities face throughout life continue through the end of life. In public health spheres, the conversation speaks to social determinants of health — the conditions in the places where people live, learn, work and play affect a wide range of health and quality-of-life risks and outcomes.[3] At the summit, experts referred to the structural and economic determinants that make the end of life as challenging for some communities as everything prior.

Experts acknowledged that people can best access comprehensive end-of-life care when they are educated about options and when they can access and afford those options. As data show for the rest of life, people need local, culturally sensitive, affordable end-of-life care.[4] All too many people do not have this access or reality.

Recommendations

» Enact interventions that include community-based solutions because barriers for communities are specific and nuanced.

» Ensure care teams look like the patients and loved ones they serve to build trust. Trust can emerge from diversity within healthcare teams and patient-provider concurrence.

» Identify solutions to ensure access for particularly vulnerable communities that are not able to secure insurance or other healthcare coverage at the end-of-life.

A lifetime of distrust and mistrust inhibits conversations that may otherwise improve the end of life

In the U.S., our systems and major institutions have harmed and continue harming the people they are intended to serve. We do not have to look back in history to see when our healthcare and legal systems forcibly "treated" immigrants, refugees, and Black and Brown people, or used people as experiments without their knowledge or consent. Mistreatment contributes to daily suffering for Black and Brown communities. And as one expert stated, a lifetime of discrimination and harm leads to a deep fear of personal harm at the end of life.

The experts caring for historically underserved communities at the end of life speak about the lifetime of experiences and harm they must "undo" to gain sufficient trust to provide palliative care and hospice services or to even talk about the end of life. Care teams successfully fostering trust offer comprehensive service options with dedicated staff who are devoted to building relationships and translating overly complicated medical information,

payment structures and supportive care options. Comprehensive teams include community health workers, community-based organizations, and loved ones or extended family to fully support individuals at the end of life. Effective advocacy organizations offer cultural humility rather than assuming a one-size-fits-all approach.

Recommendations

» Care teams must embrace skills that reflect cultural humility and cultural competencies to provide services to community members who have been traumatized and learned a rational distrust of healthcare providers and systems.

- Cultural competencies are specific skills including language justice and access, and appreciation and acknowledgement of community and individual cultures.
- End-of-life conversations must include an individual's involved loved ones and family to understand an individual's culture and history, and the context around the end of their life.

Conversations about dying and death are not normalized among health-care professional, patients and loved ones

The experts confirmed that many healthcare professionals and patients are uncomfortable and avoid talking about dying and death. In addition, training for serving patients as they are dying and through death is not standard or required for most healthcare professionals. Experts described seeking out training and education based on their own interest, rather than as a required component of their professional school curriculum.
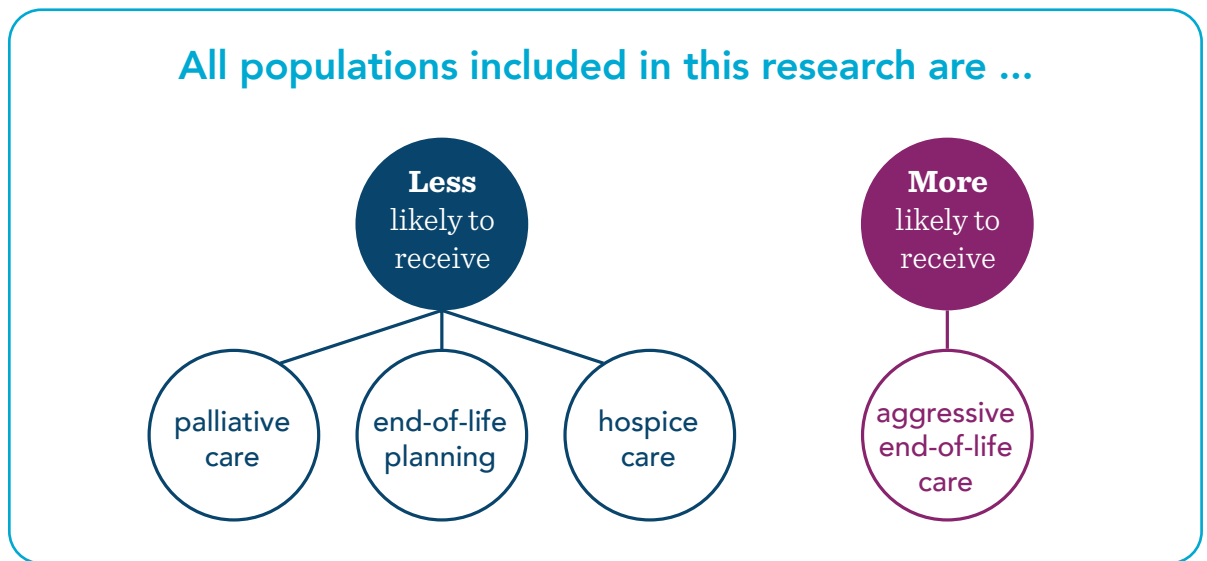
Palliative care is a newer discipline and speciality in medicine. While focused on managing side effects, palliative care takes into consideration intervention-based treatment models and includes conversations about quality of life. As a result, palliative care teams can be the bridge from serious illness care into care for the end of life. While palliative care specialists fill integral roles in serious and terminal illness care, more healthcare professionals should learn palliative care basics, if only to support improved referrals.

Experts described the urgency and crisis environment often setting the stage for end-of-life care discussions. All too often, the first time an individual starts to talk about the end of life is when that individual is receiving a serious or terminal illness diagnosis. An individual and their loved ones are pressed to make careful and planned decisions in the middle of a crisis.

Palliative care teams and general knowledge of palliative care can be employed to begin discussions slowly, starting as early as possible in connection with a diagnosis. Emergency department conversations about end-of-life care plant a seed and allow for follow-up in intensive care units. Education about end-of-life care options for healthcare providers and teams of all kinds raise awareness and offer a much more supportive, patient-centered approach. Education is widely available — professionals simply need the nudge and system support to learn.

Recommendations

» Create clear opportunities and incentives to support and uplift end-of-life education and training programs that are integrated across different medical disciplines.

» Start end-of-life care conversations with patients and their loved ones at much earlier stages in relation to diagnosis and prognosis, expecting repeated discussions over time.

» Create opportunities for community-oriented end-of-life conversations. End-of-life conversations are more patient and family-centered when the patient and loved ones learn and engage together.

» Encourage available education for all professionals who could benefit from it, from healthcare professionals to community-based workers. Those professionals who know more can encourage those who do not.

All populations included in this research are …

Less likely to receive
- palliative care
- end-of-life planning
- hospice care

More likely to receive
- aggressive end-of-life care

Planning for the end of life is not encouraged, fully supported or funded to support equity at the end of life

The experts described significant barriers inhibiting advance care planning among the communities they serve, confirming the research. For many, education about advance care planning remains unavailable or hidden, such that questions about advance care planning and its components cannot even be asked. Knowledge about the advance care planning possibilities is extremely limited, and without the knowledge and the language to ask questions, disparities persist.

There is a tremendous need for clear and simplified education about all of the advance care planning tools — from wills and trusts to advance directives, physician orders for life sustaining treatment, do not resuscitate orders, and other legal documents — defining an individual's decisions about end-of-life interventions or care.

Furthermore, many healthcare professionals support and engage with patients for advance care planning. However, there are gaps between clinical support for advance care planning and what then happens when patients return to their homes for end-of-life care.

Current systems do not support advance care planning portability. A hospital may track an individual's advance care planning decisions, but those decisions may not be readily available for home health, hospice service providers, or emergency medical technicians and other first responders including police and fire department personnel. As a result, even an individual with sufficient resources to fully plan end-of-life decisions may receive unwanted medical treatment.

Recommendations

» Provide thorough, simple and community-based information about advance care planning tools and their importance in relation to end-of-life care conversations and decisions.

» Enhance advance care planning so that it is culturally responsive, taking into account the nuances within specific communities and for each individual.

» Support healthcare professionals and healthcare students with culturally responsive, thorough and simple education about the full range of advance care planning tools and systems for integrating them into end-of-life care.

» Make advance care planning tools fully accessible and portable throughout healthcare and residential-care systems, including any services provided in people's homes or outside of medical or residential facilities.

» Fund robust reimbursement for the healthcare providers supporting patients in completing and tracking advance care planning decisions and legal documents.

Data limits and gaps in research hinder equitable, patient-directed end-of-life care and planning

Experts confirmed the need for standardized, disaggregated data collection to fully support equitable, evidence-based end-of-life care. At the same time, we know the existing policy interventions that, if fully implemented with equity in mind, would greatly improve end-of-life care and planning.

Many organizations have already defined how equitable data disaggregation collection and surveillance should proceed, ensuring people who are asked for their data are protected and safe from privacy invasion. In addition, communities impacted by exploitation in relation to their personal data must be thoroughly protected and perhaps convinced that by giving their information, they are not at risk of further harm and exploitation, and that they are contributing to a more just healthcare system.

Data disaggregation is necessary to tailor equity-based policy interventions to fit impacted communities and individuals. Presently, data collection terms are too broad, making research for specific communities impossible. For example, the term "Asian American" may include individuals who otherwise would identify themselves as Native Hawaiian, Pacific Islander, Chinese American, Japanese American, Korean American, Filipino American, Indian American and Vietnamese American, to name a few among many other "Asian" race and ethnic terms.[5] Understanding data in relation to specific populations allows for conversations with individuals who identify from those populations for engagement in policy interventions. Experts confirmed that impacted individuals must be at the center of policy change. We can foster policy change based on communities seeking support.

Experts also noted how young research is about diversity, equity and inclusion concepts in end-of-life care. Longer-term study is necessary to fully understand the challenges. At the same time, we can support policy interventions based on the information we already know.

Recommendations

» Build disaggregated data collection and surveillance systems through equitable and justice-oriented processes, ensuring privacy, to inform improved research to develop more specific, community-based policy interventions.

» Continue long-term research to better understand disparities in end-of-life care and planning.

Deepened knowledge about end-of-life healthcare finance and entry points for end-of-life conversations is needed

The summit also included presentations on the basic components of end-of-life care and planning finance, and insights into how the majority of people begin end-of-life care discussions.

Csaba Mera, MD, a national expert in medical management, population health, cost management, medical policy and healthcare quality, described value-based palliative care and the movement from inpatient and hospital-based to home and community-based care. Palliative care and hospice trends and innovations include quality improvements, expanded use of telehealth, offering care earlier to patients, new interest in providing more comprehensive services, and greater engagement by nurses and ancillary staff who can offer patients more time for advance care planning and end-of-life care discussions.

The COVID-19 pandemic has made clear that telehealth flexibility for end-of-life care should be made permanent and appropriately reimbursed through private insurance, Medicare and Medicaid. Many agencies and stakeholders advocate for these enhancements; however, current systems do not all support equitable access. Experts reflected that telehealth is necessary and resources must center on patient populations who most need support. People at the end of life suffer from the digital divide, particularly in geographic locations

without sufficient palliative care services and those that do not support digital access as government-funded infrastructure.

New players in hospice and palliative care recognize the quickly growing need for end-of-life care and planning services due to the rapidly aging U.S. population. Hospice providers understand individuals and their loved ones need comprehensive, interdisciplinary support much earlier in life. Challenges related to reluctance to talk about dying and death and sufficient reimbursement for services must be addressed.

Electronic health records systems inadequately integrate patient advance care planning decisions. Advance care planning innovations led by nurse navigators show promise for refined documentation in and portability of electronic health records and potential improvements for goal-concordant care.

Satheesh Gunaga, DO[6], a leader in advancing palliative care through the emergency department, presented data showing emergency departments as a primary portal of hospital entry for those needing end-of-life care. Dr. Gunaga spoke to data showing how often older adults visit the emergency department in the last month of life and the frequent use of emergency departments by people 65 and older.

Emergency departments can offer early conversations about palliative care options and end-of-life care decisions and planning. Oftentimes, patients and their loved ones may be too overwhelmed to take in a lot of information while in the emergency department. At the same time, emergency department teams may begin the conversations that set up better and more comprehensive care discussions for less urgent care settings.

Closing Thoughts and Next Steps

To close the summit, participants reflected on the gaps in the research and the main challenges we face as advocates and activists. As we proceed, efforts could be divided into two phases, with the first connected to community-based planning and education before an individual enters the end-of-life stage, and the second focused on the more urgent time when an individual begins accessing end-of-life care. Significant education and training about terminology and end-of-life care specialities and integration would do much to improve patient access to quality, comprehensive end-of-life care and planning. And finally, increased funding and systemic support for end-of-life care and planning through healthcare systems and providers would incentivize and advance this movement.

While knowledge related to disparities in end-of-life care and planning is growing, we need more research to fully understand the reasons for the disparities and how to respond with interventions that are informed by and best serve impacted communities.

Compassion & Choices will continue to synthesize and publicize information about end-of-life care and planning by turning to researching disparities for people with disabilities and indigenous communities, and the differences due to urban and rural end-of-life care deserts. We will continue in-depth interviews with experts in these fields, impacted communities and our advisory councils.

Through our federal policy agenda, we are already advocating for legislation, regulations and programmatic innovations to improve end-of-life care and planning. We will eagerly build a more thorough agenda to lift up, advance and align policies to specifically address identified end-of-life care and planning gaps for communities most impacted by inequities.

Endnotes

1   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-nonconforming; (6) White, non-Hispanic White, Caucasian, Caucasian American.

2   Christopher J. Yarnell et al., Association between Chinese or South Asian ethnicity and end-of-life care in Ontario, Canada, 192 Can. Med. Ass'n J. E266 (2020) https://pubmed.ncbi.nlm.nih.gov/32179535/.

3   https://www.cdc.gov/socialdeterminants/index.htm

4   U.S. Department of Health and Human Services. The Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020. Phase I report: Recommendations for the framework and format of Healthy People 2020 [Internet]. Section IV: Advisory Committee findings and recommendations [cited 2010 January 6]. Available from: http://www.healthypeople.gov/sites/default/files/PhaseI_0.pdf.

5   The Robert Wood Johnson Foundation supported a series of reports about data disaggregation in 2017. Along with the more prevalent Asian American race groups, other growing communities in the United States include individuals who identify as Bangladeshi, Hmong, Indonesian, Malaysian, Pakistani, Sri Lankan, Taiwanese, Thai, Fijian and Tongan Americans.

6   Dr. Gunaga serves at Henry Ford Wyandotte Hospital as an Emergency Medicine Physician and Associate Emergency Medicine Residency Director.

Acknowledgements

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Care and Choice at the End of Life