Engaging Social Justice Methods to Create Palliative Care Programs That Reflect the Cultural Values of African American Patients with Serious Illness and Their Families: A Path Towards Health Equity

Ronit Elk and Shena Gazaway

Keywords: Social Justice Methods, Palliative Care, African Americans Elders, Healthcare Disparities, Community Based Participatory Research

Abstract: Cultural values influence how people understand illness and dying, and impact their responses to diagnosis and treatment, yet end-of-life care is rooted in white, middle class values. Faith, hope, and belief in God's healing power are central to most African Americans, yet life-preserving care is considered "aggressive" by the healthcare system, and families are pressured to cease it.

Community Based Participatory Research (CBPR), a social justice method, involves a collaborative partnership between community members and academia, to find solutions to an unjust problem. It has been widely used in public health and proven to reduce health disparities. Our team has implemented CBPR principles to develop a culturally based: (1) Palliative care consult program, (2) Training program for clinicians caring for African Americans elders with serious illness, and (3) Goals of Care Conversation Guide based on African American cultural values.

In Part I of this article, we describe the egregious disparities that African American experience at end of life, and in Part II we illustrate how implementing CBPR methods can be used to develop palliative

Ronit Elk, Ph.D., *is Professor, Department of Medicine, Division of Geriatrics, Gerontology, and Palliative Care, at the University of Alabama, Birmingham, and Associate Director of the Center for Palliative and Supportive Care, and of the Southeast Institute for Innovation in Palliative Care. She earned her Bachelor of Social Science (Social Work) (1973), her Master's Degree in Social Science (1980), and her Ph.D. in Psychiatry (1989), all from the University of Cape Town, South Africa. Her research focuses on partnering with underserved communities to develop culturally concordant palliative care interventions based on the community's cultural values and preferences at end of life and training clinicians to provide culturally concordant care.* **Shena Gazaway, B.S.N., M.S.N., Ph.D.**, *is an Assistant Professor in the Biobehavioral Department of the College of Nursing at Augusta University in Athens, GA. She earned her BSN and MSN from Brenau University in Gainesville, GA, in 2005 and 2009, respectively, and her Ph.D. in Nursing Research from Augusta University in 2017. Her research focuses on developing and implementing culturally-based programs that support seriously ill/dying rural African Americans' faith, beliefs, and goals of care. The overall goal is the address the health disparities present for these Americans and their families at the end of life in full partnership with the community and healthcare providers.*

The Journal of Law, Medicine & Ethics, 49 (2021): 222-230. © 2021 The Author(s)
DOI: https://doi.org/10.1017/jme.2021.32

https://doi.org/10.1017/jme.2021.32 Published online by Cambridge University Press

care programs, goals of care conversation guides, and training methods for clinicians, all of which are based on the cultural values of African Americans.

Part I: Health Disparities in Palliative Care

Palliative Care

Patients facing life-threatening illness often experience unnecessary and preventable suffering including extreme and prolonged pain, psychological distress and poor communication with healthcare professionals,[1] resulting in tremendous strain on patients and caregivers.[2] Unmet needs in the physical, psychosocial and spiritual domains are common.[3] As a result, the last few weeks and months of life, and that of their loved ones, may be additionally burdened with physical, emotional, and spiritual suffering. Palliative care programs, interdisciplinary care focused on relief of pain and other symptoms in support of best possible quality of life for patients with serious illness and their caregivers, has been shown to reduce distressing symptoms,[4] alleviate suffering, improve doctor-patient communication and satisfaction with care,[5] improve caregiver satisfaction, and enhance the efficiency and effectiveness of hospital services,[6] as well as to be associated with hospital cost savings.[7] Consultations by palliative care experts on patients in hospital, often results in successfully identified unrecognized symptoms and unmet problems,[8] and have been associated with lower use of intensive care units (ICUs),[9] lower likelihood of dying in ICU,[10] lower costs of care,[11] and improvement in care processes, including opioid prescribing and documenting patient goals for care.[12]

In Part I of this article, we describe the egregious disparities that African Americans experience at end of life, and in Part II we illustrate how implementing CBPR methods can be used to develop palliative care programs, goals of care conversation guides, and training methods for clinicians, all of which are based on the cultural values of African Americans.

Role of Culture in Serious Illness

Culture profoundly shapes how people make meaning of their illness, suffering and dying, and strongly influences their responses to diagnosis illness, and their preferences for treatment.[13] Consequently, consideration of culture needs to be an essential aspect of palliative care.[14] A lack of acknowledgment and recognition of cultural differences may compromise care for minority patients.[15] The National Consensus Project[16] stresses the need to emphasize cultural aspects of care, especially during serious illness, the dying process, at time of death, and post-death. And yet, despite this, and regardless of the call for an urgent need for research that emphasizes cultural preferences of different groups,[17] to date our study[18] is the first of its kind in palliative care. Historically and until today, palliative and end-of-life care has been rooted in White, middle class cultural and religious values,[19] with its very different frame of reference, value system and life experience compared with that of many African Americans.[20] Middle-class Whites, primarily belonging to an individualistic culture, emphasize individual choice, while African Americans, who belong to a collectivist culture (cultures that emphasize the needs and goals of the group), value group support, and family-centered decision making.[21] Seventy-nine percent of African Americans are Christian,[22] and 83% of African Americans report absolute certainty in their belief in God (compared with 62% of whites).[23] Faith, spiritual beliefs, and the guidance of a spiritual leader,[24] as well as hope[25] and belief in God's healing power[26] are central to religious African Americans, especially in coping with illness and in making treatment decisions.[27] Within this spiritual belief, life or death decision lies in the hands of God, and a miracle is always possible; therefore, the continuation of care, even that which healthcare professionals consider "aggressive care," is considered life-preserving care. Is it any wonder that, despite its proven effectiveness, African Americans under-utilize palliative and hospice care?[28] This is also compounded by a history of slavery, racism, and medical experimentation and exploitation,[29] with ongoing systemic racism in our healthcare systems[30] that has, justifiably, left a legacy of mistrust of the healthcare system in the African American community.[31] Yet, instead of focusing on adapting palliative care practice to meet our African American patients' cultural values, the field has primarily concentrated efforts on attempting to make African Americans accept palliative care and hospice as is. The same efforts to force

https://doi.org/10.1017/jme.2021.32 Published online by Cambridge University Press

acceptance has focused on urging African Americans to discuss Advance Care Planning and complete Advanced Care Directives outside of culturally appropriate norms.

Advance Care Directives and Advance Care Planning

Advance Care Planning (ACP) aims to help ensure that people receive medical care consistent with their values, goals, and preferences during serious and chronic illness.[32] ACP is also an umbrella process under which various elements, such as Goals of Care conversations, and legal documents such as an Advance Directive, a living will, and a Power of Attorney reside. Goals of Care conversations are discussions about prognosis, treatment risks and benefits, and planning for intensity/type of care.[33] These tend to be reserved for people with serious illness or nearing end of life and are sometimes referred to as end-of -life conversations. Rates of providers conducting ACP conversations have increased[34] with the reimbursement from Centers for Medicare and Medicaid Services,[35] and Palliative Care and physicians in acute care setting[36] conduct the highest proportion of ACP discussions. Some studies indicate that patients who have participated in ACP or Goals of Care conversations are more likely to receive care that is less aggressive,[37] more in keeping with their goals,[38] additional and earlier hospice care,[39] and to experience more satisfaction with care.[40] Advance Care Planning is also associated with reduced distress[41] and depression, and higher quality of life at end of life for caregivers.[42] Despite the fervent national push towards obtaining Advance Directive documentation, now even more so due to COVID,[43] concerns about this process's efficacy and benefit have been raised. Several studies have demonstrated the failure of Advance Directives alone to facilitate goal concordant care,[44] indicating this may not be the magic bullet that it was espoused to be. In his recent editorial, Morrison[45] claims our push toward Advance Directives have been a failure as the ideal envisioned, i.e., that patients' stated wishes are honored by clinicians, is not the reality.[46]

Consistent evidence suggests that African Americans are less likely to participate in ACP than White Americans[47] with substantially lower Advance Directive completion rates among African Americans.[48] Several studies have examined the complex barriers to ACP completion among African Americans, yet gaps still remain in understanding these factors, as well as in finding culturally appropriate methods to improve ACP among African Americans.[49] In a systematic review of studies focusing on barriers in the African American community to completing ACP,[50] a combination of personal, interpersonal, and system-level factors, including the strong influence of the history of slavery and racism in the US, were found to have shaped the beliefs and attitudes of African Americans about end-of-life planning, which in turn influence completion of Advance Care Directives. African Americans are more likely to pursue informal planning than to document their care preferences formally. The widespread perceptions among African Americans that communication with the medical team is often poor, and the impact of family and clinician actions on end-of-life outcomes,[51] led Sanders et al. (2016) to recommend that future research focus on theory-driven approaches to engage faith and family in ACP and Goals of Care discussions to improve receipt of goal-concordant care meaningfully.[52] The need to develop culturally sensitive, tailored approaches to ACP has been emphasized by both the Institute of Medicine Report on Dying[53] and the National Consensus Project.[54]

Disparities in End-of-Life Care of African Americans

One of the most egregious realities is the finding that even when African Americans have their preferences for end-of-life care recorded in their medical charts, they are less likely than whites to have their preferences followed.[55] Additionally, clinicians are less likely to document Goals of Care discussions with African American (and Hispanic) patients and families,[56] an indication of unconscious bias or perhaps even overt racism.

There is yet another harsh reality in end-of-life care for African Americans. In addition to the belief in hope and miracles described earlier, studies have found that African Americans preferred more life-sustaining measures than whites.[57] This includes ventilator support, ICU nasogastric tube feeding, and ICU admissions. Yet emphasis is placed by medical providers on the "aggressiveness" of such care (since physiologically, the person is not likely to return to health) and the healthcare system's cost. Healthcare providers practice within their own culture,[58] and often disregard or dismiss the strong belief in hope and a miracle that is integral to 80% of African Americans, and such families are often labeled as "being in denial." Instead of considering such care as life-preserving until a miracle occurs or God decides the loved one's fate, family members are often encouraged by healthcare providers to cease such care, which is considered "aggressive" and costly. These conversations usually occur with clinicians who are not palliative care trained and could potentially leave the family wondering if the medical system doesn't want a positive outcome for their loved ones. Families of all ethnicities and cultures want their loved ones to die in the way that fits with the goals

The Journal of Law, Medicine & Ethics, 49 (2021): 222-230. © 2021 The Author(s)

https://doi.org/10.1017/jme.2021.32 Published online by Cambridge University Press

of the patient and family, a term labeled "goal-concordant care." When African American families continue to argue for their loved one's right to receive such care, they are labeled as "difficult,"[59] and the care their loved one receives is often *not* concordant with their cultural values and beliefs. This is evidenced in the consistent rating of quality of care more poorly by African American family members than white family members. Bereaved African American family members also often report regret about their decisions for end-of-life care for their loved ones.[60] Goal-concordant care is considered high-quality care and is based on good communication between the clinician and patient and family. Failure to achieve this is considered a medical error.[61] Yet until an important paper by Sanders et al., 2018, consensus was not reached on how to measure clinician communication, goal concordant care, or caregiver assessments of goal concordance.[62]

Further disparities in palliative and end-of-life care have been widely observed,[63] including in the management of pain and symptoms.[64] At least two review articles highlighting inequalities have been conducted. Both concluded that pain and symptom research is in its early stages, lacking methodological and theoretical consistency, which focuses on the description of disparities and not on strategies and interventions to address health equity.[65]

Part II. A Path Towards Health Equity Using Community Based Participatory Research

Community Based Participatory Research

Community Based Participatory Research (CBPR) is a form of action research, a process of action by a community to solve a significant problem that includes identification, strategy development, implementation (action), and then evaluation of the outcome.[66] CBPR is based on a collaborative partnership between community members and academia as a way to finding a solution to an unjust problem[67] that affects the community. The aim is to combine community input with action and thus achieve social change to achieve health equity. CBPR is a widely used public health and preventive method approach that repeatedly has been proven to reduce health disparities[68] and results in demonstrable positive health outcomes.[69] CBPR is seen as a social justice method because at its core; it is a power-sharing partnership with the community.[70] This method builds on the strength of the community, and the *community owns the process:* community members are involved in all aspects of decision-making, knowledge generation, and the dissemination of findings, and it is the responsibility of the researchers to provide ongoing feedback on study steps and outcomes to the community. Yet CBPR has not been used much in medicine in the US, primarily due to two reasons. First, a tension has been reported between a dominant scientific paradigm that considers academics' expertise to be most important versus an egalitarian CBPR paradigm.[71] Second, dominant scientific standard considers randomized controlled trials (RCT) as the gold standard for testing efficacy of clinical and community intervention. Yet RCT has overlooked the concept of external validity, which includes the need to involve community members in designing and implementing research that is appropriate for their diverse populations and settings.[72]

Despite it not being used as a tool to improve medical care, CBPR has been recommended as a promising strategy for palliative care research, as it aligns with stakeholders' priorities as a means to deliver community appropriate care to underserved communities.[73] In this next section, we illustrate how implementing CBPR methods can be used to develop: (1) Culturally based palliative care programs, (2) Training programs for palliative care clinicians in caring for African Americans with a serious illness and their family in a culturally appropriate way. (3) A community-based solution to a persistent problem in palliative care, the lack of a culturally based goals of care conversation guide. Each is discussed in turn.

(1) IMPLEMENTING CBPR PRINCIPLES TO DEVELOP A CULTURALLY BASED PALLIATIVE CARE CONSULT PROGRAM

The purpose of this study was to use CBPR methods to develop a culturally based palliative care consult program in partnership with rural, southern, African Americans and white elders with serious illness, and to assess the feasibility of its implementation at a local hospital. The study was conducted over three phases in Beaufort, South Carolina (January 2013-February 2016).[74] We formed a partnership with a Community Advisory Board comprised of equal numbers of white and African American members, and they guided the study throughout. **Phase 1:** Cultural values and preferences were determined through ethnic/racial-based focus groups comprising family members who had cared for a loved one who had died in the past year. A thematic analysis of each focus group transcript focused on cultural values and lived experiences. Themes between white and African Americans were found to be either (**a**) **Equivalent,** e.g., disrespectful treatment by patients and family by hospital physicians in the past, (**b**) **Similar but with variation,** e.g., although religion and church were important in both group, and pastors in both groups helped family members when the patient was at end of life, African Americans considered the church unreservedly central to

https://doi.org/10.1017/jme.2021.32 Published online by Cambridge University Press

every aspect of life, or (**c**) **Divergent,** e.g., African Americans strongly believed that hope and miracles were always a possibility and that God was the decider, (a theme not present in the White group), as well as a strong distrust of healthcare systems and physicians. In **Phase 2,** the Community Advisory Board (which had expanded to include several focus group members from each ethnic/racial group), the researchers, a palliative care physician, and two hospital staff worked together to create the culturally based consult program. The researchers facilitated the process; the palliative care physician explained the National Consensus Project for Palliative Care guidelines for a palliative care consult. With this knowledge, the Community Advisory Board members proposed culturally appropriate programmatic recommendations *for their specific ethnic/racial group*, and the hospital staff ensured these were feasible to be implemented in the local hospital. The culturally based recommendations were then written into two protocols, one for African Americans and the other for white patients, and then linked with the National Consensus Project guidelines. Differences between racial/ethnic group protocol[75] included: the way the palliative care physician was to greet and form a relationship with the patient and family, prognosis discussions (e.g., bringing God into the sharing of prognosis with African Americans), recognition and respect of hope and miracles in the African American community, and acknowledgment that African Americans take care of their loved ones themselves. **Phase 3:** The palliative care physician implemented these culturally based protocols through telehealth in the local hospital. Enrolled patients were African American or White patients over 65 with a life-limiting illness who had a caregiver referred by hospitalists. This protocol was found to be feasible to implement, although low referral by hospitalists was an obstacle. Caregivers were satisfied or very satisfied with the culturally based consult. *This is the first culturally based palliative care intervention ever developed.* This intervention's efficacy is now being tested in a randomized control trial[76] in hospitals in three rural, Southern states (AL, MI, SC), each of which have their own Community Advisory Board, who are involved in the study. Four palliative care physicians who will be implementing this culturally based consult for telehealth were trained in these by the original Community Advisory Board members in a two-day cultural immersion and training in Beaufort, SC.[77] Although this study's findings can only be generalizable to rural, southern older populations, this work serves as a model that can be replicated with other underserved or underrepresented communities. For example, the formation of a Community Advisory Group and the implementation of focus groups to determine the cultural values and lived experiences of other minority communities have been replicated in several different communities, including family members of older: (a) Ghanaians with serious illness in Kumasi Ghana,[78] (b) Puerto Rico population with older loved ones with serious illness in San Juan, Puerto Rico,[79] and (c) in 2021, a similar study will be implemented with family members of older Hindu patients with a serious illness in the US.80

By developing and implementing culturally concordant palliative care programs, training clinicians in culturally based care, and developing culturally based solutions to unacceptable problems such as lack of culturally based goal-concordant care at end of life, the likelihood increases of clinicians: (a) Gaining an in-depth understanding of, and therefore respecting the cultural values and lived experiences of African American patients with serious illness, (b) Changing their practice so that the cultural values of African American patients and their families are respected and valued.

(2) IMPLEMENTING CBPR PRINCIPLES TO DEVELOP A CULTURALLY BASED TRAINING MODEL FOR CLINICIANS CARING FOR RURAL, SOUTHERN AFRICAN AMERICANS

This study aimed to partner with African American community members to develop a culturally based training program for clinicians who care for seriously ill rural, southern, African American elders. Focus groups were held with African American family members caring for a loved one with a serious illness, and with pastors, community leaders integral to their constituents' health and well-being.[81] Several themes from

The Journal of Law, Medicine & Ethics, 49 (2021): 222-230. © 2021 The Author(s)

https://doi.org/10.1017/jme.2021.32 Published online by Cambridge University Press

the focus group thematic analysis were prioritized by the community members, and the group chose videos as a method to convey their messages and several videos were filmed. We developed an adult-based learning training program to accompany these videos. This is the first clinician training program in palliative care built on the African American community's explicit direction. Ninety palliative care clinicians have completed the training. Data collection is ongoing, and an article describing this study is in preparation.[82] These trainings can only be generalized to rural, southern, African Americans. Importantly, however, they serve as a model that can be replicated with other minority or underserved groups.

(3) IMPLEMENTING CBPR PRINCIPLES TO DEVELOP A CULTURALLY CONCORDANT GOALS OF CARE CONVERSATION GUIDE

African American family members consistently rate quality of care for their loved as poor and report lack of goal-concordant care. Goal-concordant care is achieved through effective communication between patients and families and clinicians. There are no culturally based Goals of Care Conversation Guides. We have partnered with African Americans to create a culturally based Goals of Care Conversation Guide that meets African Americans' cultural values and lived experiences. Palliative care clinician input will be sought to enhance feasibility of implementation. The first phase of this study was launched in October 2020 and an article will be written once completed.

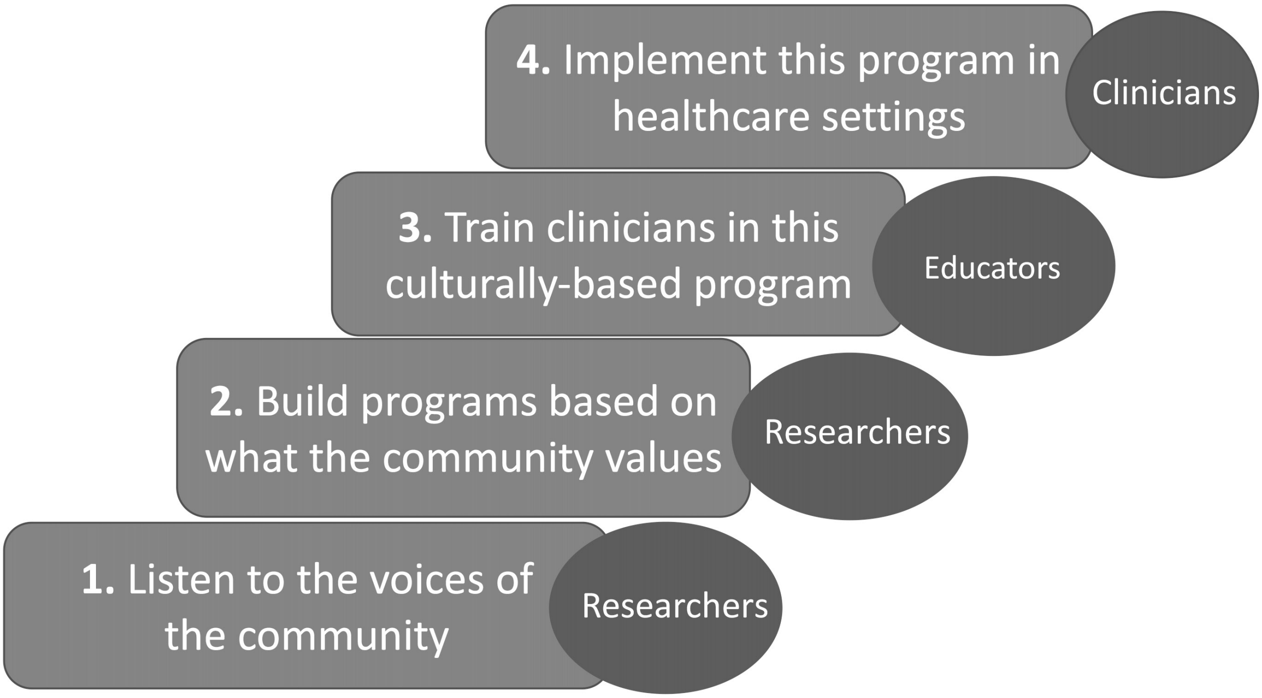
Conclusion

A Four-Step Model to Create and Implement Culturally Concordant and Socially Justice Focused Palliative Care Programs

In Part II of this paper, we have demonstrated a four-step model (Figure 1.) that can be used as a template to develop culturally concordant palliative care programs, train clinicians, and develop culturally based solutions to unacceptable inequities across a wide variety of communities. Each of the studies described illustrates the incomparable worth of partnering with underserved communities, establishing and building trust, and together building solutions to problems that have resulted in unconscionable injustices in the healthcare system towards African Americans with serious illness and their families. By developing and implementing culturally concordant palliative care programs, training clinicians in culturally based care, and developing culturally based solutions to unacceptable

Figure 1

Creating and Implementing Culturally-Based Social Justice-focused programs in 4 steps



https://doi.org/10.1017/jme.2021.32 Published online by Cambridge University Press

problems such as lack of culturally based goal-concordant care at end of life, the likelihood increases of clinicians: (a) Gaining an in-depth understanding of, and therefore respecting the cultural values and lived experiences of African American patients with serious illness, (b) Changing their practice so that the cultural values of African American patients and their families are respected and valued. In turn, this has the potential to enhance African American patients and families' satisfaction with palliative care received from culturally trained clinicians. Receipt of goal concordant care by African Americans with a serious illness has the potential to increase satisfaction with end-of-life care and in time, by having their values respected, to increase trust in a healthcare system that has for so long allowed inexusable healthcare disparities to continue. Imagine such a change across healthcare settings across the US, changes that not only reduce the currently abysmal healthcare disparities but changes that over time result in health equity for African Americans with serious illness and their families.

Note

Dr. Elk is currently funded by the National Institute of Nursing Research of the National Institutes of Health (Award Number R01NR017181). A diversity supplement funds Dr. Gazaway to the award mentioned above (Award Number R01NR011781-03S1).

References

1. R.S. Morrison and D. E. Meier, "The National Palliative Care Research Center and the Center to Advance Palliative Care: A Partnership to Improve Care for Persons with Serious Illness and their Families," *Journal of Pediatric Hematology/Oncology* 33, no. Suppl. 2 (2011): S126-S131.
2. H. M. Chochinov, T.Hassard, S. McClement, T. Hack, L. J. Kristjanson, M. Harlos, S. Sinclair, and A. Murray, "The Landscape of Distress in the Terminally Ill," *Journal of Pain and Symptom Management* 38, no. 5 (2009): 641-649; A. H. Kamal, J. Bull, D. Kavalieratos, D. H. Taylor, Jr., W. Downey, and A. P. Abernethy, "Palliative Care Needs of Patients with Cancer Living in the Community," *Journal of Oncology Practice* 7, no. 6 (2011): 382-388.
3. Chochinov, *supra* note 2.
4. M. Bakitas, K. D. Lyons, M. T. Hegel, S. Balan, K. N. Barnett, F. C. Brokaw, I. R. Byock et al., "The Project ENABLE II Randomized Controlled Trial to Improve Palliative Care for Rural Patients with Advanced Cancer: Baseline Findings, Methodological Challenges, and Solutions," *Palliative & Supportive Care* 7, no. 1 (2009): 75-86.
5. M. Bakitas, K. D. Lyons, M. T. Hegel, S. Balan, F. C. Brokaw, J. Seville, J. G. Hull et al., "Effects of a Palliative Care Intervention on Clinical Outcomes in Patients with Advanced Cancer: The Project ENABLE II Randomized Controlled Trial," *JAMA* 302, no. 7 (2009): 741-749.
6. R. E. O'Hara, J. G. Hull, K. D. Lyons, M. Bakitas, M. T. Hegel, Z. Li, and T. A. Ahles, "Impact on Caregiver Burden of a Patient-Focused Palliative Care Intervention for Patients with Advanced Cancer," *Palliative & Supportive Care* 8, no. 4 (2010): 395-404.
7. J. D. Penrod, D. Partha, C. Dellenbaugh, J. F. Burgess, Jr., C. W. Zhu, C. L. Christiansen, C. A. Luhrs et al., "Hospital-Based Palliative Care Consultation: Effects on Hospital Cost," *Journal of Palliative Medicine* 13, no. 8 (2010): 973-979.
8. F. Bailey, K. Amos, K. L. Burgio, L. L. Woodby, B. R. Williams, D. T. Redden, S. H. Kovac, R. M. Durham, and P. S. Goode, "Improving Processes of Hospital Care During the Last Hours of Life," *Archives of Internal Medicine* 165, no. 15 (2005): 1722-1727; A. Kamal, K. M. Swetz, E. C. Carey, A. L. Cheville, H. Liu, S. R. Ruegg, T. J. Moynihan, J. A. Sloan, and J. S. Kaur, "Palliative Care Consultations in Patients with Cancer: A Mayo Clinic 5-year Review," *Journal of Oncology Practice* 7, no. 1 (2011): 48-53.A; A. Kuin, A. M. Courtens, L. Deliens, M. Vernooij-Dassen, L. van Zuylen, B. van der Linden, and G. van der Wal, "Palliative Care Consultation in The Netherlands: A Nationwide Evaluation Study," *Journal of Pain and Symptom Management* 27, no. 1 (2004): 53-60.
9. A. Elsayem, M. L. Smith, L. Parmley, J. L. Palmer, R. Jenkins, S. Reddy, and E. Bruera, "Impact of a Palliative Care Service on in-Hospital Mortality in a Comprehensive Cancer Center," *Journal of Palliative Medicine* 9, no. 4 (2006): 894-902.
10. S. A. Norton, L. A. Hogan, R. G. Holloway, H. Temkin-Greener, M. J. Buckley, and T. E. Quill, "Proactive Palliative Care in the Medical Intensive Care Unit: Effects on Length of Stay for Selected High-Risk Patients," *Critical Care Medicine* 35, no. 6 (2007): 1530-1535.
11. J. D. Penrod, P. Deb, C. Luhrs, C. Dellenbaugh, C. W. Zhu, T. Hochman, M. L. Maciejewski, E. Granieri, and R. Sean Morrison, "Cost and Utilization Outcomes of Patients Receiving Hospital-Based Palliative Care Consultation," *Journal of Palliative Medicine* 9, no. 4 (2006): 855-860.
12. I. J. Higginson, I. Finlay, D. M. Goodwin, A. M. Cook, K. Hood, A. G. Edwards, H. Douglas, and C. E. Norman, "Do Hospital-Based Palliative Teams Improve Care for Patients or Families at the End of Life?" *Journal of Pain and Symptom Management* 23, no. 2 (2002): 96-106; I. J. Higginson, I. G. Finlay, D. M. Goodwin, K. Hood, A. G. Edwards, A. Cook, H. Douglas, and C. E. Normand, "Is There Evidence that Palliative Care Teams Alter End-of-Life Experiences of Patients and their Caregivers?" *Journal of Pain and Symptom Management* 25, no. 2 (2003): 150-168.
13. M. Kagawa-Singer and L. J. Blackhall, "Negotiating Cross-Cultural Issues at the End of Life: You Got to Go Where He Lives," *JAMA* 286, no. 23 (2001): 2993-3001; V. S. Periyakoil, E. Neri, and H. Kraemer, "Patient-Reported Barriers to High-Quality, End-of-Life Care: A Multiethnic, Multilingual, Mixed-Methods Study," *Journal of Palliative Medicine* 19, no. 4 (2016): 373-379.
14. Periyakoil, *supra* note 13; P. M. Mazanec, B.J. Daly, and A. Townsend, "Hospice Utilization and End-of-Life Care Decision Making of African Americans," *American Journal of Hospice and Palliative Medicine* 27, no. 8 (2010): 560-566; V. S. Periyakoil, E. Neri, and H. Kraemer, "Patient-Reported Barriers to High-Quality, End-of-Life Care: A Multiethnic, Multilingual, Mixed-Methods Study," *Journal of Palliative Medicine* 19, no. 4 (2016): 373-379; S. Lynch, "Hospice and Palliative Care Access Issues in Rural Areas," *American Journal of Hospice and Palliative Medicine* 30, no. 2 (2013): 172-177.
15. Periyakoil, *supra* note 13.
16. National Coalition for Hospice and Palliative Care, *National Consensus Project for Quality Palliative Care Clinical Practice Guidelines for Quality Palliative Care*, 4th Edition (Richmond, VA, 2018); Lynch, *supra* note 14.
17. Lynch, *supra* note 14.
18. R. Elk, L. Emanuel, J. Hauser, M. Bakitas, and S. Levkoff, "Developing and Testing the Feasibility of a Culturally Based Tele-Palliative Care Consult Based on the Cultural Values and Preferences of Southern, Rural African American and White Community Members: A Program by and for the Community," *Health Equity* 4, no. 1 (2020): 52-83.
19. C. P. Wicher and M. A. Meeker, "What Influences African American End-of-Life Preferences?" *Journal of Health Care for the Poor and Underserved* 23, no. 1 (2012): 28-58.

The Journal of Law, Medicine & Ethics, 49 (2021): 222-230. © 2021 The Author(s)

https://doi.org/10.1017/jme.2021.32 Published online by Cambridge University Press

20. M. E. Baker, "Cultural Differences in the use of Advance Directives: A Review of the Literature," *African American Research Perspectives* 6 (2000): 35-40.
21. Periyakoil, *supra* note 13.
22. Pew Research Center, US Religious Landscape Study, (Washington, DC: 2014).
23. *Id.*
24. Wicher, *supra* note 19.
25. C. L. Kennard, "Undying Hope," *Journal of Palliative Medicine* 19, no. 2 (2016): 129-130.
26. C. J. Mansfield, J. Mitchell, and D. E. King, "The Doctor as God's Mechanic? Beliefs in the Southeastern United States," *Social Science & Medicine* 54, no. 3 (2002): 399-409.
27. K. S. Johnson, K. I. Elbert-Avila, and J. A. Tulsky, "The Influence of Spiritual Beliefs and Practices on the Treatment Preferences of African Americans: A Review of the Literature," *Journal of the American Geriatrics Society* 53, no. 4 (2005): 711-719; G. True, E. J. Phipps, L. E. Braitman, T. Harralson, D. Harris, and W. Tester, "Treatment Preferences and Advance Care Planning at End of Life: The Role of Ethnicity and Spiritual Coping in Cancer Patients," *Annals of Behavioral Medicine* 30, no. 2 (2005): 174-179.
28. M. A. LoPresti, F. Dement, and H. T. Gold, "End-of-life care for people with cancer from ethnic minority groups: a systematic review." *American Journal of Hospice and Palliative Medicine* 33, no. 3 (2016): 291-305; R. Payne, "Racially Associated Disparities in Hospice and Palliative Care Access: Acknowledging the Facts While Addressing the Opportunities to Improve," *Journal of Palliative Medicine* 19, no. 2 (2016): 131-133.
29. M. Colón and J. Lyke, "Comparison of Hospice use by European Americans, African Americans, and Latinos: A follow-up study," *American Journal of Hospice and Palliative Medicine* 32, no. 2 (2015): 205-209; N. C. Ernecoff, F. A. Curlin, P. Buddadhumaruk, and D. B. White, "Health Care Professionals' Responses to Religious or Spiritual Statements by Surrogate Decision Makers During Goals-of-Care Discussions," *JAMA Internal Medicine* 175, no. 10 (2015): 1662-1669.
30. W. N. L. Pirtle, "Racial Capitalism: A Fundamental Cause of Novel Coronavirus (COVID-19) Pandemic Inequities in the United States," *Health Education & Behavior* 47, no. 4 (2020); T. Poteat, G. Millett, L. Nelson, and C. Beyrer, "Understanding COVID-19 Risks and Vulnerabilities among Black Communities in America: The Lethal Force of Syndemics," *Annals of Epidemiology* 47 (2020): 1-3; B. Jehonathan, D. Cormack, R. Harris, and Y. Paradies, "Racism and Health Service Utilisation: A Systematic Review and Meta-Analysis," *PloS One* 12, no. 12 (2017): e0189900.
31. H. P. Freeman, and R. Payne, "Racial Injustice in Health Care," *New England Journal of Medicine* 342 (2000): 1045-1047; W. H. Shrank, J. S. Kutner, T. Richardson, R. A. Mularski, S. Fischer, and M. Kagawa-Singer, "Focus Group Findings about the Influence of Culture on Communication Preferences in End-of-Life Care," *Journal of General Internal Medicine* 20, no. 8 (2005): 703-709; A. A. Sewell. "Disaggregating Ethnoracial Disparities in Physician Trust," *Social Science Research* 54 (2015): 1-20.
32. R. L. Sudore, H. D. L. You, L. C. Hanson, D. E. Meier, S. Z. Pantilat, D. D. Matlock et al., "Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel," *Journal of Pain and Symptom Management* 53, no. 5 (2017): 821-832.
33. J. J. Lin, C. B. Smith, S. Feder, N. A. Bickell, and D. Schulman-Green, "Patients and Oncologists' Views on Family Involvement in Goals of Care Conversations," *Psycho-Oncology* 27, no. 3 (2018): 1035-1041.
34. PerryUndem Research/Communication, *Physicians' Views Toward Advance Care Planning and End-of-life Care Conversations: Findings from a National Survey among Physicians Who Regularly Treat Patients 65 and Older* (2016).
35. G. Tsai and D. H. Taylor, "Advance Care Planning in Medicare: An Early Look at the Impact of New Reimbursement on Billing and Clinical Practice," *BMJ Supportive & Palliative Care* 8, no. 1 (2018): 49-52.
36. A. Brinkman-Stoppelenburg, J. A. Rietjens, and A. Van der Heide, "The Effects of Advance Care Planning on End-of-Life Care: A Systematic Review," *Palliative Medicine* 28, no. 8 (2014): 1000-1025.
37. A. A. Wright, B. Zhang, A. Ray, J. W. Mack, E. Trice, T. Balboni, S. L. Mitchell et al., "Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment," *JAMA* 300, no. 14 (2008): 1665-1673.
38. J. W. Mack, M. E. Paulk, K. Viswanath, and H. G. Prigerson, "Racial Disparities in the Outcomes of Communication on Medical Care Received Near Death," *Archives of Internal Medicine* 170, no. 17 (2010): 1533-1540.
39. B. Zhang, A. A. Wright, H. A. Huskamp, M. E. Nilsson, M. L. Maciejewski, C. C. Earle, S. D. Block, P. K. Maciejewski, and H. G. Prigerson. "Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations," *Archives of Internal Medicine* 169, no. 5 (2009): 480-488.
40. K. M. Detering, A. D. Hancock, M. C. Reade, and W. Silvester, "The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial," *BMJ* 340 (2010): c1345.
41. J. W. Mack, A. Cronin, N. L. Keating, N. Taback, H. A. Huskamp, J. L. Malin, C. C. Earle, and J. C. Weeks, "Associations Between End-of-Life Discussion Characteristics and Care Received Near Death: A Prospective Cohort Study," *Journal of Clinical Oncology* 30, no. 35 (2012): 4387.
42. Detering, *supra* note 40.
43. A. R. Rosenberg, B. Popp, D. S. Dizon, A. El-Jawahri, and R. Spence, "Now, More than Ever, is the Time for Early and Frequent Advance Care Planning," *Journal of Clinical Oncology* 38, no. 26 (2020): 2956-2959.
44. M. J. Fisch, "Advance Directives: Sometimes Necessary but Rarely Sufficient," *JAMA Oncology* 1, no. 5 (2015): 609-610; M. H. Tyacke, J. L. Guttormson, M. Garnier-Villarreal, K. Schroeter, and W. Peltier, "Advance Directives and Intensity of Care Delivered to Hospitalized Older Adults at the End-of-Life," *Heart & Lung* 49, no. 2 (2020): 123-131.
45. R. S. Morrison, "Advance Directives/Care Planning: Clear, Simple, and Wrong," *Journal of Palliative Medicine* 23, no. 7 (2020).
46. *Id.*
47. Payne, *supra* note 28; A. K. Narang, A. A. Wright, and L. H. Nicholas, "Trends in Advance Care Planning in Patients with Cancer: Results from a National Longitudinal Survey," *JAMA Oncology* 1, no. 5 (2015): 601-608.
48. K. S. Johnson, "Racial and Ethnic Disparities in Palliative Care," *Journal of Palliative Medicine* 16, no. 11 (2013): 1329-1334; A. K. Smith, E. P. McCarthy, E. Paulk, T. A. Balboni, P. K. Maciejewski, S. D. Block, and H. G. Prigerson, "Racial and Ethnic Differences in Advance Care Planning among Patients with Cancer: Impact of Terminal Illness Acknowledgment, Religiousness, and Treatment Preferences," *Journal of Clinical Oncology* 26, no. 25 (2008): 4131.
49. Wicher, *supra* note 19; A. Lovell and P. Yates, "Advance Care Planning in Palliative Care: A Systematic Literature Review of the Contextual Factors Influencing its Uptake 2008–2012," *Palliative Medicine* 28, no. 8 (2014): 1026-1035.
50. J. Sanders, M. T. Robinson, and S. D. Block, "Factors Impacting Advance Care Planning Among African Americans: Results of a Systematic Integrated Review," *Journal of Palliative Medicine* 19, no. 2 (2016): 202-227.
51. Z. Obermeyer, B. W. Powers, M. Makar, N. L. Keating, and D. M. Cutler, "Physician Characteristics Strongly Predict Patient Enrollment in Hospice," *Health Affairs* 34, no. 6 (2015): 993-1000.
52. Sanders, *supra* note 50.
53. Institute of Medicine, Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life (2015).

https://doi.org/10.1017/jme.2021.32 Published online by Cambridge University Press

54. National Coalition for Hospice and Palliative Care, *supra* note 16.
55. Mack, *supra* note 38.
56. E. Chuang, A. A. Hope, K. Allyn, E. Szalkiewicz, B. Gary, and M. N. Gong, "Gaps in Provision of Primary and Specialty Palliative Care in the Acute Care Setting by Race and Ethnicity," *Journal of Pain and Symptom Management* 54, no. 5 (2017): 645-653.
57. Mack, *supra* note 38; Smith, *supra* note 48.
58. J. J. Griggs, "Disparities in Palliative Care in Patients with Cancer," *Journal of Clinical Oncology* 38, no. 9 (2020): 974-979.
59. S. Howell, Nurse Practitioner, Center for Palliative and Supportive Care, UAB, personal communication by R. Elk.
60. E. Chuang, "A Look in the Mirror: Shifting Paradigms to Reduce Racial and Ethnic Disparities in End of Life Care," NYU Palliative Care Noon Conference, November 2018.
61. J. J. Sanders, R. Curtis, and J. A. Tulsky, "Achieving Goal-Concordant Care: A Conceptual Model and Approach to Measuring Serious Illness Communication and its Impact," *Journal of Palliative Medicine* 21, no. S2 (2018): S-17-27.
62. *Id.*
63. Payne, *supra* note 28.
64. Griggs, *supra* note 58.
65. LoPresti, *supra* note 28; D. S. Gardner, M. Doherty, G. Bates, A. Koplow, and S. Johnson, "Racial and Ethnic Disparities in Palliative Care: A Systematic Scoping Review," *Families in Society* 99, no. 4 (2018): 301-316.
66. N.V. Ivankova and S. L. Johnson, "Designing Integrated Mixed Methods Action Research Studies," in J. Hitchcock and A. Onwuegbuzie (Eds.), *Routledge Handbook for Advancing Integration in Mixed Methods Research*, (2020, in press)
67. C. Devia, E. A. Baker, S. Sanchez-Youngman, E. Barnidge, M. Golub, F. Motton, M. Muhammad, C. Ruddock, B. Vicuña, and N. Wallerstein, "Advancing System and Policy Changes for Social and Racial Justice: Comparing a Rural and Urban Community-Based Participatory Research Partnership in the US," *International Journal for Equity in Health* 16, no. 1 (2017): 17-31.
68. N. Wallerstein, L L. Giatti, C. Maria Bógus, M. Akerman, P. R. Jacobi, R. Ferraz De Toledo, R. Mendes et al., "Shared Participatory Research Principles and Methodologies: Perspectives from the USA and Brazil — 45 Years after Paulo Freire's 'Pedagogy of the Oppressed,'" *Societies* 7, no. 2 (2017): 6-27; C. Trinh-Shevrin, N. Islam, S. D. Tandon, N. Abesamis, H. Hoe-Asjoe, and M. Rey, "Using Community-Based Participatory Research as a Guiding Framework for Health Disparities Research Centers," *Progress in Community Health Partnerships: Research, Education, and Action* 1, no. 2 (2007): 195-205.
69. Devia, *supra* note 67; N. B. Wallerstein and B. Duran, "Using Community-Based Participatory Research to Address Health Disparities," *Health Promotion Practice* 7, no. 3 (2006): 312-323; D. LaVeaux and S. Christopher, "Contextualizing CBPR: Key Principles of CBPR Meet the Indigenous Research Context," *Pimatisiwin* 7, no. 1 (2009): 1-16.
70. Wallerstein, *supra* note 68.
71. Wallerstein, *supra* note 68.
72. Wallerstein, *supra* note 68.
73. Shrank, *supra* note 31.
74. Elk, *supra* note 18.
75. Elk, *supra* note 18.
76. K. A. Watts, S. Gazaway, E. Malone, R. Elk, R. Tucker, S. McCammon, M. Goldhagen, et al., "Community Tele-Pal: A Community-Developed, Culturally-Based Palliative Care Tele-Consult Randomized Controlled Trial for African American and White Rural Southern Elders with a Life-Limiting Illness," *BMC Trials* 21, no. 1 (2020): 1-16.
77. H. Gainer, "Research Community Members Train Doctors on Culturally Appropriate Palliative Care," *available at* <https://www.uab.edu/news/research/item/10969-community-members-train-doctors-on-culturally-appropriate-palliative-care?tmpl=component&print=1> (last accessed Jan. 3, 2021).
78. A. E. Agbeko, A. Owusu, V. Tate, and R. Elk, "Cultural Values, Preferences and Goals of End-of-Life Care of Family Members of Patients with Life-Limiting Illness in Kumasi, Ghana: A Community-Based Study, (TH370C)," *Abstract American Academy of Hospice and Palliative Medicine* 59, no. 2 (2020).
79. L. Viera, "Cultural Values and Preferences for Care in Puerto Ricans aged 65+ in San Juan Puerto Rico," Ongoing study.
80. R. Patel, "Cultural Values and Preferences for Care in Hindu Patients in the United States," under IRB review.
81. R. Payne, "Culturally Relevant Palliative Care," *Clinics in Geriatric Medicine* 31, no. 2 (2015): 271-279.
82. R. Elk, S. Gazaway, M. Barnett, and M. Thompson, "African American Communities Speak to Clinicians Caring for Rural, Southern Elders with Serious Illness: Evaluation of an Innovative Community-Developed Communication Skills Training Program," in press.

https://doi.org/10.1017/jme.2021.32 Published online by Cambridge University Press