The Fierce Urgency of Now: Addressing Racial and Ethnic Disparities in Serious Illness Care

Nadine J. Barrett, Marisette Hasan, Kenisha Bethea, Kimberly S. Johnson

Racial and ethnic disparities in serious illness care are profound and require an urgent response. We present actionable recommendations for health care organizations, providers, and policymakers to address disparities and advance equity.

Ms. Nazarine B. Mixon was diagnosed with colon cancer in 1986, at age 48. She was the rock of her family, a woman of strong faith, and a widow with six children. After a year and a half of treatment, she was in remission. One year later, the cancer returned, spreading throughout her colon and beyond. There were no more options for surgery or chemotherapy. She was in the hospital with a nasogastric tube, unable to eat because of a bowel obstruction. What was next? There was no family conference with the clinical team. No one asked her what she wanted; she did not have an advance directive. After several days, Ms. Mixon took charge, saying to her daughter (MH), “I want to go home.” So, Ms. Mixon returned to her home in rural South Carolina where she was cared for by extended family and supported by her church. Hospice was not available in her community. However, MH, a hospice nurse, managed her symptoms with the help of Ms. Mixon’s physician. After 45 days, she died peacefully at home, having lived her final days as she had lived all of the days that came before—the way she wanted.

It’s been over three decades since Ms. Mixon’s death. As an African American woman, her story illustrates common shortcomings in serious illness care. Compared to whites, racial and ethnic minorities—particularly African Americans and Hispanics—are more likely to have unmet needs for communication with providers and less likely to participate in advance care planning. While lack of availability of hospice care was an issue for Ms. Mixon, racial and ethnic minorities are also less likely to enroll in hospice even when services are available [1-4]. For example, in North Carolina, where hospice is available in every county, in 2018 African Americans and Hispanics made up 15% and 1% of hospice patients, respectively, although they represented 22% and 9.6% of the population; whites made up 80% of hospice enrollees while making up only 70.6% of the population [5]. There is also evidence that racial and ethnic minorities may have less access to non-hospice-based palliative care because of a greater likelihood of receiving care at institutions where these services are not available [6, 7].

Despite potential shortcomings in her care, Ms. Mixon died at home, cared for by family with symptoms well managed, receiving care guided by who she was and what she wanted—commonly referred to as goal-concordant care. However, the data suggest that such outcomes are far too infrequent for seriously ill racial and ethnic minorities who, at the end of life, are more likely than whites to experience avoidable hospitalizations and inadequate symptom management, and less likely to receive care consistent with their preferences [1, 2].

Much has been written about factors contributing to disparities in end-of-life care, including lack of knowledge of hospice and palliative care services, mistrust of the health care system, spiritual beliefs, provider bias, and policies that fail to address diverse cultural beliefs [1, 2, 8]. While this work is foundational, the need to move from description to actionable strategies to address disparities represents the “fierce urgency of now,” a phrase used by Dr. Martin Luther King, Jr., to signal the need for rapid, deliberate action. The three decades since Ms. Mixon’s death have been marked by substantial growth in interventions to improve serious illness care [3]. Health care providers and communities must work to ensure that these interventions are equally available, accessible, and of similarly high quality for racial and ethnic minorities. The following actionable recommendations are key to improving outcomes. Critical to their success is the deliberate and intentional commitment among providers and systems to do better.

Health Care Organizations Must Deliver Culturally Competent Care to Diverse Populations

For organizations, delivering culturally competent care includes ensuring the availability of culturally and linguistically congruent written and verbal communication and providing actionable assessments of the needs and outcomes of diverse groups. For providers, education and training to promote culturally effective care is paramount. Understanding and respecting cultural beliefs and values is critical to pro-
motivating positive outcomes [9]. Studies suggest that both providers and patients find cross-cultural interactions especially challenging [10, 11]. Clinicians frequently navigate care for patients whose beliefs and values may differ from their own. Cultural competency training may improve the knowledge, attitudes, and skills of providers in delivering culturally appropriate care [9]. Skills that facilitate culturally appropriate communication related to prognostic disclosure, advance care planning, and eliciting goals of care are essential. Training should be ongoing, with evaluation and feedback, and include all members of the health care team. In addition to training for health care organizations and providers, policies are also needed to facilitate equal access to resources that promote high-quality care. This includes policies that reduce barriers to completing advance directives (removing the mandatory notary requirement), make services available to those who need them most regardless of stage of illness, and address social determinants of health.

Attention to Workforce Diversity is Essential to Improving Equity in Serious Illness Care

Currently, Blacks and Hispanics make up only 5% and 5.8% of the physician workforce and 6.2% and 5.3% of registered nurses, respectively [12, 13]. These numbers are even smaller in hospice and palliative care. Health care institutions should implement strategies for identifying, hiring, and training diverse staff at all levels to increase trust, improve advocacy for the underserved, and ensure diverse beliefs and cultures are represented [9]. In addition, nontraditional health care providers, such as trained culturally congruent community health workers, may improve outcomes by assisting patients with education, communication, symptom management, and accessing services [14, 15].

Institutions Must Partner with Community Organizations

It is especially important for institutions to partner with community organizations given evidence of greater knowledge gaps and misinformation among racial and ethnic minorities [1, 2, 8]. Intentional partnerships with trusted community stakeholders can facilitate dissemination of accurate, culturally appropriate information and build trust. Given the importance of religious beliefs for many racial and ethnic minorities, the role of the church in responding to needs of patients with serious illness, and a long history of participating in activities to improve health, faith communities are important stakeholders in addressing disparities in care through activities that facilitate coping, education about services, peer support, hands-on care, and connection to resources to meet social needs [2, 8].

In conclusion, disparities in serious illness care exist within the broader context of structural inequities and disadvantages related to the social determinants of health. However, we believe that the recommendations we have outlined, when implemented with the “fierce urgency of now,” can help to interrupt current trends in racial disparities and increase the frequency with which diverse populations have the opportunity to do as Ms. Mixon did—live with serious illness in a way that respects their beliefs, values, and goals.

References

1. The National Academies of Sciences, Engineering, and Medicine. Improving Access to and Equity of Care for People with Serious Illness: Proceedings of a Workshop. Washington, DC: The National Academies Press; 2019. https://www.nap.edu/catalog/25530/improving-access-to-and-equity-of-care-for-people-with-serious-illness. Published 2019. Accessed April 23, 2020.
2. Johnson KS. Racial and ethnic disparities in palliative care. J Palliat Med. 2013;16(11):1329-1334. doi:10.1089/jpm.2013.9468
3. Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington, DC: The National Academies Press; 2015.
4. Ingersoll LT, Alexander SC, Priest J, et al. Racial/ethnic differences in prognosis communication during initial inpatient palliative care consultations among people with advanced cancer. Patient Educ Couns. 2019;102(6):1098-1103. doi:10.1016/j.pec.2019.01.002
5. Compiled by The Carolinas Center for Hospice and End of Life Care. 2018 FY North Carolina Hospice Data and Trends. Raleigh, NC and Columbia, SC; The Carolinas Center; 2019.
6. Cole AP, Nguyen DD, Meirhanov A. Association of care at minority-serving vs non-minority-serving hospitals with use of palliative care among racial/ethnic minorities with metastatic cancer in the United States. JAMA Netw Open. 2019;2(2):e187633. doi:10.1001/jamanetworkopen.2018.7633
7. Center to Advance Palliative Care and the National Palliative Care Research Center. America’s Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals. New York, NY: Center to Advance Palliative Care and the National Palliative Care Research Center; 2019. https://reportcard.capc.org/wp-content/uploads/2019/09/CAPC_ReportCard19-Digital_9_19.pdf. Accessed April 23, 2020.
8. Payne R. Racially associated disparities in hospice and palliative care access: acknowledging the facts while addressing the opportunities to improve. J Palliat Med. 2016;19(2):131-133. doi:10.1089/jpm.2015.0475
9. Office of Minority Health: Department of Health and Human Services. National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice. Rockville, MD: Think Cultural Health; 2013. https://thinkculturalhealth.hhs.gov/pdf/Enhanced-CLASStandardsBlueprint.pdf. Accessed April 23, 2020.
10. Periyakoil VS, Neri E, Kraemer H. No easy talk: a mixed methods study of doctor reported barriers to conducting effective end-of-life con-
11. Meghani SH, Brooks JM, Gipson-Jones T, Waite R, Whitfield-Harris L, Deatrick JA. Patient-provider race-concordance: does it matter in improving minority patients’ health outcomes? Ethn Health. 2009;14(1):107-130. doi: 10.1080/13557850802227031
12. Association of American Medical Colleges. Diversity in Medicine: Facts and Figures 2019. AAMC website. https://www.aamc.org/data-reports/workforce/interactive-data/figure-18-percentage-all-active-physicians-race/ethnicity-2018. Accessed April 23, 2020.
13. Smiley RA, Lauer P, Bienemy C, et al. The 2017 National Nursing Workforce Survey. J Nurs Regul. 2018;9 (suppl 3):S1-S88. doi: https://doi.org/10.1016/S2155-8256(18)30131-5
14. Fischer SM, Kline DM, Min SJ, Okuyama-Sasaki S, Fink RM. Effect of Apoyo con Carino (Support With Caring) trial of a patient navigator intervention to improve palliative care outcomes for Latino adults with advanced cancer: a randomized clinical trial. JAMA Oncol. 2018;4(12):1736-1741. doi: 10.1001/jamaoncol.2018.4014
15. Patel MI, Sundaram V, Desai M, et al. Effect of a lay health worker intervention on goals-of-care documentation and on health care use, costs, and satisfaction among patients with cancer: a randomized clinical trial. JAMA Oncol. 2018;4(10):1359-1366. doi: 10.1001/jamaoncol.2018.2446