

Improved Serious Illness Communication May Help Mitigate Racial Disparities in Care Among Black Americans with COVID-19



Lauren T. Starr, PhD, MBE, RN¹ , Nina R. O'Connor, MD, FAAHPM², and Salimah H. Meghani, PhD, MBE, RN, FAAN¹

¹NewCourtland Center for Transitions and Health, University of Pennsylvania School of Nursing, Philadelphia, PA, USA; ²University of Pennsylvania Perelman School of Medicine, Philadelphia, PA, USA.

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PERSPECTIVE

In response to decades of systemic racism, protests calling for equality are occurring across the United States. Black Americans want change. This is not surprising given so many Black Americans experience racial discrimination, including in healthcare encounters.^{1, 2} Unfortunately, the COVID-19 pandemic has both revealed and exacerbated racial inequalities in health.² Deterred by discrimination, myriad barriers, and clinician biases, Black Americans have been less likely than Whites to be referred for coronavirus testing³ and are more likely to postpone seeking care until illness is so advanced it requires hospitalization,⁴ contributing to health disparities in COVID-19 outcomes.^{5, 6} Black Americans are dying from coronavirus at more than twice the rate of White Americans,⁷ with even greater disparities among persons of working age.⁸ Although Black Americans represent 13% of the population, they represent nearly 25% of COVID-related deaths.⁷ The age-adjusted COVID-19 death rate for Black Americans is 3.6 times that of Whites,⁹ underscoring evidence that social determinants are at the root of health disparities.^{6, 10, 11} Disparities in COVID mortality rates have been attributed to higher incidence of co-morbidities (e.g., heart disease, diabetes); socioeconomic factors such as population density, residential segregation, and a greater likelihood to work in service industry jobs that increase exposure to COVID-19; limited access to care; and clinician biases that affect how providers perceive and communicate with Black patients, possibly delaying coronavirus diagnosis and affecting treatment.^{5, 10–13} Unfortunately, pandemics have historically amplified existing health inequities and disproportionately affected disadvantaged groups.⁸

In addition to enduring disparities in health outcomes, Black Americans experience poorer quality patient-clinician

communication compared to Whites.^{14, 15} This difference is problematic given effective communication is a cornerstone of patient-centered care and preference-consistent outcomes.^{16, 17} Racism, discrimination, and feeling unheard in healthcare encounters contribute to racial disparities in health communication.^{14, 18, 19} Even when seriously ill, Black Americans are less likely than Whites to experience discussions with their healthcare providers about prognosis, personal goals, values, and end-of-life treatment preferences.²⁰ In addition, lack of racial diversity resulting from relatively low numbers of Black clinicians can further contribute to poorer communication quality, information-giving, patient participation, and participatory shared decision-making for Black patients compared to Whites.^{15, 21} In this paper, we argue that engaging palliative care early in patient care may help close racial gaps in coronavirus outcomes and that incorporating goals-of-care communication tools and training across settings and specialties may improve outcome disparities among Black Americans with COVID-19.

The pandemic has highlighted the importance of discussing care goals and providing goal-concordant care to vulnerable older adults and those with chronic or acute illnesses,²² including Black Americans at greater risk for poor COVID-19 outcomes.⁶ Discussing care goals is critical given the likelihood a COVID-19 vaccine may not be adopted by Black Americans as readily as members of other racial groups.²³ Citing fear of safety and efficacy of the vaccine and concern that vaccine development is not taking the needs of Black Americans into account,^{2, 23} half of Black adults report they do not plan to take the vaccine once one becomes available—even if it is free and scientists declare it safe.²

Palliative care consultations involving discussions about patient goals and values, which are recommended by the National Institute of Health when caring for persons with COVID-19,²⁴ may help mitigate racial disparities^{20, 25} associated with serious illnesses such as COVID-19. Researchers have found Black patients are as likely as White patients to engage in goals-of-care conversations when led by trained palliative care clinicians.^{20, 25} Primary palliative care and hospital-based palliative care teams trained in serious illness communication support patient decision-making by providing

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empathic communication and culturally sensitive information sharing. The palliative care approach, which emphasizes listening to patient values and goals and clarifying prognosis and care options in addition to meeting physical needs, benefits patients and families across races.

Studies of home-based palliative care and inpatient palliative care have demonstrated favorable outcomes for Black Americans with serious illness, including increased satisfaction, increased documentation of treatment preferences, and higher rates of home death and hospice referrals.^{20, 21} Recent research shows, for example, that seriously ill Black patients who had a goals-of-care consultation were 15 times more likely to choose hospice than demographically and clinically similar, propensity score–matched Black patients without a consultation.¹⁸ Evidence also shows seriously ill Black patients live longer when they receive palliative care consultation.²⁵ These findings suggest palliative care’s approach to goals-of-care communication helps Black Americans clarify treatment preferences in light of personal goals.

As the pandemic has progressed, the field of palliative care has emerged as a leader in effective communication tailored to the needs of patients with COVID-19 and patients at risk for poor COVID-19 outcomes. Emphasizing patient health literacy and personal values and goals, palliative care clinicians have adapted goals-of-care communication to include language specific to symptom trajectories, treatment options, prognosis and risk assessment, advance care planning, and uncertainties associated with COVID-19—all in the context of individual patient needs.^{26–37} Ariadne Labs,^{26, 27} Vital Talk,²⁸ Respecting Choices,²⁹ the National Hospice and Palliative Care Organization,³⁰ the Center to Advance Palliative Care,^{31, 32} and other organizations^{33–37} offer free conversation guides, tools, and video resources designed to help clinicians lead COVID-19 care goal discussions and advance care planning across settings and languages with patients and surrogate decision-makers (Table 1).

Fortunately, palliative care providers are not the only clinicians capable of leading meaningful care goal discussions. One way to increase serious illness communication during the COVID-19 pandemic is to involve all clinicians in inpatient and outpatient care goal discussions and advance care planning.⁴⁰ By using serious illness communication tools tailored around the needs of persons at risk for poor COVID-19 outcomes, clinicians in primary and specialty care can lead these discussions across settings—including at home and in long-term care, nursing homes, dialysis centers, and other nonacute places of care before patients become severely ill.^{40–42} Engaging Black Americans and other racial/ethnic minorities in a tailored community-based communication intervention—for example, at churches or social service organizations where mistrust of healthcare systems may not be as strong a barrier—may increase prevalence of these discussions in minority communities before patients are hospitalized.^{43–46}

Table 1 Resources for Serious Illness Communication During COVID-19 Pandemic and Beyond

Organization	Resource	Description
Ariadne Labs ^{26, 27}	Serious Illness Care Program COVID-19 Response Toolkit	Free tools and communication guides for patients and clinicians in inpatient, outpatient, and long-term care settings to discuss goals, values, and care planning with patients at risk for or infected by COVID-19.
Vital Talk ²⁸	COVID Ready Communication Playbook	A free compilation of scripts, guides, and tips for clinicians to reference when discussing numerous aspects of COVID-19 with patients and families; features video examples and collaborative resources.
Respecting Choices ²⁹	Proactive Planning Conversations in the context of COVID-19	Free conversation guides and videos for patients and clinicians to support advance care planning; features general scripts and scripts for scheduling, medical priorities, and treatment priorities.
National Hospice and Palliative Care Organization ³⁰	COVID-19 Shared Decision-Making Tool	A free guide that helps patients determine COVID-19 risk level, what they’d want if they became seriously ill with COVID-19, and links to access free advance directive templates (by state) and access to The Five Wishes values assessment.
Center to Advance Palliative Care ³¹	COVID-19 Response Resource Hub: Goals of Care	A free conversation map that includes specific phrases to use when talking to patients with COVID-19 about goals of care; features multiple editable scripts for clinicians and video examples.
Center to Advance Palliative Care ³²	COVID-19 Response Resource Hub: Advance Care Planning	A free conversation map that includes specific phrases to use when talking to patients with COVID-19 about values and future care planning; features multiple editable scripts for clinicians and video examples.
Institute for Healthcare Improvement, Cambia Health Foundation, And Ariadne Labs ³³	The Conversation Project	A free guide and tool for helping people think about and document their values and what they would want if they became seriously ill with COVID-19.
	PREPARE for your care	Free online tool that helps patients identify

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Table 1. (continued)

Organization	Resource	Description
University of California San Francisco et al. ^{34, 35}		and document medical decisions; features advance care planning scripts for outpatient health professionals, tips for patients about advance care planning and planning for a potential hospital stay, and access to advance directives.
Partners Healthcare, adapted from Ariadne Labs ³⁶	Partners Serious Illness Conversation Guide	Freely available serious illness communication guide adapted from Ariadne Labs tools and implemented across primary and specialty care throughout the health system.
Stanford University School of Medicine ³⁷	The GOOD Framework	Framework that helps clinicians assess challenges and clarify uncertainties across four stages of the goals-of-care discussion (Goals, Options, Opinions, Documentation), specifically in the context of COVID-19.
Penn Medicine ^{38, 39}	Our Care Wishes	Free online advance care planning tool to help people discuss, document, and share care goals and personal values and wishes related to quality of life, treatment preferences, and healthcare decision maker.

These discussions can also be conducted via telehealth technology, a platform patients and clinicians have rapidly adopted during the pandemic.^{47, 48} When patients, families, or surrogate decision-makers cannot be physically present to discuss treatment options with clinicians, telecommunication discussions help meet patient needs²⁴ while restoring a sense of human connection in difficult social distancing circumstances.⁴⁹ Although not a replacement for patient-provider conversations, online tools such as [OurCareWishes.org](https://www.ourcarewishes.org), a free platform designed to guide patients and families through advance care planning, may also be used to help high-risk patients clarify goals and share preferences with providers^{38, 39} (Table 1).

As part of continuing education, health systems should provide clinicians with evidence-based communication tools adapted for COVID-19 and persons with serious illness^{26–37} and provide training that enables effective implementation across patient populations.⁵⁰ Best practices for using communication guides to teach basic palliative care communication skills to interdisciplinary groups across primary and specialty care are freely available.^{36, 51}

Although palliative care communication and related tools strive to place patients and families at the center of care, there is always a potential for clinician biases to influence care quality. In addition to better training clinicians in serious illness communication, particularly as it relates to COVID-19, health systems should provide clinicians with evidence-based racial and cultural sensitivity training, implicit and explicit bias training, and resources to help reduce the effects of clinician bias on patients and families.^{52, 53} Effective implicit bias training for clinicians has the potential to improve patient-provider interactions and communication,⁵³ possibly improving clinical experiences and outcomes for Black Americans at risk of acquiring or dying from COVID-19.

Using existing tools ensures patients and caregivers are given a voice in each conversation, reduces communication differences, and helps overcome clinician discomfort with talking about illness or death. Tools that guide communication also ensure patients do the majority of the talking and promote clinician listening, resulting in extremely personal, individualized conversations. Use of these tools honors each patient's personhood and helps clinicians avoid assumptions about a patient's goals and values, helping to neutralize a clinician's implicit or unconscious biases. Concerted research is needed to better understand the effectiveness of these tools in mitigating biases and reducing racial disparities in serious illness care, including the care of patients with COVID-19.

Clinicians should also initiate care goal discussions with patients at risk for poor COVID outcomes early in the illness trajectory^{54–59} and, for the most vulnerable patients including those in nursing homes or long-term care where COVID infection can spread rapidly, even before infection.^{26, 56} Given the unpredictable and sometimes swift nature of COVID-19, early discussion of risk and care preferences gives patients the opportunity to better protect themselves and think about what matters most to them should they become severely ill with COVID-19 *before* acute crises arise or they lose the ability to communicate. Early discussion helps patients, families, and clinicians work together as a team to make a plan should symptoms develop and worsen so that each patient has an opportunity to receive high quality care consistent with personal goals. Even if coronavirus symptoms do not require hospitalization, good COVID-19 communication and shared decision-making benefit patients by helping patients feel known, heard, informed, and more in control over healthcare decision-making.^{60–62}

In general, seriously ill patients across races have these conversations too close to death. Although disparities in the timing of goals-of-care conversations have not been studied among Black patients with COVID-19, the possibility of late discussions is particularly problematic for this population given their higher mortality rates. It is essential that palliative care consultations and goals-of-care discussions be of similar quality, equal accessibility, and delivered in a timely manner

to meet the needs of seriously ill patients across races.^{21, 55} Systematic early initiation of these conversations in outpatient settings among patients at risk for poor COVID outcomes and upon hospital admission may help reduce possible disparities in communication timing, which can affect decision-making and subsequent outcomes.^{55, 57, 58}

Little is known about the quality of serious illness communication that Black Americans with COVID-19 receive. Research is needed to understand if racial/ethnic communication disparities affect COVID-19 outcomes—including quality of life, quality of death, and mortality—and how palliative care consultation and communication tools may help reduce outcome disparities. To conduct rigorous research and mitigate factors contributing to COVID-19 racial disparity outcomes, healthcare systems and public health officials must work to provide high-quality data related to race/ethnicity, serious illness communication, and outcomes.⁷ Data linking use of communication tools to racial outcomes in serious illness and COVID care is especially needed. Failure to collect and use such data limits clinicians' ability to implement targeted clinical interventions that may improve the care of vulnerable Black Americans.

As subsequent waves of coronavirus infection hit the United States, mortality increases, and long-term effects of infection emerge, the COVID-19 pandemic will continue to disproportionately affect Black Americans and other racial/ethnic minorities.^{8, 9} As clinicians, it is our responsibility to identify solutions for racial inequities and work to improve outcomes for Black Americans, starting with understanding their personal care goals. Failure to engage Black Americans with COVID-19 and other serious illnesses in culturally sensitive conversations about personal values, prognosis, and care preferences may result in poorer quality care for Black Americans.^{63–65} All patients, regardless of race or ethnicity, should have the opportunity to meaningfully discuss what matters most to them. For Black Americans who already endure discrimination and disparities in serious illness and end-of-life care, these conversations are desperately needed.

Corresponding Author: Lauren T. Starr, PhD, MBE, RN; NewCourtland Center for Transitions and Health, University of Pennsylvania School of Nursing, Philadelphia, PA, USA (e-mail: lstarr@nursing.upenn.edu).

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Compliance with Ethical Standards:

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