27 African American Palliative Care amid the COVID-19 Pandemic

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Introduction

The novel coronavirus, or COVID-19, is a major health crisis across the globe. In the United States, and African Americans have been disproportionately impacted in terms of infections and deaths.[1] Medical professionals have conducted numerous studies that identify underlying health factors that correlate with high risks of COVID infections among African Americans.[2] Obesity, cardiovascular disease, cerebrovascular disease, malignant neoplasms, diabetes, high blood pressure, and asthma are foremost.[3] Because those conditions are prevalent among African Americans, they have greater risks of COVID infection and death than white people. The large numbers of African Americans employed as essential workers is an additional factor.[4] Besides working conditions and fears of infection, which all ethnic groups have experienced, mental anguish attributable to psychological and emotional distress from generations of societal injustice in the United States has compounded physiological issues among African Americans. Scientists refer to that phenomenon as the allostatic load.[5]

The coupling of the physiological and the psycho-emotional components of health with terminal physiological issues, despite treatability, is what necessitates palliative care. I will demonstrate that a variety of accessibility concerns exist for African Americans, leaving many to suffer unnecessarily. While those concerns are hardly novel, I emphasize the COVID-19 pandemic illuminates an array of health disparities about which the medical community has known but has not address properly for decades. In my judgment, old and new knowledge should spur a moral response from a broad coalition of members in the faith community.

If history serves as a guide, the longstanding epidemic of racism in the United States will cause professional healthcare and government institutions to do less to prevent COVID-19 from harming black people than white people. By offering palliative care, I submit, properly trained members of the faith community can join with other social service professionals in healthcare to reduce emotional and spiritual distress among patients with chronic and terminal illnesses the pandemic has exacerbated.

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Intersections of Palliative Care, Spirituality, and Healthcare Morality

Balfour Mount, a physician at the Royal Victoria Hospital in Montreal, introduced the *term palliative care* in 1974. There is no universal definition, but many authorities agree that it is designed to alleviate suffering for patients and their loved ones. Originally, palliative care was almost indistinguishable from end-of-life care, as both were melded with hospice care and focused on death.[6] In 1990, the World Health Organization (WHO) described palliative care as "the active total care of patients whose disease is not responsive to curative treatment. The control of pain, other symptoms, and of psychological, social, and spiritual concerns is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families."[7]

In 2002, the WHO redefined palliative care as "an approach which improves the quality of life of patients and their families facing life threatening illness, through the prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems physical, psychosocial and spiritual."[8] The shift from "disease not responsive to curative treatment" to "life threatening illness" was the most crucial element of the revised definition (which definition did not assume that diseases could respond to treatment).[9] Organizations such as the European Association of Palliative Care and the International Association of Hospice and Palliative Care did not agree with every aspect of the new definition and therefore continued to advocate for a consensus description that expanded the care continuum beyond life-threatening conditions.[10]

Whatever the particulars, introducing "interdisciplinarity into the usual functioning of a multidisciplinary team" is key to effective palliative care, according to scholar Pierre Boitte.[11] Given continuous physiological and emotional distress within African American communities, which COVID-19 compounds, compassionate redress is needed in response to government policies that generate or that sustain socioeconomic inequities causing disproportionate levels of chronic and terminal disease among African Americans.

Palliative care attends to the physical, psychological, and spiritual needs of patients with chronic and terminal illnesses. Such care also supports their families. Nevertheless, African Americans tend to underutilize it for numerous reasons, including limited awareness of the availability of palliative care and doubts about its benefits. Such doubts often stem from a broader African American distrust toward the healthcare system, especially forms of care that unfamiliar or speculative. When asked, countless people offer the so-called Tuskegee Experiment as a significant reason for mistrust.[12] From 1932 to 1972, the US Public Health Service (along with Tuskegee Institute originally) used 600 African American men in Macon County, Alabama, in a syphilis research study under manipulative pretenses, including guarantees of medical insurance the service ultimately did not provide.[13]

Beyond unfair government experimentations, many African Americans are inclined to rely strongly on spiritual means when facing challenges and uncertainties. While numerous studies affirm the importance that many patients suffering from terminal and other advanced illnesses place on spirituality and religion as coping mechanisms, some practitioners have resisted incorporating spirituality in the delivery of care—despite evidence supporting its effectiveness in certain situations.[14] To integrate spirituality into palliative care, one should understand the roles that various medical professionals perform in such integration. Some professionals avoid asking patients about their spiritual beliefs because the questions seem to invade privacy. Even so, therapist Michael M. Olson and a group of his research colleagues suggested in 2006, "openness to discussions of spirituality contributes to both better health and better physician-patient relationships."[15]

Spirituality, in the context framed by Olson and company, can be beneficial not only to patients but also to caregivers, both professional and lay. Regarding African Americans, psychologist Ronald K. Barrett in 2002 proclaimed it was "almost unthinkable that you can have an honest, intelligent discussion about death and dying, unless you deal with the centrality of spirituality in the black experience."[16] Whereas Barrett believed spirituality was foundational to any honest and intelligent conversation about death and dying, I believe human dignity and other moral tenets are the foundations of conversations about palliative and hospice care. As disease decimates a patient's body, the patient's value system tends to become more pronounced. For example, in the midst of the suffering that can accompany a terminal malignancy, nearly every patient still wants others to recognize his or her worth. Such an expectation of respect often reflects a desire to suffer and ultimately die with dignity, though nurturing that dignity can be complex, especially in relation to African Americans due to the longstanding history of sociopolitical oppression and other forms of abuse.[17]

Insufficient access to healthcare has been a persistently insidious obstacle to black well-being. When COVID-19 began spreading rapidly across the United States in early 2020, hospital administrators throughout the country realized quickly their institutions had too few intensive care unit beds, ventilators, and other resources to meet the needs of actual or projected patients.[18] In March, the month the WHO declared COVID a pandemic,[19] New York Governor Andrew M. Cuomo predicted the state would need 30,000 such beds and 40,000 ventilators.[20] At the time the state possessed approximately 1,600 and 4,000, respectively.[21] Cuomo and others in his administration helped medical centers in the state double the number of ICU beds from 1,600 to 3,500 by utilizing beds on a naval medical ship called *Comfort* and by converting space inside the Jacob K. Javitz Convention Center of Manhattan.[22]

Of course not every American city had access to a seaport where a naval vessel could supplement a shortfall in medical beds. That being the case, the likelihood of every person with severe COVID-19 symptoms receiving adequate care was extremely low. That fact posed broad moral dilemmas to government officials, hospital administrators, and other individuals who had to decide who got potentially life-saving resources. In general, black, biethnic, and other people of color suffered disproportionately to white people.[23]

The Need for Justice

Palliative care aims to alleviate the physical, psychosocial, and spiritual suffering of chronically ill people. Because a disproportionate number of people of color suffer with COVID-19, which induces psycho-spiritual distress, I believe healthcare administrators have moral and ethical obligations to allocate sufficient time and resources to address ethnic/racial disparities.

During the late twentieth century, as the palliative care movement matured in the United States, philosopher and physician Hugo T. Engelhardt Jr. helped popularize a now familiar inquiry regarding whether people were beneficiaries or victims of a natural lottery or a social lottery.[24] If one was disadvantaged because of a genetic predisposition, or was "born unhealthy," Engelhardt speculated, one had lost in the natural lottery, and other members of society had moral and ethical obligations to assist.[25] Engelhardt's contentions applied to efforts to raise awareness and, moreover, to support for birth defects such as Down Syndrome, Cerebral Palsy, and Spinal Bifida.

Engelhardt's social lottery constructs remain important to African Americans and their healthcare. While many Americans are born with serious health conditions, the natural lottery, many more African Americans are victims of the social lottery and its most persistent embodiment, racism. Distributive justice is a paradigm that seeks to address both lotteries. In 1976, medical ethicist Robert M. Veatch declared that gross social inequities in the United States were wrong and that, owing to power differentials between privileged and unprivileged Americans, the unprivileged were not situated well to represent themselves so the privileged often dismissed them.[26] For philosophers Tom Beauchamp and James Childress, justice is the "fair, equitable, and appropriate distribution determined by justified norms that structure the terms of social cooperation."[27]

In addressing distributive justice—especially health access disparities and the need for reform—ethicist Lisa Cahill's 2005 book, *Theological Bioethics*, builds on philosopher John Rawls's characterization of healthcare as an essential common good.[28] Cahill, however, qualified the issue of public responsibility for access to health by pointing out the need for spiritual responses from a variety of religious groups and respected theologians, who could undertake activism if necessary.[29] Her work is significant for my discussion of African Americans and healthcare. Among other things, she emphasized the importance of spirituality and religion to communal well-being.[30]

Conclusion

If healthcare administrators improved board-certified hospital chaplains' capacities, their visibility, and integrated them into the treatment paradigm, the administrators would take an important step toward the healthcare reform I envision. Administrators also should review policies that create moral distress among healthcare practitioners, thereby affecting practitioners' well-being and their quality of care they delivery. The considerable amount of scholarship about such distress in multiple clinical disciplines can aid the administrators.[31]

Lawmakers also have important roles to perform to ensure the type of healthcare reform I propose. They should write and adopt legislation to expand access to care for those disadvantaged on account of racism and consequent socioeconomic inequities. Such legislation is crucial to promoting the dignity of human beings, a major part of making my health equity dream a reality.

Notes

1 By late 2020, black and biethnic Americans were dying at 2.4 times the rate of whites Americans—ninety-two per 1,00,000 compared to thirty-nine per 1,00,000, respectively. "COVID-19 Is Affecting Black, Indigenous, Latinx, and Other People of Color the Most," *COVID Tracking Project*, September 15, 2020, https://covidtracking.com/race.

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