Respecting Faith, Hope, and Miracles in African American Christian Patients at End-of-Life: Moving from Labeling Goals of Care as "Aggressive" to Providing Equitable Goal-Concordant Care

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Abstract

In this article, we demonstrate first how the term "aggressive care," used loosely by clinicians to denote care that can negatively impact quality of life in serious illness, is often used to inappropriately label the preferences of African American patients, and discounts, discredits, and dismisses the deeply held beliefs of African American Christians. This form of biased communication results in a higher proportion of African Americans than whites receiving care that is *non-goal-concordant* and contributes to the prevailing lack of trust the African American community has in our healthcare system. Second, we invite clinicians and health care centers to make the perspectives of socially marginalized groups (in this case, African American Christians) the central axis around which we find solutions to this problem. Based on this, we provide insight and understanding to clinicians caring for seriously ill African American Christian patients by sharing their beliefs, origins, and substantive importance to the African American Christian community. Third, we provide recommendations to clinicians and healthcare systems that will result in African Americans, regardless of religious affiliation, receiving equitable levels of goal-concordant care if implemented.

Key Message

Labeling care at end-of-life as "aggressive" discounts the deeply held beliefs of African American Christians. By focusing on the perspectives of this group clinicians will understand the importance of respecting their religious values. The focus on providing equitable goal-concordant care is the goal.

Keywords African American values · Goals of care · Serious illness · Goal-concordant care

This article has three goals. First, to demonstrate how the term "aggressive care," used loosely by clinicians to denote care that can negatively impact quality of life in serious illness, is more often used to inappropriately label the preferences of African American patients than other groups, and discounts, discredits, and dismisses the deeply held beliefs of African American Christians. This form of bias results in a higher proportion of African Americans than whites receiving *non-goal-concordant* care. Second, is to provide insight for clinicians who care for seriously ill African American Christian patients by sharing the beliefs, their origins, and their substantive importance of scripture and biblical teachings to African American Christian communities. Third, we provide recommendations to clinicians and healthcare systems to treat African American patients, regardless of religious background, as individuals who are viewed from a place of unique personhood. The goal is to encourage open, respectful communication between African American patients and clinicians that has the potential to result in all African Americans being provided with equitable levels of respectful goal-concordant care.

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We acknowledge the potential moral distress medical professionals face when being asked by patients or their surrogate decision-makers to provide continuing intensive disease-directed care, especially when the patient's condition has been assessed as non-curative [1, 2]. Yet, we ask the reader to take this journey, recognizing that perspectives on end-of-life care, suffering, and dying are strongly influenced by the person's life experiences, cultural identity, and for some spiritual affiliations [3, 4], and that the end-of-life model prevalent in the United States (U.S.) is based on the cultural and religious values of the white, middle class [5]. The predominant model in the U.S. is based on the C. Saunders hospice and palliative care model from the UK, which emphasizes autonomous decision-making and receiving supportive care that culminates in death at home with key family members providing care [6]. This model lacks an orientation for those who may not have family that can perform tasks, nor does it account for shared decision-making, a hallmark decision method for many racial and ethnic minorities. Using critical race theory [7], a race-equity methodology grounded in social justice, we ask the reader to center their care on the perspectives of socially marginalized groups (in this case, African American Christians) rather than those of the dominant race or culture.

"Aggressive Care" Is Not an Objective Term

Aggressive care is a value-laden term used throughout medical literature. The first written records of the term "aggressive management" were found in the late 1960s–early 1970s. This term described the recommendation to manage, treat, and follow-up with high-risk pediatric populations, over and above the treatment recommendations at the time [8, 9]. This frame of reference denotes a concerted effort to identify those who have high risk for increased morbidity or mortality [10–13]. At the turn of the twenty-first century, however, the meaning of the term "aggressive" as it related to medical care began to shift.

The term "aggressive care" is not a National Library of Medicine defined Medical Subject Heading (MeSH) term, and is defined in various ways in the literature, often based on certain utilization criteria, such as emergency room visits and hospital and intensive care unit stays in the last 30 days of life and use of chemotherapy in the last 14 days of life [14]. In addition, it is often referred to as the opposite of palliative care in the last weeks or months of life. One definition includes less than 3 days of palliative care in the last month of life as "aggressive care." It is often also used interchangeably with the term "intensity" of end-of-life care [15]. In PubMed, the term "aggressive care" began appearing in the medical literature in the 1990s and peaked in 2020. Over this time period, there was increased

national concern about rampant increases in health care spending and evidence of poor quality care [16, 17]. While individual physicians and groups of providers can increase revenue by providing services that may be termed "aggressive," healthcare reforms in the early twenty-first century aimed at containing costs put health systems at financial risk for costly services through mechanisms such as paying for hospital admissions with a capped fee based on Diagnosis-Related Groups (DRGs) and fostering the development of Accountable Care Organizations; groups of health care institutions and providers who are jointly responsible for both costs and quality of care [18, 19].

In the care of patients with advanced cancer, dementia, and those with terminal illness, especially when patients are older, "aggressive care" is generally considered by clinicians to be care that results in multiple adverse consequences, which though not consistently defined generally include decreased quality of life and reduced likelihood of experiencing a "good death"[20, 21]. To our knowledge, the term "aggressive care" is not widely used by the general public, and thus the assumptions about the association between aggressive care and quality of life and death are based on clinicians' experiences. In fact, a "good death" varies greatly among individuals [22] and is not necessarily in opposition to "aggressive care" in the minds of patients and families. Despite the tenuous connection between "aggressive care" and quality of life in patients nearing end-of-life, studies of health disparities often posit African American patients' preferences for "aggressive care" as an underlying cause of differences in end-of-life outcomes (Marcewicz et al., Table 5) [23].

The distinction between ordinary and extraordinary measures to prolong life has been made since at least the sixteenth century and was used to conceptualize ethically permissible circumstances under which mechanical ventilation could be discontinued during the development of this technology in the 1950s [24]. *However, this distinction is not objective, it is culturally bound*. What is considered exceptional depends on the resources, experience, healthcare system technology, and cultural values around preserving life, and comfort. Labeling of "extraordinary" life-prolonging technology as "aggressive" or "burdensome" and linking these terms specifically to healthcare costs simultaneously imbues decisions with moral judgment and sets the stage for limiting their use in the service of containing costs.

Multiple studies have demonstrated that African Americans are, to some degree, more likely than whites to endorse wanting interventions such as feeding tubes, mechanical ventilation, and CPR, and in patients with cancer, to continue chemotherapy in the last months of life [25–29]. However, these same studies confirm that difference in preferences in African Americans and whites are statistically significant,

they are often small. For example, desire for mechanical ventilation at end-of-life was found to be 15–24% for African Americans compared with 5–13% of whites, depending on how it was measured [27, 28]. This means that at least three fourths of African American patients would not want this type of care at end-of-life.

The use of the term "aggressive care" can contribute to miscommunication between clinicians and African American patients and families in at least two different ways. First, clinicians may conflate the slightly increased likelihood that African Americans prefer care labeled as "aggressive" to mean that the majority of African Americans hold such preferences. Even though the majority of African Americans prefer comfort-oriented care at end-of-life, the literature that describes these preferences is replete with labeling this care as "aggressive" with all the negative connotations of the term including non-curative, costly, and burdensome [30]. This framing may lead to troublesome breakdowns in communication between clinicians and African Americans. Given that the body of literature firmly associates, "aggressive care" and high healthcare expenditure with African Americans, clinicians may misconstrue statements about hope and miracles as a request for "aggressive" end-of-life care, rather than carefully attending to patients' wishes and providing goal-concordant care that reflects their values [30]. Second, for the minority of African American patients who DO prefer care labeled as "aggressive," the negative connotations of this term may lead to clinician perception that discussing end-of-life care is more difficult with African American patients and families [31, 32].

High Rate of Non-Goal-Concordant Care Delivered to African Americans by Healthcare Providers

High-quality care for patients with serious illness is defined as ensuring that patients receive medical care that is consistent with *their* values, goals, and preferences [33]. Goals of care conversations are about prognosis, patient and family values, treatment risks, and benefits, and planning for intensity/type of care [34], and usually occur when curative treatment is no longer the recommendation for a seriously ill patient. Yet, studies have found that *even when African Americans have their goals of care preferences in writing*, they are less likely than whites to have their preferences followed [34–36], and that clinicians are less likely to document goals of care discussions with African American (and Hispanic) patients and families [36]. Equally egregious is when African American families advocate for their loved ones to receive continued care and are labeled as "difficult" [37, 38]. This disregard for the values, goals, and preferences of African Americans has resulted in a higher proportion of African American families who rate the care their loved one received at end-of-life as "non-goal-concordant."[39–41] While challenges remain in measuring and defining goal-concordant care,[42] failure to achieve goal-concordant care is recommended to be viewed as "a medical error that can harm patients and families" by Sanders et. al [33]. In late 2020, Miriam-Webster dictionary altered its current definition of racism, "racial prejudice or discrimination," to now include "systemic oppression"[43]. No healthcare provider wants to think of themselves as potentially "racist," and no healthcare system wants to consider itself as contributing to what is systemic oppression. And yet, the findings of higher rates of non-goal-concordant care, provided to African Americans with serious illness is a clear indicator that racism, whether by individual clinician or system-wide, exists.

The Belief in God, Hope, and Miracles Among Christian African Americans

Based on national data by Pew Research Center, whose data is collected from 10,000 random U.S. adults who self-select response categories, 59% of U.S. born Black Americans (using the consistent category of by the Pew Research Center based on U.S. born selection—this group would be African Americans) report that religion is very important [44]. Of all Black adults (not using African American because there is no delineation of U.S. born in the database for this question), seventy-five percent identify as Christian [45]. In the same vein, belief in miracles is prevalent (85%) among Black Americans (see earlier note) [46], a belief rooted in the ancestral traditions of the earliest African slaves. Survival of the treacherous Middle Passage on ships that transported enslaved Africans to the Americas was considered miraculous. When they could not practice their traditional religions, the enslaved Africans resonated with the God of Christianity as a God of miracles. The Biblical miracle narratives were particularly compelling—from the accounts of God's miraculous deliverance of the Hebrew slaves to the many stories of Jesus's miraculous works. African American Christians likewise frame their survival and thriving over the past 400 years as miraculous.

While there are multiple religious affiliations that African American Christians belong to, we are basing our discussions on people who self-identify as Christians, which typically means a belief in the teachings of Jesus Christ. However, the majority of African Americans share a historical medical experience that has left them without consistently available, trustworthy medical care for many generations [47–49]. There is a history of medical experimentation on this population [37] and centuries of healthcare disparities in both access to care, as well as in the provision of equitable care [50, 51]. Justifiably, this has resulted in a lack of trust

in the healthcare system, with the widespread belief that as African Americans they will not receive the same quality of care, nor will their preferences for end-of-life be met or respected by the medical team [47, 48].

Due to this history African American Christians learned to depend on God's miraculous healing power. Belief in healing is also informed by Biblical scripture which 51% African Americans believe is the literal word of God [52]. Scriptures such as Psalm 41:3—"The LORD sustains them on their sickbed and restores them from their bed of illness"; and Psalm 103:3—" Praise the Lord, my soul, and forget not all his benefits—who forgives all your sins and heals all your diseases…" are among the texts that are often frequently identified as "healing scriptures" cited during prayers for seriously ill patients.

Testimony services are traditional in African American churches, during which participants "testify" or share stories about their experiences of God's faithfulness [48]. Participants often share "praise reports" when they or other friends and family members recover or show improvement amid serious illnesses. A frequent theme in these accounts contrasts their faith in God "who is still in the miracle-working business" versus their long-standing distrust of physicians. The combination of strong trust in God, belief in Miracles, and distrust of clinicians may inform the decision of a seriously ill African American Christian patient to request continued high levels of medical intervention even when recommendations call for supportive care. Given that the majority of African Americans endorse desiring a comfort-oriented plan of care at end-of-life, allowing space and support for African American Christian patients to absorb and process clinical information through their preferred spiritual lens is critical to providing goal-concordant care.

The Intersection of Religion, Spirituality, and Lack of Trust in the Healthcare System at End-of-Life

Religion, spirituality, culture, and social identity are clearly unique concepts yet there is overlap/points of intersection, especially during goals of care discussions. Religion has long served as an emotionally stabilizing factor that has contributed to the mental and physical well-being of its people in the African American Christian community [47, 48, 53–55]. Religion has traditionally instilled faith and bred continuous hope for the journey of its members. *This same hope is prevalent in this population when confronted with chronic and terminal illness and ultimately becomes a mechanism for medical decision-making* [48, 54–58]. Hope supports the cultural and spiritual belief in vitalism, the idea of a long, fully lived life in this community which *rejects the idea of hastening death*.[47, 48, 56, 59] Hope encourages the

continuous desire for life-sustaining treatment and *ultimately believes in the providential nature of God to determine their outcome and not the health care system* [47, 48, 54, 56–58]. For some African American Christian's a family-centered approach to medical decision-making may incorporate the family's religious leader for guidance and the fervent use of prayer [58]. Overall, what African American Christians, just like all African Americans, need is protected and respected time to have critical conversations with those in their networks about their end-of-life care goals.

Recommendations for Clinicians and Healthcare Systems in Providing Goal-Concordant and Non-Racist Care

Based on what we have presented here, we are asking clinicians and health care centers to make the diverse perspectives of African Americans the central axis around which solutions to this problem are found. Ultimately, we seek to encourage clinicians to approach these patients as individuals who belong to a strong culture but possess various experiences that make them unique. Thus, we first ask that clinicians start by *moving away* from the negative labeling of end-of-life care, as "aggressive," and *lean towards* selecting language that demonstrates respect and understanding of the culture and beliefs of the African American Christian patient, while balancing the professional medical ethic to Do No Harm. Additionally, we recommend avoiding using "aggressive" care with any patient, as the term itself is negative and places patients and families at odds with the medical team, thereby limiting goals of care discussions. One method of achieving this balance is by engaging in critical reflection of bias and role performance [60]. This can be supported with data from implicit bias training [61], which is crucial to personal and professional ownership of how clinicians treat patients who differ from oneself. This process of reflection also allows clinicians to develop a sense of *prognostic humility*, which acknowledges that prognosis is based on clinical indicators and prediction models that can imperfectly predict outcomes based on mostly objective criteria, which rarely incorporates a comprehensive view of the patient within the context of their resilience, resources, or resolve [62]. Sharing prognostic information in a culturally-sensitive manner[63] is welcomed [59] *as long as it is done in a way that respects the patient and family's right to maintain "hope" and gives room for their belief in "miracles."* Accomplishing this task is complex and requires training, observation, and a willingness to improve the communication process. Clinicians who are willing to be fully present, are respectful, and acknowledge how this will impact care choices can bridge a cultural divide in the care and treatment of the patient [26,

48, 54, 56, 66]. Clinicians should also respond to medical mistrust and understand how it contributes to medical decision-making [48, 54, 56, 64]. Building trust takes time and includes *proof* (not only words) of true caring and respectful listening. To begin this cycle of trust building, it is key that providers exhibit patience, are respectful of hesitation in decision-making, and above all, do not counter lack of trust with defensiveness or disagreement. When clinicians approach patients with sensitivity, humility, and curiosity, they are better equipped to provide goal-concordant care that honors the patient's beliefs and begins to redress the impact of long-standing racism in health care.

Healthcare systems have a key role to play in this redress. First and foremost, there should be devoted time for clinicians to have frequent goals of care conversations with patients and families throughout each admission. Goals of care and treatment preferences may change as priorities shift as end-of-life nears; frequent conversations allow for full discussion and understanding between all those invested in the patient's care [65, 66]. These conversations should be patient and family driven and centered on the idea that African Americans are not a monolith, and while we have presented an important aspect of life for many African American Christians, not all will make decisions from a biblical frame. In addition, including families to the greatest extent possible is also advisable, even if the patient has decision-making capacity, so clinicians can assist the family through their own conflicting goals or values for care. Vital to the success of this work is incorporating African American stakeholders who live and work in the community as ambassadors to the healthcare system [67, 68]. Within these positions, diverse African Americans can serve as community gatekeepers, on bioethics committees and reorganizational boards, or give their perspectives on quality improvement projects. The lived experience of these community members serves as a knowledge base on what the community needs and expects from clinicians within the healthcare system during serious illness and as end-of-life approaches [67, 68]. Not only will the healthcare system gain valuable insights on equitable care, but their participation also has the potential to increase community trust in the healthcare system and its providers.

Conclusion

We have demonstrated how labeling care at end-of-life as "aggressive," used more often in describing end-of-life care of African Americans than for other groups, discounts the deeply held beliefs in God, hope, and miracles for some African American Christians. It is our hope that by providing insight and understanding of the beliefs, their origins, and the substantive importance of scripture and faith to the African American Christian community, we have increased awareness among clinicians who care for patients who are seriously ill. By implementing our recommendations to clinicians and healthcare systems, the dialogue on this issue can begin with the overriding goal of all African Americans receiving equitable levels of goal-concordant care at end-of-life.

Declarations

Conflict of Interest The authors declare no competing interests.

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