Catholic health care is one of the key places where the church lives Catholic social teaching (CST). Yet the individualistic methodology of Catholic bioethics inherited from the manualist tradition has yet to incorporate this critical component of the Catholic moral tradition. Informed by the places where Catholic health care intersects with the diverse societal injustices embodied in the patients it encounters, this book brings the lens of CST to bear on Catholic health care, illuminating a new spectrum of ethical issues and practical recommendations from social determinants of health, immigration, diversity and disparities, behavioral health, gender-questioning patients, and environmental and global health issues.

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LYSAUGHT AND McCARTHY

Catholic Bioethics & Social JUSTICE

The Praxis of US Health Care in a Globalized World

EDITED BY M. THERESE LYSAUGHT AND MICHAEL McCARTHY
FOREWORD BY LISA SOWLE CAHILL

and the individuals they serve. The ERDs provide ample space for integrating sustainability into clinical practice. Indeed, environmental clinical ethics fits within the already established disciplines of environmental bioethics[29] and Green Bioethics[30] in its dedication to sustainable health care, while simultaneously maintaining the immense worth of individual human life, the claims of the common good, and the moral obligations of environmental stewardship.

Today, the environmental crisis presents a unique opportunity for Catholic health care to practice clinical ethics in a way consistent with the ERDs and wider Catholic social thought on justice and the environment. Using environmental clinical ethics to evaluate medical treatments, especially at the EOL, can support the patient and provide a sense of connection to the common good when a dying patient needs it most.

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[29] Cristina Richie, "A Brief History of Environmental Bioethics," *AMA Journal of Ethics* (formerly *Virtual Mentor*) 16, no. 9 (2014): 749–52; Michael McCally, ed., *Life Support: The Environment and Human Health* (Boston: MIT Press, 2002); Jessica Pierce and Andrew Jameton, *The Ethics of Environmentally Responsible Health Care* (New York: Oxford University Press, 2004); David Resnik, *Environmental Health Ethics* (Cambridge, UK: Cambridge University Press, 2012).

[30] Cristina Richie, *Principles of Green Bioethics: Sustainability in Health Care* (East Lansing, MI: Michigan State University Press, forthcoming).

Chapter 8

Racial Disparities at the End of Life and the Catholic Social Tradition

Sheri Bartlett Browne and Christian Cintron

Angela's tiny, one-pound baby, Faith, arrived unexpectedly at twenty-four weeks gestation after a precipitous labor and delivery.[1] As Faith was alive at birth, Angela requested that every effort be made to save her life. Faith's subsequent prolonged neonatal intensive care unit (NICU) stay was in many ways remarkable. In addition to 175 days of mechanical and noninvasive ventilation, she endured two surgeries, several life-threatening infections, and severe lung disease. Her parents were told to prepare for her death numerous times, but for six months Faith defied the odds.

Faith's Black parents were unmarried, underemployed, and estranged from other family members. Angela's pregnancy had been complicated by poorly managed hypertension, obesity, and infrequent prenatal care. Faith was airlifted a few hours after her birth to a hospital over 100 miles away from the rural town and small apartment Angela shared with Faith's father and her two teenage boys. During this time, Angela had no reliable transportation between home and the hospital, greatly complicating her ability to care for her sons and her new baby.

Angela was fiercely devoted to Faith and distrusted the all-White clinical staff caring for her baby. She demanded that occupational

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[1] To protect patient and family confidentiality, identifying information has been removed from this case narrative.

and physical therapists teach her how she could participate in Faith's care, even though she perceived that "They don't like it that I want to do all her care that I can." In addition, she rarely missed morning rounds with the medical team because she wanted to understand what was being done for and to Faith. These meetings, however, caused significant anxiety and frustration on both sides. Often rejecting information the medical team provided as "destroying my hope," Angela developed a reputation for yelling at physicians and nurses. "They think I'm stupid and don't understand, but I do," she reported. From the team's perspective, though, Angela was a problem parent that failed to accept the NICU environment and authority structure.

Committed to her Pentecostal faith tradition, she believed that God would provide complete physical healing if only the medical team would not "give up on Faith." The team differed, believing that Faith was likely to survive less than a year and would not leave the hospital without a tracheostomy for long-term mechanical ventilation and a permanent feeding tube. In fact, they presented these two grim realities as a choice for Angela to make. She could accept that Faith would die and explore hospice resources or agree to a tracheostomy and hope that Faith eventually would go home with 24/7 supportive care. These emotionally fraught options only increased the probability that Angela would be, as a social worker put it, "explosive and difficult to manage."

When Faith was six months old, with her condition worsening, Angela made the agonizing decision to approve the tracheostomy. But there really was no other choice to make, as Angela rejected outright ending curative treatment and accepting comfort care. "God and I are not giving up on her," she told the attending physician. The morning before Faith's scheduled surgery, however, she rapidly deteriorated. Early the next day, she went into cardiac arrest. After multiple rounds of CPR inflicted on Faith's ten-pound body, which Angela reported was the "most horrible thing I ever saw," she begged the medical team to stop. Hours later she said, "She didn't want that trach. And now she doesn't have to have it. She's with Jesus."

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Angela's and Faith's heartbreaking story is multilayered and complex, particularly in its psychosocial, medical, and theological dimensions. This family's experience is not unique and illuminates challenges inherent in addressing health care disparities at the end of life (EOL). For example, at several critical junctures in Faith's medical journey, a "comfort care" hospice approach was offered to Angela. That she refused it outright at every point, insisting as well that Faith be treated fully to the end, typifies a Black American approach to EOL care, rooted in a history of racist culture in medicine and reflected in troubling health disparities.

In 1985, the US Department of Health and Human Services (DHHS) issued a report that launched over thirty years of research, clinical interventions, community education, and millions of dollars in health care funding. The Heckler Report acknowledged that "persistent, significant health inequities exist for minority Americans" and further noted that "efforts of monumental proportions were needed" to address disparities in health care. In stark terms, the report presented a health care crisis and national embarrassment that reflected the US racial divide.[2]

As a response, beginning in 1990, Healthy People campaigns brought to the forefront the issue of health disparities.[3] Recognizing that Black Americans, Native Americans, Hispanic Americans, and Asian/Pacific Islanders suffered and died from preventable and treatable illnesses at rates far exceeding those of the White population, policy makers, scholars, and community leaders decided to direct most of their attention to eliminating health disparities among Blacks, then the largest minority group in the country. Yet thirty-three years after the Heckler Report, success in eliminating racial disparities in health care remains elusive. While significant gains have been made in the treatment of and outcomes for Black patients with cardiovascular disease and specific cancers, for instance, many of the problems the DHHS identified in 1985 have been intractable.[4] Black

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[2] US Department of Health and Human Services, "Report of the Secretary's Task Force on Black and Minority Health" (1985): 2, and opening letter from Secretary Margaret M. Heckler, https://minorityhealth.hhs.gov/assets/pdf/checked/1/ANDERSON.pdf.

[3] See Centers for Disease Control and Prevention (CDC), "Healthy People 2000, 2010, and 2020," https://www.cdc.gov/nchs/products/hp_pubs.htm.

[4] David Williams notes that despite improvements in treatments for heart disease and cancers, the gap between Black and White survivability persists. See Institute of Medicine, *How Far Have We Come in Reducing Health Disparities? Progress Since 2000:*

Americans' lack of access to and utilization of care is therefore a matter of community urgency and social justice.

This essay examines cultural and structural barriers that Black individuals face in utilizing health care, with specific reference to EOL issues such as hospice care and advanced directives. Black Americans bring perspectives to EOL care that reflect their experiences as a historically marginalized and systemically oppressed people; these perspectives help to illuminate more broadly dynamics that underlie health care disparities in the United States. Furthermore, we argue that the Catholic social tradition (CST) provides a liberative paradigm for ethical and equitable treatment that requires relational, intentional, and community-oriented approaches to ending racial disparities in health care.

The Persistence of Racial Disparities at the End of Life

It is well known in the EOL literature that Black patients and families generally eschew hospice care for terminal and life-limiting illnesses. Medicare is the main payer of hospice services for people aged 65 and over, yet in 2015, Blacks represented only 8.2 percent of Medicare-eligible hospice patients when they were 10 percent of the total Medicare-eligible population. State-specific data are even more revealing of the gap between eligibility and utilization; in eight southern states, Blacks are more than twenty percent of eligible beneficiaries. The disparity in accessing adequate EOL care stems from a wide range of factors: socio-cultural, spiritual, and the historical isolation of the Black community within predominantly White medical systems.[5]

Hospice seeks to provide physical and medicinal comfort, counseling and spiritual support, and family bereavement services to individuals whose terminal illness or injury is not viewed as curable.

Workshop Summary (Washington, DC: National Academies Press, 2012), 13, https://www.ncbi.nlm.nih.gov/books/NBK100492/pdf/Bookshelf_NBK100492.pdf.

[5] See National Hospice and Palliative Care Organization, "Facts and Figures," (2016), 3–4, https://www.nhpco.org/sites/default/files/public/2016_Facts_Figures.pdf; The Henry J. Kaiser Family Foundation, "Profile of Medicare Beneficiaries by Race and Ethnicity: A Chartpack," March 9, 2016, https://www.kff.org/report-section/profile-of-medicare-beneficiaries-by-race-and-ethnicity-chartpack/.

Yet entrenched racism and systemic discrimination support Black beliefs in rejecting hospice care.[6] The deaths of Black men, women, and children are portrayed relentlessly as sudden, violent, and/or a product of dysfunctional communities. Black life expectancy is lower than Whites by an average of four years for men and three years for women.[7] Equally alarming, as Aana Vigen's chapter notes, Black women's maternal mortality rate is four times that of White women and Black infants are twice as likely to die before age one.[8]

To live one more day, when Black lives are portrayed as expendable, is viewed as a victory over death itself. Ending potentially curative interventions is perceived often as giving up the battle. "If there is any chance that life is there, I would suggest to go the extra means. Technology is there to keep people alive and give people longer lives."[9] These comments echo the sentiments of Angela with respect to Faith, "We never gave up on her. We did good." However, Angela felt she faced a daily battle to convince the medical team to fight harder for Faith, which created a persistent sense of distrust. Although Angela's feelings and experience were personal, they also reflect a long history of racially based medical abuse.

Black Americans have been targets and victims of medical experimentation from the era of slavery into the late twentieth century, including gynecological and neurological experimentation as well as forced sterilization.[10] Perhaps most egregious was the infamous Tuskegee Syphilis study (1932–72). Four hundred men in Macon

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[6] See Annette Dula and September Williams, "When Race Matters," *Clinical Geriatric Medicine* 21 (2005): 240–43.

[7] For Black life expectancy, see Centers for Disease Control and Prevention, "Changes in Life Expectancy by Race and Hispanic Origin in the United States, 2013–2014," https://www.cdc.gov/nchs/products/databriefs/db244.htm.

[8] See Aana Vigen's chapter in this volume for data on disparities in maternal and infant mortality (chap. 5).

[9] Catherine M. Waters, "Understanding and Supporting African Americans' Perspectives of End-of-Life Care Planning and Decision Making," *Qualitative Health Research* 11, no. 3 (May 2001): 390.

[10] Daniel P. Scharff, et al., "More than Tuskegee: Understanding Mistrust about Research Participation," *Journal of Health Care for the Poor and Underserved* 21, no. 3 (Aug. 2010): 880; Irin Carmon, "For Eugenic Sterilization Victims, Belated Justice," *MSNBC*, June 27, 2014, http://www.msnbc.com/all/eugenic-sterilization-victims-belated-justice. Regarding gynecological experiments, see J. Wasserman, et al., "Raising the Ivory Tower: The Production of Knowledge and Distrust of Medicine among African Americans," *Journal of Medical Ethics* 33 (2007): 178.

County, Alabama, suffering from syphilis were studied in a decades-long experiment to investigate the natural course of the disease. Even when antibiotic treatment became widely available, these men did not receive it.[11] As one focus group participant from St. Louis stated, "Just that awareness [about Tuskegee] is enough to stand up generation after generation."[12] Medical mistrust also became a point of contention between Angela and Kevin, Faith's father. He did not want Angela to go home to visit her sons for fear that "these people will do something to [Faith] when we're not here." It is difficult to make critical medical decisions for yourself or a loved one when you lack a fundamental sense of trust in those providing patient care. These tensions can become heightened when discussing patient wishes around DNR (do not resuscitate) orders.

Many studies attest to Black patients' reluctance to sign a DNR form or any type of advanced directive.[13] Rather than viewing a DNR as a means to prevent unwanted, aggressive measures in the dying process, many Blacks view the forms as yet another way that a medical system and its providers can reduce or eliminate care of an expendable Black life. These forms are often referred to colloquially as "death warrants," reflecting Blacks' lived experience of discrimination and historical memories of institutional abuse and betrayal.[14] Angela refused even to discuss a DNR for Faith because she was convinced the doctors "would just let her die." The burden of addressing this mistrust should not rest with the Black population; instead, medical teams and hospital systems must demonstrate through compassionate actions and culturally compassionate communication that they are trustworthy to care for Black patients. Yet these considerations fall often outside of the traditional purview of bioethics.

Inadequate Frameworks for Racial Disparities

EOL care represents a founding set of ethical questions within both a secular and religious bioethical discourse. Within Catholic bioethics, EOL care is equally prominent but negotiated within a distinct moral framework. Issues include an array of technical ethical distinctions regarding forgoing treatment and seemingly uncomplicated topics such as pain management and advanced care planning.[15] While these distinctions and terms can be helpful in discerning what is morally appropriate in light of a patient's situation (health, family, social), the perspectives of Black patients highlight how traditional frameworks such as Tom Beauchamp and James Childress's principles, in which many clinicians and ethicists are trained, obscure critical and operative racial and cultural dynamics.

As the preeminent value in American culture, autonomy's place in biomedical ethics is commensurately privileged as the primary principle toward which patients, physicians, and other health care workers look for guidance. "Respect for the autonomous choices of

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[11] This research project involved a whole cohort of physicians (both Black and White) and the approval of the US Public Health Service. See Bernice Roberts Kennedy, et al., "African Americans and Their Distrust of the Healthcare System: Healthcare for Diverse Populations," *Journal of Cultural Diversity* 14, no. 2 (Summer 2007): 56.

[12] Daniel P. Scharff, et al., "More than Tuskegee," 884.

[13] Advanced Directives, including Physician Order for Life-Sustaining Treatment (POLST) forms, are common and widely used in hospice and other EOL care situations, because they provide a written record of a dying person's medical wishes, in which a patient often elects to restrict the use of extraordinary medical interventions such as cardiopulmonary resuscitation, mechanical ventilation, artificial hydration, and nutrition that would not provide sufficient benefit. See, for example, Faith P. Hopp and Sophia A. Duffy, "Racial Variations in End-of-Life Care," *Journal of the American Geriatrics Society* 48, no. 6 (June 2000): 658–63; and Kimberly S. Johnson, et al., "What Explains Racial Differences in the Use of Advance Directives and Attitudes Toward Hospice Care?" *Journal of the American Geriatrics Society* 56, no. 10 (October 2008): 1953–58.

[14] Dula and Williams, "When Race Matters," 242.

[15] See part five of United States Conference of Catholic Bishops, "Issues in Care for the Seriously Ill and Dying," *Ethical and Religious Directives for Health Care Services*, 6th ed. (Washington DC: USCCB, 2018), which outlines the traditional list of end-of-life topics in bioethics, both generally and in the Catholic tradition. A primary emphasis in directives 55 and 59 is on the role of informed consent and patient autonomy in the patient's opportunity to choose a morally appropriate treatment. Directives 56 through 58 address ordinary and extraordinary means of care, including the use of artificial nutrition and hydration. Directives 60 and 61 outline the importance of effective pain management in care for the dying, particularly as means of maintaining the patient's dignity. See also "Forgoing Treatment at the End of Life," in *Health Care Ethics: Theological Foundations, Contemporary Issues, and Controversial Cases*, ed. Michael R. Panicola, David M. Belde, John Paul Slosar, and Mark F. Repenshek (Winona, MN: Anselm Academic, 2011).

persons," argue Beauchamp and Childress, "runs as deep in common morality as any principle."[16] While this may resonate with most as a result of an American cultural leaning toward individualism, the priority of autonomy, albeit unintended by Beauchamp and Childress,[17] has caused disagreement among biomedical ethicists about how and why autonomy should be valued over and against other ethical principles and the competing values of health care professionals and/or cultural values of patients. In light of the increased emphasis on autonomy as (unrestricted) individual liberty, patients are more empowered, both intellectually through expanded access to medical and health care information and by exploiting clinicians' fear of legal or administrative censure.

Still, the autonomy of patients of color is stymied by systemic injustices, of which the most basic form is a failure or unwillingness to listen to the patient. Unfortunately, traditional Catholic bioethics implicitly supports this model of care and decision-making insofar as it promotes the autonomy of the person vis-à-vis the synergistic *telos* of the good life that coincides with the grace of free will. Oftentimes, the Catholic tradition turns instead to the language of dignity over autonomy, without considering how the two terms may be used synonymously throughout American society. When dignity is substituted for autonomy and vice versa, the whole of the patient's experience as contextualized subject is lost.

The USCCB's *Ethical and Religious Directives for Catholic Health Care Services* (ERDs) directives 24 and 25 outline a patient's right to an advanced directive (AD) consistent with Catholic teaching, and further stipulate conditions for surrogate decision-making. However, it is no surprise that ADs are underutilized by patients skeptical of the medical system. Similarly, the Catholic tradition encourages hospice care, claiming "patients should be kept as free of pain as possible so

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[16] Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* (New York: Oxford University Press), 99.

[17] Ibid. The authors maintain while the first principle appearing in the text is autonomy, it is not an indication of their opinion on the moral priority of autonomy. They argue that while their "critics suggest that the principle for respect for autonomy overrides all other moral considerations," their work is in no way "excessively individualistic."

that they might die comfortably and with dignity, and in the place where they wish to die."[18] Yet, this support from the tradition does not address the systemic reasons underlying reduced availability and use of these services by Black patients. Despite their importance, the traditional teachings of Catholic bioethics prove to be ineffective practically for the patient and the clinician.

In addition to the cultural and historical reasons outlined above, a further issue lies in the theological anthropology that grounds these teachings. Womanist Catholic theologian M. Shawn Copeland argues that the undignified and sinful treatment of the Black community perverts traditional theological anthropology, expressed as *imago Dei*, and rejects the "Black body as a site of divine revelation."[19] Persistent failure to recognize the sacramentality of the Black body has contributed to, and at times legitimized, systems of oppression, and perpetuates bias toward Black persons and has indeed denied their innate human dignity. So, while dignified treatment of persons as an integrated whole is expected, Bl~~acks are~~ denied that type of care, directly or indirectly, through systemic or individually perpetrated violence. Precisely because of persistent and pervasive failures to encompass Black bodies within its theological anthropology, Catholic bioethics has not only turned a blind eye to medical abuse or neglect of Black patients; it also has failed to provide a sufficiently robust framework for championing the specific dignity of embodied Black people. Dignity can continue to offer a critical lens for assessing Black American responses to EOL care as long as dignity is not an abstract principle. Even then, however, dignity alone cannot fully respond to health care systems' unjust practices that contribute to the continued marginalization of Blacks, for dignity is only one component of theological anthropology. Only by incorporating the social nature of the person can we chart a path forward in correcting racial disparities at the EOL and care for Black bodies as sites of divine revelation.

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[18] United States Conference of Catholic Bishops, *Ethical and Religious Directives*, directive 61.

[19] M. Shawn Copeland, *Enfleshing Freedom: Body, Race, and Being* (Minneapolis, MN: Fortress Press, 2009), 24.

"White Spaces": Reconsidering the Social Nature of the Human Person

CST illuminates a second essential anthropological feature, namely, people's social being. Persons are relational, only finding fulfillment through "the social ties of family, associations, and political community."[20] Honoring this dimension of an individual's life is as important when one's life is coming to an end as it is at any previous time. Only when persons are considered within their social milieu, and, in the particular case of Black Americans within their historical context, can we begin to appreciate the complex dynamics that Blacks bring to EOL care and how health care as a "White space" often impedes their integral fulfillment.[21]

Elijah Anderson describes White spaces as those which are characterized by the presence of White people and the absence of Black people. When Blacks do enter such spaces, he notes, "others there immediately try to make sense of him or her—figure out 'who that is,' or to gain a sense of the nature of the person's business and whether they need to be concerned."[22] Health care is a White space, and racist treatment has been a dominant feature of US health care. Black bodies have been treated as less than and disposable, resulting in a lack of attention to Black persons as a unified whole; an unwillingness to address them as socially situated perpetuates biases on the part of health care providers and results in inadequate EOL care options. CST challenges these biases by emphasizing "we cannot fight for our lives in isolation . . . we must recognize the biological, social, environmental, and economic conditions that surround us and have profound impacts on our health."[23] The social dimension of the human person counters the White space of health care and its White notions of autonomy that frame EOL conversations.

CST's focus on the social nature of the human person highlights and counters the White Western liberal emphasis on individual autonomy that pervades traditional bioethical discourse and its inherent bias that tends ironically to "disregard innovative and good ideas that might come from non-privileged groups."[24] In the individual model, the clinician remains susceptible to viewing patients as a condition-to-be-treated, rather than cared for as a person in the context of a community. A focus on the relational dimension of autonomy incorporates the patient's context, perceived and real, addresses power dynamics existing between autonomous patient and clinician, and confronts the assumption that patients' understandings of autonomy coincide with those of traditional bioethics. The relational dimension of autonomy at the EOL does not magically resolve the myriad issues facing Black patients; it represents, rather, an important turn in caring for patients as socially situated or relational beings, an important first methodological insight of CST.

Second, the CST's response to marginalized persons and communities aims to correct both acute and systemic causes of injustice in pursuit of the common good. The pursuit of the common good, validated in the preferential option for the marginalized, is further elucidated in the CST's principle of solidarity. In *Sollicitudo Rei Socialis* (1987), Pope John Paul II called solidarity the remedy for social sin. "Solidarity is a firm and persevering determination to commit oneself to the common good, that is to say, to the good of all."[25] Black patients experience inequitable treatment at the EOL for numerous reasons: power dynamics that exist between providers and patients, social determinants of health contributing to patients' conditions at the EOL, and discriminatory practices that limit access to hospice and other EOL services to name a few. Solidarity, coupled with the preferential option for the marginalized, mandates an obligation to care for those who have been subjected to systemic oppression or denied basic rights.

The preferential option obliges health care providers and relevant political organizations to improve care available to these patients, ensures that care is equal to the care of others, and also corrects the very social structures that have created an environment in which Blacks at the EOL do not choose or are not offered adequate and equitable care. Responses to structural sins of racism, socioeconomic

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[20] Charles E. Curran, *Catholic Social Teaching: A Historical, Theological, and Ethical Analysis* (Washington, DC: Georgetown University Press, 2002), 133, summarizing *Gaudium et Spes* 24–25.

[21] Jamelle Bouie, "White Spaces," *Slate* (April 17, 2018); Elijah Anderson, "The White Space," *Sociology of Race and Ethnicity* 1, no. 1 (2015): 13–15.

[22] Anderson, "The White Space," 13.

[23] Emilie Townes, *Breaking the Fine Rain of Death: African American Health Issues and a Womanist Ethics of Care* (Eugene, OR: Wipf and Stock, 2006), 119.

[24] Copeland, *Enfleshing Freedom*, 14.

[25] Pope John Paul II, *Sollicitudo Rei Socialis* 38, para. 5.

oppression, and racial disparities in health care must comprise fortitude to seek lasting societal change and commitments to love and serve one another, to see our common humanity as fundamentally interconnected. These liberative dimensions of the CST are bound to the very mission of health care, and such an approach may also well lead to changes in EOL paradigms, as Black perspectives and experiences bring correctives to standard White practices.

Moving Forward Together

The historical, cultural, theological, and ethical complexities surrounding racial disparities in EOL care are obviously daunting. Indeed, there is no "band-aid" that can heal the wounds of racism, slavery, segregation, disfranchisement, medical experimentation, and forced sterilization. Yet, there are approaches to EOL care, informed by CST, that promote physical, spiritual, and psychosocial healing and foster relationships of trust. These include the reevaluation and expansion of cultural humility curricula; the adoption of aggressive measures to racially and ethnically diversify the clinical workforce; and advocacy and promotion of palliative care as a holistic and compassionate approach to chronic and life-limiting illness.

First, medical schools and health care systems must be committed assertively to cultural diversity. They must offer robust training and curricula in cultural humility rooted in pedagogies of solidarity and the obligation to care for and improve the condition of the marginalized. These curricula ought to replace current approaches to "cultural sensitivity" training that by design undermine its significance by reinforcing racist stereotypes about "the other" and present minority cultures and beliefs as a problem to overcome. Contrary to what many employees and administrators may think, the purpose of training in cultural humility is not to help us be nice to each other but is meant to help us truly care for one another.[26] In caring for one another, the entirety of the health care ministry engages in the praxis of solidarity.

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[26] Aana Vigen, "'Keeping it Real' while Staying out of the 'Loony Bin': Social Ethics for Health Care Systems," in *On Moral Medicine: Theological Perspectives in Medical Ethics*, 3rd ed., ed. M. Therese Lysaught and Joseph Kotva (Grand Rapids, MI: Eerdmans, 2012), 172–74; and Carolyn Waters, "Understanding and Supporting African Americans' Perspectives," 396.

Indeed, as Copeland argues, the praxis of solidarity begins with "anamnesis—the intentional remembering of the dead, exploited, despised victims of history," which imposes an obligation upon Christians to shoulder "responsibility for that history."[27] Approaching culture in the spirit of solidarity places the emphasis on an encounter with the other, while at the same time recognizing and addressing the structural injustices that affect the Black community.

These curricula for Catholic health care systems should be designed to challenge learners' assumptions and understandings of systemic racism and structural oppression. CST emphatically states that racism and poverty are social and structural sins that must be acknowledged and eradicated. Doing so provides an opportunity for health care systems to learn from Black Americans' sociocultural history within medicine and their current social location, as clinicians and health care systems strive toward models of health care delivery that truly embody solidarity. Preferably, this curriculum would be taught by specifically trained practitioners who are not majority White and could be developed or expanded based on cultural sensitivity resources already present within Catholic health care systems.

Another possible approach to this curricula, which honors people's relational and social ties to family and community, is through shared partnership opportunities in neighborhood clinics, organizations, or churches, enabling clinicians to listen to and learn from people whose sociocultural and medical experiences are different from their own.[28] One such model that immerses participants in the praxis of solidarity is the "Neighborhood-Engaged Care" curriculum developed for medical students participating in the Urban Bioethics Program at Temple University in Philadelphia. Students enrolled in a semester-long Community Engagement course are integrated as learner-practitioners into neighborhood health clinics and nonprofit organizations serving specific diverse urban populations.[29] In so

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[27] Copeland, *Enfleshing Freedom*, 100.

[28] Aana Vigen, "'Keeping it Real,'" 172–74.

[29] Norma Alicea-Alvarez, et al., "Impacting Health Disparities in Urban Communities: Preparing Future Healthcare Providers for 'Neighborhood-Engaged Care' Through a Community Engagement Course Intervention," *Journal of Urban Health: Bulletin of the New York Academy of Medicine* 93, no. 4 (2016): 732–43; see also Copeland, *Enfleshing Freedom*, 94.

doing, participants are confronted by and challenged to address oppressive causes of suffering and bear that burden for the other.

In developing partnerships, insights and tools of clinical pastoral education (CPE) prove helpful for reimagining competency curricula. CPE long has been recognized as a necessary educational component of health care chaplaincy and is also highly recommended for community pastors who wish to serve capably their ailing and dying congregants. It is a model for the type of solidarity advocated by the CST, caring for one another with dignity, respect, and informed awareness of a patient's relational, social, and theological milieu. CPE's hallmark learning style is praxis oriented, focusing on action-reflection-action in clinical settings. It requires that the learner/practitioner embrace self-critique, particularly in challenging of one's sociocultural assumptions and how those assumptions affect care provided to others.[30] Perhaps most important, CPE requires that practitioners build skills in attentiveness and deep listening. To truly listen signals respect and empathy for the speaker's circumstances; it indicates a desire to be fully present and attuned to another's tone and body language. Especially in reference to death and dying, Black patients feel keenly that they are not worth the time, that their stories are a waste of time, that their family members will take too much time.[31] Recall that one of Angela's primary frustrations with the physicians caring for Faith was that she believed they did not listen; therefore, she felt their attitude toward her was patronizing and dismissive. Listening is one of the most significant ways in which to honor the life story and dignity of a fellow human being.

Our second recommendation addresses the structural change that needs to happen among educators, medical schools, health systems, and Black communities to mentor, recruit, and retain qualified clinicians who are not majority White.[32] The mistrust and unease that Angela and Kevin expressed about leaving Faith alone in the hospital was partly related to the racially stratified staffing they saw around

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[30] See Logan C. Jones, "You Learn it in Your Heart: Transformative Learning Theory and Clinical Pastoral Education," *Journal of Pastoral Care and Counseling* 64 (December 2010): 1–10.

[31] See Carolyn Jenkins, et al., "End-of-Life Care and African Americans: Voices from the Community," *Journal of Palliative Medicine* 8, no. 3 (2005): 585–92.

[32] For more on the importance of diverse staffing for patient care and satisfaction, see Robert Gordon's chapter in this volume (chap. 10).

them. "The only Black people I see here are the ones cleaning the floor," Angela said. National trends in Black medical student graduates have held steady at roughly ten percent of the total graduate population, but these figures will result in a shortfall of tens of thousands of Black physicians by 2025, especially in southern states where the majority of Blacks reside.[33] One prototype for increasing racial diversity among practitioners comes from a partnership between Ohio Hearts and Minds and Mercy Health in Cincinnati. They have implemented a mentoring program for Black youth from fifth through tenth grade to introduce them to Black medical professionals and careers in health care.[34]

Third, health care systems must embrace fully a model of comprehensive EOL care that is underutilized and poorly understood within society: palliative care. The philosophy of palliative care is multilayered and interdisciplinary, with teams including various subspecialties as well as chaplains and social workers. Palliative approaches focus on holistic and dignified health consistent with the Catholic tradition for those in chronic pain, with multiple co-morbidities, and those who are or will soon be experiencing the dying process.[35] Unlike hospice, it offers opportunities to continue curative therapies while addressing such factors as pain management and emotional support. It also can be effectively delivered in multiple medical venues as well as at home.

For Black patients, barriers to palliative care mirror those of hospice described above and require careful analysis to overcome.[36] However, a main objection that these patients voice regarding hospice

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[33] See the Association of American Medical Colleges, "Enrollment, Graduates, and MD-PhD Data," https://www.aamc.org/data/facts/enrollmentgraduate/; and Robin Warshaw, "Priming the Medical School Pipeline: Schools Reach Out to Teens in Minority and Underserved Communities," *AAMC News* (Association of American Medical Colleges), September 29, 2016, https://news.aamc.org/diversity/article/schools-minority-underserved-communities/.

[34] Kathleen Nelson, "Doctors Capture 'Hearts and Minds' of African-American Boys," *Catholic Health World* (Catholic Health Association of the United States, February 15, 2017).

[35] For a definition of palliative care, see National Hospice and Palliative Care Organization, "An Explanation of Palliative Care," https://www.nhpco.org/explanation-palliative-care; and USCCB, *Ethical and Religious Directives*, 55–59, 61.

[36] See, for example, LaVera Crawley and Richard Payne, et al., "Palliative and End-of-Life Care in the African American Community," *Journal of the American Medical Association* 284, no. 19 (November 2000): 2518–21.

are perceptions that one is "giving up" on treatment and therefore giving up on life. Opportunities to continue curative measures and participate in palliative therapies must be clearly and compassionately discussed with patients and their families. The meaning of hospice and palliative care often are conflated, which increases the chance that palliative care also will be rejected. For these reasons, it is imperative to work in and through existing community structures to provide information regarding EOL care.

These three recommendations require collaboration with local communities, draw from the CST's emphasis on solidarity and subsidiarity, and could be administered effectively through partnerships between Catholic health care ministries, local parishes, and community centers, possibly as part of community benefit programs. The programs not only would address the EOL concerns raised above, but would also facilitate improved relationships between community members and local health care ministries in an effort to address thoughtfully and compassionately lingering effects of medical mistrust. One example of this type of health care community collaboration is Samaritan Center, a facility that formerly housed Detroit Mercy Hospital. The center hosts primary care and dental clinics as well as seventy other tenants providing "a platform for addressing social determinants—including homelessness, hunger, joblessness, illiteracy and poverty—that have a significant impact on people's health." While its focus is not specifically on EOL care, the center is a model for social service and health care outreach. According to its Executive Director Mark Owens, "This is a place that gives people hope."[37]

Initiatives such as Samaritan Center additionally would provide an opportunity to address the general health of the neglected Black population toward improving the aging process itself. With this outreach and focus, the EOL process would not be a shock to patients and their families. These programs also would provide a familiar and comfortable environment for communicating more effectively the

purpose and benefits of palliative care. Ecumenical collaboration with Black pastors in the community, including the requisite medical ethical training of the pastors themselves, would allow for Catholic health ministries to serve better their Black patients who have established relationships with leaders of their respective congregations. A community-based approach such as this can truly illuminate and respond to concerns of Black patients approaching or already dealing with the EOL in a manner consistent with the CST.

Finally, from a health care systems and leadership perspective, addressing and eliminating racial disparities in EOL care requires that resources for palliative care must be a priority, not only in terms of expansion and funding but in terms of commitment to executing high quality care. It is especially unfortunate that palliative care is not always available in communities with large populations of vulnerable and marginalized people. Recent data demonstrate an acute shortage of palliative care resources in areas where the vast majority of Black patients live.[38] Pediatric palliative care has been available for only a few years in many large teaching hospitals, though its availability is even more limited in the South. At the southern hospital caring for Faith, the only pediatric palliative care physician had been hired just a few days before her death. One wonders what difference a culturally sensitive palliative approach might have made in medical decision making for Faith and in the bereavement support provided to her parents.

Conclusion

Racial disparities in health care have been a blight on the American health care system for decades. Resolving inequities in access to and utilization of treatment, particularly at the EOL, requires a holistic approach, one that takes into account Black Americans' lived and historical experiences as well as their cultural and theological perspectives. This brief essay is an attempt not only to understand the general problem and persistence of disparities and their possible

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[37] Julie Minda, "Repurposed Trinity Hospital is Health, Social Service Hub for Detroit's East Side," *Catholic Health World*, Catholic Health Association of the United States, March 15, 2018, https://www.chausa.org/publications/catholic-health-world/article/march-15-2018/repurposed-trinity-hospital-is-health-social-service-hub-for-detroit's-east-side.

[38] Center to Advance Palliative Care, "America's Care of Serious Illness: 2015 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals," https://reportcard.capc.org/wp-content/uploads/2015/08/reportcard-2015-table-a.pdf.

solutions but also to bring specific underserved voices into the discussion. Indeed, the voices of Black individuals often have been disregarded in the search for an end to disparities, and their specific health care needs frequently go unmet. For these reasons, we assert that CST's liberative dimension, as evidenced in the principles of solidarity, the option for the marginalized, and the pursuit of the common good, united with a theological anthropology that embraces human beings as social, relational, and interdependent, provides an ethical path forward on the journey toward ending disparities.

PART THREE

Incarnating a Just Workplace

Turning the lens of Catholic social thought on the practice of Catholic health care brings into view not only new community-based issues or subtle dynamics of patient-physician encounters; it also illuminates the often ethically fraught work context of health care associates. How an organization treats its employees—be they providing direct patient care or serving in less direct capacities—has a direct impact on the identity of the organization as well as its ability to embody that identity in practice. Questions of workers' rights, racial equality, and how to fairly organize a work environment to meet the needs of health care professionals remains a constant struggle. These questions are properly the purview of Catholic bioethics not only due to the long history of attention to the rights of labor and the integral meaning of work for human fulfillment in the Catholic social tradition. They are highlighted, again, in the *Ethical and Religious Directives*:

> A Catholic health care institution must treat its employees respectfully and justly. This responsibility includes: equal employment opportunities for anyone qualified for the task, irrespective of a person's race, sex, age, national origin, or disability; a workplace that promotes employee participation; a work environment that ensures employee safety and well-being; just compensation and benefits; and recognition of the rights of employees to organize and bargain collectively without prejudice to the common good.[1]

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[1] United States Conference of Catholic Bishops (USCCB), *Ethical and Religious Directives for Catholic Health Care Services*, 6th ed. (Washington DC: USCCB, 2018).