



Correcting Health Disparities at End-of-Life in Persons of Color

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ABSTRACT

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Forty years after the creation of the Medicare hospice benefit, low use of hospice and palliative care services in persons of color increases suffering and aggressive care at the end of life related to social determinants of death. A lack of culturally appropriate programs, diversity in hospice personnel, and education for health care personnel, and marginalized populations remain problematic. This article provides tools for nurse practitioners and other health care personnel in spiritual, cultural, and goals-of-care assessments, quality improvement, and an explanation of the benefits of faith-based programs and partnerships

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Introduction

The Medicare hospice benefit was a unique addition to the United States (US) health care system in 1983 during the Reagan Administration through amendments to the Social Security Act. It was envisioned to provide a flat rate payment for end-of-life care to those with a ≤ 6 -month prognosis, providing 4 levels of care, including routine home hospice care, continuous home care for crisis periods instead of hospitalization, general inpatient care for severe symptom management, and inpatient respite care to give up to 5 days' break for caregivers.¹

Although the hospice benefit has been available for >40 years, it is underused by persons of color, who are more likely to choose aggressive care due to many structural barriers in the form of cultural assumptions, lack of education, lack of diversity in hospice personnel, lack of assessments of patients goals, values, and wishes, social determinants, and lack of referrals to hospice or palliative programs.²

Preferences for Aggressive Care

Persons of color are also more likely to choose aggressive care on state-run Medical Orders for Life-Sustaining Treatment (MOLST) or Physician Orders for Life-Sustaining Treatment (POLST) forms that describe care preferences at end of life and are used in those with complex, chronic illness, to include hospice and palliative care patients.³ These forms, which can be matched to death records, document a tendency toward more aggressive care in persons of color that is often due to differences in cultural values and beliefs. A Maryland study found persons of color were more than twice as likely, at 62%, to select "attempt CPR" as White patients, at 32%.⁴

Various reasons exist for the preference for more aggressive care, ranging from socioeconomic status and educational level, lack of diversity in hospice and palliative care personnel, preferences for informal discussions with family, wishes for only family members

to care for them and advise on their care, historically rooted concerns about discrimination in health care causing distrust, and preferences for religious support from the community.⁵ The differences in preferences and beliefs often lead to a tendency toward more aggressive care at the end of life, which may lead to increased suffering.⁵

The Nurse Practitioner Role in Addressing End-of-Life Disparities

This article aims to address the role of the nurse practitioner (NP) in addressing problems caused by a lack of spiritual and goals-of-care assessments, describe the history of racism in health care that leads to distrust, and to describe potential solutions to barriers that decrease use of hospice and palliative care services. Additionally, innovative faith-based programs are described as a possible solution to these barriers, along with tools for the assessment of spiritual values and care preferences.^{6,7}

NPs are well positioned for roles in addressing end-of-life health disparities due to expertise in symptom management and ability to teach about disease progression, honesty in discussing prognosis and advance care planning, hospice eligibility, provision of psychosocial support, and advocacy abilities to ensure patient rights and wishes considerations. They occupy trusted positions in communities, have an established rapport with their patients, and have the ability to ensure goal-concordant care that aligns with patient and family goals and wishes.⁸

Health Literacy and Cultural Considerations

An international study shed some light on cultural considerations, such as verbiage and reading level, that could be important in parts of the US. Mayoral et al⁹ examined cultural adaptations needed for the global use of MOLST or POLST forms, or perhaps in parts of the US that are non-English speaking or have poor literacy rates. Because the Centers for Disease Control and Prevention (CDC)

recently updated its definition of health literacy in 2023 to include an individual's ability to use information to make well-informed decisions instead of just simply understanding the information, this study can help attain the new organizational responsibility to promote the use of information and not just the understanding of it.¹⁰

A new toolkit has been published by the Agency for Healthcare Research and Quality to improve health literacy. The toolkit includes guidance on "universal precautions," which is the assumption that all patients may have problems with health literacy. The teach-back method is important to be implemented throughout the visit and not just at the end. The toolkit recommends Plan-Do-Study-Act (PDSA) cycles to improve quality with health literacy initiatives, with additional resources given for medication adherence, communication practices, and referral techniques, taking extra care not to rely on patients to relay information. To address language barriers, they recommend identification of the language they speak with "I speak" cards and use of language services and posters in waiting rooms describing the use of interpretive services. Providing succinct instructions on what the patient needs to do and needs to know can simplify the visit information.¹¹

Adjusting the verbiage and reading level of such documents can aid in health literacy and achieving less aggressive interventions that may include the use of the Medicare hospice benefit or palliative care programs.¹⁰ The Flesch-Kincaid formula for reading level assessment is available in Word (Microsoft Corp.) through the spelling and grammar tool, and it is recommended to stay at the average sixth grade reading level or below, with adjustments made based on the patient population.¹²

Additionally, the very act of assessing patient preferences with a MOLST form was found to result in more goal-concordant and less aggressive care in 95% of patients, which can lead to options for comfort-focused care such as the use of the Medicare hospice benefit or palliative care services.¹³ Forms, such as a MOLST or POLST, can be valuable tools in assessing patient preferences but can also segue into discussions of hospice and palliative care. They can bridge from assessment to person-centered recommendations based on preferences or even increase the use of the Medicare hospice benefit if the preferences align with comfort and safety.¹³ Some states, such as Massachusetts, offer MOLST forms in many languages.¹⁴

Summary and Recommendations for US Health Disparity Populations

Health disparities are defined by the US Department of Health and Human Services as differences in health outcomes that are closely linked with social, economic, and environmental disadvantages.¹⁵ They designate Black/African Americans, Latinos, American Indians/Alaskan Natives, Asian Americans, Native Hawaiians, and other Pacific Islanders, socioeconomically disadvantaged populations, rural underserved populations, and sexual and gender minorities as US health disparity populations.¹⁵ These health disparities comprise social determinants of death, defined as the general socioeconomic, cultural, and environmental conditions, living and working conditions, social and community networks, and lifestyle factors associated with death in the elderly or those experiencing severe illness.¹⁶ These social determinants of death that affect death can also affect the education, beliefs, and barriers to use of services at the end of life, including the Medicare hospice benefit or palliative care services for complex chronic illness.

In outpatient settings, persons of color and those with lower socioeconomic status are referred less often for palliative care and have fewer opioid prescriptions and higher pain scores.¹⁵ Even in elderly African American populations, disparities exist in pain

management, with mismanagement often severe due to increased pain levels and potentially inappropriate medication use, such as nonsteroidal anti-inflammatory drugs (NSAIDs) not recommended for the elderly.¹⁷ The 2023 updated Beer's list from the American Geriatric Society discourages the long-term use of NSAIDs, unless other drugs cannot be used, due to the risk of gastrointestinal bleeding from erosive esophagitis, renal and cardiovascular adverse effects, and drug interactions that can cause risk for bleeding.¹⁸ Ali et al¹⁹ recommend alternatives such as acetaminophen, lidocaine, capsaicin, or opioids be used. The NSAIDs could still be used if others are ineffective.

The NP and other clinicians should be familiar with the attitudes, beliefs, and norms of persons of color to better understand their cultural assumptions.¹⁵ Cultural assumptions, such as drug-seeking behaviors, are cautioned against because they assume the belief systems or behaviors of persons of color before fully assessing their beliefs, values, and goals.⁵ These misunderstandings can translate to a rejection of end-of-life services, including the Medicare hospice benefit. Although the availability of hospice care exists, underuse by persons of color leads to more aggressive care at the end of life. Barriers to accessing hospice services for this population include spiritual beliefs and personal preferences, mistrust, as well as the social determinants of death.

Changes in program structures, thinking, and policy will be necessary to address the lack of diversity, cultural assumptions of health care personnel, and lack of assessment of goals, values, and preferences that lead to lower use of the Medicare hospice benefit or palliative care programs.² Examples of history of distrust, needed changes, such as public health initiatives and spiritual and person-centered interviewing, will be discussed further in their sections.

Structural Barriers

The History of Prognosis Teaching

Worldwide, only 14% of people requiring palliative care services receive these services, indicating a global problem.²⁰ In the US, ~70% of Americans say that they would prefer to die at home.²¹ However, only 20% to 30% of those wishing to die at home will due to many barriers.¹¹ The National Hospice and Palliative Care Organization reports that hospice use in the US varies by state, with Utah Medicare beneficiaries having the highest use of hospice, with 60.7% of Medicare deaths occurring on hospice; whereas, New York had the lowest use, at 24.7%. The national average was at 46.7% in 2020. Persons of color had lower use, at 33% to 36%. For all hospice enrollees, the median length of stay was just 18 days, with 50% of decedents receiving just ≤ 18 days of hospice care, even though the benefit was intended for use in the last 6 months of life.²²

The barriers to availability have a history that dates to the 1940s when prognosis teaching in US medical schools became outdated. A technology boom in the 1940s brought forth the thought that technology and prognosis could not coexist. In 1947, instruction on prognosis ceased in medical schools due to expanding technologies that made prognosis unclear. In the coming decades, medical schools began teaching that hospice and palliative care were giving up or taking hope away from the patient. By the 1970s, the word "prognosis" was removed from textbooks, but is slowly returning. Today, our nation continues to hold deeply cultural beliefs that death is to be fought and avoided and that other models of care may be considered giving up.²³

Although medical schools consistently fail to provide training regarding serious illness conversations and prognosis teaching, this is also slowly improving. Palliative medicine rotations are being offered to medical students with techniques such as curriculum mapping to identify gaps in serious illness training.²⁴ In nursing

programs of study, end-of-life training is expanding. With the advent of the End of Life Nursing Consortium (ELNEC) training, tens of thousands of nurses have been trained in end-of-life care and serious illness conversations.²⁵

NPs and other clinicians may fear taking away hope by discussing prognosis or using the Medicare hospice benefit and palliative care services. It is essential to teach patients that palliative care, unlike hospice, can be offered concurrently with disease-modifying treatments.²⁶ As a result of a death-avoidant medical culture that may confuse palliative care with hospice, patients often remain uninformed of their prognosis, their disease trajectory, expected outcomes as the disease progresses, what is treatable under current technology, and what treatments are likely to affect the quality of life or even shorten prognosis. Their symptoms are often poorly managed, and great suffering may occur as they approach their last years of life.²³

Although the Medicare hospice benefit and palliative care programs and practices were meant to address the needs of those approaching the last years, months, or days of life, they remain underused due to cultural values that are more disease-focused.²⁷ Disease-focused vs person-centered care remains a structural barrier in providing hospice benefit or palliative services, not just for persons of color, but for all persons worldwide.²⁷

Discrimination and Distrust

The US death-avoidant medical culture was compounded in persons of color by the addition of human rights violations, discrimination, slavery, and unethical conduct that have seeped into the public health, causing disparities in health care delivery, lower use of the Medicare hospice benefit and palliative programs, and a distrust of the medical system driven by historical contexts and personal experiences.²⁸ The historical barriers include end-of-life care when a suggestion that aggressive treatment may not be effective might be perceived as discrimination or may not align with spiritual beliefs, requiring more chaplain support and spiritual assessments.¹⁵ Still, by better understanding a patient and family's cultural views and preferences, health care providers can become more culturally sensitive while providing care valued by the patient and family.¹⁵

Culturally relevant faith-based programs improve end-of-life care for persons of color with the use of newer tools and models along with the development of faith-based programs that are more culturally relevant and are described below in their sections as ways to enhance cultural competence, humility, and diversity in the delivery of end-of-life care.^{6,29} These tools and programs, such as the FICA (Faith, Belief, Meaning, Importance or Influence, Community, and Address/Action) Spiritual History Assessment tool and faith-based programs, help address social determinants of death and health disparities of marginalized populations at the end of life.⁶ They aid in preventing harm through in-depth assessments that prevent non-goal-concordant recommendations that do not match the patient's values, goals, and beliefs.⁶ The harm from non-goal-concordant recommendations through lack of assessment can lead to avoidance of services for end-of-life care, the Medicare hospice benefit, or palliative services.⁶

Distrust in the medical system is most frequently born of personal experiences with racism, with the Tuskegee Syphilis study serving as a commonly used example of the history of distrust in racism in health care; however, other scientific misconduct in medical experimentation was documented by the *New England Journal of Medicine* in 1966. These included vulnerable populations, such as disabled children infected with hepatitis to test a γ -globulin treatment, and elderly Jewish patients who were injected with liver cancer cells and observed for tumor growth.²⁸

Although the Tuskegee study is often cited as a catalyst, personal experiences of inequality foster further mistrust of medical systems. Ongoing inequality in recruitment for studies, unethical practices in pharmaceutical trials, and coercive sterilization of Native American and Puerto Rican women are examples of historically rooted concerns of inequality that prevent engagement in health care or cause unwillingness to trust medical advice.²⁸

The "Islamophobia" of recent years and during presidential campaigns has affected the everyday life of Muslims, including their willingness to seek health care or accept teaching regarding their health.³⁰ The involvement of religious leaders and chaplain support in health care teaching is a way to correct health disparities born of spiritual concerns or mistrust in medical systems due to past histories of unethical or insensitive treatment.³¹

Cultural Preferences

Cultural views worldwide on how end-of-life decisions are reached are essential to consider, because US medical culture stresses patient autonomy, which may not reflect the values of other cultures.¹⁵ A focus on patient autonomy may only sometimes be relevant to other cultures that prefer family-based, clinician-based, or shared clinician and family-based approaches to care. Although patient autonomy is more favored by European Americans and African Americans, Asian and Mexican Americans often favor more family-centered decision-making models. In some countries, families have a high level of respect for the clinician and paternalism in health care delivery and appreciate a more paternalistic approach.¹⁵

All persons of color had lower rates of advanced directive completion, often due to their cultural decision-making preferences that may not value personal autonomy at the end of life, may have spiritual views that advance care planning does not recognize the authority of God in such matters, or may distrust the US medical system.¹⁵ Artificial nutrition via feeding tubes that can prolong death was more prevalent in persons of color due to distrust and spiritual views of the end of life.³² Artificial nutrition could have symbolic importance, such as being equivalent to caring and love, requiring cultural sensitivity in teaching and assessment.³³

Religiosity can be associated with aggressive treatment preferences, as persons of color express their reasons for existing in terms of family virtues and religion.³⁴ Key themes in end-of-life decision making among African American, Latino, or Asian Americans included family involvement, provider communication, religion and spirituality, and patient preferences.³⁴ Although spiritual care has been acknowledged as an intrinsic and essential component of palliative and hospice care, it remains the most neglected and least developed. Spiritual care is defined as "the dynamic dimension of human life that relates to the way persons experience and express true meaning, purpose, and transcendence, and the way that they connect to the moment, to self, to others, to nature, to the significant and the sacred," according to the European Association for Palliative Care.³⁵ Religion and spirituality become topics in many interviews with patients and families facing serious illness.³⁶

Faith-Based Programs and Health Care Quality Improvement

Johnson et al³⁷ found that the volunteers of many church-based ministries in African-American churches advising church members at the end of life lacked basic knowledge about the difference between goals of care (patient values and wishes), processes of care, and basic understanding of common interventions such as cardiopulmonary resuscitation and artificial feeding. They often had limited knowledge of hospice and palliative care services, suggesting a need for church-based education and support programs.

The needs assessment showed that church volunteers who were members of health or bereavement ministries, deacons or deaconesses, or church members desired more education regarding end-of-life resources.

They described 3 aspects of faith: trust in the power of God, recognition that death is the beginning of a new life, and belief in a better life after death. Concern was also expressed about the brevity of time with health care professionals to explain patient conditions and treatments at the end of life. Because end-of-life care discussions were previously rare among church volunteers who provided practical help, but felt uncomfortable around end-of-life topics, the faith-based educational program represents a valuable area to correct end-of-life disparities in a culturally appropriate way through lay or peer advisors and clergy from local churches.³⁸

After the needs assessment, Johnson et al³⁸ published a separate curriculum to teach lay volunteers about hospice and palliative services and sought to dispel many common misconceptions about end-of-life care. To address social determinants of death, the Listening, Identifying, Guiding, Helping, Translating (LIGHT) curriculum was published by Johnson et al³⁸ in 2022 as a helpful guide. Correct response rates to most of the questions doubled from pretest to posttest. Basic teaching included teaching on common symptoms: that narcotics are not addictive at the end of life, feeding tubes do not prolong life in terminal stages of disease, cardiopulmonary resuscitation does not lead to full restoration of function, listening is as important as giving information, food and fluids given to the actively dying patient can be harmful, efforts to prolong life may cause physical or emotional distress, family members and patients may have conflicting goals of care at the end of life, the word hospice does not mean a place for dying, and that the primary role for the health surrogate is to do what the patient would have wanted.³⁸

Historically, low hospice enrollment among those of the Muslim faith leaves room for improvement in learning the traditions of Islam and end-of-life practices. Because the religion of Islam does not explicitly prohibit the use of hospice and palliative services, the low hospice enrollment is attributed to a lack of culturally competent care and simply a lack of education and referrals being offered to those of the Islamic faith.³⁹ A new faith-based program consisting of a partnership between the Hospice and Palliative Nurses Association and the Council on American-Islamic Relations has been outlined in a new video that aims to increase awareness of end-of-life practices of Muslims in hopes of promoting better understanding and culturally competent care that could lead to better outcomes and hospice use.⁴⁰ Such vital information as providing prayer rugs, a compass showing the direction to Mecca, and a Quran for use while hospitalized, providing same-sex clinicians for Muslim women, or sensitivity to prayer rituals that make opioids and other sedating medications undesirable at the end of life are examples.⁴⁰ When possible, it is also recommended to consult with Islamic religious leaders regarding the health care of Muslim patients.⁴⁰

Tools for Quality Improvement of Spiritual Care in Public Health

These culturally sensitive and appropriate faith-based programs are examples of potential quality improvement projects to promote more spiritual assessments at the end of life. Such programs exist within the context of public health and are a deliberate improvement process that responds to the needs of the community.⁴¹ Public health palliative care is “a term that can be used to encompass a variety of approaches that involve working with communities to improve people’s experience of death, dying, and bereavement.”⁴² Social models of care, such as faith-based programs and compassionate communities, can speak more to the social, cultural, and

economic factors influencing living and dying. Compassionate communities are described as “communities that develop social networks, social spaces, social policies, and conduct that support people through the day, weeks, months and sometimes years of living with a life-limiting illness, aging, grief, and bereavement, and long-term caregiving.”⁴³ Predominantly disease-oriented models of care in internal medicine and primary care may need help to address these factors.

Quality improvement measures are therefore needed in the public health domain, encompassing newer public health care models such as faith-based programs or compassionate communities. Disease-oriented models are thereby replaced by social constructs that can address the whole person.⁴³ For example, when the PDSA cycle is combined with a tool such as the FICA tool described below, outcomes can be improved in the provision of care that addresses the whole person in a way that disease-oriented care is unable.^{6,44} As such, the American Nurses Association recently presented a funding opportunity to create programs that address racism and structural racism in nursing and recommended PDSA cycles as a measure of outcomes of quality improvement in this domain.⁴⁵ An example of the FICA tool, which provides a spiritual history framework to prevent the spiritual distress linked to worse physical, social, and emotional distress, can be found in the [Table 6](#).

Other Approaches in Cultural Competence

Other approaches to end-of-life cultural competence include recruiting culturally diverse staff for hospice and palliative programs and faith-based programs. Encouraging certified nursing assistants with diverse backgrounds to return to school for nursing and to consider a career in hospice is also recommended. Hospice and palliative care teaching to nursing students is beneficial because they may be offered very little or no teaching in their curriculum related to end-of-life care and the death and dying process.²

Examples of Cultural Humility in Practice and Program Development

Community Health Evangelism in Transformational Leadership

A new nonprofit was founded by a palliative care NP and researcher who sought to create faith-based programs and relationships with local clergy of African-American, Latino, Muslim, and Indian Sikh churches/mosques as a way to correct cultural barriers to end-of-life care in historically marginalized populations. By supporting and educating church leaders and volunteers using a Community Health Evangelism (CHE) model, an integral mission

Table 1
The FICA Tool

Components	Questions
F (Faith, Belief and Meaning)	Do you have spiritual beliefs, values, or practices that help you cope with stress? If they respond No, the nurse practitioner might ask, “What gives your life meaning?” ⁶
Importance/Influence	“What importance does your faith or belief have in your life?” “Have your beliefs influenced you in how make medical decisions?” “If so, are you willing to share those with your health care team?” ⁶
Community	“Are you part of a spiritual or religious community? This community can be a church, temple, mosque, or like-minded friends, family, etc.” “Is this of support to you and how? Is there a group of people you love or who are important to you?” ⁶
Action	“How should I address these issues in your health care?” ⁶

health model addresses social, physical, and spiritual well-being. Originally used in the medical mission field, education is provided to church members in a culturally competent way through volunteers and clergy that they trust (R. Gagne-Henderson, personal communication, April 1, 2023).

Effectiveness is variable, and additional studies are needed to strengthen the model, which can be accomplished by developing faith-based programs like one in Connecticut.⁷ The model connects community resources to church members who serve on the CHE ministry with such volunteers as lay members from the personal ministries, health ministries, board of elders, and health care professionals in the church, thus allowing health care services to become “the right arm of the Gospel.” This represents an example of a faith-based program aimed at better serving congregations.⁴⁶ The nonprofit began recruiting culturally diverse advisory board members and officers and scheduling meetings with Connecticut clergy to correct a health disparity in marginalized populations of Connecticut (R. Gagne-Henderson, personal communication, April 29, 2023). These actions align with prior recommendations to recruit diverse staff to provide end-of-life care.²

In this way, transformational leadership is demonstrated by creating a vision and empowering others to develop solutions to forms of structural racism at the end of life.⁴⁷ The transformational leadership regarding hospice care began in 1969 with the collaboration of the Dean of the Yale School of Nursing, Florence Wald, and Dr. Dame Cicely Saunders, founder of the hospice movement in London. The collaboration led to the formation of the first hospice home care program in 1974 in New Haven, CT, and continues today with the progression to other types of programs, such as faith-based programs, that can make end-of-life care more accessible to those of various backgrounds and cultures.²⁷

The official specialty of palliative medicine branched off from hospice in the US in 2006 to encompass all with life-limiting and complex chronic illnesses, regardless of prognosis or goals of care, and is meant to be flexible for all cultural backgrounds, whether aggressive or conservative care is desired.²⁷ This further demonstrates transformational leadership in adapting programs to meet end-of-life needs.⁴⁷

Transformational leadership skills are a critical skill set in transforming palliative care programs to meet the needs of diverse populations. NPs are change agents who consider attitudes, perceptions, and outcomes in planning innovative programs. They express a clear vision and motivate and inspire others to embrace that shared vision.⁴⁸ The formation of the palliative care specialty in 2006 in the US also demonstrates transformational leadership in the adaptation of programs to better fit the needs of all with life-limiting and complex chronic illnesses, regardless of prognosis or goals of care, and is meant to be flexible for all cultural backgrounds, whether aggressive or conservative care is desired.²⁷ These are examples of the role of the NP and other professionals in policy, practice, and transformational leadership through innovation in the adaptation of new programs and models such as the CHE model and the formation of the palliative care specialty in 2006.⁴⁶

Everyday Examples

Common examples have occurred in the lead author's author's practice, demonstrating the need for cultural competence in person-centered care. A 67-year-old female Latina patient had a stroke 8 years earlier, requiring a feeding tube, which had led to frequent aspiration pneumonia, slow neurodegenerative decline, and weakness. Thus, the family struggled to get her to follow-up appointments but still wished for regular follow-up visits with gastroenterologists for gastrostomy tube changes and pulmonologists for tracheostomy tube changes. Otherwise, their goals of care

were mainly for comfort and function, as they wished for more homecare services and no further hospitalizations or aggressive care. However, they still found benefit in home physical therapy through a local agency.

Family meetings with several family members indicated reluctance and even anger regarding suggestions for hospice care. This caused several family members to question contradictions between specialist and primary care reports that conflicted with teaching regarding her decline and disease trajectory. They were left with the statement that they could decide on end-of-life care at any point they felt ready. The daughter called 6 months later and reported that disease trajectory teaching regarding infections and slow neurodegenerative decline had occurred and that she expected a hospice consult due to prior teaching. The patient had declined drastically, telling her family, “I want to die.”

Assessment findings indicated an ileus and absence of bowel sounds. Keeping the tube feeding running at average rates would be impossible. However, the family strongly desired to keep the tube feedings running due to the cultural symbolism placed on artificial nutrition, which is symbolic of love and caring. Many cultures value the symbolism of giving food to loved ones. Feeding tube prevalence is significantly higher in patients of a minority race/ethnicity compared with Whites after strokes.⁴⁹ Teaching was offered regarding the natural dying process that does not equate to starvation but is instead the consequence of end-stage illness because cultural norms may equate the dying process with starvation.

The family desired to continue feeding their mom despite teaching about the dying process and risks. This symbolic gesture was honored by keeping the tube feeding running at just 5 mL an hour, unless the patient began vomiting, to which they were amenable. The daughter remembered that this author had told her she could ask for end-of-life services at any point, and she did. However, this patient had emigrated from Colombia and was not eligible for the Medicare hospice benefit. The private insurance her daughter had purchased would be primary instead of the Medicare hospice benefit, which was atypical. This caused one hospice to admit and immediately discharge her because they did not accept the plan, but another hospice was glad to admit her the next day. The patient died on hospice services a short time later.

This case illustrates cultural competency in adjusting the plan to accommodate a symbolic gesture of nutrition, assessing person-centered goals of care regarding values, and CDC recommendations for promoting not just learning but also the ability to use information for one's best interests, as well as unavailability of the hospice benefit for new immigrants to the country.^{10,44,50} Many hospices see patients without private insurance without charge through donation programs they maintain for the uninsured.⁵⁰

Another example includes 2 African American families with different preferences, illustrating the importance of not assuming the wishes for the type of care acceptable in persons of color.⁵ The family of an 82-year-old African American man with metastatic lung disease and bone metastasis felt that the aggressive care that was exacerbating intolerable symptoms, including pain crises, dyspnea, and mental status changes, was preferable to hospice services based on their goals for longevity, so that they could move to Georgia to be near family. When assessing values and wishes, the patient and family were not amenable to disease trajectory teaching indicating a limited prognosis and wished for limited involvement from the home-based palliative care practice except for symptom management. However, the prognosis was just weeks to months. They preferred for only family to care for the patient and remained distant or distrustful when end-of-life care options were discussed. They preferred family and community involvement, as evidenced by discussions about the type of area they wanted to move to. The family did not discuss spiritual practices but valued

family and community involvement, which is part of the FICA assessment.⁶

This scenario demonstrates higher preferences for aggressive care, family-centered approaches to decision making, distrust, and the benefit of the FICA tool in the assessment of support systems in persons of color.⁵¹ They subsequently moved out of the service area but were thankful for increased symptom management offered by the home-based palliative care practice.

Another African American family lived nearby of an 85-year-old African American man with New York Heart Association stage IV heart disease with dyspnea, dizziness, weakness, a 20% weight loss, and declining mobility, which caused the patient to become homebound. When assessing family values, his wife would only wish for a hospitalization “if he was suffering,” was not agreeable to the cost of ambulance transport to appointments or the hospital, but would value more home care services to assist her in caring for her husband. She was unaware of his limited prognosis but accepted teaching regarding his prognosis, risks, and hospice eligibility.

The wife and daughter were pleased to accept hospice services the following week. They had no advance care plan in place, having never followed-up with prior discussions, but this was quickly addressed. They became impatient with their integrative medicine physician, who seemed disappointed about their wishes for comfort measures and hospice services, which the family perceived was for financial reasons due to the expensive vitamins sold at the office.

Distrust can be preventable by using the FICA tools and exploring patient knowledge, goals, and wishes. Thus, the family chose the hospice medical director as their primary physician, an option in some larger agencies. When the patient died 6 weeks later, the family thanked the hospice for their compassion in the obituary. Because this was a family simply in need of more education on available end-of-life services and the disease trajectory, they were enabled to meet their goals of care for comfort. Although they did not discuss spiritual concerns, hospices routinely offer chaplain support as part of the care plan for those who desire this, and this family perceived the benefits of hospice as compassionate care.⁵² The new guidelines for health literacy by the CDC are demonstrated, as is the importance of the FICA tool for person-centered spiritual care to assess availability of support systems.^{6,10}

Summary/Recommendations

Limited prognosis in persons of color who historically have had low use of available hospice and palliative care programs due to a range of structural barriers that do not adequately assess for person-centered goals of care in various cultures and religions and, therefore, may lead to assumptions that do not demonstrate cultural humility or competence and are not well-informed.² Tools such as the FICA are recommended to correct such disparities by assessing values, goals, preferences, support systems, and knowledge.⁶

Faith-based programs are an innovative way to address the recommendations for preferences that value faith and church community and foster trusting relationships with providers of end-of-life care by partnering with the church community as the conduit.^{38,46} The CHE model is recommended in allowing programs to improve the church community's health and become “the right hand of the Gospel.”⁴⁶ These tools and programs align with recommendations for more innovation, diversity, and education to be used as platforms for culturally competent care. This should be a goal for all NPs.

It is also recommended to encourage ethnically diverse students and allied health personnel to become hospice or palliative care

nurses and to provide education regarding end-of-life care whenever possible.² These are many of the considerations needed to develop policies and programs for the future of transcultural nursing and improved access to the Medicare hospice benefit and palliative care.

CRedit authorship contribution statement

Leah D. Ward: Writing – review & editing, Writing – original draft, Validation, Supervision, Formal analysis, Data curation, Conceptualization. **Anthony Young:** Writing – original draft.

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