Key Topics on End-of-Life Care for African Americans

An intellectual discourse derived from The Last Miles of the Way Home 2004 National Conference to Improve End of Life Care for African Americans

May 30, 2006

Dear Reader:

On behalf of the project team, authors and participants, I welcome you to read the manuscripts that we have published in this electronic book form, titled *Key Topics on End of Life Care for African Americans*. These manuscripts represent the most important subject areas covered in a landmark national conference called *The Last Miles of the Way Home©*, presented in Atlanta, Georgia in 2004. The Last Miles© conference was the first of its kind, giving voice to issues in end of life decision-making and caregiving unique to African-American patients, families and communities. The topics covered in this book range from the impact of health disparities on end of life decision-making to spiritual aspects of care at life's end, to sociological and cultural perspectives on death and dying and finally, even to health policy considerations.

The authors represented here are leading thinkers in this field. This series of papers will provide useful information for individuals and organizations interested in increasing their understanding of African-American perspectives on end-of-life care that influence important questions such as access to hospice and palliative care, and the quality of care delivered in those settings. We hope that these papers will lead others to do further scholarly work and spur others to think about demonstration projects and other practical programs that provide beacons to shine light on best practices for delivering quality end-of-life care to African-American patients and families.

The Last Miles© conference and the published papers represented here are products of ideas conceived under the guidance of the late Dr. Marian Secundy of Howard University. We dedicate this project to her memory.

Richard Payne, MD.
Esther Colliflower Director
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IN TRIBUTE

Who Always Spoke Truth to Power

Marian Gray Secundy, PhD

Dr. Secundy was the director of the Tuskegee University National Center for Bioethics in Research and Health Care from 1999 to 2002. The first of its kind in the nation, the Center explored the core issues that underlie research about, and the medical treatment of, African Americans and other underserved people.

Between 1971 and 1999, she was the professor and director of the program in clinical ethics, Howard University College of Medicine, Department of Community Health and Family Practice. Her research interests included the ethical dimensions of patient care and minority aging. Dr. Secundy had been a consultant to the U.S. Department of Health and Human Services and had served on several National Institutes of Health advisory panels. She was a former member of the Mayor's Task Force on Hospice Licensure in the District of Columbia and the National Capital Health Ministries. Dr. Secundy was a visiting scholar at the Pritzker School of Medicine (University of Chicago), the Health Policy Institute (University of San Francisco), and the University of Cape Town, Republic of South Africa, among others.

Throughout her career Dr. Secundy worked tirelessly to correct the racial injustices and insensitivities that have blighted the United States health care system for centuries and continue to this day. As a bioethicist with a background in social work, she understood the ethical legal and social consequences of race in the health care of African Americans, and she addressed these issues openly and boldly. A major focus of her work was on training and engaging health care professionals in areas of ethics, human values in patient care and death and dying.

It was Dr. Secundy who garnered funding from The Robert Wood Johnson Foundation for **The Last Miles of the Way Home** conference. Unfortunately, she passed away before she could see her efforts bear fruit. This body of work is the realization of Dr. Secundy's vision, dedication and commitment.

May 30, 2006

Dear Readers,

"Education is the only solid bridge you can rely on to transport you over your troubled waters. So on that premise, I'll say to you: Use that bridge to get on the other side where you can stand up and be counted, thereby leaving footsteps in the sand of time for others to follow."

<div align="right">

Strong and Beautiful Voices
Quotations from Africans Throughout The Diaspora
Author, Christine B. Forte

</div>

My mentor and friend, the late Dr. Marian Gray Secundy, was a true visionary and as such, she led the charge to empower patients and their families to choose their individual paths for the final journey with respect, dignity and comfort. Moreover, Dr. Secundy firmly believed that in order to eradicate health care disparities and improve the overall quality of end-of-life care received by African Americans, education is indeed the solid bridge by which we can begin to close the gap. I feel honored and privileged to have worked under her tutelage.

The manuscripts, Key Topics on End-of-Life Care for African Americans, are the culmination of Dr. Secundy's endeavors. The body of work presented here is from an esteemed group of leaders in their respective fields. The papers are intended to provide a platform for furthering the mission to provide culturally competent care to African Americans nearing the end of life. I would like to thank each of the authors and commentators, as well as the entire Last Miles project team, for their contributions and untiring efforts on this project. Without their dedication and commitment, the Last Miles conference and these commissioned papers would never have come to fruition.

As stated in Christine Forte's quote above, it is clear that education can empower a people and their community. I encourage the reader to embrace this mindset as you explore the various topics covered here and challenge all of us to forge new paths toward delivering equitable, quality care to African Americans, each leaving our own set of footsteps to be followed by those behind us.

Sincerely,

Sharon R. Latson

Sharon R. Latson
Co-Principal Investigator

Key Topics on End-of-Life Care for African Americans

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Racial Attitudes and Health Care Disparities in African American Communities
Historical Perspectives and Implications for End-of-Life Decision-Making

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[abstract here: About 100 to 150 words]

Racial classifications of human populations are politically and socially determined. There is no biological or genetic basis for these racial classifications. Health behaviors may be influenced by culture and poverty. Disparities in health outcomes, sometimes resulting in higher mortality rates for African-Americans appear to influence end of life decision-making attitudes and behaviors. To improve the quality of end of life care in African-American communities, health care professionals must better understand and work to eliminate disparities in health care, increase their own skills, knowledge and confidence in palliative and hospice care, and improve awareness of the benefits and values of hospice and palliative care in their patients and families.

Racial Attitudes and Health Care Disparities in African American Communities

RACIAL ATTITUDES IN AMERICA AND THE EFFECTS ON HEALTH DISPARITIES—A PERSPECTIVE

The concept of racial differences and all that this has come to imply is perhaps the single most important social issue in the history of the United States. Since the "discovery" of America in 1492 by Columbus, the importation of the first African slaves in 1619, and the infamous *Dred Scott* and *Plessy* decisions in the 1800s that legalized separate status of African Americans, racially-based social, legal and *health* inequalities have persisted to the present. In fact, during the Civil Rights Movement in the mid-twentieth century, Dr. Martin Luther King famously said, "of all the forms of inequality, injustice in health care is the most shocking and inhumane."[1]

Dr. King was referencing a growing body of observations documenting racially and ethnically based disparities in health outcomes. Although these health disparities are associated with race, it is important to note that racial classifications are politically and socially, but not biologically, determined. In fact, contemporary genomic studies have determined that the genetic variations within a so-called racial group may reach 95%, compared to a 5% variation between so-called racial groups.[2] Therefore, to explain the unequal burden of disease between whites and other groups, one must consider factors beyond biological differences such as socioeconomic level, cultural and behavior determinants of health status.

Race is, in reality, a socially and politically determined designation. It is also often a surrogate designation for more direct and authentic causes of health disparities. Conceptually, one can consider the effects of poverty and low economic status,

interacting with social injustice and cultural factors (i.e. diet, tobacco use, etc.) to determine how these factors collectively influence important health determinants such as the use of preventive services, early detection of disease, ready access to medical care for accurate diagnosis and treatment, etc.[25] Differences in these health determinants could readily explain important disparities between black and whites in terms of incidence of disease and ultimately mortality. Poverty, acting through the prism of substandard housing, inadequate information and knowledge of disease and preventive practices, risk-promoting lifestyles, attitudes, behaviors, and diminished access to health care can directly influence health status.[26] Although there is a wide spectrum of wealth in minority communities, according to the U.S. Census Bureau, 35 million Americans (12% of the US population) are classified as poor, but African Americans and Hispanics comprise 24% and Hispanics 22% of this group. This compares to 8% of whites who are classified as poor.[3]

Disparities in health between blacks and whites are manifested in all major disease categories and occur in all clinical settings—hospitals, outpatient clinics, emergency departments, operating rooms, and nursing homes.[4–6] Examples of health disparities are shown in Table 1.

TABLE 1
RACIALLY BASED DISPARITIES IN HEALTH OUTCOMES
SOME EXAMPLES

Condition	Example	Reference
Cancer (all sites)	Incidence, 1996-2000 561.2/100,000 white men 696.8/100,000 black men	NCI Seer Data, 2003[19]
	Death Rates, 1996-2000 249.5/100,000 white men 356.2/100,000 black men	NCI Seer Data, 2003[19]
Cancer (lung)	Rates of Surgery for Stage I & II disease 76.7 % whites 64 % blacks	Bach, NEJM, 1999[6]
	5 Year Survival 34.1 % whites 26.4 % black	
Renal Transplantation	% Evaluated for transplant 70.5% white women 50.0 % black women 76.2 % white men 53.9% black men	Ayanian, NEJM, 1999[16]
Pain Management	Likelihood of access to opioids 74% white neighborhood 24% non-white neighborhood	Morrison, NEJM, 2000[22]
	Analgesics for bone fracture Blacks 66% less likely to receive analgesics than whites	Todd, Ann Emerg Med, 2000[23]
	Hispanics twice as likely than whites to receive no analgesics	Todd, JAMA, 1993[24]

The impact of these disparities is profound. A recent report observed that if differences in age-adjusted mortality between African Americans and whites were eliminated between 1990 and 2000, then approximately 890,000 African American lives would have been saved.[7]

A recent Institute of Medicine (IOM) study found that "although myriad sources contribute to these disparities, some evidence suggests that bias, prejudice, and stereotyping on the part of health care providers may contribute to differences in care."[8] These sources of disparity are manifest in all parts of the health care system and involve administrators as well as providers. Bias and stereotyping is likely, in most instances, to be subconscious. For example, one study found that mental health professionals who were "primed with stereotype-laden words" were more likely to evaluate hypothetical patients more negatively than when primed with neutral words.[9] Another study noted that doctors rated black patients more negatively than white patients in a number of categories—intelligence, likelihood to abuse drugs and alcohol, likelihood of adherence to treatment recommendations—even after the patients' income, education and personality factors were described.[10] These studies and others support a conclusion of the IOM study, which is "there is considerable empirical evidence that even well-intentioned whites who are not overtly biased and who do not believe that they are prejudice typically demonstrate unconscious implicitly negative racial attitudes and stereotypes."[10(p4)] In fact, conditions of clinical uncertainty accentuated by time pressures are features which promote stereotyping,[8] making African American patients and their doctors facing the complexity of end-of-life decisions even more vulnerable than in other clinical settings.

The IOM study recommended several approaches to minimizing health disparities. *Awareness* of the extent and impact of health disparities is essential. Dissemination of *cross-cultural educational programs* that focus on understanding attitudes, increasing knowledge of different cultures, and acquiring skills to improve communication and caring across cultures is another essential step. More data about specific patient characteristics and outcomes, generated by *standardized data collection* methods is also critical to overcoming disparities. Many other strategies such as increasing availability of quality translational services; health system changes to decrease care fragmentation and the more widespread utilization of evidence-based clinical practice guidelines must also be incorporated with these core educational and clinical recommendations to have a truly durable impact on improving racially based disparities.[8]

DEATH AND DYING IN CONTEMPORARY AMERICAN SOCIETY

Definitions of hospice and palliative care, and current rates of hospice utilization.

Palliative care is a relatively new term, particularly in the United States. There are many published definitions, but essentially all encompass the terms included in the 2002 World Health Organization description of palliative care which is *"an approach which improves quality of life of patients and their families facing life-threatening illness…through the prevention and relief of suffering…by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."*[11] This definition is attractive because it emphasizes the comprehensive approach to assessment and care, focuses on the need to attend to suffering, and is does not restrict the need for this type of care exclusively to dying patients. Hospice care can

be considered as subtype of palliative care applied to dying patients and their grieving families. Palliative and hospice care comprise an array of services at the core of which involve around the clock availability of a interdisciplinary team typically consisting of a physician, nurse, nurse aide, chaplain and social worker. The services provided by high-quality palliative care and hospice teams include ongoing communication and care coordination, expertise in symptom assessment and treatment, anticipatory guidance, crises prevention and early management, the provision of spiritual care and advance care planning, and bereavement support for the family.   Hospice is a proven model of palliative care delivery for dying patients. Much of palliative care delivered in hospitals and outpatient clinics and offices are delivered by teams of doctors and nurses which are not a part of community-based hospice programs, although there are exceptions.   By contrast, more than 90% of hospice care delivered to dying patients is done in the home or nursing home setting.   In hospitals and physician offices, most palliative care is delivered by clinicians who are usually not part of community-based hospice teams.

In 2006, there were approximately 2.4 million deaths in the United States, and about 2 million of these can be anticipated. In theory, these 2 million deaths would be appropriate for hospice care. In 2004, there were approximately 3,600 hospices in the United States, and about 1.6 million individuals, representing nearly 60% of eligible patients and families.[12] This number has grown by about 44% since 2002 and is likely to increase given the aging of the United States population. Cancer was by far the most common diagnosis associated with hospice entry, accounting for 45% of patients, followed by heart failure, dementia, lung, and kidney disease. It is worthwhile noting, however, that non-cancer diagnosis accounts for much of the increase in hospice

Racial Attitudes and Health Care Disparities

utilization over the past five years. This very respectable growth in hospice services is tempered by the relatively short lengths of stay in hospice care. Under the Medicare Hospice Benefit, patients may enter the hospice up to six months prior to death if two physicians confirm that the individual has a terminal prognosis, and the patient is willing to elect the benefit. Despite this, the median length of stay in hospice programs across the United States in 2004 was only 22 days.

Fewer than 10% of patients utilizing hospice in 2004 were African American, even though they make up more than 13% of the U.S. population, suffering a disproportionately higher mortality than whites.[12] The reasons behind this disparity are complex and incompletely understood but will be described in more detail in an accompanying chapter in *African American Perspectives in Pain and Palliative Care.* The gaps in hospice utilization between blacks and whites persist across age groups.[13]

End-of-life "movement" in USA in latter 20ᵗʰ Century

In the past 25 years, in part spurred by the highly publicized "right to die" cases Karen Ann Quinlan in 1985 and the publication of the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) studies in 1995, there has been a remarkable increase in attention to the needs of seriously ill and dying patients.[14] This attention has become manifest in several ways. Hospital-based palliative care teams have increased by 90% from 1998–2003, according to the American Hospital Association (AHA) annual survey of hospitals.[15] Hospice programs are growing and seeking to expand access to previously underserved ethnic minority populations and to dying children. The education of physicians, nurses, and social workers to improve their

skills and confidence in the practice of palliative medicine has received increased attention, and there are formal curricula available for clinicians which have been endorsed by the major professional organizations representing these disciplines. Physicians can now earn certification in palliative medicine from the College of Hospice and Palliative Medicine,[16] and formal designation of the specialty of Palliative Medicine by the American Board of Medical Specialties is anticipated within the next five years.

We have an emerging consensus on the essential aspects of quality end-of-life care, based on evidence obtained from well-designed studies surveying patient and families and health-service research critically evaluating relevant parts of the health care system. A high quality health system should practice patient-centered care at its core, emphasizing attaining the correct medical diagnosis and customizing evidence-based therapies, particularly pain and symptom management, and should provide non-fragmented treatment, which anticipates and prevents crises whenever possible. Care should acknowledge and respect the role of the patient in family and community. The overriding goal is to help the patient live as fully as possible, with the highest possible quality of remaining life. Thus the key domains for quality care at the end of life as emphasized by several researchers and the National Hospice and Palliative Care Association (NHPCO) include pain and symptom management, shared decision making, a focus on patient satisfaction, and coordinated, non-fragmented care, ultimately leading to safe and comfortable dying, self-determined life closure and effective grieving for the family left behind.[17]

Realities of death and dying for African Americans

Given the background detailed in the prior section, we can now place the contemporary circumstances of African American patients and families in perspective. An undeniable reality of the legacy of societal and medical racism and its lingering effects into the 21st Century is the persistent gap in death rates and life expectancy between blacks and whites in the United States**.** Although deaths rates from all causes fell consistently for blacks and whites in the second half of the twenty century, blacks continued to die at 1.5 times the rate as whites (see Table 2).

TABLE 2
MORTALITY RATES-ALL CAUSES, 1950–1998

YEAR	WHITE	BLACK	B/W RATION
1950	8.0	12.4	1.5
1960	7.3	10.8	1.5
1970	6.8	10.4	1.5
1980	5.6	8.4	1.5
1990	4.9	7.9	1.5
1998	4.4	6.9	1.5

In 2003, the age-adjusted death rate for the black population was still 30% higher (1.3 times greater) than the white population.[18] There are many reasons for this persistent gap, including differences in rates of health insurance, which are critical to access to health care services; a greater likelihood of advanced stages of cancer and HIV-AIDS in blacks vs. whites at time of presentation for medical care; higher rates of tobacco and alcohol use in blacks vs. whites; and generally lower rates of utilization of health-promoting lifestyles and use of preventive measures. As indicated earlier, these

socioeconomic circumstances and health behaviors have at their root complex

interactions between race, culture and poverty.

For example, cancer death rates for the years 1996–2000 were 356 per 100,000

African American men, compared to 249 per 100,000 white men.[19] It is also true that

poor Americans, irrespective of race, have a 10% to 15% lower 5-year cancer survival

than wealthier Americans.[20] Many African Americans share a similar cultural

background, if culture is defined by characteristics such as a shared communication

system, similar physical and social environments, common beliefs, values, traditions, and

world view leading to similar lifestyles, attitudes, and—most importantly—behaviors.[25]

Acting additively or synergistically, the factors of poverty and culture influence the social

environment in which one lives as well as access to information and knowledge and may

be associated with the engagement of risk-promoting behaviors (e.g., tobacco use,

consumption of high-fat diets). When one then adds greater probability of diminished

access to health care, it is not difficult to understand how these circumstances could lead

to higher cancer incidents and decreased survival.

Superimposed on the above are the effects of unequal treatment documented in

the IOM report.[8] Thus the manifestation of these profound health inequalities occurs, in

part, because health care providers see their patients (consciously and subconsciously)

through the powerful lens of race. This often leads to false assumptions that result in

serious harm. The unequal burden of disease in our society is a challenge to our

scientific and medical abilities, vision, and presents a profound moral and ethical

dilemma for our society.

CONCLUDING THOUGHTS—DISPARITIES & IMPLICATIONS FOR EOL DECISION-MAKING

The greater mortality rates from almost all diseases for blacks compared to whites must be considered in clinical and health policy considerations concerning end-of-life care and decision-making. Almost all frameworks that evaluate the quality of end-of-life care include the components of symptom management, spiritual and personal growth, death in a familiar setting, surrounded by family and loved ones; understanding information to guide decision-making and planning; confidence that one will not be a financial, emotional or physical burden, and the right of self-determination and control of treatment decisions and choices.[21] The effects of racism and poverty and the associated marginalization compromise the attainment of quality caring in these domains of end-of-life care. The challenge for clinicians and policy makers is to overcome this ultimate of inequalities in health care.

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Key Topics on End-of-Life Care for African Americans

An intellectual discourse derived from The Last Miles of the Way Home 2004 National Conference to Improve End-of-Life Care for African Americans

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COMMENTARY: by Kristy F. Woods, MD- Maya Angelou Center for Minority Health, Wake Forest University, Winston Salem, NC

Historical Perspectives on Racial Attitudes and the Impact of Health Care Disparities on End-of-Life Care in the African American Community

How do racial attitudes and disparities in healthcare impact end of life decisions? The past century has witnessed incredible advances in the prevention, diagnosis and treatment of acute and chronic diseases. With current and anticipated developments at the cellular and molecular level, future opportunities for continuing these advancements to improve life expectancy and quality of life for Americans are enormous. For those with incurable disease our ability to provide comprehensive care and palliation has similarly improved. Despite these achievements, it is clear that all of our citizens have not benefited equally. Differences in the incidence, prevalence, mortality rate of disease and other adverse health conditions persist among racial and ethnic minorities, the underinsured, and the poor in our country and remain a national tragedy.

On almost every health indicator collected by various U.S. government agencies, African Americans fare significantly worse than do white Americans. The 2005 National Healthcare Disparities Report notes that racial disparities in healthcare quality extend throughout the American healthcare system and are observed in almost every aspect of care, including end-of-life care. Payne and Freeman's chapter draws specific attention to the historical perspective of these differences, highlighting that disparities in health status and healthcare quality have plagued blacks in this country for more than 350 years.

Any professional who manages the care of African American patients understands that the sources of racial and ethnic disparities are complex. In addition to the role of behavioral, environmental, and genetic factors, there is overwhelming evidence that access to care and healthcare quality significantly impact health outcomes.

This chapter highlights the overarching contribution of social and political influences on health determinants and inequities in healthcare. Sociopolitical factors have always impacted - and will continue to impact - poverty and socioeconomic status, public policy, health policy, and prejudice and/or bias based on race. For instance, the authors note that racial bias and stereotyping by healthcare professionals, while perhaps subconscious, may contribute to the lower quality of healthcare observed among African Americans, in general. For the chronically ill, vulnerable minority population dealing with end-of-life issues, differential decision-making based on race complicates the already challenging delivery of supportive services and palliative care.

The article concisely reviews the end-of-life movement and the growth of hospital and community-based hospice programs in America during recent decades. The goal of palliative care is to provide a death free of avoidable distress and suffering - that is, 'a good death,' as defined by the Institute of Medicine Committee on End of Life Care. Payne and Freeman note that while African Americans comprise 13% of the US population and experience disproportionate death rates from HIV/AIDS, cancer, heart disease and other chronic conditions, fewer than 10% are utilizing hospice care. I believe that this disturbing fact touches on one of the most fundamental concerns regarding end-of-life care for African Americans - the urgent need to address the multifactorial causes of disparate healthcare quality and utilization.

For example, one may assume it is a part of the human condition to desire a 'good death'. Why then, are African Americans not utilizing available services at the same rate as whites? How does lifetime experience with the healthcare system influences end-of life decisions? Addressing these questions requires a comprehensive approach. Lack of access to quality and continuous care may result in lack of knowledge about these services. Lack of a primary care provider may also result in a black patients being referred less frequently to long and short-term care facilities. In addition, patient-centeredness of care takes on a more significant role as a quality indicator at the end of life. African Americans more often report poor patient-provider communication and mistrust of the healthcare system. Unique cultural and spiritual views may also contribute to decision-making during this time.

In order to fully reduce or eliminate healthcare disparities at the end-of-life, we must first address the compound causes of racial disparities that occur throughout the lifespan and that are highlighted historically in this chapter. We must also move forward with a patient-centered approach that focuses new efforts on the unique needs of African American patients, their families and their caregivers.

In Collaboration With:
Duke Institute on Care at the End of Life
Initiative to Improve Palliative Care for African Americans (IIPCA)

ABSTRACT: African American Perspectives on Pain and Palliative Care

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African American opinions about end-of-life care and decision making are shaped by contrasting views. On the one hand, African American religious and literary traditions celebrate a traditional Christian view of death as a welcomed friend. On the other hand, many African Americans struggle with the acceptance of high death rates resulting from the impact of disparities in health outcomes and insistent on life-prolonging treatments often are against the advice and wishes of their doctors. The impact of racially and socio-economically-based health inequalities, lead to considerations of the trustworthiness of the health care system, which can influence end of life decision making for African Americans. Community-based initiatives in palliative and hospice care are described which acknowledge these important perspectives, and offer models for improving access to care and the quality of end of life care.

Key Topics on End-of-Life Care for African Americans

An intellectual discourse derived from The Last Miles of the Way Home 2004 National Conference to Improve End-of-Life Care for African Americans

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African American Perspectives on Pain and Palliative Care

Everybody wants to go to heaven, but nobody wants to die. It's not so much the act of dying itself, but the things that are surrounding death: injustice, poverty, mistreatment and evil..." There's a sense that we won't be stopped by those things— our 'somehow theology.' Some how, some way, we will get through this."

—Rev. Frank Jackson
Faith Presbyterian Church

Introduction

A cartoon from *New Yorker* magazine shows the figure of the Grim Reaper with his infamous sickle in hand, standing at the door of an African American man saying, "You'll be happy to know that race played no part in this decision!" If only this were true! Although death rates for all Americans have been falling over the past century, there is still a persistent gap; blacks still die at faster rates than whites. In 2003, the death rate for African Americans was 30% higher than whites **{{Hayert DL, 2006 #20431} Hayert DL et al., 2006}.** [1] Higher mortality rates for African Americans compared to whites are caused by many factors, chief among which are racially and socioeconomically based disparities in access to health care and disparate outcomes of health care **{IOM report, 2003}.** [2] A recent analysis of mortality data in the United States concluded that if deaths rates between blacks and whites were equalized during the ten years from 1990-2000, nearly 900,000 African American lives would have been saved **.{Woolf SH et al, 2004}.** [3]

It should not be surprising to note that the impact of these dismaying facts is to shape attitudes about death and dying in African American communities and to influence decision-making of dying individuals and their families.

The quotation by Rev. Jackson above, eloquently states the circumstances and dilemmas faced by African American individuals and communities when confronting the realties of death and dying. It captures the sense of struggle and triumph that has so characterized the African American experience in the United States and how this ethos is reflected in views about death and dying. This paper reviews in more detail information about attitudes toward death, dying and end-of-life care in African American communities. The discussion is informed by our clinical experiences as well as a review of the recent literature. We also describe recent attempts to overcome barriers and improve care by highlighting innovative community-based programs involving faith communities and medical centers, and hospice and palliative care programs.

African American Attitudes About Death and Dying

Weep not, weep not,
She is not dead;
She's resting in the bosom of Jesus.
Heart-broken husband—weep no more;
Grief-stricken son—weep no more;
Left-lonesome daughter—weep no more
She's only just gone home.
—James Weldon Johnson

Go Down Death {James Weldon Johnson, 1927} [4]

* * *

"So now they are trying to get us comfortable with dying?"
—Dick Gregory

Studies of knowledge and attitudes about end-of-life care among African Americans

The two quotations describe the contrast and spectrum of thought in African American communities when discussing and experiencing death. Our Christian religious heritage, captured by the James Weldon Johnson spiritual, emphasizes an aspect of death as "welcomed friend," carrying one away from the burdens and unfairness of this earthly life, to meet the resurrected Christ in heaven. On the other hand, as Dick Gregory extorts, why should African Americans embrace a philosophy of life or health care—affirmed by most hospice programs—which stresses the need to be more accepting and comfortable with dying, thereby seeming to concede to the unfairness of racism, social and health inequalities, and premature deaths in our communities? The tension between death as a welcomed friend bringing the decedent to their spiritual home, and death as a struggle to be overcome, just as other examples of injustice and inequality must be overcome, is an ever-present dynamic influencing African American attitudes and decisions about death and dying **{Crawley L and Payne R et al, JAMA, 2000}.** [5]

Other narratives exemplify this tension **{Payne, Washington Post Editorial, 2000}**.[6] An elderly African American man with advanced prostate cancer was asked about his wishes for future care. During the course of the interview, he was asked about cardiac resuscitation status and if he was interested in a referral to hospice. He replied, "Do you ask *all* your patients these things?" In other words, he was concerned that his doctor wanted to make the hospice referral and forgo cardiac resuscitation because he was somehow not entitled to the so-called first class care of continued hospitalization and full cardiac code status that others—particularly younger, white patients—would get.

The context of understanding hospice care or end-of-life decision making for this elderly African American man reinforced his concerns that the motives of the health care

professionals and institutions might not be pure; in fact, he assumed them to be based on his perceived marginalized status.

Similar themes emerged in conversations with African American pastors about potential collaborations with a major cancer center and their churches to facilitate advance care discussions and to disseminate information about hospice and palliative care to their congregations. The pastors were concerned that the motives of the cancer center could not be accepted at face value because of a past record of discrimination and mistreatment against African Americans. Furthermore, they questioned why they should prioritize end-of-life care when their congregations still did not have full access to state-of-the-art cancer treatments, and the medical center seemed uninterested or incapable of recruiting significant numbers of African American physicians to their staff. **{Payne, Washington Post Editorial, 2000}.** [7]

These stories are supported by more formal studies and observations of African American attitudes toward the completion of living wills, appointment of health care surrogates and utilization of hospice services. For example, in a study of cancer patients, by McKinley and colleagues, it was observed that black patients desired "more life sustaining treatments" and "were less likely to want to complete a living will at some time in the future" than white patients from similar socioeconomic backgrounds. **{McKinley ED et al, 1996}.** [8] Of note, blacks and whites were equally likely to express trust in the medical system and in the action of their physicians, a result which was unanticipated by the investigators.

However, in this study, blacks were at least twice as likely to endorse the belief that "living wills increase a sense of hopelessness" and "decrease the quality of medical care." These findings suggest a relatively greater influence of spiritual concerns in African American patients than in Caucasians, which will be discussed in more detail below.

Hopp and Duffy also studied differences in advance planning attitudes between blacks and whites **{Hopp FP, et al, JAGS, 2000}.** [9] Like the McKinley et al study, they found that whites were significantly more likely than blacks to complete a living will, to designate a durable power of attorney for health care, and to discuss treatment preferences before death, even when similar socioeconomic groups were compared. Also similar to the McKinley findings, they noted that blacks as compared to whites were more likely to desire "all care possible in order to prolong life." However it is important to note that these investigators also cautioned about overgeneralization, noting that many African Americans in their study did participate in advance care planning activities and did ultimately make decisions to limit treatment at life's end. As recommended by them, it is clear that palliative and end-of-life care services for African Americans should be infused with cultural sensitivity, and advance care planning discussions should be part of a larger communication strategy to understand preferences at the end of life in the context of these cultural concerns.

In 2002, The American Association of Retired Persons (AARP), North Carolina division, conducted an End-of-Life Care Survey, in collaboration with the Carolinas Centers for Hospice and End-of-Life Care.

This survey evaluated more than 3500 people, 11% (382 individuals) of whom were African American **{Straw G, Cummins R, AARP study, 2003}**. 10 The issues which emerged as most important for African Americans are abstracted and listed in Table 1.

Table 1
Most Important Concerns of African Americans at End-of-life Care*

Category	Findings
Talking and Thinking About Death	• 76% of African Americans "somewhat comfortable" talking about death; most likely to attend funerals or memorials of friends and relatives • Only 50% have talked with family about wishes for end-of-life care; 20% have talked to no one; twice as likely as whites to have spoken to no one about end-of-life wishes • Only 8% have talked with clergy and only 5% have talked with doctors
End-of-life Concerns	• 75% said that "total physical dependency" would be worse than death"; about 60% say that not being able to communicate their wishes or living with great pain is "worse than death" • About 50% fear dying painfully; 40% fear dying from long illness (but less likely than whites to fear dying painfully, from long illness, in an institution, or alone) • 64% concerned that they will be a burden
Pain Management	• 80% said they would only take pain medicine when pain is severe; 66% would take the lowest amount possible and save doses for later if pain became worse • 50% fear becoming addicted to pain medicines (more likely to fear this than whites)
End-of-life Needs	At least 80% of African Americans rated the following as very important in dealing with their own dying • Being at peace spiritually (93%)* • Not be a burden (86%) • Knowing medicine was available (85%) • Honest answers from doctors (85%)

	- Having things settled with family (84%) - Being physically comfortable (83%) - Understanding treatment options (83%) - Being free from pain (80%) *African Americans more likely to list this as their #1 need, compared to whites, and more than 90% of African Americans rated themselves as somewhat spiritual/religious, compared to 83% of whites
Advance Care Planning	66% of African Americans did not want to be on life support machines, but only 30% had an advanced directive to indicate this* *This compared to 58% of whites with advance directive in North Carolina
Hospice Services	80% of African Americans said they heard of hospice, but only 15% knew Medicare pays for it. - Almost 60% of African Americans who knew about hospice said they would want hospice support when dying
*Adapted from Straw et al. *AARP End of Life Report, 2003* 26	

The most important conclusions of the North Carolina AARP study concerning African American attitudes about end of life are that although 75% of those responding to the survey said they were comfortable talking about death, only about 30% had expressed their end-of-life concerns either formally or informally, and 20% had not talked to anyone. This occurred despite 93% of the African Americans who responded identified themselves as being spiritual or religious, and despite two-thirds of respondents saying that they did not want to be on "life support machines." The study's findings are consistent with other reports and suggest that, among other things, building on the importance of spiritual concerns is an important element of end-of-life planning for African Americans.

Another recent study reported on the results of focus groups of African Americans and Hispanic-Americans concerning end-of-life care **{Born et al, J Palliative Med, 2004}.** [11] There was great similarity among the two ethnic groups and several common themes emerged. There was a preference for family-provided care as long as caretaker burden was not excessive. Spirituality was viewed as a primary means of coping and as part of a holistic concept of care and well being of patient and family.

Generally spiritual concerns at the end-of-life center on the following points:

- To make meaning of the experience
- To receive recognition of the value of their lives
- To have companionship

- To die appropriately—safely, comfortably, and in a familiar setting
- To be given hope for a way to cope through the experience.

Many patients express their spiritual concerns through their religious beliefs, but spirituality is not synonymous with religion. A recent study reported on the spiritual beliefs and practices in African American families in detail **{Johnson et al, 2005}.** [12] These investigators reviewed more than 500 literature citations spanning from 1966 through 2003 and reported on details of 27 studies bearing on views of spirituality and illness, and 13 additional studies which evaluated African American views of spirituality and treatment preferences. The results are summarized in Table 2.

Table 2
Spiritual Issues in EOL Care for African Americans

Spiritual Beliefs-General   • Spiritual beliefs and practices are source of comfort, coping and support (n=19 studies)   • Spiritual beliefs are most effective way to influence healing (n=6 studies)   • God is ultimately responsible for physical and spiritual health (n=6 studies)   • The doctor is God's instrument (n=3 studies)
Spiritual Beliefs-Related to End-of-life Concerns   • Only God has power to decide life and death (n=6 studies)   • Belief in divine intervention and miracles (n=4 studies)   • Religious prohibitions against euthanasia, PAS, limiting life-sustaining treatments and advance directives (n=10 studies)   • Spiritual beliefs and practices are important source of comfort, coping, guidance and healing (n=2 studies)
*Adapted from Johnson KS, et al. The Influence of Spiritual Beliefs and Practices on the Treatment Preferences of African Americans. *JAGS* 2005;53:711-719.

These general beliefs expressed in Table 2 strongly influence end-of-life decision making for some African Americans and must be understood by clinicians caring for them if true collaborative management decisions are to be made.

It is important to understand whether cultural preferences of African American physicians influence their counseling of patients and management decisions for their patients during end of life. Although there are no studies which answer these questions

directly, Mebane and colleagues studied the influence of physician race, age and gender on attitudes concerning end-of-life decision making **{Mebane E et al, 1999}**.[13]

These investigators mailed a survey to more than 500 physicians (157 black, 280 white) and obtained a 28 per cent response rate. White and black physicians differed considerably on the definitions of heroic care and the appropriateness of physician-assisted suicide as an option for end-of-life care. For example, 58 per cent of white physicians saw "tube-feeding of terminally ill patients as heroic, but only 28 per cent of black physicians agreed, and black physicians were more than six times more likely than white physicians to request cardiopulmonary resuscitation and mechanical ventilation for themselves when in a persistent vegetative state. With respect to physician-assisted suicide, white physicians were more than twice as likely as black physicians to request aid in dying when "hopelessly" brain damaged.

The Mebane study supports the previously noted differences in black-white attitudes toward end-of-life care and suggests that these variations in cultural values and treatment preferences should be taken into account as medical educational programs, palliative care curricula and clinical practice guidelines are developed for end-of-life care.

In fact, the authors have been involved in the development of a palliative care curriculum that targets clinicians serving African American communities. Called APPEAL® (A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End), this program has eight modules which focus on explaining and teaching many of the points raised in this paper through interactive teaching strategies, role plays and didactic presentations designed for a multidisciplinary audience of health care providers **{See description of [APPEAL curriculum](#)}.** [14] There is a specific module on spiritual assessment and interventions for African American patients and another module which details fundamentals of hospice care (see below). The curriculum has been taught to more than 200 clinicians in the past two years.

Hospice utilization by African Americans

Palliative care is a model of holistic medical care, which highlights the importance of the prevention and relief of suffering in seriously ill and dying patients, and accentuates the connection of the patient and family as a focus of care. Hospice is the most complete service delivery model of palliative care applied to dying patients and their families. Although hospice and palliative care teams typically have chaplains as members and include spiritual assessments and interventions in their management repertoire, these aspects of care are often peripheral to the medical treatments offered. One might predict that the knowledge, attitudes and opinions of African Americans described above would be reflected in views of hospice care and actual rates of hospice utilization, and indeed, there are correlations.

The consistent findings relating to relatively low rates of discussing end-of-life concerns, completion of advance directives, and the underscoring of the value of the spiritual dimension of care, all predict that hospice utilization rates in African Americans might be

lower than in whites. In fact, as reported by the National Hospice and Palliative Care Organization (NHPCO), in 2004, African Americans represented fewer than 10 per cent of the nearly 1 million Americans who utilized hospice care **{NHPCO Fast Facts, 2004}**.[15] This is a much lower than expected rate of hospice utilization because African Americans represent more than 13% of the total population and have higher mortality rates than whites.

Several recent studies have investigated hospice usage by African Americans and other minority groups in the United States. One study evaluated hospice usage in 23,000 deceased individuals using death certificates and interviews with relatives (the 1993 National Mortality Followback Survey, NMFS), and found an inverse proportional relationship between hospice use and African American race/ethnicity and that was "independent of income and access to health care." It also showed, however, that cancer diagnosis and the completion of a living will increased the chances that African Americans would utilize hospice. **{Greiner KA et al, 2003}.**[16] Using similar methodology to the NMFS, another study evaluated more than 1500 deaths in which 111 decedents were African American and asked families of non-hospice users if hospice had been offered as an option. **{Rhodes et al, J Pall Med, 2006}.**[17] These investigators found that 68 per cent of the African Americans had not used hospice services, and of these, more than half had not been informed about the availability of hospice.

In fact, only a few (12 individuals, or 8.9 per cent) refused hospice even though informed. This suggests that strategies to improve awareness of hospice services may have great benefit in increasing African American access to this type of care.

Trust and Breech of Trust

Several studies have commented on the potential importance of mistrust in the health care system as a barrier to more complete utilization of advance directives and hospice usage. The hypothesis of the McKinley study cited earlier was that the black-white differences in completion of advance directives could be accounted for by higher levels of "mistrust" exhibited by African Americans patients. However they were surprised to learn that black and white cancer patients were equally trusting of their physicians and the medical system **{McKinley, 1996}.**[18]

In fact, ethicists and clinicians have commented that the concept of "trust" may have different connotations, and this may account for the unexpected answers reveled in these studies **{Mechanic D et al, 2000}.**[19] For example, one can speak of *dispositional* vs. *situational* concepts of trust. Dispositional trust refers to a culturally based attribute of individuals or a population with exists a priori to any medical encounter. This is the sense in which the concept of trust and mistrust is typically used when statements such as the following are expressed: "the lack of trust and suspicion about the health care system is a significant influence in shaping the attitudes of the African Americans with whom we spoke **{Hauser et al, 1997}**,"[20] or "Among African Americans, the reasons for [not] completing formal advance directives ... may involve issues such as distrust of the medical profession... **{Murphy et al, 1996}.**"[21]

Conceptualizing the attitudes of African Americans as emanating from a sense of dispositional mistrust mischaracterizes the situation and runs the risk of further alienation by cultivating a posture of "blaming the victim."

On the other hand, one can think of trust as an "iterative process, built over time through experiences," which is the foundation of the meaning of situational trust. This conceptualization acknowledges that patients, families and communities make conclusions about their physicians and the health care system by evaluating their behaviors against their expectations and from their historical understanding to make value judgments about the *trustworthiness* of people and institutions.

The differences in conceptualization of these two meanings of trust have important clinical implications for end-of-life care. Dispositional mistrust implies that African American patients and families should simply change their attitudes about end-of-life care. Embracing the concept of situational mistrust demands that health care providers behave in ways that engender confidence that they and the health system that they represent will, in fact, behave in the best interests of the patients and families.

For example, better end-of-life care for African Americans starts by exploring concerns about discrimination and marginalization within the health care system and acknowledges the evils of past medical racism and the persistence of health care disparities that lead to premature dying. It is in this context that more honest communication can occur and truly collaborative end-of-life decisions can be made.

Strategies for the Way Forward to Improve End-of-life Care

You may write me down in history
With your bitter, twisted lies,
You may trod me in the very dirt
But still, like dust, I'll rise
....
Out of the huts of history's shame
I rise
Up from a past that's rooted in pain
I rise.

—Maya Angelou *Still I Rise*
{Maya Angelou, 1978} [22]

Maya Angelou's poem movingly captures the African American heritage of struggle and triumph. We have discussed the sources of tension surrounding end-of-life care in African Americans. There are also many positive developments resulting from innovative and creative thinking and hard work represented by demonstration projects and other programs aimed at providing culturally sensitive and high-quality palliative and hospice care. Strategies for addressing better end-of-life care in African American communities include:

- the development of specific access and diversity programs in hospices to increase the number of African American patients served
- collaborations with faith communities to enhance spiritual caring and assist in capturing earlier referrals for hospice and palliative care
- the development of community-oriented hospice and palliative care programs that provide medical and non-medical support for dying patients and their families and which support earlier, non-crises referrals for end-of-life care

Programs resulting from these general strategies are described below.

Access and diversity initiatives in hospice and palliative care programs

The National Hospice and Palliative Care Organization (NHPCO) recently launched an Access and Diversity Council, with a goal of providing resources to the more than 4,000 hospices in the United States to increase referrals for all underserved populations, including African Americans. NHPCO has developed an Access and Diversity Toolkit, which provides information and guidance to enhance cultural awareness of diverse populations by hospice providers. In addition, many hospice programs have developed their own access and diversity initiatives, resourced with staff charged with enhancing culturally competent care by developing in-house training manuals and community outreach programs.

The Balm of Gilead program in Birmingham, Alabama, is an example of a palliative care program which serves a predominately African American population **{Kvale E et al, J Palliative Medicine, 2004}.** [23] This program derives its name from an African American spiritual and was funded by a Robert Wood Johnson Foundation Promoting Excellence in End of Life Care Award. The Balm in Gilead end-of-life program was designed as an inpatient service to overcome the barriers of providing care to Birmingham's medically underserved for whom outpatient and home-based models of care were inadequate.

Patients are admitted to the palliative care unit at Cooper Green Hospital who had been hospitalized for more than seven days with a terminal diagnosis and who had medical conditions likely to cause death within a short period of time.

Homelessness, lack of family support or caregivers and inadequate financial resources were contributing factors in the care of most of the patients. Two-thirds of the patients served were African American and more than 50% were Medicaid recipients. An important feature of this program included the prominence of spiritual and community support, including an Adapt-a-Room program in which local church congregations (half of which were African American) and civic organizations furnished inpatient rooms, visited patients and hosted social events at the palliative care unit. Evaluation of the program indicated a very high degree of satisfaction with care, and patients recorded high scores on the "transcendence/spiritual" domain of the Missoula VITAS scale despite being very ill and debilitated. The Balm of Gilead program serves as a model inpatient palliative and end-of-life care program for poor African American populations.

Unfortunately the program could not be sustained by local government and community resources when the grant period ended.

Faith-community collaborations in end-of-life care

Recall that more than 90% of the African Americans who responded in the North Carolina-AARP survey self-identified themselves as "very spiritual or religious" **{Straw, 2003}**. [24] As noted above, a major component of the success of the Balm of Gilead program related to its inclusion of African American churches and the emphasis on the spiritual dimension of end-of-life caring. Other programs have also focused on the important role of faith communities in improving end-of-life care for African Americans.

For example, the Institute on Care at the End of Life at Duke Divinity School offers regional community-based conferences called *Crossing over Jordan*[©]. These conferences provide local education for communities connecting faith institutions (especially black churches) with hospices and other community resources to provide end-of-life care. Following a community readiness assessment, a day-long conference is organized in which national experts in African American end-of-life matters join with community speakers to provide educational talks and workshops. The program is evaluated, in part, on the success of sustaining enduring networks and partnerships between hospice and palliative care groups and faith institutions.

Recently the Duke Institute on Care at the End of Life partnered with VITAS Healthcare Corporation, the largest for-profit hospice in the United States and [Samuel D. Proctor](), a network of African American pastors focused on social justice and health ministries in their congregations. This partnership has produced a covenant of care at the end of life, which is reproduced in Appendix I. This covenant emphasizes the scriptural basis of caring and counseling of church members in end-of-life matters and acknowledges the need to work for improved access to all forms of health care, while attending to the end-of-life needs of their congregations. One potential outcome of this collaboration is a program to enlist members in several hundred congregations to train as spiritual care volunteers in hospices throughout the nation.

Community-oriented palliative and end-of-life care

The Harlem Palliative Care Network (HPCN) and the Harlem Community Hospice represent the intersection of churches and community organizations with hospice and palliative care programs focusing on the needs of African Americans and other underserved minorities in New York City. The Harlem Palliative Care Network (HPCN) was established in 2002 as a result of a partnership between North General Hospital, The Visiting Nurse Service of New York, and Memorial Sloan-Kettering Cancer Center **{Canning et al, 2005}**. [25] The basic idea of this program was to establish a grassroots network of service providers to interface with the palliative care program at the North General Hospital, which serves the Harlem community.

Physicians, pharmacists, home care agencies, social advocacy and welfare groups, and nursing homes were partnered in an informal relationship to identify patients and families with five medical conditions—end stage renal disease, metastatic or advanced cancer, chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), and end-stage renal disease—and provide complementary services or social support for the families with these conditions. Core staff of the HPCN consisted initially of a social worker and an advanced practice nurse, who worked in collaboration with the inpatient palliative care team at North General Hospital, and provided comprehensive assessments of patients and families referred to the program. These assessments included the spiritual, social, pain and symptom management and physical condition of the patient and resulted in the formulation of a comprehensive end-of-life care plan.

In the course of the three-year program, 230 patients were referred to HPCN. Fifty-seven percent of the patients were less than 65 years of age, and 75 per cent were African American. This young age distribution, similar to that experienced in the Balm of Gilead program, reflects the excess mortality of these medical conditions in the African American community.

In the first year of the program, 25 of the of first 79 patients were enrolled for more than 6 months, attesting to the success in referring and maintaining patients with terminal prognosis for length of stays that were much longer than conventional hospice programs. Basic evaluation of HPCN included measures of pain relief, assessment of the location of death and the degree to which advance care planning was accomplished. Patients referred to HPCN did achieve satisfactory pain control, since 58 per cent of patients enrolled in the program for 120 days reported pain scores of 4 or less, on a 0-10 numerical rating scale. Most patients preferred to die at home, but this was achieved in only 16 of the first 64 deaths.

The most common reasons precluding the option to die at home were the absence of a caregiver or the lack of a suitable home environment. In fact, 18 of the first 64 deaths in HPCN involved individuals who had no caregiver. Advance care planning was done with each patient on admission to the program and included life reviews, discussions of the need for proxy decision makers or a durable power of attorney, review of resuscitation status, guardianship issues and funeral planning. Of the first 111 patients, 19 designated a health care proxy, 6 identified a durable power of attorney, 18 executed a living will, and 4 patients signed outpatient DNR orders.

Following conclusion of the grant support for HPCN, North General Hospital administrators negotiated with a New York City hospice provider to license 14 beds and established the Harlem Community Hospice as the first comprehensive inpatient hospice unit for the Harlem community. This is the legacy of HPCN. (See Figure 1 below)

Figure 1
Harlem Community Hospice

The Harlem Community Hospice is a 14-bed inpatient unit, located on the 7th floor of North General Hospital. The beds are licensed by the Jacob Perlow Hospice Program of the Beth Israel Hospital in New York City. Dr. Stacie Pinderhughes (pictured) is an African American board certified palliative medicine physician and geriatrician. The hospice unit serves a predominately African American, Afro Caribbean and Latino population living in East Harlem.

A corollary program to HPCN involved was established to provide sustainable support for dying patients and their families within local churches in Harlem. This program was called the Palliative Training and Education Program (PTEP), and involved the training of 130 pastors and senior lay people to do bereavement ministries and support groups in their congregations and to more effectively advocate for their church members when they were in medical settings.

PTEP involved the teaching of a curriculum that covered topics such as the origin and effects of health disparities; grief and bereavement fundamentals; advance care planning concepts; basic issues in pain management and other common symptoms of terminal illness; the fundamentals of good communication skills; the physical processes associated with dying; the "how tos" of a hospital visit; establishing a memorial service; and creating bereavement support groups in their churches, mosques or parishes.

The curriculum was taught in 3-hour blocks, twice a week for 12 weeks. More than 30 percent of PTEP trainees had a high school education or less, and 80 per cent were African American. The trainees pledged to develop ministries in their churches to support terminally ill patients and to do grief and bereavement care for families. In this way the programs were able to sustain a core of "foot soldiers" to support patients and families needing end-of-life care in their communities.

Summary

Major challenges face African American individuals and communities in the quest to provide high-quality caring at the end of life. The tension caused by confrontation with social injustice and racially based health disparities producing premature death can be tempered with a focus on meeting the human needs of people who are suffering, regardless of the cause or external circumstances.

Studies consistently find that African Americans are generally reluctant to execute advance care documents given the lack of trustworthiness of the health care system in the past, but when offered opportunities to plan appropriately and participate in end-of-life

programs that respect cultural values and the spiritual dimensions of care, African Americans will actively take part. Future studies and initiatives should focus on implementation of concepts and programs such exemplified in the Balm of Gilead project and the Harlem Palliative Care Network which have demonstrated that effective intersection of comprehensive palliative care plans and cooperation of faith communities can result in the gift of dying well.

Appendix I

Covenant of Care at the End of Life

For I am persuaded that neither death, nor life ... shall be able to separate us from the love of God, which is in Christ Jesus our Lord... — **Romans 8:38-39**

Whereas,
We are the image of God and every life has infinite worth

Whereas,
Each life has purpose and meaning

Whereas,
Care at the End of Life recognizes the continuing personhood of those who are in transition despite the sorrow that the end of life can bring, we hold fast to the assurance of the joy of Jesus.

And,

Whereas,
Persons of African descent have higher death rates and shorter life expectancies than other ethnic groups:

Wherefore seeing we also are compassed about with so great a cloud of witnesses ... **—Hebrews 12:1a**

Therefore, we covenant with one another to support and honor our dying by:

- Recognizing our mortality and practicing ministries of presence and action that overcomes the alienation of death which threatens to separate us from body, community and God.
- Advocating for justice and access in healthcare and delivery.
- Modeling the compassionate and caring spirit of Jesus Christ.
- Challenging our faith communities to foster greater awareness around death and dying and quality end of life care such as hospice and palliative care to address the continuing disparities of health care outcomes for African Americans which have a negative impact on the well-being of our communities.

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Duke Institute on Care at the End of Life
Initiative to Improve Palliative Care for African Americans (IIPCA)

Key Topics on End-of-Life Care for African Americans

An intellectual discourse derived from The Last Miles of the Way Home 2004 National Conference to Improve End-of-Life Care for African Americans

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COMMENTARY on African American Perspectives on Pain, Palliative Care and End-of-Life Care

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Palliative care and its final stage, hospice, represent one of the arenas of health care disparities. Health care disparities result from a complex, sociologically nuanced, race-based triage system. In this system, peoples of color, particularly African Americans and Hispanics, disproportionately have end-of-life care initiated in public long-term care hospitals. Taken in aggregate, staffing in these settings is not at a full complement for the acuity of care reflected in end-of-life diagnosis and palliative care. Inadequate staffing diminishes the value of palliative care in the eyes of the communities using public medicine, in part, because dying in public nursing homes and long-term care hospitals is seen, prima facie, as a failure by most African Americans.

Drs. Crawley and Payne have underscored the disproportionately high-death rates associated with the triaging of African Americans due to increased life-threatening illnesses. These authors elucidate some nuances associated with the distrust of health care systems, including palliative care in communities of color. Successful community-based programs in end-of-life care, established during the late 1990s via philanthropic, governmental, and faith-based communities, are enumerated. Many of these successful programs evolved during the unprecedented Centers for Disease Control and Prevention and philanthropic organizations' commitment to community engagement via direct community-based allocation of funding. Also highlighted by Crawley and Payne is the grim reality that many of these programs are at risk or have ended due to insufficient funding in the wake of shifts in fiscal policy.

The above represents the context in which the preferences around end-of-life care for African Americans and Hispanic peoples have been shaped in the first half of this decade. Exciting and significant in these reports is an emerging consensus that with increased education, the majority of African Americans will use end-of-life services and advance directives to clarify their preferences around dying. The movement to improve the quality of end-of-life care can take credit for this shift in perspective.

The hospice units of public hospitals are charged with providing a safety net for the frail elderly and other dying persons. Much palliative care for African Americans is administered in long-term settings that are resource stressed and not necessarily in the hospice units of those facilities. This care is implemented by interdisciplinary teams whose patients' diseases are at end stage. Often these patients are long-term residents.

Consequently, these hospitals are their homes, and they are entitled to hospice care in their home environment.

As all humanitarian care, palliative care is dependent on *presence* and *communication* . The interdisciplinary team (IDT) structure of long-term care is ideally suited to meet these requirements of palliative care/hospice. The IDT typically includes social workers, nurses, doctors, behavioral scientists, pharmacists, and clergy and chaplains. When patients require more focused interdisciplinary care of this kind, very few facilities have the coordinated interdisciplinary team to provide such caring unless a hospice referral is made. As patients shift into the end-of-life phases, however, there is often no fiscal capacity to provide the increased human resources needed in navigating the final stage of life.

Pain management is the paradigmatic approach for team-based elimination of noxious symptoms causing suffering near life's end and is often at the heart of compassionate care near life's end. It is instructive to examine the intensity of resources required for appropriate pain management and to juxtapose this against the reality of care afforded in resource-stressed clinical settings, which are only able to supply minimal staffing. Palliative care is intensive care for dying people, which when properly applied does not necessarily cut the cost of end-of-life care; it improves the quality.

Quality pain management requires holistic evaluation and intervention including: 1) establishing a pain-rating system consistent with the patients capacity to express levels of pain; 2) physical exams providing clues to the physiologic causes and types of pain; 3) initiation of interventions in several modalities, including medications and non-pharmacological approaches such as psychological support, and spiritual care, and 4) evaluating the efficacy of the interventions in time-sensitive intervals. Each therapeutic intervention must be reassessed utilizing the tried and true palliative care approach of appraising: 1) the adequacy in eliminating the symptom; 2) adverse effects on activities of daily living; 3) aberrant usage; and 4) the patient's underlying psycho-physiological potential for addiction.

Addiction potential is a significant area of concern for African Americans as noted by Crawley and Payne. Assessment of aberrant drug use behaviors in patients taking opioids for pain management becomes relevant at the end of life, however, in only small groups of patients. African Americans who are dying from complications of AIDS and who acquired HIV as a result of intravenous drug use are part of such a population.

Naive health care provider assumptions that dismiss unassessed addiction potential are likely to be suspect by individuals aware of families and communities that have been dismantled by substance abuse. It is not enough to say, "Pain medication will not cause addiction when used against real pain." Reducing the fear of addiction potential near life's end, however, is an appropriate clinical goal of care.

Additionally, without an assessment of addiction potential, patients may be under-medicated, plagued by the effects of rapid development of tolerance, or medicated with

inappropriate combinations of medications. For example, patients on methadone maintenance should have their historical methadone maintenance dose considered as a physiological baseline, not as pain medication. The addition of more methadone versus other opiates for increased pain is weighed against risks of extremely long half-lives and increased adverse effects associated with high-dose methadone use. Individuals with documented addiction potential may respond better to one form of breakthrough medication than another and require shorter dosing intervals. An improved understanding of addiction science and behavior is necessary to address the expressed concerns of African Americans around pain and symptom control near life's end.

In the context of a system overwhelmed by end-stage diseases of disparities, providing fiscal support for adequate palliative care is fundamental to its expanded use. There is a Medicare and Medicaid hospice benefit that provides fiscal support for palliative care.

In communities victimized by health care disparities, the age of patients with end-stage illnesses is ever decreasing. This changes the long-term care environment substantially, which is traditionally funded based on skilled nursing for the geriatric peer group.

In part, the evolution of hospice derives from a volunteer movement. In communities tattered by health care disparities, volunteer capacity, as clinical professional capacity, is frequently outstripped by palliative care need. *Palliative care requires intensive multidisciplinary care for dying people.* While working to prevent more people of color, and the poor in general, from dying of end-stage diseases, the need for greater fiscal support of palliative care/hospice must be recognized. The best hope for providing quality end-of-life care for African Americans at life's end is providing *more equitable access* to high-quality end-of-life care.

Palliative & Hospice Care in HIV/AIDS–A Community Care Perspective

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Palliative & Hospice Care in HIV/AIDS–A Community Care Perspective

A Clinical Viewpoint

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INTRODUCTION

First described in 1981 as Gay Related Immune Deficiency (GRID), end stage Human Immunodeficiency Virus (HIV) infection or Acquired Immune Deficiency Syndrome (AIDS) has presented some of modern medicine's greatest challenges and triumphs. Human immunodeficiency virus is the virus that causes AIDS. In the 1980s someone with the diagnosis of AIDS was not expected to live for more than two years. Medications at the time were geared toward management of opportunistic infections (infections that take the opportunity to attack the immune system when not working well), prophylaxis (prevention through antibiotics) of pneumocystis carinni pneumonia (a serious pneumonia known to persons with HIV), and symptom management.

Over the past two decades there have been tremendous advances in treatment of HIV infection with the advent of anti-HIV or highly active retroviral therapy (HAART) and improved treatments of opportunistic infections. Along with the advances in treatment there have been a remarkable decrease in deaths, hospitalizations, and disability from HIV. Despite these advances in medical therapy and increased life spans of persons living with AIDS, there remains a disproportional death rate of persons of African descent diagnosed with HIV. Persons of African descent not only lead the United States in the number of new cases of AIDS, accounting for more than 50% of all new cases, they also account for more than 50% of deaths from AIDS. [1]

Yet people of African descent only comprise approximately 13% of the general population. Persons of African descent should not be considered a monolithic cultural or social community. Persons in this community include immigrants, such as Haitians, Jamaicans, Africans, and others who were not born in the US and may or may not be naturalized citizens, as well as the African Americans who trace their lineage to slaves or freeman of pre-Civil War America. And HIV/AIDS affects every economic and educational level.

The Centers for Disease Control and Prevention (CDC) also reports that AIDS remains the number one cause of death for men of African descent ages 25 to 44. [2] While these statistics remind us of the continued need for improved access, prevention, and advocacy, they also highlight the need for good palliative care.

Palliative care is comprised of multi-dimensional services that mitigate one's transition from the "cradle to the grave." It can include pain management, care, and concern for human suffering-physical and mental, and loss and bereavement. According to the World

Health Organization, palliative care is defined as "the active total care of patients whose disease is not responsive to curative treatment. Palliative care

- affirms life and regards dying as a normal process,
- neither hastens nor postpones death,
- provides relief from pain and other distressing symptoms,
- integrates the psychosocial and spiritual aspects of patient care,
- offers a support system to help patients live as actively as possible until death,
- offers a support system to help the family cope during the patient's illness and in their own bereavement.

The goal of palliative care is to achieve the best quality of life for persons who are living with diseases that are non-responsive to curative treatment, while offering support to family members and/or significant persons who are care providers.

Recent reports appear to confirm what HIV care providers have felt to be true-which is that low CD4 (an important immune system white blood cell) counts increase risk of death from not only AIDS and/or opportunistic infections but also from heart disease, malignancy, and liver disease. [3] This increase in death due to non-HIV diagnoses presents an added challenge to the HIV provider to not only treat HIV, but also to consider co-morbidities (such as hypertension and diabetes) in the prognosis of these patients' health.

The primary care provider plays an important role in the community in recognizing this need and understanding the coalescence of medicine, spirituality, and social services. Care should be coordinated within a multidisciplinary team comprised of physician, nurse practitioner, case manager, substance abuse counselor, mental health counselor, pastoral care, and peer coordinator, such as similar teams at the Luck Care Center.

Background of the Luck Care Center

On the Southside of Chicago in the mid-1990s, there began to emerge startling numbers of HIV-positive people of African descent. This was especially alarming to the community of Roseland, located 13 miles S of the Loop of Chicago. Roseland was a neighborhood whose origin until the 1960's was primarily of Dutch descent, an area of blue collar workers from the railroad, steel and automobile industries.

The area thrived into the 1960's even with its newfound diversity from the migration of African Americans families to the area. However, when inflation hit in the 1970's followed by the collapse of the aforementioned industries, it left this new migrant of community residents without stable employment.

The education system struggled, businesses left for the suburbs, community institutions that had helped residents in earlier times when the area was mostly white, had now abandoned it new Roseland residents. The outcome was the economic decline of a once thriving community. This also resulted in the flight of working class blue and white collar

African Americans from the area. The end result ... a community broken shattered and forgotten. Sadly today, 70% of the residents are now on public assistance.

During the initial diagnosis in the late 1980's most of the HIV positive persons were gay white men. However it became apparent that this horrific disease did not discriminate. The Centers for Disease Control and Prevention provided the following fact sheet on AIDS in 2004. [4]

1. African Americans accounted for 20,965 (49%) of the 42,514 estimated AIDS cases diagnosed in the United States (including US dependencies, possessions, and associated nations)].
2. The rate of AIDS diagnoses for African American adults and adolescents was 10 times the rate for whites and almost 3 times the rate for Hispanics. The rate of AIDS diagnoses for African American women was 23 times the rate for white women. The rate of AIDS diagnoses for African American men was 8 times the rate for white men].
3. The 178,233 African Americans living with AIDS in the United States accounted for 43% of all people in the United States living with AIDS].
4. Of the 48 US children (younger than 13 years of age) who had a new AIDS diagnosis, 29 were African American].
5. Since the beginning of the epidemic, African Americans have accounted for 379,278 (40%) of the estimated 944,306 AIDS cases diagnosed.
6. From the beginning of the epidemic through December 2004, an estimated 201,045 African Americans with AIDS died.

AIDS hit the Roseland area like a thunderbolt! Fear of stigmas associated with the virus, denial and limited information from the onset has left the community of Roseland devastated. Although it is a community cloaked in plight, it is nonetheless a community and one that is in dire need of good quality care, education and support for its residents.

Sherry L. Luck, MD, an African American board-certified internal medicine physician, had a vision of providing care for HIV-positive patients and their families in this underserved area of Chicago. Through diligence and preservation in economically daunting times, Dr. Luck's vision was realized. Dr. Luck was able to sustain an in-patient HIV clinic at Roseland Community Hospital through her own personal funds and from community fundraisers until the clinic received funding through the Ryan White Care Act. The Ryan White Care Act is federal funding for persons living with HIV who were uninsured. Dr. William A. Johnson became the medical director of the newly rededicated Luck Care Center after Dr. Luck's sudden death in May 1999.

The Luck Care Center is a private not-for-profit HIV/AIDS clinic. The staff is 100% persons of African descent as well as the board of directors. The clinic provides HIV primary care to approximately 200 patients, of which 98% are of African descent.

Services include medical management of HIV and other illnesses, such as diabetes (sugar diabetes), hypertension (high blood pressure), mental health counseling, substance abuse

counseling, nutrition counseling, prevention counseling for sexually transmitted infections, pastoral and bereavement care, massage and chiropractic therapy, case management, support groups, and peer education.

The Case Study: Part I

To put a face on HIV/AIDS, follows the history of a patient from the community.

Mrs. S, a 44-year-old woman of African descent, presented an AIDS diagnosis at the clinic in 2000. She is a professional woman working on the Southside of Chicago. Prior to this meeting, Mrs. S decided to visit a local hospital that was educating people to the threat of HIV in African American communities through a free HIV testing day. Although Mrs. S thought she had not engaged in high-risk behaviors, because she was married with five children, she decided to have the HIV test. Mrs. S's test for HIV was repeatedly reported as positive. It was clear that Mrs. S was seething with anger when she was referred to the Luck clinic; she came in for her first visit in great psychological pain, frightened and spiritually wounded. Even in her anger she encouraged her husband to get tested and the outcome of his results was even more distressing. Her husband was not only HIV positive, he had AIDS. Both Mrs. S and her husband were full of despair and anger. Why me God? was the question she kept repeating out loud during her visits to the clinic.

The burden was too much; she lashed out at her husband in anger and demanded that he leave their home. He in turn suffered a mental breakdown and had to be placed in a locked psychiatric unit and placed on psychotropic medications.

When Mrs. S husband was later discharged on antidepressants and antipsychotics, Mrs. S reluctantly accepted him back into their home with the provision that he get HIV treatment. After he returned to work, a few months later Mr. S was fired from his job; this left Mrs. S as the sole provider for the family. It was very difficult for Mrs. S to come to the clinic for routine care, she herself was a medical professional and her fear was that she would run into people who knew her and suspect that she was seeking treatment. She was very afraid of the stigma of HIV and the possible discrimination by others and her church; these feelings brought on increased anguish and anxiety for Mrs. S. Social complications and privacy concerns are still very real in communities of color and oftentimes prevent patients from being tested and/or treated. Mr. and Mrs. S began to take antiretroviral (anti-HIV) medication. Mrs. S had HIV but no symptoms of the infections.

Even though the HIV infection was stable, Mrs. S did develop several problems over the course of her treatment that was not related to HIV. The first problem was a blood clot in her leg that caused a great deal of swelling and pain.

Pain and Persons of African Descent

Since the beginning of the HIV epidemic, clinical studies have documented a high prevalence of pain in patients with AIDS. [5] Numerous studies also have shown pain to be underreported and underrated. [6, 7]

Pain in AIDS patients can be due to opportunistic infections (headaches from meningitis or abdominal pain from disseminated *Mycobacterium avium* Complex-a tuberculosis-like illness disease-from HIV itself as in neuropathy, medication related, or the effects of chronic debilitating illness.

The approach to treating AIDS-related pain is similar to any chronic debilitating illness. First and foremost a detailed and thorough history and physical is mandatory. An assessment of pain should include location, radiation, timing, quality, severity, aggravating factors, relieving factors, previous therapy, and impact on the activities of daily living. The pain assessment requires very good communication skills, active listening, observation, and knowledge of how pain is managed culturally. There are generational issues that providers should consider, for example, stoicism regarding pain is perhaps a factor that may inhibit patients from letting the provider know they are in pain. Elders of African descent may view pain as a way of life; to withstand it without complaining reflects strong character. Their spiritual and religious foundations contribute to their high tolerance for pain, which prayer can alleviate and "laying on of hands."

Once a thorough assessment is done a treatment regimen can be established. Frequent documentation of pain assessment and reassessment of pain is essential. Pain assessment includes determining a pain rating. Using a 0 to 10 pain scale, with 10 being the worst pain experienced. Pain scores can then be compared to determine effectiveness of therapy.

Pain scores should be taken at each visit and recorded. Pain management of persons of African descent in the community clinic, with a large proportion of patients with substance abuse histories, requires a great deal of trust, patience, and documentation. Since pain is a very subjective experience, prior to therapy guidelines must be established and shared with the patient. Pain contracts which explain medication prescribed, the pharmacy to be used, how often medication can be refilled, and policy on lost or stolen prescriptions are often utilized and renewed annually.

Also, consultation with an addiction specialist if a patient is on methadone maintenance therapy is mandatory, if a patient is to start opiate therapy for pain control. Pain assessment includes a determination of the type of pain: muscular, bone, internal organ, or nerve pain. Muscular and bone pain occur as a result of tissue injury (somatic).

Pain from internal organs can result from stretching, distension, or inflammation of the internal organs of the body. This pain usually is well localized and may be described as sharp, dull, aching, throbbing, or gnawing in nature and typically include bones, joints, and soft tissues.

Nerve pain occurs as a result of injury to peripheral nerves or central nervous system structures. Nerve pain may be described as burning, shooting, tingling, stabbing, or like a vise or electric shock and affects the brain, central nervous system, nerve plexi, nerve roots, and peripheral nerves.

A full assessment of pain is important in determining the correct therapy. One set of accepted and excellent guidelines are the World Health Organization's, which state that treating pain with a rating of 1 to 3 starts with acetaminophen or nonsteroidal anti-inflammatory drugs (NSAID); 4 to 6, with narcotics combined with acetaminophen; and ratings 7 to 10 requires strong narcotics.

Examples of strong narcotics include morphine and oxycodone. After determining appropriate medication and dosage, reassessment of pain is essential at every visit. Pain therapy also depends of types of pain. Muscle and bone pain most often responds to NSAID and narcotics, whereas nerve pain often requires narcotics along with adjunctive therapy of tricyclic antidepressant, anticonvulsants, and steroids.

HIV neuropathy (nerve pain) poses several challenges to the HIV provider and can be difficult to control. This pain is due to peripheral nerve injury caused by HIV or medication used to treat HIV infection-particularly the thymidine analogue nucleoside reverse transcriptase inhibitors (didanosine, stavudine, and zalcitabine).

Pain is described as numbness, burning, and tingling. This pain is oftentimes severe and constant. HIV neuropathy is a significant cause of disability in HIV patients with advanced disease. Drug therapy of HIV neuropathy should start with acetaminophen or NSIAD. Many patients will require acetaminophen with codeine or acetaminophen with hydrocodone for relief.

Adjuvant therapy with gabapentin has proven to be highly effective and shows superiority to tricyclic antidepressants. [8] Neuropathic pain is chronic and largely irreversible and requires chronic therapy often using multiple medications alternative therapies such as acupuncture.

The Case Study: Part II

Although Mrs. S suffered in pain from the blood clot she did not want to have her leg examined by another physician and she refused diagnostic tests because she was afraid that once it was revealed that she was HIV positive, her treatment and the physician's perception of her would change. At this time, Mr. and Mrs. S had not disclosed to anyone outside of their families that they were both HIV positive.

Symptom Management

Symptoms other than pain in patients with late-stage HIV disease can be managed successfully in a community-based practice. Some of the common symptoms experienced include constitutional symptoms (fatigue/weakness, anorexia, and fevers), gastrointestinal

(nausea/vomiting, diarrhea, and constipation), respiratory (dyspnea, cough, increased oral secretions), dermatologic (skin rash, pruritis, and decubiti), and neuropsychiatric (delirium, dementia, agitation, and depression).

Causes of fatigue and weakness are numerous in patients with AIDS and often treatable. Patients with long term anemia (low blood) secondary to renal failure, medications, and HIV often complain of weakness and fatigue. Treatment of anemia with epoetin once weekly, and transfusion for hemoglobin of less than eight are accepted and effective therapies. Other efforts also include discontinuation of medications which cause anemia, i.e., AZT. Fatigue secondary to opportunistic infections and AIDS may respond to stimulants such as methylphenindine, if the infection is going untreated.

Case Study: Part III

Mrs. S developed anemia, which at first was thought, to be related to her HIV medication. She was complaining of fatigue and weakness, which was making it very difficult for her to work. Mrs. S was taken off of her HIV medication to see if that was the cause of her anemia and put on iron and epoetin once weekly in an attempt to increase her red blood cells (hemoglobin).

Unfortunately, that therapy had no effect, so she was referred to a hematologist (physician who specializes in blood disorders), but she refused to go because she did not want to disclose that she was HIV positive. Her symptoms were so severe that she became short-of-breath and could hardly get out of the bed to care for her children, nor could she go to work. She had to be admitted to the hospital where she received multiple blood transfusions, but she still did not disclose her HIV status to the physician.

At the Luck Care Center considerable time is spent discussing with the patients the importance of disclosure of their HIV status to sexual partners, physicians, dentists, etc. The Luck Center provides ongoing support in group settings and privately if that is the patient's preference.

Gastrointestinal symptoms are varied and common. First steps are assessment of symptoms. Difficulty swallowing is most often secondary to yeast infection in the throat and esophagus and most often can be treated with oral flucanozole. Also canker sores (sores in the mouth) can be a cause of difficulty swallowing and can be treated with corticosteroids like prednisone. Nausea and vomiting is commonly caused by oral medication, and therefore all medications should be reviewed and unnecessary medications stopped. Other treatments include metoclopramide, phenothiazines, and antacids. Phenothiazines are particularly useful since they can be given by multiple routes (oral, rectal, or intravenously). [9]

Respiratory symptoms are common in the late stages of AIDS. Pneumonia (community acquired, pneumocystis or other opportunistic infections), pneumothorax and severe anemia are all causes. Treatment includes supplemental oxygen in most cases. Morphine

sulfate in low doses and/or anxiolytic agents to alleviate air hunger is very effective. Antibiotic therapy may be warranted if pneumonia is suspected or diagnosed.

Terminal delirium, depression, and anxiety are neurologic symptoms that HIV providers have

to be able to address with their AIDS patients. Phenothiazines such as haloperidol are used in moderate to high doses, which may be required to treat delirium in the terminal AIDS patient. Inpatient care may be required for treatment and safety reasons.

Appropriate therapy also includes patience, reassurance, and frequent visits by health care personnel. Along with what has previously been stated, treatment of depression and anxiety follows the traditional therapies and may require psychiatry referral.

Dermatologic conditions are seen in every stage of HIV infection but become increasingly more problematic as the CD4 count decreases. Dry, itchy skin is seen in most patients with end-stage HIV infection and is a major complaint. Treatment of skin rash-often times seborrhea dermatitis-relieves itching. Skin infections may require systemic antibiotics and are typically easily treated.

Opportunistic Infections

While the incidence of opportunistic infections (OIs) has decreased in the United States due to the use of HAART, there are still a significant number of OIs in the patient population. Consequently patients with terminal disease may also need treatment of these infections for symptom management. There are several common conditions treated at the Luck Care Center worthy of discussing in terms of their etiology, clinical manifestations, diagnosis, and treatment.

Pneumocystis jiroveci pneumonia (PCP) occurred in 70% to 80% of patients with AIDS before the widespread use of HAART.[10] The most common clinical manifestations of PCP are fever, progressive shortness of breath, nonproductive cough, and chest discomfort. Low oxygen level in the blood is the most characteristic laboratory abnormality. Diagnosis usually requires bronchoscopy with bronchoalveolar lavage.

Treatment with trimethoprim-sulfamethoxazole is preferred and can be given orally in mild to moderate cases. Dapsone, primaquine plus clindamycin, intravenous pentamidine, and atovaquone suspension are alternative therapies in patients allergic to sulfa drugs. [11]

Other infections include a brain infection known as Toxoplasmosis which can cause fevers, headaches, and seizures. Treatment with oral medication is also available. Another brain infection known as Cryptococcus can also lead to fevers, headaches, seizures, and weakness. Treatment is with antifungal medication and can also be taken by mouth. Both of these infections require hospitalization and a spinal tap.

Hospice and HIV

During the early days of the HIV epidemic hospice care was often times needed. OIs were common and the cause of death for many HIV-infected patients. Antiretroviral therapy and prophylactic medication are responsible for the declining death rate from OIs, while death from cardiac causes, liver failure and non-HIV-related malignancies are increasing in percentage.

Traditional criteria for prognosis of less than six months include CD4 count of less than 25, weight loss of greater than 10% of normal body weight or body mass index (BMI) less than 21, serum albumin less than 2.5, CNS lymphoma, toxoplasmosis, cryptosporidiosis, progressive multifocal leukoencephalopathy, renal failure, and CHF.

Patients with advanced HIV who refuse antiretroviral therapy or who are unable to tolerate it due to side effects, highly resistant virus, and advanced liver disease also may have prognosis of fewer than six months and can be referred to hospice.

Selwyn et al have reported in a study conducted in 2000 to 2001 that the only variables that did predict risk of dying were markers of impaired functional status, such as Karnofsky score, MMSE, and deficits in daily living. [12]

Hospice consists of an interdisciplinary care team which includes a physician, nurse, social worker, and chaplain. Also included are a nutritionist, home health aide, and other health care personnel. Care of the patient revolves around the needs of the patient and family. Personal care provided by the home health aide has been sited as one of the most significant aspects of hospice care for the terminal AIDS patient in surveys of families. There are four levels of care: home care, inpatient care, continuous care, and respite care. Medication and other treatment related to the terminal diagnosis are covered by hospice.

Hospice care for HIV patients works best when the HIV provider remains active in the care of the patient through death. Patients and families become accustomed to the specialized care and expertise of the HIV provider. Experience shows continued antiretroviral therapy, MAC prophylaxis, PCP prophylaxis, CMV prophylaxis, cryptococcal prophylaxis, and frequent office or home visits are oftentimes essential for psychological, social, spiritual, and physical comfort, which is the essence of hospice care.

While conventional wisdom would have the provider to stop all antiretroviral medications, recent reports tend to show that despite multi-resistant virus being present in heavily treated patients, most patients would still benefit from continued antiretroviral therapy.

However it is likely that patients with end-stage AIDS are no longer on antiretroviral therapy or have never been adherent to their ARV regimen. Also continuation of PCP prophylaxis, MAC and toxoplasmosis prophylaxis allows for avoidance of opportunistic infections.

Hospice care also provides bereavement services for friends, family, and loved ones. It is equally as important to provide bereavement services to staff members who are usually very involved in the patient's care. To this end there are annual memorial services remembering patients who have died during the previous year. Former patients' families are invited as well as current patients.

There are typically family members from years past who participate in the service and express their appreciation for the clinics services. Hospice care provides needed support for patients, which is particularly important for some of the HIV infected who have not disclosed their condition to their family and friends or who have been otherwise isolated because of their disease.

Case Study: Part IV

After continuous pleading with the patient to disclose her HIV status Mrs. S was finally convinced that it was paramount that she make known her HIV status to the hematologist. While she was in the hospital for another blood transfusion she gave permission to verbally confirm her HIV status to her hematologist over the telephone. She was crying over the phone; it was a huge relief and turning point for Mrs. S to release this heavy burden.

After several diagnostic tests it was found that she had leukemia (a blood cancer).

Mrs. S had to undergo chemotherapy to try and stop the growth of cancer and she developed horrific and painful side effects.

The first couple of cycles of chemotherapy were not effective, so her children begged her to try it one more time; unfortunately this did not stop the cancer. During her treatment for the leukemia, Mrs. S's husband left their home.

It was then suggested by the physician treating her leukemia that she consider hospice as an option for care. The physician informed Mrs. S and her family that the care she received from hospice would mange her pain, and assist them with her daily care. Since traditional therapy had not improved her condition and that all options for treatment had been exhausted she agreed to be admitted to hospice. As it turned out Dr. Johnson, the internal medicine physician for the Luck Center is also a medical director for a hospice company in Illinois. The hospice team managed Mrs. S's severe pain, they also addressed her psychosocial, and spiritual needs. This brought her solace during her final days and she died in her home with dignity and in comfort with her family and friends at her side.

The Luck Care Center honors the memory of Dr. Sherry Luck, the founder of the center and patients each year with a memorial service in the community she faithfully serviced. In May 2006 the center honored Mrs. S along with the numerous other patients that the Center serviced throughout the year. These services give the family member(s), friends and the staff a setting in which they can fellowship and come together, emotionally,

spiritually and sometimes physically to reflect and honor the memory of their loved ones and former patients.

At the Luck Care Center, providing counseling for spiritual distress is a very important component of the comprehensive care for the Center's HIV positive patients and their families. In the next segment of this chapter Ms. Pernessa Steele will discuss the important role of the church in the providing spiritual care for persons of African descent with HIV/AIDS.

A Faith Perspective and Initiative
Pernessa C. Seele
Founder/CEO, Balm In Gilead
Terrie E. Griffi, DMin

THE BALM IN GILEAD

"Years ago, when I was working at Harlem Hospital, I was stunned by the sight of people and families suffering from AIDS amid a seemingly heartless community that neither understood the reasons for their pain, nor sought to alleviate their suffering. It was revealed to me that what was missing was the faith imperative-the directive from religious leaders to their congregations to learn, act, and care as their Lord would expect of them in the age of HIV/AIDS".

<div align="right">Pernessa C. Seele</div>

The Balm in Gilead was established to develop educational and training programs specifically to meet the needs of faith communities that attempt to become compassionate centers for HIV/AIDS ministries and education. Today, thousands of Black churches throughout the community are delivering AIDS education and direct services to those infected with HIV, and spiritual care to all affected by this epidemic. The Balm In Gilead spearheads a dynamic response to the AIDS crisis in the Black community.

How has the Balm In Gilead accomplished such a monumental feat in such a short time? It was clear the center had to develop educational and training programs specific to the needs of faith communities. Under the umbrella of the Balm In Gilead and with the tireless commitment from the staff and the community at large, the center developed various programs to address this pandemic crippling our communities.

Balm In Gilead Programs

- **The Black Church Week of Prayer.** The Black Church Week of Prayer for the Healing of AIDS is a week-long education and awareness campaign highlighting the role of the black church in addressing the AIDS crisis. This campaign serves to pave the way for the continuous delivery of prevention education and services to the African American community via faith communities.

- **Our Church Lights The Way-HIV Testing Campaign.** The Black Church HIV Testing Campaign engages the support of black ministers to empower and support individuals to be tested for HIV.
- **Faith Based HIV/AIDS National Technical Assistance Center.** The Balm In Gilead operates the nation's only HIV/AIDS technical assistance center designed specifically to serve churches as well as public agencies and community-based organizations that wish to work with black churches on AIDS issues. The purposes of the National Faith-Based HIV/AIDS Training & Technical Assistance Center are:
- To enhance the ability of black churches to respond to HIV/AIDS by providing capacity building and technical assistance services;
- To increase the cultural competence of public health professionals as well as medical and other direct service providers to work appropriately and effectively with the black faith community.

Black Church HIV/AIDS Training Institute

The Black Church HIV/AIDS Training Institute is designed to convene pastors, deacons, missionaries, church school educators, youth ministry leaders, church nurses, and other auxiliary leaders of the black church to examine, discuss, and seek solutions that effectively address the continuing impact of HIV/AIDS on black people. At the Black Church HIV/AIDS Training Institute, we invite all church ministries to re-dedicate themselves to the critical role of leader as we seek God's guidance in living through this sad hour of history, when more than 25 million people with HIV/AIDS in the world today are African or of African descent.

Palliative Care and the Role of the Church for Persons of African Descent

Untimely death is a seemingly common element of today's society. It is no longer just the last rite of passage of the elderly but a constant presence of violence and incurable diseases that strike the young and old-a multitude of life threatening illnesses, suicides, and homicides. Perhaps not since the days of slavery and lynching in the public square have the lives of African Americans seemed to be so dispensable. Emotional suffering, loss, and bereavement are common elements of life in our communities today. Compounded by the stigma associated with HIV/AIDS, parents, and children are choosing to die silently from loss and grief as they sit quietly inside and outside our church doors.

The role of the African American church in palliative care, though historically it may not have been seen as such, is based on a holistic model of care. Holistic care embraces the total person-physically, spiritually, and emotionally. However, one cannot make inquiries into the role of the African American church in palliative care without taking into consideration the role of the leader of the church, the pastor.

Since the term pastor is derived from the word shepherd, this metaphor is important in understanding the nature of pastoral ministry. The image of God as shepherd in Psalm 23

is a reflection of the character of God and the certainty of God with us. In some religious traditions and denominational distinctions, ministerial leadership roles may be referred to as bishop, elder, priest, or overseer. He or she is the one who has been called and commissioned by God to serve the people of God and to " equip the saints for the work of ministry, for the building up the body of Christ" (Ephesians 4:12 RSV). Pastors have been given the ministerial office to occupy in a representational role on behalf of the church. The pastor fills a powerful symbolic role as he or she ministers to and with the congregation of God's people.

Recognizing that both pastor and people are in ministry together, there are four critical components that I believe guide the role of the African American church in palliative care:

- Pastoral preparation and leadership
- Pastoral counseling and care
- Ministerial support and advocacy
- Prayer

1. **Pastoral Preparation and Leadership.** *I will give you shepherds after my own heart, who will feed you with knowledge and understanding.* Jeremiah 3:15 NSRV.

   The pastor and a cadre of those called to the ministry of care, work in tandem to provide compassionate care to persons as they go through the various stages of life, which inevitably includes pain and suffering, loss, and bereavement.

   The pastor is the theologian-in-residence of the church and must embrace palliative care with skill and knowledge to affirm life with all of its many challenges. The essential preparation of the pastor enables him or her to think and see clearly all of the components of an individual's life without judgment and/or criticism. The pastor must have the capacity to offer insights and give direction through the prism of an inclusive loving God to those who serve with him or her in ministry and to those individuals seeking care and support. The care of souls is sacred; as such, it is a shared responsibility among pastors, lay leadership, and those called to the ministry of care.

2. **Pastoral Care and Counseling.** *Come to me, all who labor and are heavy laden, and I will give you rest. Take my yoke upon you, and learn from me; for I am gentle and lowly in heart, and you will find rest for your souls. For my yoke is easy, and my burden is light.* Matthew 11:28-30 RSV. The significance of pastoral care and counseling has been recognized by the church from its inception. Bearing another's burdens, and as such fulfilling the law of Christ (Galatians 6:2), is a responsibility entrusted to every member of the community of faith but is specifically charged to the pastor as the "shepherd of the flock."

The African American pastor's role as caregiver and counselor, alongside those in the church who are called and certified with appropriate intervention skills, has been a part of the African American church tradition before clinical and pastoral counseling as a specialty became normative. Historically, in the black church experience, the pastor was the one who was trusted; he or she was considered insightful, compassionate, and concerned about issues of social justice affecting his or her parishioners. The same view is held today.

The pastor, as caregiver and counselor, strengthens the weak, heals the sick, binds up the injured, and brings back those who stray (Ezekiel 34). The pastor attends to the overall well-being of his or her parishioners, whatever their physical, spiritual, or emotional state may be, and encourages them on their journey with God. This is the foundation of pastoral care.

In the black church tradition, the pastor is one who walks with the Master, and whose own life is held together by grace and mercy. It is in this context, that pastoral care and counseling is extended to those who suffer and to those who provide care for the suffering.

The pastor, through his or her life experience and training, is therefore able to affirm life during sickness, pain, loss, bereavement, and in moments of transition during the process of dying. He or she addresses the end of life with the assurance that God has provided for us a better place after death. Throughout the grief process and bereavement, support networks are in place, ministers and home missionaries (those who care for the needs of people within the church and community-at-large) stand ready to walk through the drama and chaos long-term illness can present. Additionally, they are equipped to assist in identifying community resources should the need arise.

3. **Ministerial Support and Advocacy.** *[E]ncourage the fainthearted, help the weak, be patient with them all.* I Thessalonians 5:14 RSV. Ministry is always comprised of both the laity (the people) and those called and ordained to a designated leadership role, who are symbolically representative of the whole. In most African American churches, there are ministers and laity who support the work of the pastor by walking with and standing by those who are wrestling with feelings of hopelessness and despair in the midst of their pain and life-altering crises. Specifically, there are those persons in the African American church whose role is to serve as advocates for the voiceless and act as a liaison between institutions of care to assist families who are unable to navigate through the bureaucratic chaos often associated with long-term care needs and terminal illness.

   Ministers of care are often assigned to hospitals, prisons, nursing homes, and hospice care facilities to keep watch over individuals and to visit with family members and friends. Support to the sick and dying, family and friends, and to those providing care includes the provision of prayer, meditation materials, and

daily calls of concern. Advocacy, in the black church, is the promise of God's presence. Pastor and laity alike represents the Divine Incarnate walking alongside those who are sick, suffering, and standing in need of holy intentions. Ministers of care enable individuals to face their situations with dignity and even in the midst of stigma and shame affirming always that "nothing shall separate us from the love of God" (Romans 8:39).

4. **Prayer.** *Give ear to my words, O Lord, give heed to my groaning. Hearken to the sound of my cry, my King and my God, for to thee I pray.* Psalms 5:1-2 (RSV). Prayer, therefore, is lifted up to the "hearer of the prayer" and has power to act on behalf of the petitioner. It has been documented time and time again for non-believers that prayer can provide relief from pain and suffering. A significant role of the African American church in palliative care continues to be the mobilization of prayer partners and intercessory prayer groups to intercede on behalf of those who are living with pain, anguish, and, sometimes, daily uncertainty.

   Gathering families together for prayer is another way to show support for families coping with a loved one's illness and their own bereavement. Prayer works. Prayer involves devotion, trust, respect, and a sense of dependence on the One to whom prayer is directed. The African American church tradition is steeped in the power of prayer and God's word as recorded in the various transliterations of the Bible. The entire scriptural record affirms that God is the One to whom prayer should be directed. Prayer is the power that brings the breakthrough in sickness and in death. " Therefore I tell you, whatever you ask in prayer, believe that you have received it, and it will be yours." Mark 11:24 (RSV).

   And so the role of the African American church in palliative care takes on many dimensions, among which are *pastoral preparation* and *leadership,* the pastor having skills and knowledge to affirm life and all of its many challenges from birth to death; *pastoral care* and *counseling* , strengthening the weak, offering care to the sick and giving hope to the dying; *ministerial support* and *advocacy,* walking with and standing by persons who are voiceless and whose faith may be wavering; and *prayer,* the power to change and sustain.

   These are the crucial elements that guide the role of the African American church in palliative care through "the valley of the shadow of death." Through many dangers toils and snares, the African American church must continue to beam a light on the path of one's journey through life, from the cradle to the grave. We are eternally reminded that we must not fear, because the One to whom we pray is always with us.

CONCLUSION

Consistent follow up, appropriate symptom management, pain assessment, and provider commitment are needed for complete care of patients with HIV. Palliative care in general and HIV care share a similar philosophy. Both types of care embrace a holistic approach,

providing nursing care, psychosocial care, medical care, symptom management, case management, and dietary and medication management.

Culturally competent, holistic, comprehensive, spiritual, and compassionate care for HIV-positive clients must be prioritized. As we move forward in this fight against AIDS, we must be mindful that it is the silence, denial, and stigma of AIDS that continues to cripple a community's response to AIDS education, HIV testing, and treatment. The involvement of the medical community and churches in this battle against AIDS is imperative if we are to conquer this epidemic here and throughout the global community. It is vital that leaders of the community organize to educate and empower the residents with the essential information and tools to enable them to advocate for good quality, equitable care. The Black church must respond to the needs of the community by providing unbiased spiritual care when it is most needed for its parishioners.

It is not enough to express our sympathy by words; we should be ready to crystallize it into actions.

— Frances E. W. Harper
African American writer and poet

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In Collaboration With:
Duke Institute on Care at the End of Life
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Key Topics on End-of-Life Care for African Americans

An intellectual discourse derived from The Last Miles of the Way Home 2004 National Conference to Improve End-of-Life Care for African Americans

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ABSTRACT: Spiritual Care Near Life's End including Grief and Loss in the African American Community

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The recognition that spiritual exploration is an integral part of the dying process is based on an understanding of the universal nature of spirituality and the ways that spirituality affects everyday life. Faith often plays an important role in the coping responses of persons faced with life crises such as a serious or life-threatening illness. Spirituality encompasses one's central values in life, especially those values that give life its meaning. Research suggests that for most persons, spiritual issues become paramount at the end of life. Focusing on spiritual rather than religious concerns, the emphasis of spiritual care at the end of life is on addressing the spiritual needs of the dying patient and family.

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Spiritual Care Near Life''s End including Grief and Loss in the African American Community

"Dying is a spiritual process with medical implications."

Original quote:
Gwendolyn London, DMin

The recognition that spiritual exploration is an integral part of the dying process is based on an understanding of the universal nature of spirituality and the ways that spirituality affects everyday life. The word spirituality is derived from the Hebrew word *"ruach,"* which is usually translated as "spirit" but can also mean breath and wind. *"Ruach"* was understood by the Jewish Kaballah to refer to the emotional self, which was believed to be one of the three parts of the human soul.

For purposes of this discussion, spirituality is defined as **"the inner desire to connect with a higher reality and to experience through that connection a sense of completion and wholeness."** At the heart of spirituality is the human desire to find meaning in life and the universal search for that meaning. This search is grounded in the awareness that, as humans, we are part of some reality that is greater than ourselves.

Spirituality is elusive and can be difficult to understand but reflects the awareness that the "spirit" of each person is inherently related to some larger reality, which is often described as a higher power. Spirituality is the relationship of a person's inner being to that power, however it is conceived and expressed. Spirituality encompasses one's central values in life, especially those values that give life meaning.

It is these values that influence a person's deepest sense of who one is and what life is about. Spirituality is the inner search for meaning and an understanding of universal questions of human existence such as "Who and I?," "Why am I here?" and "What is my purpose in life?" **When a person's spirituality is denied or not acknowledged, it can be experienced as an insult to that person's inner being.**

Though often viewed as synonymous, spirituality is a much broader concept that may encompass many of the habits, rituals, gestures and symbols of religion but does not reside entirely in the domain of organized institutions of religions. Spirituality is an inner search to find meaning and an understanding of the universal questions of human existence. Religion is a set of structured guidelines and beliefs that are practiced within a religious tradition or institution. Religion is structured around doctrines that propose answers to the universal questions of spirituality. All religions are a form of spiritual expression but no one religion encompasses the totality of spirituality.

In recent years, spirituality *in* religion has come to represent the believer's faith as being more personal, less dogmatic, more open to new ideas and influences, and more pluralistic than the beliefs expressed by established religions. It is also thought to express the personal nature of a believer's relationship with God as opposed to the general nature of the relationship that is understood in many religions.

Conversely, some persons speak of spirituality as opposed to religion and generally believe that there are many "spiritual paths" and that there is no objective proof about which is the best path to follow. These persons emphasize the importance of finding one's own path rather than following the path set out by other persons or religious doctrines.

There is an ongoing debate among some religious groups about the idea that an approach based on "spirituality" rather than the observance of a specific religious doctrine is not a true expression of our relationship to God. In fact, most African Americans practice some form of organized religion and, within those structures, embrace a wide range of religious beliefs. This diversity of beliefs, customs and practices is superimposed over their shared history of slavery, discrimination and oppression, which has been a factor in the shaping of the spiritual and religious understandings of the African American community.

Research suggests that for most persons, spiritual issues become paramount at the end of life. Faith often plays an important role in the coping responses of persons faced with life crises such as a serious or life-threatening illness. Even persons who have not previously ascribed to a specific religious tradition often begin a spiritual search when suppressed or ignored spiritual concerns begin to emerge. Spirituality encompasses one's central values in life, especially those values that give life meaning.

SPIRITUAL ISSUES AND SPIRITUAL NEEDS

The spiritual tasks of dying revolve around identifying, developing or reaffirming sources of spiritual energy that can encourage faith and hope. Spiritual issues are unresolved questions or concerns that deal with one's ultimate purpose in life, one's relationship to God and one's relationship to other people. Spiritual issues can be expressed in a number of ways and are often difficult to identify or decipher .

Patients who are approaching the end of life often articulate their spiritual issues in the form of questions or statements that may have various interpretations. Some examples of spiritual issues that may be raised by patients include the following:

Who am I?
What do I really believe?
What are the things that I value in life?
Is this all there is to life? Is there any more?
What are the things that give my life meaning?
What have I contributed by this life that I have lived?
What are the things that I have left behind that are good?

What are the mistakes that I have made?
What are the things that I have left undone?
What is the state of my relationships?
What are the things that I have left unsaid?

Because spirituality is personal and unique, it can manifest in a variety of expressions, including prayer, meditation and other spiritual practices that are utilized to address spiritual needs. It is important that persons who are providing spiritual care at the end of life be able to identify spiritual needs that need to be addressed. Spiritual needs generally fall within the following areas:

Need for Belonging and Need for Relationship:

- To be cared for, not abandoned or isolated
- To give and receive love
- For comfort and peace
- Relationship needs: family, significant others, higher power

Need to Explore Meaning in Life, Suffering and Death:

- To experience affirmation or self-worth
- For acceptance of self, of others, of human events
- To recognize sources of strength to face death
- To contemplate what gives a sense of purpose and fulfillment
- To discover personal meaning of pain and death
- To refine hopes and goals
- To move on to detachment and solitude
- To die appropriately
- To find hope that extends beyond the grave
- To acknowledge unfinished/unresolved conflicts
- To recognize nagging resentment and bitterness
- To recognize feelings of guilt and blame
- To be able to forgive and accept forgiveness

Just as some patients may experience or report serious physical pain, some patients will experience spiritual pain. Spiritual pain is pain in their inner being and can be a greater deterrent to comfort than physical pain.

Spiritual pain is a distinct factor in total suffering. It is important to remember that spirituality involves the moral consciousness and includes thinking, motivation and feeling. If an individual is dissatisfied with his or her inner being, there will be spiritual distress. Inner anguish is often expressed by physical symptoms because it may be easier than articulating difficult spiritual concepts.

Patients search for answers to the meaning of their illness, why they have to suffer and what is going to happen next. Even when medical interventions may be deemed futile, much can still be done to provide spiritual care as the end of life approaches.

THE ROLE OF SPIRITUAL CARE

Focusing on spiritual rather than religious concerns, the emphasis of spiritual care at the end of life is on addressing the spiritual needs of the dying patient and family. Religion can be defined as an organized set of practices that surround a traditionally prescribed belief in the existence of God or a divine ruling power. Religion can also be seen as a set of tools used to express or practice one's beliefs, so religious issues are usually related to a specific faith tradition or community and are attached to an agreed- upon set of doctrines.

Spirituality is one's relationship with the divine and the way that relationship is lived out with one's fellow men and women. It is the God in each person; that part that can commune with the divine. Spirituality is what is sought when persons reach for meaning in their lives. If spirit is what gives life animation, then spirituality is about the life of faith—what drives and motivates it and what people find helpful in developing and sustaining it.

Spirituality is the outworking in real life of a person's faith—what the person does with what he or she believes. A life-threatening illness often causes patients to re-examine their spiritual beliefs as they search for ways to understand the meaning of their lives in light of their life-threatening illness. Even persons who do not have traditional religious beliefs or who have not followed any particular religious tradition can be drawn to spiritual exploration as a way to make sense of not only their illness but their entire lives.

An important concept that undergirds spiritual care at the end of life is the idea that each patient has the right to chart his or her own spiritual course. At this stage in a patient's life, every belief is subject to reexamination as he or she tries to prepare for an experience unlike any they have had before.

The primary role of the spiritual caregiver is as partner in and facilitator of that spiritual exploration. The goal is to help the patient examine and explore his or her own spiritual concerns, issues, beliefs, values and spiritual resources to assist in life's closure, whatever the religion or lack of religion may be.

CHARACTERISTICS OF SPIRITUAL CARE PROVIDERS

Each end-of-life care patient has the right to chart his or her own spiritual course, so anyone offering spiritual care to the dying must be sensitive to their right to do so. The most important skill that spiritual care providers must possess is the ability to listen without judgment.

Spiritual care providers for those at the end of life are often asked if they find the work depressing. The answer is almost always "no." Most will say that they feel called to this work and are renewed and refreshed by this particular opportunity for service.

Patients and families greatly appreciate someone who is understanding and not judgmental. All too often, patients have spiritual concerns but reject spiritual care for fear that the care provider will be preachy and want them to assert specific beliefs. This work requires an attitude that is directly opposite. Some refer to the work of the spiritual caregiver as a ministry of presence. The spiritual care provider is consistently present for the patient and loved ones regardless of their beliefs and issues. In so doing the care provider connects on the level of the s pirit and conveys the loving, accepting and inviting attitude of God.

Most African Americans, in fact, most people, travel the journey from initial diagnosis to death with the support of a community of like-minded believers. Within these communities they pray and are prayed for, study sacred texts, share faith stories that are both communal and personal, and sing songs of inspiration.

Many of these activities are provided by members of the faith community for the dying patient when that person is no longer able to communicate nor is conscious. Faith communities, whether or not they are represented by clergy, are often a primary source of support for African American terminally ill patients.

This discussion does not focus on the ordinary needs of dying patients but explores those who experience spiritual distress at life's end and require more than the usual attention from a spiritual care provider.

They can be grouped into three categories: those who struggle with end-of-life decision making; those who are concerned about afterlife; and, those who incessantly search for meaning and/or a way to understand suffering. Certainly, these concerns can be issues for patients and/or their loved ones, which can include the biological family as well as friends.

END-OF-LIFE DECISION MAKING

At key junctures along the journey toward death, patients and their families face choice points:

- Upon diagnosis, they may have to decide whether to undergo curative treatments that might have distressing side effects. This decision too often calls into question the patient's will to live, either in his/her own mind or in the minds of those who love the patient.
- Most families desire to keep their loved one in the home. and most patients desire to die at home. Nevertheless, caregiving can become a challenge that requires outside support. At this time, the family might be forced to consider nursing home placement and/or hiring private caregivers to assist with home care. These

- decisions often have financial implications and can raise concerns about depleting the family's resources.
- When the patient's physician determines that curative treatments are no longer effective, the patient must decide whether or not to continue trying despite medical opinion. Sometimes, the patient and family might be offered the opportunity to engage in experimental trials of exploratory medications.
- Most people fear pain more than they fear death. Fortunately, in today's world, rarely is there a need for anyone to endure discomforting pain, yet the issue of what kind of pain medication and how much loom large for a lot of patients and families. Fears of addiction and the wish to remain alert and communicative compete with the desire for comfort.
- Two vexing issues for a number of patients and families involve feeding and resuscitation. The inability to eat is especially troubling to a number of patients and families for whom feeding is a sign of loving. Even when medical burdens outweigh benefits, the patient and family might have trouble foregoing artificial feeding approaches and agreeing to a Do Not Resuscitate Order that can be viewed as choosing to die.

These are difficult issues, especially for families that have not engaged in Advance Care Planning. The difficulty can be exacerbated if the patient and/or loved one believes that there is a response desired by God. Too often, deeply held religious views are invoked to compel a particular decision by someone who is well-meaning. The spiritual care provider can play a pivotal role by diffusing the tension that exists within the patient or between the patient and loved ones or among loved ones.

In a training video on end-of-life care, Reverend James Forbes of Riverside Church in New York told two sisters that "God does not have the answer," as they argued about taking their father off a ventilator following a stroke that left him in a persistent vegetative state. How true!

People should be encouraged to pray and talk to God about the decisions they are facing, but it is misleading and potentially destructive to allow anyone to be oppressed by the belief that there is only one good decision and that God wants them to choose it.

People need to understand that it is their decision and that God will continue to support and love them regardless of what they choose. We have been given minds to use—to think and weigh options prior to deciding. We do so by gathering all the available information and perspectives, i.e., by being well-informed. (If the patient is not capable or is unwilling to digest data, then a chosen loved one can do it for him/her.) Intelligent decision making reflects our human nature—products of God's self.

God also wants the patients and loved ones to engage in harmonizing processes. In other words, God wants the participants to engage in a process of decision making resulting in closer relationships with one another and with God. How does that happen? It occurs when the participants enter a process of discernment and engagement that has integrity and involves listening and hearing intently. Each person should know that his/her point of

view has not only been heard but is valued. We know that we have been heard when the other participants are able to accurately reflect our point of view—both in content and in meaning.

God's investment is in thoughtful, loving processes, not particular outcomes. To be sure, it is not always possible to engage in such processes. Sometimes people refuse to value the opinions of others. When that occurs, the spiritual care provider must support the patient in her/his discernment process and help the patient articulate his/her perspective to those who might disagree.

The spiritual care provider does so even when he or she disagrees with the patient's decision. The spiritual care provider can assure others that the patient's decision making was thoughtful and prayerful, if it has been. Clerical support for an unpopular decision can prove invaluable.

Sometimes patients and/or loved ones pray for a cure despite medical predictions to the contrary. Aware of their fervent prayer request, the spiritual caregiver should pray for a cure with and for the patient and/or family member. Doing so will not induce false hope. The patient and/or family have been told that the patient is dying. They need the spiritual caregiver to hear and respond to the hope they have in God's ability to perform a miracle. They will appreciate someone who understands them and be thankful even if the patient dies. God, not the spiritual caregiver, will be held responsible for the death and, more than likely, the prayerful person will now say that the death was God's will.

CONCERNS ABOUT THE AFTERLIFE

Spiritual caregivers who work with people who are nearing life's end are fortunate to encounter many different belief systems including some who profess no belief. At some point, the spiritual caregiver will learn what the patient and loved ones believe happens at the end of life. Afterlife beliefs can be a source of comfort to patients and/or love ones. Even those who do not believe that there is an afterlife can be comforted by the recognition that pain and other forms of suffering will end. Some applaud science and aver that the life cycle makes room for others.

Those who believe in reincarnation often look forward to the chance to live an improved life the next time around. Others assert that their concept of afterlife is vague—they believe that the energy that is life does not dissipate but are unsure what form afterlife will take.

Most African Americans are either Christian or Muslim and believe in heaven; many also believe in hell. Conflicts about qualifying for heaven can occur within the patient or a loved one or between the patient and a loved one or between loved ones. Some people are unsure about getting to heaven on philosophical grounds.

They assert that they cannot know the will of God because no one can, and they are comfortable being ignorant. Others have doubts or feel that they are not heaven bound.

They believe that their past behavior(s) are preventing them from entering heaven. Sometimes it is not the patient but a loved one that has the concern.

The spiritual caregiver must put him/herself in that loved ones shoes and think about how bad it feels to believe that the person you love is going to hell, especially if your concept of hell is everlasting excruciating pain. Although the spiritual caregiver's ultimate concern must be the patient, there is an enormous responsibility to minister to the entire network of loved ones. That task becomes complicated when there is disagreement.

Whether it is the patient or a member of the love relationship, concerns about afterlife imply one of the following beliefs: that the Divine is punitive, that the patient does not deserve forgiveness or has not asked for it or that the patient is unworthy.

The antidote for acute afterlife concern is acceptance of God's forgiveness and love. Too often, patients with this level of suffering have a punitive concept of God. Helping them to feel forgiven even when there is no apparent wrongdoing is the role of the spiritual caregiver.

Whether or not the spiritual caregiver believes that the patient has erred is unimportant if the patient or loved one believes it. The spiritual caregiver offers the patient an opportunity to be forgiven and emphasizes God's desire to reward (have a close relationship with) all of God's people.

Those who seek/need forgiveness can point to a historical act or acts that give rise to the need for forgiveness. If they can believe that their error is the most grievous ever enacted, it can be helpful for the spiritual caregiver to provide assurance that s/he is aware of a range of injurious actions for which others have sought and felt forgiveness.

It can also help to emphasize that God forgives those who sincerely ask for it, and that God looks at the current state of one's heart, not past injustices. Finally, it can help to insist upon the loving nature of God that continues to call us into a closer relationship with God. The loving forgiveness of God is manifested in the consistent and understanding presence of the spiritual caregiver who is not daunted by knowledge of the person's past.

There are times when forgiveness is sought from another person who cannot or will not give it. The person seeking forgiveness is helped to understand that God's forgiveness trumps all.

The most challenging people to work with in relation to afterlife issues are those who feel inherently unworthy. Instead of pointing to an act or acts for which they feel responsible, those who feel unworthy point to themselves as undeserving of forgiveness and/or God's love.

Those who feel this way more than likely have histories of serious childhood abuse and/or neglect. Early in life, others responded to them in ways that made them feel

unlovable. They usually require a professional in mental health to help them overcome their beliefs. The spiritual caregiver consistently continues to manifest God's love and forgiveness and finds consolation in knowing that one day the person will know his/her inherent worth in God's eyes.

THE SEARCH FOR MEANING

Some patients and loved ones strive to make sense of their experience or to find meaning in it. They are suffering and ask the questions "Why me?" or "Why my loved one." Pain and suffering are personally determined and cannot be compared to another's. What one experiences as painful, another might not.

It is never appropriate to trivialize the person's suffering by suggesting that s/he should not feel that way. It is the person's experience and should be honored as real for that person. Sometimes the person's suffering is complicated by well-meaning religious people who aver that "if you know God or know where you are going (heaven), you should not be suffering as you do."

Try as one might, oftentimes, people never come to terms with the circumstances they have faced. For example, it is especially difficult for mothers to make sense of, or find meaning in, the suffering and death of a child.

In fact, it doesn't make sense. Yes, there are those who console themselves by saying that tragedy and the suffering consequent to it are God's will, but there are others who rail against that same God for causing such agonizing pain. Still others are confused and question their faith. Each of these reactions is normal and to be expected.

Some dying patients who have lost mobility will ask God to take their lives.

They feel useless, have no unfinished business and are ready to die. They cannot understand why the God for whom they have been faithful now allows them to suffer unbearably. The spiritual care provider is unable to respond in a satisfactory way because immediate death is the only resolution desired. The role of the spiritual caregiver is to bear witness to the suffering and in so doing "burden share" with the sufferer. The spiritual caregiver consoles him/herself with the knowledge that the sufferer will have a different perspective in death.

There is research evidence that the longer a person searches for meaning in the tragedies of his or her life, the more likely he or she is to experience mental health difficulties. In other words, this relentless irresolvable search eventually gives rise to illness.

Although it is impossible for some people to find meaning or make sense of their circumstances, there can be long-term benefit in surviving tragedy and suffering. Surviving the unthinkable often demonstrates that the person has greater capacity than anticipated—more emotional strength and/or greater resilience and/or stronger relationships and/or more faith. God may be credited with giving the survivor the ability

to pull through. The survivor is heard to say "I never thought I could get over that." Sometimes the survivor develops a new understanding of his or her faith and relationship with God. This new faith can accommodate tragedy that had never been contemplated before the suffering. His or her understanding of the nature of God has broadened.

GRIEF AND LOSS

Understanding grief and loss is important for persons who are providing spiritual care to dying patients and their families. The terms "grief" and "loss" are often used interchangeably but have different meanings and implications. The dictionary definition of grief is "a poignant distress caused by a loss." The word "loss" is defined as "the act of losing possession of someone or something" and as "a feeling of being deprived as a result of a loss or separation from someone or something."

Grief is the name we give to the various feelings and thoughts we experience when we face, or think that we might face, a loss. In fact, grieving is the process by which we heal following a loss. Grief is a natural reaction to the experience of many kinds of loss, not necessarily a loss through death. The pain, suffering and search for meaning one experiences all help the griever to come to grips with loss and go on with life. To be sure there are some who remain stuck—unable to get beyond a certain point in the grieving process. We refer to their grief as complicated.

Although some people experience grief exclusively as a cognitive process, most talk about the feelings associated with grief—anger, sadness, relief, joy, bitterness. It is fair to say that losing makes us feel. Human beings are marvelously made and,as such, are capable of experiencing more than one emotion at the same time.

The griever may be sad because the loved one will not be seen again, relieved that his/her suffering has come to an end and envious that the griever will see predeceased loved ones in heaven. The complexity of feelings can be great, and the griever may not be able to tease out a particular emotion.

Grief is not confined to the person who is losing or has lost a loved one. Grieving begins for the patient and family at the moment of diagnosis of a life-limiting illness. Sometimes patients and/or loved ones act as though they never heard the diagnosis. Some well-intentioned or misguided individuals will say that that is an indication of denial. Denial is a pejorative term that does not respect the time needed to adjust to this new and devastating news. When diagnosed with lung cancer, the man who has smoked four packs a day wants nothing more than a cigarette. He is not in denial; instead, he is resorting to familiar and dependable anxiety-reducing behavior. After all, it takes time and experience to adjust to news that one's life is likely to end much sooner than expected. There are so many things that this person can be thinking of—death, family reactions, financial implications, whom to tell and why, possibilities of pain. The mind has difficulty dealing with all of these issues at once, so this first grief reaction affords time to decide where to focus and when—that is not denial.

During the process of grieving, the person learns to accept that the loss is real and permanent—the dead loved one is not coming back; the body will not be whole again. While accepting that the loss is real, the griever is also beginning to adjust to living without that which has been lost.

The experiences that come with time force the griever into a new way of being. The widow learns to write checks, and the ill person learns to accept assistance with tasks of daily living. There are feelings associated with each mini-loss and each requires an adjustment. Each loss, is, therefore, grieved.

Although the time varies from person to person, the griever eventually begins to reinvest energy into creating a future. The widower might consider dating and seek companionship; the person who is terminally ill begins to set goals for him/herself. At each stage in the illness process, abilities wane, and new goals are set that are realistic for the time being and give meaning and purpose to life. The serious pain of loss gives way to an ever-present reminder that something has been lost.

CONCLUSION

Grieving, like spirituality, is personally determined. It is, therefore, very inappropriate to suggest that grief should be resolved within a specific time frame. In fact, resolution is an inappropriate term for people learning to live with loss, and, for some, the pain of it never completely goes away. The griever (including those who are dying) requires someone who is willing to be a witness to, and bear, some of the pain.

The loving acceptance of the spiritual care provider provides the secure backdrop against which the person works through issues to a more peaceful acceptance. At least, that is the goal. That does not always happen, and some people die grieving, kicking and screaming.

Nevertheless, the consistent presence of the spiritual caregiver continues to convey the message that Spirit is present remains present and supportive and continues to invite a closer relationship with the person in pain. Supporting people who are at this stage in life is an honor and a privilege and should be valued as such. The spiritual caregiver will find that he or she reaps the greater reward.

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An intellectual discourse derived from The Last Miles of the Way Home 2004 National Conference to Improve End-of-Life Care for African Americans

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ABSTRACT: End-of-Life Care Ministry in the African American Church

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The character and identity of the African American church has been forged out of a particular historical, cultural, and theological context. As a result of the long, difficult and often violent history of slavery, racism and continuing oppression that African Americans have suffered in this country, the church has traditionally been and continues to serve as the center of African American community life. Because of the danger and the threat of physical violence that has always been a part of African American life in this country, one of the most important of those transition points was at the time of death or when a member of the community was dying. It is indeed true that the church needs to be involved in the ongoing dialogue and in the changes that are occurring in the medical system as a result of the principles of palliative care. But, it is also true that for the African American church and its members, those principles need to be redefined in a way that takes into consideration the uniqueness of their history and the psychological, emotional, spiritual and practical consequences of the oppression that makes up that history.

End-of-Life Care Ministry in the African American Church
"God of our weary years, God of our silent tears,
Thou who has brought us this far on our way,
Thou who has by thy might led us into the light,
Keep us forever in the path we pray."

<div align="right">

Lift Every Voice and Sing - Negro National Anthem
James Weldon Johnson

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The character and identity of the African American church has been forged out of a particular historical, cultural and theological context. As a result of the long, difficult and often violent history of slavery, racism and continuing oppression that African Americans have suffered in this country, the church has traditionally been and continues to serve as the center of African American community life. In addition, the church has been viewed as the institution that African Americans have turned to most often for comfort and support during the periods of crisis that have occurred at various points of transition in life. From birth to death, the church has been the place where African Americans have come to share their joys and their sorrows when the larger society refused to grant them dignity or respect. Because of the danger and the threat of physical violence that has always been a part of African American life in this country, one of the most important of those transition points was at the time of death or when a member of the community was dying.

Historical and Cultural Context

The history of African Americans in America is a history filled with violence and death. This history is referred to by Dr. Karla Holloway in her book, "Passed On: African American Mourning Stories" as "black death and dying." Dr. Holloway defines "black death and dying" as a century-long experience that is characterized by a particular vulnerability to untimely death.

Holloway sees black death and dying as death that results from white rage and violence and what she cogently refers to as "color-coded death, which is death that occurs for no other reason than the victim's skin color. She defines this color-coded death as death resulting from the residue of riots, executions and suicides, all the result of African Americans being viewed as having less value than whites.

In addition to the kinds of violent death that are included in Dr. Holloway's description of black death and dying, African Americans have also suffered untimely death and dying as a result of hazardous and unhealthy work conditions through the exposure to asbestos and other carcinogens in the coal mines and shipyards of the south and manufacturing plants of the north.

Apart from the violent and untimely deaths described above, African Americans have suffered unnecessary death at the hands of the medical establishment resulting from unethical experiments such as the well-documented syphilis experiments at Tuskegee

University and similar studies at John Hopkins, Chicago Medical College and the Medical College of Virginia.

The most well-know example of this practice was documented in the Tuskegee Syphilis Study. This study, also known as the Public Health Service Syphilis Study, was a clinical trial that ran from 1932 through 1972. The trial, conducted around Tuskegee, Alabama, included 400 poor, mostly illiterate African American sharecroppers who became part of a study on the treatment and natural history of syphilis. Individuals enrolled in the study did not give informed consent, were not told of their diagnosis and were denied treatment that could have resulted in a cure, so that researcher could observe the natural progression of a disease that resulted in death.

In addition, a historical progression of poor health care and a lack of access to quality health care services have created a deep-seated distrust in the health care system. For African Americans, the system, designed to provide care and an opportunity for healing, has often resulted in untimely and unnecessary death. Because of this distrust, African Americans are generally less compliant in following medical regimes during illnesses. This has resulted in increased mortality among African Americans for cancer and other serious illnesses that could have been treated more successfully with earlier detection.

The result of this difficult and painful history has been the development of a collective cultural psyche toward death and dying. The implications of such a collective cultural psyche developed as a result of violence and oppression are important and far-reaching because this approach can be very useful in understanding how African Americans view death and dying.

Because of the violence and oppression they have endured and the ways that oppression has affected and influenced their experiences with death and dying in America, African Americans have generally not denied death. Rather than fear death, African Americans have often viewed dying as an opportunity to be liberated from a racist reality and as a way to freedom from the troubles of a mean old world.

According to Dr. Holloway, death and dying have historically been viewed as an ever-present part of the African American reality. Far from being unusual occurrences, to African Americans, death and dying have been seen as persistent events in the cycles of daily life. To her, they constitute an untimely accompaniment to the life of black folk.

From the hush harbors of the "Invisible Institution" of the Antebellum South, to the organized independent "Black Churches," the African American church has been the institution that has ministered to the needs of black people in this country. E. Franklin Frazier wrote in his book, *The Negro Church in America*, that it was the black church that provided the social cohesion for black people in America. Even prior to the organization of the black church as a formal institution, slaves who had been introduced to "Christianity" by their masters exercised the social function of the church when they gathered in secret to practice the spiritual rituals and sing the newly learned songs that sustained them in their difficult everyday life.

These gatherings provided the slaves with an important orientation to their new world. From that initial orientation, the slaves went on to develop a unique religious expression that was forged from the African religions of the motherland mixed with the Christian religion of their new-world experience. The merger of the two created an African American religious experience that spoke to their existential plight as Africans in America.

In his works, *Deep River* and *The Negro Spiritual Speaks of Life and Death*, Howard Thurman provides some insights on how the slaves sought to address the challenges of theologizing about their experiences with death and dying in America. According to Thurman, death was not the worst of all possible things that could happen to an individual, as there were some things in life that were worse than death. To Thurman, the necessity of living in a climate that stripped the human spirit of its essential dignity was worse than dying.

Death was theologized by the slaves as release and was regarded as complete surcease from anxiety and care. For them, it was not a renunciation of life because its terms had been refused, but an exulting sigh of sheer release from a very wearying burden:

I know moon-rise, I know star-rise,
I lay this body down.
I walk in the moon-light; I walk in the star-light
To lay this body down.
I walk in the graveyard, I walk through the graveyard
To lay this body down.
I lie in the grave and stretch out my arms,
To lay this body down.

According to Thurman, another attitude of the slaves toward death and dying was one of resignation mixed with elements of fear and a manifestation of muted dread despite the fact that there seemed to have been a careful note of familiarity with the experience of death. In contrasting contemporary attitudes toward death and dying with that of the slaves, Thurman says:

"We know that death is a commonplace in the experience of life and yet we keep it behind a curtain or locked in a closet, as it were. To us, death is gruesome and aesthetically distasteful as a primary contact for ourselves and our children.

For most of us, when members of our immediate families die, the death itself takes place in a hospital. From the hospital, the deceased is carried to the mortuary. When we see the beloved one again, the body has been washed, embalmed, and dressed for burial. Our exposure to the facts involved, the silent intimacies in preparation for burial are almost entirely secondary, to say the least. The hospital and the mortuary have entered profoundly into [modern life] at this point. The result is that death [and dying] has been largely alienated from the normal compass of daily experience...."

This was not the situation with the creators of the Spirituals. Their contact with dead [and dying] was immediate, inescapable, and dramatic. The family or friends washed the body of the dead; the grave clothes were carefully and personally selected or especially made. The coffin itself was built by a familiar hand....During all these processes, the body remained in the home...In the case of death from illness all of the final aspects of their experience were shared by those who had taken their turn "keeping watch."

Every detail was etched in the mind and emotions against the background of the approaching end. The "death rattle" in the throat, the spasm of tense vibration in the body as the struggle for air increased in intensity, the sheer physical panic sometimes manifest—all these were a familiar part of the commonplace pattern of daily experience. Out of a full knowledge of fact such a song as this was born:

I want to die easy when I die,
I want to die easy when I die,
Shout salvation as I fly,
I want to die easy when I die.

According to Thurman, the good death [as theologized] by the slaves was a quiet death without the seizure of panic, the closing of the door to earthly life...to die easy when they died. Death and dying was a personal and attached experience for the slaves. Family and friends were with loved ones when they died.

The "slave songs" sung in the hush harbors and cotton fields of the Antebellum South were more than mere songs, they were ritualistic responses of the slaves to their experiences with black death and dying and serve as a foundation for end-of-life care ministry in the African American church.

The African American church was first organized as an official institution in Philadelphia in 1787. Unlike most religious groups that are born out of a theological or doctrinal issue or concern, the African American church began in protest. Following the leadership of Richard Allen, a former slave who is considered the founder of the African Methodist Episcopal Church, a group of black parishioners walked out in the middle of a Sunday worship service because they were not allowed to kneel for prayer in the section of the church where they wished to sit. Allen, an influential member of the Philadelphia community and an expert in extemporaneous sermons, was invited to preach at St. Georges, the first Methodist Church in America.

Allen's preaching was so successful that many new members, most of whom were black, joined St. George's on a weekly basis. Recognizing that black parishioners had special spiritual needs and that the white members were becoming uneasy with the large number of new black members, Alan approached the elder at St. George's and asked permission to establish a black church. The elder denied the request, and a year later when Allen made another request, that one was denied as well.

On April 12, 1787, Allen and Absalom Jones formed the Free African Society. Though not a religious organization, the Society served the black community much like a church.

The Society was funded by dues-paying members whose goal was to extend aid to widows, the sick and the jobless. Allen believed that members, while lifting themselves, could lift all black people. The Society also regulated marriages, taught the importance of thrift, condemned the practice of adultery and worked to improve moral values in the community.

The mounting racial tensions at St. George's finally came to a head on the first Sunday after completion of a newly constructed upper gallery. Unknown to the black parishioners, they were to be relegated entirely to this area. When Allen and Absalom Jones took seats outside of the gallery, they were accosted by a trustee as they knelt in prayer. Allen and the other black parishioners were incensed by this insult and left the church in a body, never to return again. Allen and his followers later organized Bethel Church and, in 1816, established the African Methodist Episcopal Church as a separate denomination with Richard Allen as its first bishop.

The Role of the Church

With this history as a backdrop, it is important to consider how today's church has been— and continues to be—shaped and influenced by that history. Building on Richard Allen's original vision of the church as a center of social, moral and economic support in the midst of racial, social and religious oppression, the African American church has continued to evolve. In the midst of the racism and violence that has characterized the African American experience since the end of slavery, the church has been the most visible and vocal institution working to ensure the rights and the value of African American life. When African Americans were shut out of mainstream opportunities by segregation, the church led the way to the development of a viable community.

Some of the many important contributions of the African American church to the betterment of African American life fall within the areas of education, health, socialization and economic development.

In the volatile Civil Rights era of the 1960s, the church and its leaders led the way in the struggle for equality and equal rights. In the two hundred years since its official beginning, the African American church has become the repository of African American life, African American values, African American history and the African American's hope. It was this hope that allowed them to live in an oppressive society that in many ways embodied an absence of hope and to find ways to transcend that absence.

One of the most important roles that the African American church has traditionally filled is the care and service that it offers to its membership and to the larger community at the time of death.

The church has been the institution that African Americans have turned to for comfort and support during the periods of crisis that have occurred at various points of transition in life. Because of the danger and the threat of physical violence that has always been a part of African American life in this country, one of the most important of those transition points was when a member of the community died. In the African American community, the funeral service is an important ritual that calls the community together in recognition and celebration of the life of the deceased and in support of the family and friends. As the place where the funeral was held and as the organization that stepped to the front to provide most of the services related to the event, the church was at the center of this occasion for both its members and for persons who were not a part of the church body.

Developing End-of-Life Ministries

While the African American church has always had a commitment to pastoral care for its members, developing a ministry especially dedicated to serving dying persons and their families could be one of the most significant services that a church can provide. Visitation of the sick is one of the primary tasks of African American ministers, but few churches have developed focused end-of-life care programs. A small number of larger, more progressive churches have developed such programs, but they represent a small percentage of the whole. To undertake this focus requires a great deal of commitment and a major educational effort to obtain information about the current trends and issues surrounding the increasing public dialogue about palliative medicine and end-of-life care.

A recent survey of all faith leaders in the Kansas City metropolitan area conducted by the Center for Practical Bioethics revealed the following:

- Thirty-seven percent of faith leaders surveyed thought they minister "very effectively" to those who are seriously ill or dying.
- Less than 44 percent of faith leaders surveyed thought they were "very prepared" to minister to those who were seriously ill or dying..
- Only 8 percent 21 of the faith leaders surveyed thought that their congregations were "very prepared" to minister to the seriously ill and dying.
- More than half (57 percent) of the congregations surveyed had not participated in any program to enhance their ability to minister to the seriously ill and dying.
- Sixty-six percent of the congregations surveyed did not have any programs or other means of teaching members of their congregation how to minister to the seriously ill and dying.
- About 50 percent of the faith leaders surveyed rated their familiarity with the resources that are available to help them minister to the seriously ill and dying as "poor" or "very poor."

Recent studies have shown that people in America die in hospitals isolated from meaningful human contact with their family and friends. In the past, dying was considered a natural part of life, and most people died at home. Medical advances in the late 20 th century created a new milieu so that now most people die in the hospital where

death is seen as a technological and medical failure. Dying persons can suffer needlessly because the medical team has not been trained to offer compassionate care, and communications can be poor between the patient and family and the medical team.

The focus of dying has shifted from the spiritual realm of reconciliation and the healing power of God to the secular realm of medical technology. Secular views of dying, which often promote a cure at all costs, can conflict with Christian views, which see death as a natural part of the life cycle and which encompass a different form of healing—God's action to bring peace to the dying person. As a result, the process of dying in America has become detached and impersonal. As more and more palliative medicine and end-of -life care programs have developed, much has been written about how the church can play a larger role in propagating palliative care and encouraging African Americans to embrace these principles. Many believe that the church is the only institution in the African American community that can address these issues.

What has not been given proper consideration is the fact that as the repository of African American history, culture and values, any approach that the church might take must be one that honors that history, culture and values.

It is indeed true that the church needs to be involved in the ongoing dialogue and in the changes that are occurring in the medical system as a result of the principles of palliative care. But, it is also true that for the African American church and its members, those principles need to be redefined in a way that takes into consideration the uniqueness of their history and the psychological, emotional, spiritual and practical consequences of the oppression that makes up that history. Because the larger white society placed so little value on the lives of African Americans, African Americans have not been eager to accept the concepts of palliative care that have become so prevalent in white society and have no faith in the medical establishment to decide who should live or die.

The basic principles of end-of-life care are supposedly based on the ancient Christian tradition of caring, but for African Americans in this country, there is very little relationship between those principles and the way that their lives were impacted. Because of the understandable distrust that African Americans have for the medical establishment, any effort to engage the church must be informed within a context of providing the church and its people with knowledge so that they can make their own choices.

What End-of-Life Care Ministry Should Include

What we know about ministry in the African American church from a historical, cultural and theological perspective as well as what we know about the ongoing dialogue in contemporary society can help to shape a more effective approach to end-of-life ministry in the African American church.

A number of factors should be considered:

- Use of Sermons - In order to set the tone for the church, the minister must be willing to use sermons to help the congregation understand that death is a natural part of life and that intentional care of the dying is an important part of the church's ministry.
- Educational Programs - Any church-based end-of-life program should offer intentional opportunities to increase the congregation's awareness of "culturally sensitive" resources that are available to assist the seriously ill and dying as well as opportunities to improve the congregation's ability to address issues related to death and dying.
- Skill Development - In addition to educational programs, congregations can establish programs to help members develop the skills within the congregation that will enable the church to effectively address the needs of the seriously ill and dying.
- Advocacy - Ministers and other church leaders can become knowledgeable enough to join the dialogue in order to take their place as advocates for the persons that they serve.
- Establishment of Support Programs - The church is a natural and ideal place for the establishment of support groups for patients, family members and other persons who are impacted by a life-threatening illness.
- Development of Rituals - End-of-life care ministry should work toward developing culturally sensitive rituals that value in death what the seriously ill and dying valued in life. As the slaves created the spirituals or "slave songs" that ritualized death and dying, so must the African American church create similar rituals to serve a similar purpose.
- Explore the Use of Community Resources - Because the church represents a large number of members, a congregation can collect information on the resources that are available in the community and establish partnership relationships with them on behalf of its members.

Conclusion

As a result of the long, difficult and often violent history of slavery, racism and continuing oppression that African Americans have suffered in this country, the church has traditionally been and continues to serve as the center of African American community life. The church has been viewed as the institution that African Americans have turned to most often for comfort and support during periods of crisis. Because of the danger and the threat of physical violence that has always been a part of African American life in this country, one of the most important of those transition points was at the time of death or when a member of the community was dying.

The focus of dying has shifted from the spiritual realm of reconciliation and the healing power of God to the secular realm of medical technology. Secular views of dying, which often promote a cure at all costs, can conflict with Christian views, which see death as a natural part of the life cycle and which encompass a different form of healing—God's action to bring peace to the dying person. As a result, the process of dying in America has become detached and impersonal.

As more and more palliative medicine and end-of-life care programs have developed, much has been written about how the church can play a larger role in propagating palliative care and encouraging African Americans to embrace these principles. Many believe that the church is the only institution in the African American community that can address these issues.

It is indeed true that the church needs to be involved in the ongoing dialogue and in the changes that are occurring in the medical system as a result of the principles of palliative care.

But it is also true that for the African American church and its members, those principles need to be redefined in a way that takes into consideration the uniqueness of their history and the psychological, emotional, spiritual and practical consequences of the oppression that makes up that history.

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Key Topics on End-of-Life Care for African Americans

An intellectual discourse derived from The Last Miles of the Way Home 2004 National
Conference to Improve End-of-Life Care for African Americans

African American Perspectives on Advance Care Planning

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African American Perspectives on Advance Care Planning

Advance Care Planning - An Overview

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Advance care planning is generally used to refer to oral and written instructions about one's future medical care in the event that one becomes unable to communicate these instructions. Advance care planning is a process involving oral conversations and written instructions that outline a person's health care preference for the future, in the event that the patient becomes unable to make or communicate decisions for themselves.

Advance care planning is a process that involves the following steps:

- Speaking with loved ones about preferences for end-of-life treatment
- Getting information about the patient's illness, reflecting upon the available choices about treatment and deciding what is most important
- Deciding which person the patient would like to make health care decisions on their behalf in the event they are unable to make them for themselves; it is important that the patient talk to the chosen person to make sure that he or she agrees to do this and he or she knows the patient's preferences

Advance care planning involves three basic elements. First, it is important for the patient to spend time thinking about their health care preferences and what they would want should they not be able to speak for themselves. The more time spent prioritizing their wishes, the easier time they'll have communicating these wishes to their loved ones. Second, after receiving a commitment from a trusted friend or family member to act on their behalf in an emergency situation, the patient should talk to them in detail about their wishes. It is to not rush the conversation. The more detail covered, the clearer the patient's wishes will be should an emergency occur. Finally, the patient must document and notarize their wishes and be sure to distribute copies to all parties involved.

The Advance Care Plan

The advance care plan is the outcome of the advance care planning process. Developing an advance care plan allows you to make a permanent record of the conversations you have had and to maintain a clear and up-to-date document about your preferences. The written portion of an advance care plan can take a number of forms. Some examples of the possibilities can include but are not limited to the following:

- A letter to the person who will be responsible for this decision-making

- An entry into the patients medical record
- A formal, legal appointment of a medical guardian
- An advanced care directive or any combination of these things

Recent advances in medical technology permit life to be sustained long after the human body has permanently lost its natural ability to perform basic tasks. Use of the advance directive allows patients the opportunity to provide statements, which may be periodically updated, documenting the type and extent of life-sustaining medical treatment they desire at the end of life.

Advance directives give patients a voice in decisions about their medical care in the event that they become unconscious or too ill to communicate these decisions. As long as patients are able to express their own decisions, the advance directive is not used, and medical treatment can be accepted or refused. If, however, the ability to participate in discussions about treatment is lost, the advance directive is used, if it has been duly executed. Because both federal and state laws govern the use of advance directives, statutory requirements regarding their use may vary from state to state. All 50 states and the District of Columbia have laws recognizing the use of advance directives.

There are two types of advance directives-the living will and the durable power of attorney for health care. The living will allows the patient to place their instructions for medical treatment in writing. The state law in which the living will is executed may define when the will goes into effect and may limit the treatments to which it applies. Typically, the living will contains the patient's precise choices regarding treatment options, should they become unable to communicate these choices to their health care professionals.

The durable power of attorney for health care may also be called the medical power of attorney, health care proxy or appointment of health care agent. This document enables the patient to appoint someone to make decisions about their medical care if they are unable to make these decisions. In many states, the person appointed is authorized to speak for the individual at any time he or she is unable to make her own medical decisions, not only at the end of life.

Studies show that while African Americans support the concept of advance care planning, they are less likely to execute or use advance directives. Some believe that planning for death initiates the process of dying. "If I don't acknowledge that I need a living will or durable power of attorney for health care, then I'm alright. If I do, then that means I need it."

The African American community is rich with - tradition and symbolism that is largely influenced by religious and spiritual beliefs and practices. A notion of "a beautiful home-going" or funeral is often viewed as an end-of-life celebration. However, the research continues to suggest that African Americans request aggressive medical treatment at the end of life even when it is unlikely that such treatment will improve outcomes. While a consistent rationale for this treatment option remains unclear, some have indicated that

their requests are based primarily on mistrust and negative experiences with health care systems. A further explanation may be the patient's mistaken belief that any option that fails to include aggressive treatment is a breach of the standard of care to which the patient feels legally entitled.

There are varying reasons as to why African Americans do not use advance care planning documents. Oftentimes the documents are comprised of confusing legal terminology and are difficult to understand, and in addition, many African American patients are unaware of the various treatment options at the end of life. In these instances, the health care providers' attitudes toward advance care planning and how this information is communicated have contributed to the failure of African Americans to better utilize advance directives. Research suggests that while physicians recognize the importance of advance directives in directing treatment options, they express reluctance in initiating dialogues regarding these documents with their African Americans patients. In situations where these conversations have been initiated, physicians spoke for the majority of the time using vague terms that rarely explored the patients' beliefs and values. More desirable outcomes occur when African American patients are provided opportunities to communicate their views regarding end-of-life options with physicians with whom they have established trusting relationships and who have demonstrated a cultural sensitivity to their beliefs and values.

Statistical research reveals that the perception of some African Americans is that if they had an advance directive, they might be cared for to a lesser degree by medical personnel and this conclusion seems to be consistent with elderly African American patients as well. In one study elderly African American patients were significantly more likely to request the use of life-sustaining medical interventions when compared to other groups examined, while white patients were significantly more likely to have completed advance directives. While the literature on the issue of racial differences and the use of advance directives is somewhat limited, it continues to present two very interesting conclusions: 1) African Americans complete advance directives less frequently than do whites, and 2) unlike whites, those African Americans and other people of color who have completed advance directives tend to indicate that they do want life-sustaining medical treatment administered and continued regardless of the state of their illness, and even when there is no medical hope of recovery.

Even in instances in which African Americans are medically declared to be in a persistent vegetative state, life-sustaining medical intervention continues to be the preferred option of care. Generally, people of color are less likely to complete advance directives and are more likely to request aggressive end-of-life care. Some emerging research tends to suggest that a dominant influence on African Americans in their decision-making in end-of-life care is their spiritual and/or religious convictions.

In addition to research on African American patient populations, some studies have examined differences of African American health care professionals regarding end-of-life treatment options. Of particular note is one study that concluded that while African American health care professionals have positive attitudes toward advance directives,

they are less likely to have actually executed directives documenting their own preferences. Further research indicates that African American physicians choose aggressive medical interventions significantly more frequently than white physicians.

Ultimately, the research clearly indicates that end-of-life planning and treatment choices are directly related to race and culture. African Americans seem more likely to defer end-of-life treatment options to family members, believing that family will make the best decisions at the appropriate time. Some African Americans indicate that they did not consider completing advance directives because they believed that informal discussion and family communications were sufficient. They remain reluctant to sign advance care planning documents, fearful that they do not understand the documents and or the documents may somehow be used to prematurely limit treatment before all life-sustaining measures have been exhausted.

Moreover, their religious and spiritual convictions and general mistrust of health care systems are also relevant factors to be considered in their failure to execute end-of-life documents. Accordingly, it is crucial to understand the relationship between the values, beliefs and experiences of African Americans when examining their reluctance to use advance care planning documents. Many African Americans view advance care planning as "giving up hope." Physicians and other health care professionals who treat African Americans must convey to patients that their cultural and personal values will be respected when they are dying.

Statistics indicate that African Americans do not have access to good health care. Studies indicate that populations of color are predominantly served by physicians of color, including many foreign born medical professionals whose cultural experiences and training are vastly different from the patient base they serve. It is imperative that medical school programs work to increase the number of physicians and other health care programs across America must do likewise. Doing so will improve access by diverse communities to both health care in general and to physicians and others who are sensitive to attitudes of diverse populations toward end-of-life care in particular.

Poverty can play a large role in shaping African Americans' attitudes toward end-of-life care. Some African Americans perceive that they would not have access to life-sustaining treatment because they could not afford it, or that the care would not be covered by their insurance.

A number of situations regarding end-of-life care often find their way into courtrooms. Advances in technology and medical treatment have heightened the expectations of patients and their families regarding expected outcomes. Some expectations, often unrealistic, have been promoted and fueled by mass media attention.

Why would these medical situations stimulate legal debates and discussions of multi-million-dollar lawsuits? Has the courtroom become the final arbiter for setting the standard of medical care, thus abrogating the traditional judgment and responsibility of the physician and other health care professionals?

Specifically in the area of end-of-life care, certain ethical and legal issues have become dominant. They include:

- Competent/incompetent determinations
- Validity of advance directives when challenged by family members
- Physician-assisted suicide
- Withholding and withdrawing of life support
- Medical futility
- Medical malpractice
- Organ donation
- Autopsy

While there is no indication that these issues impact African Americans more significantly than other groups, they remain constant challenges in discussions of end-of-life care for all people. It is important for health care professionals and policymakers to recognize that medical care, especially at the end of life, is not an exact science. Treatment options are not, and should not, be considered medical guarantees.

Advance Care Planning- A Family Caregivers Perspective

Camilla Hudson
Patient Advocate

Throughout my childhood and well into adulthood, my parents were the people I could always rely upon - for advice, for financial assistance, for support of any and every kind. So, as they aged and their health declined, it was a difficult transition for me to make as they were less able to function as my support network and I was confronted with the need to reverse roles and become their primary caregiver. At the age of 78, my mother was diagnosed with mild-stage Alzheimer's disease and at that time, she was my father's primary caregiver.

My father, then age 79, had a long history of heart disease, high blood pressure and major complications from diabetes including blindness and a below-knee amputation of his left leg.

I grew up on the south side of Chicago in a solid and stable, middle-class African American community. Our household consisted of my mom, my dad, my maternal grandmother, my younger sister and me. My father was originally from Clarksdale, Mississippi and had migrated north in the late 1930's. After an entrepreneurial stint owning his own candy store, my father went to work for the Rock Island Railroad in the late 1950's, where he eventually became their first African American mechanical foreman. My dad retired from the railroad in 1991 after more than 30 years of service. My mother, originally from Mobile, Alabama, also migrated to Chicago in the late 1930's. Like many woman of her generation, she initially worked in a domestic capacity then later went to work for Montgomery Ward & Company as a billing clerk. My mother retired in 1982 after more than 35 years of service.

Growing up with my grandmother in the house taught me a lot of lessons that I did not necessarily understand as I was learning them. When I reached my teen years and my grandmother's health began to fail, it was a given that my grandmother would remain at home with us. Over time, as my grandmother developed dementia, I watched my mother lovingly care for her mother even when there were times that it had to be exceptionally difficult for her. My mother never expressed a sense of burden or hardship and she never complained. In fact, she frequently commented that she was glad that she could care for her mother, that it was what she wanted to do.

In light of my mother's Alzheimer's diagnosis, I was faced with taking on the responsibility of my father's care and experienced a steep learning curve with regard to what needed to be done to ensure my mother's well being. As I moved into the role of primary caregiver, one of the first tasks was to determine my parent's overall state of affairs. While I'd regularly assisted my mother with my father's care, I had always held a supporting role. Now, assuming the lead meant having thorough knowledge of not only their medical diagnoses and plans for care, but also becoming thoroughly familiar with their financial situation and their daily care needs as well. While I'd always suspected that my parents had not taken the time to write and properly execute a will, I really had no detailed knowledge regarding what plans they might have put in place. Moreover, I had no solid idea of what types of plans or arrangements they might need and/or want to establish.

As I began the process of discovery and had initial conversations with each of my parents, I came to learn that while my parents had planned fairly well with regard to having sufficient income for their later years, which was apparently all that they had done to address their long term future needs. Not only did they not have a will, they also had no plans or directives in place for their long-term medical and health care needs. This was of especially great concern to me given my mother's Alzheimer's diagnosis. Generally speaking, all of their financial matters were set up making them one another's primary beneficiary. Therefore, in the event of my father's death, all financial and decision making responsibilities would automatically revert to my mother, who was far from being of sound mind. Were that to happen, it would be necessary to go to court, have my mother declared incompetent and then have a judge decide how my parents' affairs should be managed and who should have the authority to make decisions on my mother's behalf. Needless to say, this was a situation that was far from ideal!

The very idea of it all was somewhat overwhelming. My feeling was that something needed to be done to correct this situation and it needed to be done immediately. However, when I talked to my father and told him that it was imperative that he draft a will and make formal arrangements regarding both his own medical care as well as my mother's, he simply didn't want to hear it. While he didn't dismiss me outright, he avoided giving direct answers to my questions and refused to have detailed discussions on these matters. When I attempted to push him further, he became angry and would tell me that he didn't need me to tell him what he needed to do and that he was an adult and therefore quite capable of determining his own needs. Many times, our conversations

ended in arguments, with both of us fuming. There were times when I just wanted to stop pushing him, even though I knew I was right about what needed to be done.

As my mother's illness progressed, the more worried I became about my parents' lack of planning. I made every adjustment I could on the financial matters, such as setting up direct debit from my parents' checking account for utility bills and various other bills requiring monthly payments. It was necessary to hire someone to care for my parents during the daytime hours and I simply paid them from my own checking account and wrote myself a check from my parents' account as reimbursement. While it could be argued that it would have been easier to manage these necessities had the proper planning been done, nonetheless all of their day-to-day needs were met and somehow or another, nothing fell through the cracks.

With regard to the medical aspect of things, we were not faring quite as well. First and foremost, I was not exactly certain what my parents did or did not want in terms of life saving measures. - i.e. did my dad want "heroic" action taken in the event that his heart stopped, just how far did he want them to go and, specifically, which procedures would he want or not want to have performed if he was in a coma or if he had brain damage. While my family had discussed these things vaguely over the years, we'd never had a discussion to address the specifics and emphatically determine what either of them might want or not want. For my mother, given the progression of her Alzheimer's Disease, it eventually became an easy matter to say no to all of the above, simply because her mental status was deteriorating rapidly and it was obvious that her quality of life was already compromised beyond recovery. During the earlier stages of the disease, I would sometimes find my mother sitting on her bed or off in a corner crying quietly to herself. When I would ask her what was wrong, she would respond by saying that she didn't understand why the Lord saw fit for her to live this way, or she would ask why the Lord didn't just take her and deliver her from the pain of this awful disease.

My father was a different matter altogether. While my mother was physically well but experiencing a mental deterioration, my father was the exact opposite. He was quite clear and alert mentally but his physical well being was on a steady and constant decline. This left him very angry and very bitter. He'd worked hard over the course of his life and had been looking forward to enjoying his retirement. However, when he finally retired at the age of 72, he had been forced to retire as a result of his declining health. Therefore, instead of enjoying his retirement years, he'd spent them getting steadily sicker and sicker, and in the process, had lost the ability to do many of the things he loved and had planned to enjoy in retirement.

I slowly came to the realization that it was very possible that my parents were going to die without a will and/or any other legal documentation in place regarding their finances and their wishes for their medical care in the event that they were unable to make decisions for themselves. My mother's Alzheimer's disease had already progressed to the point that she was no longer considered competent and my father was therefore the designated decision maker given that they were married. I recognized that if my father were to die before my mother, I would certainly face whatever was required of me. Yet I

remained committed to helping my father understand that he truly needed to "put his house in order," so to speak, and get all of his financial and medical affairs addressed in as timely a manner as possible.

Over the course of my mother's illness, I learned a great deal about the legal aspects a family faces when a loved one is terminally ill. Learning and becoming fully familiar with the terminology was just the beginning - living will, durable health-care power of attorney, a

Do-Not-Resuscitate order (otherwise known as a DNR) and many others. Initially it was sometimes a little bit difficult to answer a medical provider's questions fully and accurately because I just wasn't certain as to what my father's wishes were with regard to many of these matters. However, over time, I learned that while it wasn't ideal, it was still acceptable to say that my father did not have a living will and I simply wasn't certain as to whether or not he would want to be resuscitated.

As these incidences increased, it led to more discussion with my father as to making some decisions and putting some things formally into place with regard to his wishes for both himself and for my mother. Given that my mother had reached the more advanced stages of Alzheimer's disease and her overall quality of life was significantly reduced, I eventually took it upon myself to tell medical professionals that she was to be designated as "DNR" or Do Not Resuscitate and no one ever questioned my authority to do so. While I felt completely right and within appropriate boundaries in making this decision, I still felt that it was my father's responsibility, as her husband and as her direct next-of-kin, to put the right documents in order so that any and all questions on this matter were properly addressed. Despite this, my mother's illness progressed and in the end, she passed without my father ever so much as verbalizing anything specific with regard to advance directives for either of them

While I will never really know, with certainty, what changed and what made the difference in my father's attitude but after my mother's death, my father seemed to take on a different perspective with regard to his financial and medical affairs. I do attribute it to the finality and realness of my mother's passing and the fact that my father could no longer deny - to himself or to anyone else - exactly what was happening in his life. The first real breakthroughs came on the financial side, when my father finally agreed to talk to an attorney about his wishes for his property and his other financial matters, and he admitted that he knew he needed to create a will. Unquestionably, it was very helpful that the attorney he spoke with was one of my childhood friends, someone my father knew and remembered from my elementary school orchestra - someone he felt comfortable with, someone he knew he could trust. Still, despite going through all of the necessary details and specifics required for legally executing a will, my father remained less than cooperative about establishing something legal and tangible with regard to his health concerns. He had reached the point of acknowledging the fact that it should be done and needed to be done, but he still procrastinated when it came to actually doing it.

Again, over the course of my mother's illness and in watching the gradual decline of my father's physical well-being, I'd made a point of learning as much as I could about my rights and responsibilities, and just what I could or could not do within legal boundaries, given the fact that I didn't have power of attorney for either of my parents. One item of particular interest was a document titled Five Wishes[©], a living will publication distributed by Aging with Dignity.

The Five Wishes[©] document is a unique type of living will that not only addresses the medical aspects of end-of-life care, but also addresses the personal, spiritual and emotional aspects of end-of-life care as well. I'd talked to my father many times about filling out a Five Wishes[©] document for himself as well as for my mother but he was never receptive to talking about it in any detail. One morning, after we were well into the process of drafting his will with my friend/attorney, my dad actually asked me what else he needed to do. Initially, I didn't understand what he was asking me, but once I did understand, I was absolutely amazed and quite surprised. The fact that my father had progressed to being able to discuss his mortality with me was such a hurdle for both of us to conquer.

My father, being legally blind, certainly wasn't able to read over the Five Wishes[©] document for himself but I was happy to read it to him and discuss the various questions with him. The purpose of Five Wishes[©] is to allow the individual to choose the person they want to make health care decisions on their behalf if the individual is not able to make them for themselves, to state what types of medical treatment the individual wants or doesn't want and to state what specific information the individual wants to share with their loved ones. This type of empowerment was especially important to my father who, as a proud African American man,

had always been the decision maker for himself as well as his family. Being able to state exactly what he did or did not want gave him a sense of control and made him feel that the entire process was conducted on his own terms, not something specified or laid out by someone else.

As I read through each of the various components of the Five Wishes[©] booklet, my dad and I discussed everything in great detail. At some points, my dad would ask me to explain something a little more fully or differently, while other aspects of the form were so straightforward that no further explanation was required. In the end, some very important matters were discussed and decided upon and I finally had the tools I needed to make care decisions on my dad's behalf that I knew, without question, were in line with what he wanted or didn't want.

When my father reached the last stages of his illness and was ready to make his final transition, there were many aspects of his care that required my consent or a decision on my part. Given the things my dad and I had discussed and everything he outlined in his Five Wishes[©] document, it was always easy for me to say yes or no to a specific procedure and know that the decision was completely in line with my father's wishes. Unquestionably, there were difficult moments and I had to give some decisions a second

thought but I could always rest assured that my father's wishes were being honored, no matter what the outcome. My father passed on April 19, 2006 with his family at his bedside, content with the knowledge that we'd made the right choices.

Summary

Discussing advance directives with patients can increase the chance that care at the end of life will be consistent with a patient's goals and values and will enhance quality communication, decision making, and the patient and family's opportunity to come to terms with death. Physicians and other health care professionals who care for African American patients must be willing to explain the advance care planning process while demonstrating sensitivity to these patients' cultural values and beliefs. Equally important, it is imperative for African American patients and their families to not only have those "kitchen table conversations" but to take it a step further by utilizing documents that will ensure that their wishes are known and can therefore be followed.

As the medical community strives to improve care at the end of life, it is necessary to consider issues of cultural differences so that all patients can be served equally by the advance care planning movement. Medical professionals need to familiarize themselves with the literature on cross-cultural issues where religion, gender, age, socioeconomic status, ethnicity, sexual orientation, and acculturation status have been identified as features impacting end-of-life care decisions. It is always the patient who remains the expert on cultural knowledge and from whom the medical community must elicit personal preferences, and then follow through by respecting and honoring those preferences.

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Key Topics on End-of-Life Care for African Americans

An intellectual discourse derived from The Last Miles of the Way Home 2004 National Conference to Improve End-of-Life Care for African Americans

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ABSTRACT: The Witness of History: Cultural Narratives at the End of Life

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The deaths of African Americans throughout their history in this country too often have been marked by violence, particularly the violence of racism. In significant ways the deaths of the young of the African American community have set the public tone for the meanings of "black death." The manners that African Americans observe and internalize the passing of their loved ones are derived from social, cultural, religious, and spiritual rituals that provide solace, hope, and unity at times of great loss and stress. The black church and family are institutions that have provided crucial sources of strength and comfort for a community that has suffered inordinately because of whom its people were: the enslaved, the emancipated, the segregated, and the integrated. Holloway recounts her exploration of "black death" in the arts, through encounters with the living, and travels to the final resting places of black folk ... everyday people and the legendary.

The Witness of History: Cultural Narratives at the End of Life

INTRODUCTION

I have found a space in this collection of papers that is both academic and personal. It is a space of research and scholarship on death and dying in African American communities, and it is the space of a citizen of that community touched personally by the kinds of stories that I have shared in *Passed On: African American Mourning Stories—A Memorial*. [1] The stories I recall there cohere into a collective cultural memory, and that memory frames a certain understanding based on "How *We* Die," a color-coded death— the residue of riots, executions, suicides, targeted medical neglect—a range of bodily violence. They are stories that urge us not to forget. And in resisting the urge myself to forget the unspeakable, I have researched and excavated a particular view of black death that seems, in its intimacy with African American life, a cultural haunting, a "re-memory" in the way that Toni Morrison's novel *Beloved* insists that "not a house in the country ain't packed to the rafters with some dead Negro's grief." [2]

Although I wanted to both find the expression of that grief and follow it to its conclusion, I knew as well that black folks, whose indomitable and remarkable presence articulates the best of this country's spirit, intelligence and politic, bridges this cultural haunting with hope, grace, and resilience. Given that paradox, I wanted to come as close as I could to these final moments as represented in biography, performed in literature and the visual arts, and experienced within the records of both history and memory. James Baldwin made clear the associative nexus between black memory and the experience of black death, writing in *The Evidence of Things Not Seen* that "memory makes its only real appearance in this life as this life is ending." [(page xv)]

It is an appropriate view of our dying where the only thing we know for sure are the times past. Memory is our touchstone, and I rely on it here to help shape and explore the experience of African America with black death.

That private anticipation of death and dying which figures itself into the experiences of black folks throughout their lives is so persistent and so much more prevalent than it is for other Americans that lamentation and mortification became a part of the race's public persona. The twentieth century's literature and film, its visual arts and music (from early-era spirituals to latter-day rap as well as contemporary street corner memorials) consistently called up the ghostly presence of a passed-on narrative. Black culture's dead and dying stories were inextricably linked to the ways that the nation experienced, perceived, and represented African America. Whether one recalls what W.E.B. Du Bois called the "sorrow songs," spirituals such as *Soon I will be done with the Troubles of de world* , the burning crosses of the Klan, or the burning communities whose rebellions provoked white rage and violence, black folk have come to know black death. The cycles of our daily lives—whether as infant or as an elder—were so persistently interrupted by the specters of death that we worked this experience into the culture's iconography and included it as an aspect of black cultural sensibility. Little wonder that rap artists like Tupac Shakur or the Ghetto Boys titled their albums "Resurrection" or created cover

photos where they lay reposed in caskets. They knew the marketability of images of death and dying were intimately tied to the ubiquitous experience of black death and dying.

African American mourning stories revolve around the angst of the liberal circulation of black death, that is, without discrimination between black parents and their youngsters, elders, and their adult children. All could find an eerie familiarity with the fact that the formative years, the waning years, and each day between these is haunted by the spiritual's refrain, "soon one morning, death will come a-calling." The dead and the ways of our dying have been as much a part of black identity as have been the ways of our living.

I. Suffer the children

Certainly our singular stories and memories drift toward, are shared, and are finally echoed within community narratives. And, because a community's identity is fully and expressively engaged in its youth, there is a space as undeniable as it is pitiful in history's acknowledgement of the ways that black children are forlorn legates of the cultural experience with black death.

For many of us, the story of children's experiences with "public" death is fixed with five youth. One is Emmett Till who was called affectionately "BoBo" by his mother when she sent him from their Chicago home to visit relatives in the south. His lynching in Mississippi in 1954 is remembered by still-aggrieved generations—a lingering melancholy in the memory of black folk. Bobo's loss is a familiar because ironically, scores of years later, we still find no lack of familiarity with a storied loss like this one of sons and souls of black folk. Indeed, one of the most striking stories of black cultural history is the recurrent narrative of parental loss.

The second public moment, which was seared into our national memory, is the 1963 assassination of four little girls, Cynthia Wesley, Addie Mae Collins, Carole Robertson, and Denise McNair, who were murdered in a Ku Klux Klan-engineered bomb blast during a summer Sunday school service in Birmingham, Alabama, at the Sixteenth Street Baptist Church. We rehearse the memory of this story so consistently that it has even appeared in our fiction. Consider the text of the following passage from Toni Morrison's novel, *Song of Solomon* :

Every night now Guitar was seeing little scraps of Sunday dresses—white and purple, powder blue, pink and white, lace and voile, velvet and silk, cotton and satin, eyelet and grosgrain. The scraps stayed with him all night... bits of Sunday dresses that... did not fly; they hung in the air quietly, like the whole notes in the last measure of an Easter hymn. Four little colored girls had been blown out of a church.... [3]

No fiction, however, could displace the pathos of the factual moments—in this instance recalled by a heartsick Mamie Till Bradley, who went to identify her son Emmett's body when he was returned to Chicago :

I didn't want that body.... That couldn't be mine. But I stared at his feet and I could identify his ankles. I said, those are my ankles. Those are my knees. I knew the knees... and then I began to come on up... until I got to the chin and mouth... those were Emmett's teeth, and I was looking for his ear. You notice how mine sort of curls up... Emmett had the same ears.... [T]he one eye that was left, that was definitely his eye, the hazel color confirmed that, and I had to admit that that was indeed Emmett and I said that this is my son[;] this is Bobo. [4]

Although the story of children reveals something especially poignant in our histories of death and dying, there is a dimension of the business of burial—the occupation of the funeral professionals, where children give us a particularly thoughtful glimpse into the labor and work days of "death care providers"—funeral home directors and morticians. These youngsters also appear in stories about these adults because of the generational link between many black mortuary professionals.

Many youth grew up in homes that housed both the family and the family's business. One young man explained to me how he grew up to "stand next to his father" working right alongside him in the funeral home. He saw his first dead body at thirteen while "looking for his father in the back rooms of the funeral home, ducking his head into hallways, calling out for Pops, opening and closing doors," until he picked the door to the embalming rooms and saw 'gentlemen back there embalming.'" He was pensive as he recalled how he "used to really dislike coming down here, I was quite frightened about death and dying and bodies." But he has now inherited his father's business, passing it on and keeping it in the family, in the way that has come to be common among black mortuary professionals.

Despite their nearness to the profession, children whose parents were in the business harbored as many strange understandings of what happens in the back rooms of their homes as did their friends who did not live as intimately with death. A brief vignette from some of my discussions with some of the smallest children of black funeral directors and morticians, who have been known to march into the annual business meeting of the black professional association, the National Funeral Directors and Morticians Association, proudly wearing T-shirts printed with the association logo and the phrase "Future Mortician."

In my interviews with them, I asked about their parents' jobs. "He fixes dead peoples," one explained. "They hang them [the deceased] up to dry, and then they dress them up and put them in those boxes." Another happily shared with me, "I get to push around the baskets [caskets]," but then he added a more cautionary note, "But I can't go in there where he gets the dead peoples from." Curious about their knowledge, I pressed further. "Where do they come from?" I asked.

"From the hospital," one child told me assertively and with just a bit of exasperation at my lack of knowledge. But then another youngster interrupted his age-mate with a correction. "No? No he don't! He gets them out of the freezer and has to wait thirty

minutes, and then he can come in to eat dinner. After that, then they unfreeze, and he puts clothes on them and then we put them in the car and I help."

"He gets them out from under the ground." I was told by an eight-year-old girl— interested in showing off her superior knowing. She continued. "And then, he puts those fancy dresses on them [the industry's name for these is "garments"], and then he puts them back. After that we can eat."

There was another participatory mode that children have in my research that was informative about the subject but very distant from this telling. The stories that emerged from African American children's deaths brought the morbid experiences of African American communities into sharp focus. One would anticipate that theirs should be unexpected events in the life/death cycle. But from their too familiar circumstances and oft-anticipated occasions emerged a perspective of a community's life that told a larger story than the single, pitiful event of a child's dying and burial.

Stories like Emmett Till's haunted our fiction, appeared in autobiography and memoirs, and because of the excess of their generation and our response, became our folk and news stories. In essence, children's stories persist long past their passing on, and their deaths made apparent both the persistence of memory and the necessity of memorial.

One form of memorial appeared in the artistry of the photograph. Whether they were Polaroid shots stuffed between family photos in an old black page album, or the formal photographs of the dead by professionals as James Van Der Zee and Richard Samuel Roberts, the documentary record of black death was captured in black and white. We begin to get a glimpse of this ironic intersection of creative imagination and damnable public circumstance with the great migration of the second decade of the twentieth century. It dramatically impacted African American's experiences with death and dying, and in this era, the dead were disproportionately young. In Harlem, for example, some funeral directors whose parents were in the business during the 1920s and 1930s recalled to me the seemingly "endless" procession of small white caskets that became ordinary as black children succumbed in disproportionate numbers to the tuberculosis epidemic and the pneumonia—called "consumptive disease"—that ravaged the community. An October 24, 1929, article in the *New York Times* led with the headline that "Congestion Causes High Mortality" and detailed the 40% higher death rate in the crowded neighborhoods of Harlem than the rest of the city. There was a ready and available source for artistry like that of Harlem photographer James Van Der Zee.

Van Der Zee was well known for his vivid documentary pictorials of Harlem lifestyles, but he was celebrated as well for the powerful photographs of mourning that he took early in the century. He understood his work was in the tradition of archive and documentary. His photographs might be the only way that some families would have to remember a child.

One especially poignant Van Der Zee portrait shows a wife gently leaning over her husband as he sits cradling their dead infant. The image is intentionally constructed as a

domestic vignette. The father is in what seems to be a rocking chair and a radio in the background suggests the setting is the family's front parlor. The dead baby, dressed in white garments like those worn for a christening and nestled in his father's arm, looks as if asleep and both parents' affect suggests an eerie peace as they look lovingly down on their child with a calm that belies the fact of the still life story constructed for the photographic occasion. Van Der Zee explained that the picture was not taken in their home, but it was composed and shot "in the funeral parlor. [A] radio was in the picture to make it look more homelike. It belonged to the undertaker anyway. It was my suggestion to have them hold the child while the picture was being taken to make it look more natural."

When asked how the parents felt about holding the dead child he replied, "Well it was their baby.... Most of these babies, they all died of pneumonia; chest gets filled up with colds because they were living in cold flats. It was a common thing in those days for people to be without heat." [5]

Contemporary accounts suggested the most dreaded disease in the densely populated projects of Harlem was pneumonia. But tuberculosis as well took its toll.

A 1934 survey of 20,000 residents of Harlem revealed that 3% had pulmonary tuberculosis. The disease was so pervasive, that one city block was known among the epidemiologists as the lung block. These were the days of segregated medical care. Most hospitals in the city that were treating tuberculosis refused to admit "Negro" patients, so they were squeezed into the wards of Harlem Hospital, just as they were packed into the blocks of Harlem streets and its tenement houses. Both kinds of congestion contributed to the virulence of the disease: a fact that led to the high morbidity and mortality. Harlem Hospital was referred to as 'the morgue' in the community and there was great distrust of its facilities. The common story in the streets was that you went there to die.

But the story of children's deaths was not limited to the early century. And it was not limited to the terror of Emmett Till's boyhood vulnerability or to the benign neglect of white racism. At the end of the twentieth century, the backlog of children's violent deaths in some urban areas made weekday rather than weekend funerals an ordinary event in some cities and led funeral directors in other cities to refuse to handle the funerals of children. One funeral director in Buffalo, NY, expressed to me the concern of the professionals. Explaining to me his reluctance to handle the funerals of children and youth he said, "They come in here with guns and all, and they act up."

Youth cultures, always dramatic, noticeable, and brittle, carried through their drama with their dying. Elaborate rituals evolved for gang deaths in Los Angeles —testimony to the familiarity of this particular dimension of cultural death.

A cottage industry furnished floral tributes draped in gang colored ribbons, sweat shirts and T-shirts with the deceased member's name in a variety of fonts and with a choice of texts like "R.I.P. Homie." Street corner memorials, with children's toys stacked on a

sidewalk, poetry sketched on building walls, and declarations of love and goodbye messages scrawled on sidewalks became familiar, if transient, urban markers.

The business has had an ambivalent response to the deaths of children. These are generally not businesses whose finances are especially liquid. Nevertheless, understanding that a business philosophy should be forward thinking, and because children's funerals were nearly always unexpected, "we encourage our funeral directors to absorb the costs for a child's funeral," a North Carolina funeral director and officer in the state NFDMA explained to me. "The average person does not expect to lose a child, and there's no generally no insurance to cover the cost of their burial." But because of the precarious finances that haunt too many black businesses, this was a decision that some African American funeral directors were hesitant to make.

Although every funeral had the potential of adding to their income, some were reluctant to carry this loss, even though it would likely and eventually lead to other business from that bereaved family. I was told by some of the younger members of the profession whose investment in finance and planning was substantial that, "If you do the baby well, when the mother or daddy dies, we'll get them on down the road." With a critique of some of their colleagues, they noted that "some of them don't see it, but children's funerals give directors exposure to a particular customer base."

At the end of the twentieth century, these narratives of business and exchange and their embedded texts of absence and loss found themselves woven into a cultural fabric. Black death—that is, the dying of African Americans that was in some way related to cultural identity—continued to be specific and identifiable, as did the cultural familiarity with and acknowledgment of the consequences of loss.

II. Looking back, and wonderING

The stories of the twentieth and twenty-first century professionals are deeply indebted to the history of the profession. The dense weave locking the threads of black death framed the history of the century as well as its people.

After the Civil War, America's troubling response to its newly freed black citizenry was a constructed pattern of violence. The extent to which lynching became associated with black presence rather than black conduct inculcated a sense of vulnerability. And as the nineteenth century turned, the violence directed toward blacks did not dissipate. In fact, it increased. It was the singular, colored vulnerabilities of these victims that made the crime so wicked and vicious. And it was the shared understanding and experience and anticipation of that vulnerability, whether one was directly affected by this violence, or just afraid of it, that cooperated in forging a cultural association, a shuddering memory, if you would, between color and death.

On too many occasions, these were not just crimes of a raging mob in pursuit of one or two persons. Sometimes an entire community was targeted. In Rosewood, Fla, the

precipitating event was a familiar one—the accusations of a white woman against a black man. The concluding event was as familiar.

On New Year's Day 1923, all of Rosewood—its homes and gathering places, the lodge and the churches, as well as its residents were marked for destruction and death. Seventy years after the New Year's Day tragedy, journalist Lori Rozsa wrote of Rosewood survivors as:

... still tortured with the lingering image of a parent or grandparent being lynched or shot, of the family home being burned to the ground, of crawling through the woods in the dead of night... hiding from an armed and crazy mob... hunted and attacked for nothing more than their color... black man whose left arm was paralyzed was forced to dig his own grave, then was shot and shoved into it. Another black man was hung from a tree in his front yard when he told the posse he couldn't lead them to the alleged rapist. A pregnant woman was shot as she tried to crawl under her porch for protection when the mob rode in. [6]

And if one might think that these were events of an early century, we need only recall the 1998 lynching of James Byrd in Texas and one might as easily include the 1999 murder of Amadou Diallo, who stood in the vestibule of his New York City apartment building and judged suspicious by policemen, was shot more than three dozen times. Such recurrent moments required studied ceremonial response. It called for ritual.

The century's consistency seemed to be that black folk were likely to die before their time in America. And given this sensibility, and what I have come to understand both differentially and together as both the urge toward life and an insistent hope, the black community nurtured two institutions—churches and funeral homes—both which would succor this grief and contain these narratives. Our community gained both expression and experience in handling this seemingly inevitable complication of black life.

While one might have anticipated black folk as overwhelmed by the persistence of such a history, stammering and stuttering a fractured response to living in America, instead the spiritual stature of the black church gave its community a powerful witness. And the spirit that invested in both the ministerial anticipation and the mortuary experience gave balm and solace in deeply personal and specifically professional ways. The close association of the black pastor and mortician represented a consummate merger of cradle to grave services as two institutions that were both consistently defined through their racial exclusivity shared clientele for the most critical ceremonies in one's life.

Ironically, though, the black church has been both a haven from the outer world, while, at the same time, vulnerable to its hatred and resentment. Its own visibility, coupled with society's understanding of its racial association and business made the edifices themselves susceptible to racial hatred. Throughout the twentieth century, black churches were assaulted—the target of bombs, arson, and vandalism specifically because of their racial activism and racial identification.

One dimension of my research, an exploration of *How* We *Die* speaks to the complicity of other institutions, including the institution of medicine in particular. I've mentioned the way in which, early in the century, Harlemites distrusted Harlem Hospital. But mid-century, this time in the South, distrust of the care doled out by doctors and hospitals, and deaths from what were equally treatable diseases, would fuel a similar mistrust. Black men died of what they were told was their "bad blood." Tuskegee Hospital at Tuskegee Institute, Alabama, was the site of the murderous maltreatment where white physicians participated in a project funded by the National Public Health Service to study the effects of syphilis on black men, certain that the effects of the disease—especially in terms of syphilitic heart disease—were racially distinct.

His only way of proving his hypothesis, as he explained in a letter to a colleague, was "the continuance of the observation of the Negro men used in the study with the idea of eventually bringing them to autopsy." [7]

In other words, the physician watched syphilis progress and made no attempt to treat it. "As I see it," one of the doctors observed, "we have no further interest in these patients until they die." At which time the autopsy, necessary to get the data to fuel the study's hypothesis, was urged on the families. The Public Health Service offered burial stipends in exchange for permission to perform the autopsy.

For forty years, black men in the Tuskegee study died, went blind, or experienced insanity in an egregious violation of medical ethics and in a prejudicially distorted hypothesis of medical science. Trust in hospitals and in the government, never strong in the black community, especially in concert with the numbers of hospitals who refused black patients, even those emergency victims of accidents, was further eroded by this sorry episode. To some, then, the way in which this legacy of mistrust re-emerge later in the century, specifically during the AIDS crisis that began in the 1980s was no surprise.

Like the other issues in black American history, the funeral industry was not far behind in its response to the crisis, and like the public response, it too suffered from misinformation and panic. More than one black mortician at a 1990s convention of the professional association explained to me how these professionals were "especially susceptible" to "the AIDS," and it was clear, in our discussion, that they didn't just mean because of their contact with body fluids.

One black-owned chemical company's response to the fear in the black mortuary community was to manufacture a special fluid for the embalming of victims of AIDS, not so euphemistically labeled "AIDS O'Dyne."

Whether as late century AIDS or as early century tuberculosis, when it came to death rates, race was a consistently predictable factor in patient mortality. This was true in every decade of the century, for urban as well as rural areas, and for northern as well as southern regions. The following (Table 1) is illustrative of the point of black death and dying.

Table 1
Tuberculosis Death Rates, 1939-41

CITY	FOR WHITES	FOR NEGROES
Chicago, Illinois	45.4	250.1
New York, New York	40.4	213.0
Philadelphia, Pennsylvania	44.3	203.5
Detroit, Michigan	36.5	189.0
Los Angeles, California	49.7	137.3
Reproduced from Drake and Cayton, *Black Metropolis* (204)		

Given what some in the death care industry could interpret here as a market survey, it is possible to use these kinds of statistics to understand how the financial aspects of death and dying came to matter greatly in black communities. One dimension of the early twentieth century evolution of the black funeral home was the way in which the role and perception of the mortician in the black community were closely associated with issues of class and social status.

As the century began, the mortician emerged as a businessman in a community of few independent black-owned businesses. Sometimes, he was the only one, other than the preacher who wore a suit during the week, and the fact that it may have been his only suit mattered less than the fact that his business gave him license to wear it on days other than Sunday. Indeed, the "24/7" suit and the authority it brought was not insignificant to the decisions some young men made to go into "the business." From his perspective, his appearance was an important and visible sign of status, from his consumers' perspective, as was widely noted among members of the professional organization, "Our people like to put on a good show." But "show is going to cost you," as one Tennessee funeral director explained to me, even then recognizing the way in which, among black folk, performance—its drama, elegance, and extravagance—was critical to the occasion.

Many families were concerned not only about the overall extravagance of the occasion, but also about its details. A Tennessee funeral director told me, "Cars are important for our people. We want to have four or five cars in the procession. It's something our folk are looking for." Another interrupted and said,

But at the same time, we do strange stuff like—with my business, we have white cars. Everybody in the city knows we have white cars. And then folk come to me, make arrangements for the service: pick out the casket, select the flowers, get the obituary ready, all of this and then they say, "Just one thing: I want black cars." Now they tell me—why'd they come to me in the first place? Everybody knows we've got white cars.

If they wanted somebody's black limousines, they should've gone across town. Sometimes we just don't make sense!

In addition to the issues of cars, caskets are the most attended to item on the list of costs—and a number of stories I found were related to financing an expensive casket.

Some funeral directors complained that "our people" still believed that caskets were reused from burial to burial. Even though America was not the home of "slip coffins" with hinged bottoms that could be lowered halfway into the grave and then opened, dropping the bodies into the earth, stories of reused coffins were recycled in black communities. One Louisiana funeral director told me about a time when he drove one of the limousines in a funeral procession. He left the cemetery following the hearse after the graveside service had ended. Both he and the driver of the hearse looked back and noticed that one of their staff had been inadvertently left at the grave site. The hearse's driver turned around to go back and get him. To a person, the mournful occupants of his car emerged from their grief just long enough to comment sarcastically: "See, I told you they go back to get the caskets!"

In upstate New York, one black family has habitually stayed behind at the graveyard on the occasion of a death in the family. After the other mourners leave, family members bring out hammers and axe handles to bang and dent the casket before it is lowered into the grave. The mortician who told me this story said:

We keep telling them we don't reuse these caskets, begging them not to destroy their purchase, but they want to make certain that after they are through with it, that there is nothing but damaged goods left behind. So now we all know what's going to happen whenever somebody in that family goes. I just sit in the car and wait while they just go on hammering and banging away until they make that beautiful casket look like it came out of a war zone.... It's just pitiful to see.

By mid-century, suppliers to the funeral home business were fully appreciative of the money available from its culturally concerned clientele. As black consumer culture started to make its own 'dent' on advertising and product strategies, one of the largest casket companies in the business, Batesville, designed a line of caskets that catered to black families, complete with an "African" inspired fabric selections that could be made into funeral garments for the deceased. The pity is that a best-seller among this line, the Kente Casket, with its Kente cloth bunting and even an option for an exterior metal in the Kente design, was used mostly by baby-boomer aged parents to bury their teen-aged or adolescent children—a decision that not only pointed to the market-line strategy but to the available market, and cultural experience of black death that guaranteed the viability of the product line.

III. A season of despair, the power of hope

To discover these stories and those who have lived them, I've wandered the exhibits in a museum of the funeral industry and congratulated soon-to-be graduates as they waited for

final reports from their mortuary school examination. I have visited with funeral directors and morticians in the places where they practice and the spaces where they plan (Las Vegas, Nev, in 1996). I have stopped at roadside memorials and lingered in museums and art galleries. I have consulted archives and manuscripts that ordinarily would be a historian's labor—talked with physicians, casket manufacturers, casket shopkeepers, hospice administrators, makers of funeral "garments," reporters, palliative care teams, embalming chemical businessmen, hospital chaplains, neighborhood ministers, and neighborhood residents.

I also went to the places where, quite frankly, I found as much ease and quiet as was intended for the residents. My graveyard visits, interspersed between the research and writing brought certain calm. I came to depend upon their silence and solitude, feeling comfort and ease in these stilled cemetery spaces. Many times I traveled to them alone but sometimes with my husband or daughter.

Some years into this process, I left behind the sense I was searching for tombstones. I was looking instead for Harriet, or Billie, or Richard. It became a personal, even an intimate sojourn among my cultural kin.

When we found Billie Holiday's grave in New York City, the lyrics and melody of *God Bless the Child* moved from memory to mouth and soon, I was standing before the tombstone she shared with her mother, in full voiced song. An elderly white couple tending a grave some rows down left their work and came to where I stood with Billie and her mother and asked if I knew her. Before I could help it I heard myself say, oh yes, she's my great aunt. Of course, it wasn't at all true, but at that moment, I *felt* like kin. Well, we take care of her, they told me. Whenever we come to tend our parents' graves, they said, we clear away any weeds in front of Miss Holiday's as well. I was touched by their neighborliness and told them so. I think I even said the family will be so grateful. I know I could have said this, it would have been easy...poetic license.

I left a flower at the grave sites of the twentieth century African Americans whose memorials I wanted to assure with this project. And despite all the various shades that have dimmed the past years of my own life, I can remember distinctly each moment when I discovered a grave.

The shivering embrace of the chilled air on the fall afternoon in Paris is with me still. At Le Cimetiere du Pere-LaChaise, I walked without sense or care of the time that was passing, down byways thickened with monuments. I did not know then that there was a cemetery map that would have led me directly to the columbarium and Richard Wright's space there among the cremated.

Later, I actually came to prefer to search without a map, to wander these serene spaces unguided, giving the imaginations I constructed on my grave meanderings time to develop. When the caretaker in Monaco told me that not one of legendary singer and performer Josephine Baker's children came to visit their mother's (1986) grave, my English "tsk, tsk" echoed hers in French.

Others have their stories as well. I was grateful, for example, for the controversial decision of his family to keep Arthur Ashe and his mother Mattie in Richmond's historically black cemetery, Woodland. There is a history of segregated graveyards in this country and the stories you discover about them are both like the lyrical images of the distinct decorative art that sketch designs in conch shells across the gravestones, or carefully broken vessels left beside the grave, noting the spirit's break with the world of the living.

There are as well the nearly disabling stories of shame associated with these segregated distinctions, like veterans being denied burial in flag-draped coffins when they are returned from wars, as recently as Vietnam, or stories like Whitney Elaine Johnson's, an infant who had been buried in Barnett Creek Baptist Church Cemetery in Thomasville, Georgia, when church deacons approached her obviously grief-stricken white mother and black father and asked that they exhume their daughter's body and move her to a cemetery that would accept blacks.

I found that the memories did not begin and end with those I researched. I, too, was shaping my own in this journey. There were experiences that helped me understand this new terrain that I was negotiating and the business of burial. For example, when my husband and I went in search of Ida B. Wells-Barnett the fearless anti-lynching crusader, suffragist, women's rights advocate and journalist, the personnel in the cemetery office looked at us carefully. But then they surprised us both and asked if we were married. I said yes, wondering why that was in any way relevant. But when she followed up her question by asking if we were interested in a plot for ourselves, I realized the business of burial never concludes.

Perhaps one of the most poignant postmortems of the century is the way that for a moment near the century's end, Malcolm X's modest grave site in Ferncliff Cemetery told the story of a summer tragedy and echoed his own prophetic words: "I always knew I would die a violent death, in fact, it runs in my family."

His grave site had been marked with the small, flat-against-the-ground brass plate, riveted to a concrete slab, characteristic of all in the cemetery in Ardsley-on-Hudson.

But thirty years after his had been secured to its place, in the summer of 1996, I looked for Malcolm. At first I was merely disappointed to find the site had been disturbed and his marker removed, temporarily replaced with a bouquet of flowers, withered in the summer's sun, and a T-shirt, with Malcolm's own words emblazoned in red across the black cloth. Was it taken by a souvenir hunter? Perhaps. But the absence of his marker prompted an appreciation for the tragic generational vitality of his own prophecy, and it brought me to tears. This was the summer of the death of his wife, Betty Shabazz, which she suffered at the hands of their grandson, Malcolm. Her body, but not her name, had already been placed in the grassy bronzed pathways of Ferncliff.

The stories of graveyards do not only point inwards, towards the personal, but outwards as well, to the public. Certainly the dramatic difference between the final resting places of

two men of the century's most significant stature and renown—Malcolm X and Martin Luther King Jr.—suggests a very interesting post-mortem narrative. We did not look very long before we found a parking place near the city block in Atlanta, Ga, that had become King's grave site, mausoleum, museum, historical center, and souvenir store. It was early on a Sunday morning, and the city streets were not very busy. The mega-block of King's memorial revealed the constantly evolving post-mortem capitalist construction of his singular legacy. But when the site is juxtaposed against the modest grave site of Malcolm, who is buried in a place full of gone-but-not-forgotten souls, the narrative text of culture, capital, and memory is declared, and this merely through juxtaposition. I felt as if I had made a requisite tourist stop, as I stood staring across at King's sarcophagus safely isolated in the middle of a reflecting pool; but that was all I felt.

Those who gave shape and contour to African America in the twentieth century are neither fully memorialized in the photographs of their grave sites nor in the narratives that composed *Passed On*. But those who are here might appropriately stand in for the others. The very last grave site I visited before I brought this project to its end was actually the first. I returned to Paris and Pere LaChaise. My daughter Ayana was with me, and I wanted her to see Richard Wright. It was the summer of 2000—the first grave site trip I had taken in about two years. We took the subway from our hotel on the left bank, easily changing stops at Odeon, and Strasbourg-St. Denis without any difficulty. I knew the way back. It was an early morning and the cemetery gates reliably rose into view as we climbed the stairs up from the Metro.

The day was cool but bright and sunny, and we were in no hurry. We strolled casually, shifting back and forth between the stone paths that edged the cemetery's thicket of small mausoleums to the gravelly roadway that stretched out before and beyond them, remarking only on the chestnut trees that lined the road and the way the sun stretched and streaked between leafy vistas. I told Ayana how I used to collect chestnuts on my walks home from school when I was young, and string them into necklaces. We were relaxed and at ease until we got to the site of those who had been cremated. There I stopped silent, stilled but for the tears that clouded my sights.

Just as I neared the conclusion of this project, everything I had written transformed from page to personal when my own son was killed. Standing there in that cemetery, thinking of my child, our son, her brother, I could go no further. And so we left together, her hand in mine, turned toward home.

In many ways, this project, and its aftermath constitute my own journey and how I finally came to the space where bearing witness was less choice than necessity. Writing these stories became a way of memorial, a measure of hope in the midst of seasons of despair.

I conclude here with a message from a black sermon—words and ideas that have historically captured what I have come to understand as the spirit of African America. Despite its vulnerability and challenge, despite its intimate arrangement with black death, black *life* urges us all toward hope. And "The power of hope," as that sermon reminds us, "is the power to run and not be weary, to walk and not faint...The power of hope is the

power to stand, when no one will stand with you, and having done all to stand, stand anyhow." That sermon then turns to a preacher in James Baldwin's novel, *Another Country*.

The preacher's homily speaks both to fictional moment and fact when he says to a grief-stricken family: "Don't lose heart, dear ones—don't lose heart. Don't let it make you bitter. Try to understand. Try to understand. The world's already bitter enough; we got to try to be better than the world." [8]

It is my hope that the power of witness and the resilience of memory is one way to be better than the world.

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Key Topics on End-of-Life Care for African Americans

An intellectual discourse derived from The Last Miles of the Way Home 2004 National Conference to Improve End-of-Life Care for African Americans

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COMMENTARY: The Witness of History: Cultural Narratives at the End of Life

Commentary by LaVone V. Hazell
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On June 26, 2003, it was a privilege to meet Dr. Holloway during the signing of her book, *Passed On* , at the Schomburg Center for Research in Black Culture, Harlem New York and to attend her book presentation on February 27, 2004, at the Last Miles of the Way Home Conference in Atlanta, Georgia .

As I read the powerful trajectories of grief in sections of the text there was a constant tug of war between my intellect, my physical senses, and my spirit as I absorbed the powerful content of the book. The poignant descriptions of "black death and dying" and the mourning process of African Americans made the uniqueness of our sorrow and grief apparent. Experiencing a peripheral as well as a personal view of death, I found approaching this commentary somewhat of a challenge.

I had an epiphany from a personal interface with Dr. Holloway's descriptions of the funeral traditions, which mirrored my three decades of familiarity with the funeral industry. In neighborhoods across the country far too often funeral directors officiate over the young. The mournful black death among our youth from street violence or racist acts of hatred and violence has become all too familiar.

Dr. Holloway's references the 1955 brutal murder of Emmett Till, a young African American man taken from his bed in the middle of the night, beaten beyond recognition and then lynched for allegedly whistling at a white woman. She later recounts the horrific occurrence at the 16 th Street Baptist Church bombing in Birmingham, AL in 1963, where four little girls; Carole Robertson, Addie Mae Collins, Denise McNair and Cynthia Wesley Carole were killed as they prepared for Sunday service. These references rekindle such deep grief and sorrow that I had to lay the book down for a few moments to reflect. The deaths of these, and so many other black children, are violent memorials of the attempts of those who sought to destroy and weaken us by killing our future generations. Sadly, many more deaths of young and old followed as a result of the Civil Rights Movement.

Oftentimes funeral professionals had to find a delicate balance between the grieving process that they experienced in burying the young and the profound realization that it could be one of their own children. Burying so many of the young beckons the question by the funeral directors...why? Perhaps the answer is, as given by Dr. Holloway in *Passed On* , when she quotes the words of W.E.B. Du Bois when writing of his son's

dying as "liberation," that these children were "not dead, not dead, but escaped; not bond, but free." If I had a dollar for every mother or father who said "now I know where he or she is," I'd need a decade to count the sum of their grief. What a sad commentary that the last place of solace for many parents is the cemetery.

The funerals of young people can be especially volatile, but the presence of the clergy and family elders seems to maintain a certain measure of calm. To reiterate a segment of Dr. Holloway's narrative, "the black community nurtured two institutions—churches and funeral homes." Dr. Sharon Wyatt, of the University of Mississippi 's

Medical Center, states in her research that: "Our findings show that the integration of religion and spirituality - attending church and praying - may buffer individual exposure to stress and delay the deleterious effects of disease." From the baptism of our babies

to their last rites at graveside, we have been nurtured by our clergy and put to rest by our morticians.

A child's funeral should be a gift from the community, with the professional services of the funeral director and clergy and appropriate things from its vendors donated as a way of giving back to the families who have given their faithful support to the community throughout the years.

In a passage of Dr. Holloway's book she references and discusses the somber, amusing and real life stories that the funeral directors children talk about as she engages them in conversation during a funeral directors convention. An innocent passage, but one that has broad implications as to how the next generation will view and look upon death and dying.

It is unfortunate that children in the black community, regardless of class or social status, have fallen prey to medical care that underserves by reason of their race. From the twentieth to twentieth-first centuries, there are still more questions than answers. Still, one persistent and pervasive question emerges from one decade to another, "Where are we now?"

As a funeral director I particularly appreciated the Dr. Holloway's descriptions of the funerals and grave sites as they related to public figures. Funerals are for the living; as caretakers of the dead and caregivers for the living, funeral directors are entrusted with the responsibility to assist a family through the crisis of the death ritual. The funeral and the gravesite oftentimes reflect the life of the individual. The juxtaposition of the massive memorial for Dr. Martin Luther King Jr. compared to the modest grave site of Malcolm X brought to mind the way Muslims bury their dead. Most funerals are very modest, with the only mandate being that the grave is facing east or toward Mecca .

In the African American community, music and food are pivotal components of the funeral ritual. Music ties the funeral service together, and the meal or repast, which takes place after the burial, most often in a church dining hall, is meant to transition grief, and

to honor the dead and their beliefs about the hereafter. African American preachers, stand on faith that things will get better, they offer their parishioners and the hopeless a light of hope. They give comfort when the cloud of black death passes over their followers.

W. Franklyn Richardson is the pastor of Grace Baptist Church in Mt. Vernon, NY . In his chapter, Holding on to Your Song, (2002, Keeping the Faith Haskins, James and Angelou, Maya), he urges those members of his congregation not to give into the destructive emotions following the 1990 beating of Rodney King in Los Angeles, and the subsequent, and controversial, trial. Richardson 's introduction states that the message to follow transcends the moment, giving solace to all facing tribulation, not merely those facing a trial. It is now 2006, and an incident similar to King's took place in Florida, with the beating and death of a young black man by guards in a boot camp. Exactly—where are we now?

We are indebted to Dr. Holloway's powerful narrative for "making sure we will never forget" that "black death and dying" and grief are indigenous to a people who *also* have the power of hope and the strength to endure.

In Collaboration With:
Duke Institute on Care at the End of Life
Initiative to Improve Palliative Care for African Americans (IIPCA)

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The Future of Hospice Care for African Americans: Clinical, Policy, and Caregiver Perspectives

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The Future of Hospice Care for African Americans: Clinical, Policy & Caregiver Perspectives

In a changing world, the challenge for the health care professionals and providers in the hospice and palliative care movement is to build upon that which has successfully served our patients and families and to embrace with enthusiasm the opportunity to create innovative new programs which appropriately serve and increase access and utilization by African Americans.

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Sitting three feet from the bronze and blue casket placed at the center of the church auditorium is the weathered face of a loving 65-year-old mother who is reflecting over the last six months of her second son's life. The physicians diagnosed him with prostate cancer, but she knows that he simply lost the will to fight this battle here any longer. She knows that he is gone on to a better place of rest. Folding and unfolding the obituary of her 45-year-old son, a man who worked too hard and died too soon, she finds relief from the large host of family members and friends who have come to this place to communally mourn her loss and provide support. With a gentle smile that offers as much comfort as she receives, she nods at her next-door neighbor, who was like a second mother to her son. This valiant mother, who experienced great ambivalence when approached by the hospital social worker, reflects on her refusal to give upon her son and her fight to explore other options of treatment as recommended by the care team. Slowly wiping away the latest round of tears from her eyes, she is grateful for the team that supported her and managed the care of her son during the last two months of his too short life.[1]

"African Americans have been caring for their loved ones at home since the beginning of time. It was never called home care. They have cared for their dying relatives equally as long. It was never called hospice. Relatives come home from various parts of the country to relieve the caregivers, and it was never called respite care. They come to give relief to mama, papa, sisters, brothers, aunts, uncles, cousins, grandma, and grandpa. They talk with each other, share experience, and give advice and counsel. It is never called networking. Last, but not least, they serve as volunteers in their own communities, in their own churches, and on their own streets. They wear no uniforms, record no hours and receive no awards. Nor do they expect to be rewarded. It is family caring for family, neighbors caring for neighbors and communities caring for each other."[2]

African Americans and other populations of color underutilize palliative and hospice care, even when they have access to end-of-life care services. The causes for underutilization may be many and varied. It is necessary to embark upon further scientific research to gain a complete understanding of the dimensions of this important problem.

As we look to the future of hospice and palliative care for African Americans, it is imperative to develop an effective strategy to overcome the inherent problems associated with underutilization and minimized access. A willingness to openly dialog about the

intricacies associated with some of the ugly societal issues must be faced if we are to look with hope and expectancy to the future with the goal of realizing equitable working solutions for quality end-of-life care for African Americans.

Background: Review of Hospice Care in the United States

The 1983 public policy decision of Medicare to include hospice care in the Medicare program has increased the capacity of health care providers to support dying patients and their families. This grew out of a desire to provide compassionate dignified care that respects the rights of the individual to choose how they will live until they die. The number of hospice programs has increased steadily since 1983, and Medicare has become the primary payer for almost two-thirds of all hospice patients.[3]

The traditional definition of palliative care is *an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*.[4] The specialty of palliative care has evolved out of the collective hospice experience and is a broader application of the concepts of hospice care. Patients who demonstrate a significant burden of illness and are identified earlier in the disease trajectory (when death is not imminent—months to years) may benefit from palliative care services. Hospice would then be the natural transition into the final months of care when no aggressive curative intervention is desired.

There are an estimated 3,300 operational hospice programs (includes primary and secondary locations for individual hospices) in the United States. Of the estimated more than one million patients served in 2004 by hospice programs, 81.2% were Caucasian, 8.1% African American, 6.2% Latino or Hispanic, and 4.6% classified as multiracial or "another race." 5 The percentage of African Americans served was significantly less than the 13% that matches the proportion of African Americans in the United States.

Recent research and literature cites the health disparities experienced by ethnic minorities, and the reported underutilization of hospice care is consistently noted by people of color. 6 For those patients who are enrolled in hospice, 50% die at home with their loved ones, 7% in a hospice unit, 4% in a residential care setting, 7% in a free-standing inpatient facility operated by the hospice, and only 9% in a hospital setting.[5]

Hospice care provides the most highly developed model of care, providing comfort, aggressive pain, symptom management, and quality-of-life care. Recent statistics show that African Americans are more likely to die in the acute care setting of a hospital, with less satisfaction regarding quality care at life's end.

This paper will look at reasons for the underutilization of hospice and palliative care services in the African American community and suggest broad areas of policy changes that could promote this model of care as part of the spectrum of quality health care delivered to African Americans during their lifespan. These areas will be *reimbursement*

issues that impact on access; *access to care* issues in general; *education* regarding cultural proficiency, especially regarding the issue of mistrust in the African American community; *disparities* in care; consumer and caregiver *awareness and engagement* ; and health care providers' organizational *policies and mission* . These critical areas will be explored to gain an understanding of their impact on referral of African Americans to hospice and palliative care, and subsequent utilization of those services. Through appropriate engagement of these critical factors, our hope is that more African Americans will come to the realization that hospice is not resignation to death but a proven means of providing quality care at the end of life.

Determining Hospice Eligibility

In order to be eligible for this benefit, a medical doctor and the hospice medical director must certify that the patient has a terminal or life-limiting condition with a prognosis of six months or less to live. Physicians have difficulty admitting that they cannot cure a disease and difficulty identifying when their patients might be appropriate candidates for hospice.[7]

The patient must sign a statement electing hospice care instead of routine Medicare Part A Hospital benefit. The ambivalent feelings evoked by this choice may cause some patients and families to have concerns over loss of coverage options. The ability to utilize inpatient services may offer significant comfort to a struggling family that is already concerned about its inability to cope with the loss of function and disease progression.

Understanding of the benefit as well as a clear expectation of the patients goals and wishes are one of the keys to assuring that a clear understanding of the services are received. Without this clarity, the patient or family may feel that it is too early to choose this option for care.

It is the responsibility of the providers, physicians, case managers, and discharge planners to discuss options of care and answer patient and family questions, without inserting their biases, in a manner that patients and families understand. A physician may recertify that a patient has six months or less to live after two initial 90-day benefit periods, followed by an unlimited number of 60-day periods. Often, patients and their families will hear "six months to live or less" and will focus on nothing else. Both health care providers and patients and families are often unaware of the extended benefit periods available indicating that the patient has lived past six months; they are also often unaware that some patients "graduate" from hospice.

When patients graduate, they improve and/or are no longer declining from their disease and are discharged from hospice. This does not mean cured, simply that the progression of their disease has reached a plateau and hospice services are not needed until progression of the disease continues. This window offers an excellent opportunity for palliative services.

Understanding the Four Levels of Hospice Care

The hospice benefit allows for four general levels of care to manage the needs of patients and families over the continuum of the illness. These services are required of every certified hospice program; however, different programs may vary in the manner in which services are offered.

- Routine care is care that is needed on a regular basis, part time basis and is provided in the recipient's place of residence (e.g. home or nursing facility).
- Respite care, the second level of care, is almost always provided in an inpatient setting. This is generally limited to five consecutive days within a benefit period.
- Continuous care accounts for less than 1% of total hospice days and is typically utilized when a patient is "actively" dying at home and needs a more intensive level of care and support and does not wish to return to a hospital or acute care setting.
- General inpatient care, the fourth level of care, comprises about 4.3% of all hospice days. All Medicare-certified hospice programs must have the availability of inpatient care. Some hospices use contracted beds within a hospital, skilled nursing facility or long-term care facility.

Under Medicare rules, hospices cannot use more than 20% of their total days in inpatient care, although an individual patient is not restricted to this percentage. A willingness to accommodate more inpatient care within the "20% rule" is a possible policy change, which would enhance the use of hospice in the African American community. This would, hopefully, begin to address the caregiver burden in the community.

Reimbursement Issues

Access to hospice care via a third-party payer source may present a challenge regarding coverage of services. Coverage may vary from a nominal reimbursement under smaller plans, with the ability to negotiate for expanded services under larger fee sources like Blue Cross Blue Shield and Kaiser Permanente. A source sometimes overlooked is the hospice benefits of the Veterans Administration (VA). This system offers multiple options of support and can be combined with other fee sources. There are other private insurers that will allocate some days for hospice but none as expansive and realistic as Medicare or VA. Many insurance providers have some form of reimbursement for hospice care, and their guidelines may be modeled after the Medicare Conditions of Participation (COP). The Medicare Hospice Benefit utilizes the Medicare Part A (hospital insurance) for coverage of hospice services.

One area of challenge is the use of culturally insensitive language and a style and manner that does not reflect a complete understanding of the values and beliefs of the community.

When the alternative to aggressive treatment is presented in this manner, the potential beneficiary (and family) may feel unsure about making a choice for services that sound good and may be ambivalent regarding perceived loss of Medicare coverage. If this seems to occur, the beneficiary (and family) making the choice requires additional *and*

patient counseling that fully explains the benefit options and alternatives available for treatment. The health care providers must realize that the initial delay in making a final decision for (or against) care is necessary as African Americans gain a sense of comfort with services that are not traditionally understood. This will be discussed in greater detail in the following section of determining eligibility.

After electing to use the hospice benefit, a Medicare recipient may have the following services provided by a Medicare-certified hospice:

- Physician services for the medical direction of the patient's care
- Intermittent home visits by registered nurses and licensed practical nurses
- Intermittent home health aides for services such as dressing and bathing
- Social work and counseling services, as well as the provision of spiritual care if desired
- Medical equipment, such as hospital beds, oxygen, etc.
- Medical supplies such as bandages and catheters
- Medications for symptom control and pain relief, and other medications related to the end-of-life diagnosis
- Volunteer support to assist patients, families, and loved ones
- Physical therapy, speech therapy, occupational therapy, and dietary support as indicated
- Bereavement support for families after the death

No Insurance or Inadequate Insurance: the Impact of Poverty

The current statistics reveal that approximately 40% of the American population is either uninsured or underinsured. In most states, Medicaid will cover traditional aggressive treatment but not all states have a Medicaid hospice benefit at this time.

What occurs with patients who have no Medicaid reimbursement in their state or who have no health insurance? The burden of payment for each day in hospice falls on the patients and their caregivers.

Anyone who has provided end-of-life care to people of color, a disproportionate number of whom are in poverty and typically receive unequal treatment, recognizes consistent, recurring themes. The poor experience:

- Decreased access to health care and higher death rates.
- Increased pain and suffering.
- Increased obstacles to obtaining health care.
- More sacrifices in order to provide a cure such as loss of a job to take care of a dying family member.
- Inadequate and insensitive educational outreach efforts.
- More fatalistic approaches to end-of-life care.[8]

Cultural Factors Relative to African Americans and the End of Life

Our responses to death have been evident since early recorded history. Fear has been the dominant emotion. Conscious efforts to reduce this fear have subordinated intellect to emotions; that is, explicit ideas about death have served primarily to inspire emotionally generated concepts of immortality.

Expressions of immortality themes are abundant, ranging from the crude animism of early human beings and modern aborigines to the sophisticated and carefully reasoned theologies that are an important part of the modern cultural fabric.

The problems of how death affects human motivation and integration at the individual level have been discussed by Freud, who cited aggression, guilt, incorporation, and identification with the dead love "object."

The fundamental needs of dying persons and their families appear to be universal. The only differences are how societies and groups within societies go about meeting these needs, which impacts services and determines the quality of care. Caregiving should enhance the dignity and self- respect of the dying, their families, the caregivers themselves, and hospice workers as well. Caring for individuals throughout the spectrum of illness, in general, is a challenge for health care professionals. Caring throughout the spectrum of illness until life's end for patients and families of different races, cultures, creeds, national origins, social and economic classes, and religious denominations and spiritual beliefs is the greatest challenge of all for the health care professionals. Why? Because this is the dying individual's last chance to experience love, deep caring and compassion, as well as the health care professional's last opportunity to provide sensitive, professional and culturally competent care for the individual. This should not only involve the terminally ill but their families and significant others as well.

Today, health care professionals can make the difference between success and failure in caring for African Americans and their families at life's end. Health care professionals must be selected and trained on the basis of their ability to care for patients and families. The attitudes of the health care professionals as they formulate caregiving modalities and strategies will be crucial in the care of African Americans at life's end.

Defining and Understanding Culture

Culture can be defined as an integrated pattern of human behavior, which includes but is not limited to thought, communication, languages, beliefs, values, practices, customs, courtesies, rituals, manner of interacting, roles, relationships, and expected behaviors of a racial, ethnic, religious, social, or political group; the ability to transmit the above to succeeding generations is dynamic in nature.[9]

Culture provides people with a design for living and interpreting their community, environment and world. It provides human beings with both identity and a framework for understanding experience. The recent trend and focus of engaging diverse populations has been aimed at developing an awareness of cultural diversity. Many professionals and organizations believe that one avenue to gain an awareness is to develop cultural

competency. Culture is one resource that cannot be ignored in this process of building on the strengths of communities.[10] Developing cultural competency enhances the providers' abilities to establish trusting relationships with the population and community being served.

The knowledge of cultural differences and sensitivities that professionals should possess as they deal with different cultural norms or caregiving responsibilities is complex in one sense yet not so complex in others. The complexity is related to the fact that cultural differences do not operate in a vacuum just as patients and their families do not exist in isolation.

They exist within a dynamic, independent, yet interdependent health care system, involving localities, communities, states, and nations. Our global world is made of thousands of languages and dialects that have cultural dimensions and cultural connotations.[2]

When interacting with the African American population, there is an unconscious tendency to see the color of the skin and make assumptions about the culture and experiences. Often overlooked is the fact that all Americans with a darker hue may not identify their roots as being from Africa. If the health care provider makes assumptions about a particular ethnicity and culture without taking the time to gain a more complete understanding of who the patient is, an opportunity for demonstrating respect and gaining understanding might be missed. Once again, a barrier of mistrust is often erected, and opportunities for trust and engagement have been lost. Taking the time to find out where people are from and what road they have traveled as they are facing their final journey is seen as an honest attempt to understand who they are behind the diagnosis they bring. This is an initial step of establishing trust between the health care provider and community.[1]

Diversity is multifaceted and includes characteristics and qualities that go beyond race, ethnicity and language. It also includes religion, socioeconomic status, sexuality, demographic identity, country of origin, and how life experiences shape these.

The United States has been recognized as a cultural melting pot; more recently, however, experts refer to the United States as a salad bowl. We are all in the same bowl, but we still have unique traditions, beliefs and values that maintain our own cultural integrities.

Understanding a Mindset of Mistrust and Betrayal in African American Culture

The issue of trust or lack of trust in the health care system by the African American community has been explored and detailed in health care literature and, most recently, with the video documentation of oral histories by patients and providers contained in the APPEAL (A Progressive Palliative Educational Curriculum for Care of African Americans at Life's End) curriculum.[8]

IOM 2003 Report - Unequal Treatment stated that "Racial & ethnic minority Americans are less likely to receive even routine medical procedures and tend to receive a lower quality of health care than non-minorities, even when access related factors, such as patient's insurance status, income, age and severity of conditions are comparable."

The decision to engage hospice and palliative care can evoke memories of historical mistreatment and abuse. The manner in which the initial discussion regarding options for hospice/palliative care begins sets the stage for acceptance or rejection of end-of-life care services. 1 As a people, African Americans have been clearly aware of health inequalities even before research documented the consistent and glaring realities of health care disparities.

Because of these injustices experienced throughout American life, health care providers must be willing to understand that the expectation of many African Americans—that they will not receive equal treatment.

Unless providers are willing to walk in the psychological shoes of African American families, the opportunity to establish trusting relationships will remain a challenge unfulfilled. A verbal validation of the patient/family's history and current circumstances along with a genuine willingness to openly discuss a real plan that addresses barriers to care are essential to building trust.[11]

A long history of prejudice and mistreatment has shaped the mindset of many groups. African Americans have been particularly impacted. To one degree or another, African Americans share a legacy of slavery. Part of the culture of African Americans is the history of slavery and continued disparities, economically and in health care. Providers must be willing to understand that the mistrust of the health care system evidenced in the African American community is based a history of malfeasance, neglect and inequality in health care.

Developing Trust in the Health Care System

While lack of trust is one of the primary issues regarding underutilization of hospice by African Americans, it is hoped by addressing the areas delineated above that trust will be built between African Americans and the hospice community. The following case study is an example of the importance of trust and caring.

Case Scenario

Ambulance 39 rushes through the door of the Emergency Department (ED) carrying a 65-year-old African American gentleman found lying down in his tub not breathing and without a pulse. It is unknown how long he was in the tub. His wife of 40 years discovered him. With great effort, she pulled him from the tub and started CPR. When the paramedics arrived at the house, they inserted a tube for the patient to breathe and took over the chest compressions from his wife. The health care team thought this patient was dead upon arrival in the ED, based on the length of time when the patient was last

seen alive and his arrival in the ED. As the paramedics rushed thru the doors they stated, "The wife and son are right behind us. They are very anxious." The ED team of nurses and physicians took over for the paramedics, knowing their efforts would be futile. The wife and son, upon their arrival wanted to see their loved one; they wanted to know that the health care team was at least trying to make an attempt to save him. The physician allowed the wife and son to view the resuscitation attempt of the team. Once the wife and son saw that their loved one was being worked on, they began to accept the reality that he would die. When the patient was pronounced dead, the wife and son were able to accept that the health care team had at least tried to save their loved one and not "just dismiss him." Seeing the health care team attempt a real effort of resuscitation established trust between the team and the patient's family and made it easier to accept his death.

Racism, stereotyping and prejudice are frequently the "normal" interaction that some groups experience when they encounter the medical system. Stereotyping, as defined by the APPEAL Curriculum, 8 is the process by which people use social categories (such as race, sex) to acquire, process, and recall information about others.

Stereotyping does serve a function. It allows persons who have some fear of engaging with certain populations an opportunity to simplify complex situations and gives them greater confidence in their ability to understand, predict, and potentially control situations and people.

Whether assumptions are made with malevolent intent or from plain ignorance of the population being served, the consequences are the same. The potential for unequal and inadequate treatment is real. Health care providers may receive messages about African Americans because of stereotyping and, consequently, interact with patients from a flawed knowledge base.

Prejudice and stereotyping are dehumanizing and interrupt the fulfillment of the goals of quality health care, one of which is adequate utilization of hospice and palliative care by a population that would benefit the most from it.[11]

Knowledge is power, and power should be translated into empowering African Americans and effectively meeting their needs. Health care professionals must be educated and trained and must develop a knowledge base, and the commitment and dedication to understanding and appreciating cultural differences. To facilitate effective interaction and culturally competent care, a provider has to become knowledgeable of the background of the group/population that is being served.

African American Culture and the Impact of Religion and Spirituality

Among cultural influences, religion and spirituality of African Americans always have played a special role. Historically the church has been the place of caring, a place of acceptance regardless of education, training, degrees, economic levels, security, or lack of security. The church, in all of its diversified venues, has been a sanctuary for many in the African American community.

The influence of religion and spirituality must always be considered, and health care providers should familiarize themselves regarding how these influences will factor into the decision making regarding their health care choices.

For many African Americans, these influences are integral to their existence. Again, we must be careful not to generalize, because just as diverse as the hues of the skin color of African Americans, we find diversities of religion and belief at the end of life.

The perception of God and suffering may be a challenge for some providers to understand when they are providing care to African Americans. Culture fundamentally shapes how individuals make meaning out of illness, suffering, and dying. With increasing diversity in the United States, encounters between patients and physicians (and other health care providers) of different cultural backgrounds are becoming more common.

Thus the risk for cross-cultural misunderstandings surrounding care at the end of life is also increasing.[12] Many religions are hesitant to entertain discussions regarding ending a life or withdrawing aggressive treatment.

Some persons accept suffering as a part of being human and a challenge to overcome to prove their faith in God. Other members of the African American community are conflicted because giving up aggressive treatment means that they are giving up on their hope that God will provide not only a spiritual healing in "the kingdom to come" but a physical healing in the here and now.

Imagine the potential for conflict that could be experienced by a devout Muslim who believes that "your life is entrusted to you by God and that you should do everything in your power to preserve it." The potential for cultural clash among the medical establishment recommending hospice care, the patient and family, and the hospice/palliative care organization is high indeed.

It is important that providers not allow their lack of understanding of religion and culture to cause them to make assumptions about African Americans' cultural and religious beliefs. Assumptions, beliefs and generalizations may lead to even greater misunderstandings during intercultural exchanges.

Health care providers should assess the cultural background of each African American family they interact with. There are diverse faith traditions and spiritual communities in which African Americans participate. Faith in God is central for many patients and families, and their belief will impact many of the decisions made when facing end of life. The dichotomy experienced from the realization that there is no possibility of medical cure and the belief that

God knows all and is in control may cause the African American family to hold on stronger to their faith. These strong statements of belief may not be well received by the

health care provider, and the interaction among hospice worker and patient and family may create further mistrust.

It is imperative to inquire about values that may affect care at the end of life. Assumptions and generalizations that people of color living in one particular area have similar beliefs should never be made. Providers should become aware of the specific beliefs and practices of the populations they serve; always remembering to inquire whether an individual patient adheres to a particular belief.

If individualized assessments of religious and faith traditions are done, there is a greater likelihood that a peaceful and compassionate palliative care will result. The following key points should be considered regarding spiritual interventions in the African American population:

- Respect the unique spiritual needs of individuals in the African American community. While hospices are generally able and open to provide a wide variety of spiritual care through their own spiritual counseling, African Americans have a rich spiritual heritage that is deeply rooted in community worship.
- Spiritual needs are most frequently a major priority, and the need for this type of counseling support should always be assessed early at the start of care.
- It is imperative that hospice and palliative care programs address the spiritual needs of African Americans in a way that demonstrates respect for the community's existing religious framework. One strategy for successful engagement is to create a network of faith leaders who will be available to provide spiritual care. A thorough assessment of the different religions and faiths represented in the community is necessary.

There should never be a delay in providing spiritual support because the hospice does not know a local imam or has failed to establish relationships with traditional and non-traditional faith leaders.

- The program that recognizes that the church has always been the cornerstone of the African American community has identified a strong resource as they seek to provide holistic and quality end-of-life care to the community.
- There is a need to develop educational programs that reach out to health care providers to facilitate a level of comfort in exploring the role of religion and spirituality and how religion and spirituality might conflict with the values of physicians.

Health Disparities of African Americans

Common diagnoses for patients receiving hospice care are cancer (50%), heart disease (10%), lung disease (7%), and kidney disease (3%). African Americans disproportionately have higher death rates from cancer, AIDS, and cardiovascular diseases (often secondary to hypertension and diabetes mellitus, which are more prevalent in African Americans).

Blacks are less likely than whites to receive curative surgery for early-stage lung, colon, or breast cancer. Ayanian reported the referral rate for evaluation at a transplantation center was 50.4% for black women compared to 70.5% for white women and 53.9% for black men compared to 76.2% for white men. In 1993, Whittle et al. documented that blacks are not referred for coronary artery catheterization as frequently as whites, even after presenting with symptoms suggestive of acute coronary artery disease. Disparities in care for life-threatening diseases are seen from initial presentation, referral, treatment, and ongoing management. Treatment inequalities for African Americans vary in the acute setting as well as the palliative setting.

While the numbers of African American utilizing hospice and palliative care are clear, there is still a lack of established research to study the various influences that impact utilizations and how to improve access to care for all minorities. Greiner et al 13 used data from the National Mortality Followback Survey to find that African Americans had 40% lower hospice utilizations than white Americans. However, their analysis was not independent of other socioeconomic characteristics, such as education and income, suggesting that additional research might reveal disparities not specific to race/ethnicity but also to socioeconomic status. Another study indicated that African Americans may not have the necessary knowledge to seek out or accept hospice care, again indicating that education and income might play a role in improving knowledge of available services and, thus, increase utilization. 14

Organizational Change

While the traditions and culture of African Americans are rich and unique, they are also encompassed in a history of mistrust and pain. If providers and health care professionals are to provide end-of-life care for African American communities in a culturally appropriate context, there must be addressed a variety of issues that focus on the sensitivities required by health professionals and their organizations as they care for African Americans.

The goal is to identify responsibilities and to help professionals to maximize their potentials and talents in caring for African American families for whom they have the privilege to serve.

Developing a Sense of Inclusion

An individual in an organization can begin to gain cultural competence through formal training. However, it takes consistent individual practice and the support of a culturally competent organization to continue to develop and maintain individual cultural competence.

Education, sensitivity, and awareness are all essential components of creating a climate for change, but none of these alone are sufficient to achieve a sense of inclusion. Even developing cultural competence, changing work practices, and creating leadership and management accountabilities will have little lasting impact if they do not facilitate a

transformation in thinking. We must let go of the naive assumption that "we can't dictate how you think, but can insist on how you behave." Behavior modification alone does not produce irreversible change. The commitment to change the organizational climate of an organization starts at the top with the leadership.[15]

An organization committed to serving people of color in the African American community must develop a policy of inclusion. If this is missing, changing the culture of the organization is the biggest and probably most difficult task that the leadership will take on.

Board support is critical, and bottom- line support is ultimately responsible for assuring that the organization is making progress toward achieving its mission. If there is no buy-in at this top level, it is highly probably that the leadership of the organization will follow similarly. The inconsistency in the walk and talk of the organization will be noted by the community, and additional barriers will be constructed. If an organization is experience success serving the African American community, it must first evaluate its mission and commitment to this community.

The organizational leadership is responsible for ensuring that the appropriate policies and procedures are in place to support the mission, visions, and values of the organization. The provider must consider how organizational values will affect the commitment to become a part of the fabric of the community.

There will be challenges inherent in serving a diverse population. But the potential impact of an organization demonstrating that it respects the traditions, beliefs, and values of the African American community can be significant. An organization or health care provider who will evaluate areas of compromise and change can increase the possibility of successful engagement in the community.

Just like a culturally competent individual, a culturally competent organization develops and improves over time. As an organization matures in the area of cultural competence, it will introduce and fully develop the following elements.[16]

- Openness and respect for diverse staff and clients.
- Access to a diverse cadre of professional interpreters.
- Signs and written materials in the languages of its clients.
- A culturally diverse staff that ideally reflects its client mix.
- Cultural competence orientation and training for medical and non-medical staff at all levels.
- Services and programs that address the very different needs of different client populations.
- Routine evaluation of treatment outcomes by racial, ethnic, and language groups.

Self-Inquiry and Awareness

Health care professionals who would be successful in working with African Americans and their families must come to grips with their own feelings about their own mortality, life's end, and the 'in-between' life processes. Harper addressed these areas in her book, *Death: The Coping Mechanism of the Health Professional* . The premise of this volume is specifically that "professional anxieties in catastrophic diseases and terminal illnesses are observable phenomena for which a coping mechanism can be developed."

The health care professional is then enabled to provide culturally sensitive caregiving which gives strength and support to patients and relatives. Central to this thesis is the Schematic comforAbility Scale in Coping with Professional Anxieties in Death and Dying. *The Cross Model of Cultural Competence* presents six demarcations on the Cultural Continuum: Cultural Destructiveness, Cultural Incapacity, Cultural Blindness, Cultural Precompetence, Cultural Competence and Cultural Proficiency. Characteristics of "Cultural Proficiency" in the individual or organization are to actively educate others about cultural differences; move beyond merely accepting, tolerating or accommodating cultural differences; hold cultures in high esteem; seek out knowledge, develop skills to interact in diverse environments; and align with and be comfortable interacting in multicultural settings.

Recommendations and Interventions Strategies Relative to African Americans and End-of-Life Care

This paper has addressed a variety of areas relative to African Americans facing the end of life. Culture and its many ramifications was the major focus by design and purpose because, after all, culture matters, just as race matters for all people. These recommendations have been forged out of the essence of knowledge and forethought of long-held traditions, experience, and the current knowledge of the authors of this paper; albeit, a bit of bias will be involved.

This stands out clearly and for good reason, as the presentation is about African Americans, perceived, developed, and written by three African Americans. Thus, the recommendations and suggestions made in the *Future of Hospice for African Americans: Clinical Policy and Caregiver Perspectives* are derived from practice, research, intervention strategies, and recommended policy changes.

Community outreach and marketing of hospice and palliative care services must be planned and intentional if the desired population is to be maximally engaged. The grapevine network of the African American community is a powerful force and can be just as effective as African drums that were used during times of slavery to communicate critical knowledge and information. Personal experiences and word-of-mouth networking may make or break any program of services outreach.[1]

Focus on Strengths Instead of Weaknesses. Engage the community by inventorying its assets. Community mapping has emerged as a successful strategy for community engagement. While affirming the history of the African American community, this interaction focuses on building and enhancing the existing strengths and assets of a

community rather than on reducing or mitigating its deficits. Working with culturally diverse African American communities requires that we must first acknowledge that culture is a predominant factor in shaping behaviors, values, and institutions.

Utilize Nontraditional Methods. Traditional methods of going into African American communities may not yield the same results as other communities. As a community, African Americans are empowered if they can identify with the messenger and feel that the message being delivered can be trusted and is in their best interest. Sending an African American hospice worker to give a talk to a local community group may be an effective primary measure of engagement. It is important to realize that the barrier of mistrust is hard to breach, because there is still a belief that the hospice employee is speaking on behalf of the organization and may not be looking out for the best interests of the community.

Identify the Real Leaders and Stakeholders. It is imperative to identify the true stakeholders in the community and be aware that while there may be some similarities, the socioeconomic class of the community may change the dynamic of the choice of message as well as messenger. Some social classes may perceive that the words of the pastor, bishop or reverend are gospel when it comes to making decisions about health care choices. Other communities may choose to trust the message only if it comes with science and documented research. Regardless of the community, it is a mistake to assume that all African American communities share the same value system and resources. The work of inventorying the stakeholders and leaders must be done on an individual community basis before proceeding to engage.

Take Advantage of Strong Community Resources. Enlist the help of leaders and stakeholders in the community to assist in your outreach and engagement. Listen to the leaders and tailor the outreach programs according to the recommendations of the community leaders. Recognize that outreach programs can have a greater impact when implemented in conjunction with community leaders such as ministers and civic leaders.

It may be necessary to allow the community to take the lead and have the hospice program take a back position as it supports the capacity of the organization. This level of cooperation will gain significant ground in building trust with the African American community.

Communication Is Critical. The appropriate use of language and understanding styles of communication are important aspects of effective engagement. A health care provider may assume that an African American family is being recalcitrant when they refuse to sign or accept hospice services. In reality, the client's level of literacy or issues of trust should be considered as alternative reasons.

Become a Genuine Model to Your Community. Make sure your hospice is a model for the community. If you serve a large demographic of African Americans, it is imperative to explore opportunities of outreach. Engage appropriately, and show respect for the cultural heritage and uniqueness of the African American community. It is not enough to

say that you care about the diversity of the community you seek to serve. Genuine caring is demonstrated by a respect and sensitivity to diverse cultures served by the hospice organization.

This is a huge step toward showing a community that the interests of African Americans are important to you. This will be reflected in your history of recruitment and hiring practices and written policies. Hospices cannot simply rely upon sending its own representatives into a community to provide hospice education.

Do Not Make Assumptions. Don't assume that because you understand that hospice services are great that you should enter a home and begin talking about what the organization is going to do to make someone's life better. It is imperative to allow the dialog to facilitate the opportunity of the patient and family to tell their story. Let the African American family tell what is needed to make life better.

As hospices and palliative care programs become more open to non-traditional methods of community engagement that have proven to be successful in outreach, they will gain a greater understanding of the challenges that African Americans face when confronted with advanced illness; thus, the uniqueness of African Americans' approach to dealing with living, surviving, and dying will be better understood.[1]

Organizations must develop a planned strategic evaluation of their organizational positions, policies and practices for the engagement of diverse groups of people. The use of self-awareness tools (many are available on the Web), such as Toolkit for Serving Diverse Populations available from National Hospice and Palliative Care Organization (NHPCO), will assist the organization in its strategic outreach.

We have identified the impact of mistrust in the medical system, which has resulted from abuses of medical experimentation and the legacy of slavery and social injustice; the lack of cultural proficiency and working knowledge of African American traditions, beliefs, and values; the need for campaigns that increase the use of advance directives; unequal treatment in the health care system and unequal access to care; no insurance or inadequate insurance; and the need for systemic health care practices and policies that diminish/remove barriers to utilization of hospice and palliative care by African Americans.

Hospice Recommendations

It is recommended that:

- All hospices focus their activity on access and the development of a fully integrated effort across a wide scope of health care organizations, social care facilities, and spiritual and religious programs in creating community ownership of hospice programs.
- Hospice and palliative care programs develop proactive programs that anticipate the needs of African American communities and that these programs serve as a

relationship builder in forging integrated services and continuity of care in the community

- Hospices communicate the opportunities for care and the use of services to African Americans
- Hospices establish higher, more visible profiles relative to their programs and services for the diverse African American communities within the suburban, rural, urban, and metropolitan areas.
- A willingness to accommodate more important inpatient care within the "20% rule" is a possible policy change which may enhance the use of hospice care in with African Americans which may address the lack of and /or caregiver burden in this community.
- Changing the policy of the hospice benefit to a (longer time) where aggressive palliative management is a model for all patients may provide quality care along the spectrum of a patient's disease instead of only the last six months of life.

If hospices and end-of-life programs are going to meet the needs of African Americans, they need to take new and necessary steps in recruitment of board members, volunteers and staffs reflective of this population group.

This would include a total agency assessment of end-of-life and cultural issues relative to African Americans. The organization must commit to develop an African American strategy or agenda to keep the issues on the front burner, i.e., in the forefront of their strategic planning. There can be no out-of-sight, out-of mind approach. It is further recommended that every hospice administration evaluate his or her staff and make the best determination of who can best undertake an "African American Strategy." This is not segregation. It is integration in the best sense of the word.

The summary of recommendations is as follows:

- Address the mistrust issue directly.
- Promote cultural proficiency.
- Educate health care providers, the African American community, and the majority community, and major stakeholders financing health care regarding hospice use and referral.
- Acknowledge and continue to monitor for unequal care/access.
- Level the reimbursement field to provide better access to hospice care.
- Empower the African American community by identifying its leaders and resources, and involving them in promoting hospice use.
- Develop policies for health care providers that allow for maximum utilization of hospice by patients.

CONCLUSION

This paper has examined the future of hospice for African Americans by reviewing the historical perspective, the data regarding hospice use, and reviewing the literature identifying barriers to hospice use. It has also made recommendations on increasing

hospice use by and for African Americans. While admittedly there are still a lot of unanswered questions regarding why hospice is underutilized—i.e., research is needed in this area—implementation of the recommendations in this paper will definitely increase use of hospice, which overall will begin to address some of the disparities in health care for African Americans with advanced illnesses, and their families and caregivers.

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In Collaboration With:
Duke Institute on Care at the End of Life
Initiative to Improve Palliative Care for African Americans (IIPCA)

The Future of Hospice Care for African Americans:
Clinical, Policy, and Caregiver Perspectives

Commentary by Congresswoman Donna Christian-Christensen, MD
US Virgin Islands

As a physician with over two decades of medical practice and hospital administration experience, I have treated patients throughout the continuum of life. I have been there to celebrate their births and have been present to mourn their deaths. I have held their hands as they entered the final stages on their journey home and have comforted their families throughout the heartbreaking process of caring for their loved ones at the end of their lives. The process is painful and often overwhelming, but can be ameliorated with hospice care.

If you have never been through it, imagine that your husband, wife, mother, father, daughter, sister, brother, or friend is told that their illness has progressed to the point where nothing else can be done for them medically. Envision the agony of being told that you are dying and trying to reconcile that you are at the end of your life's journey and must begin to prepare for the final stage of your life. Imagine the turmoil and anguish of the entire family that now must find a way to deal with the pain and sorrow of their loved one dying. More so, imagine the challenge of trying to coordinate the care for the medical and emotional needs of a loved one who is dying while trying to cope with the pending loss.

I have seen individuals and families struggle with the challenges I described above. Many, especially African Americans, struggle through these challenges unnecessarily alone despite the fact that there are over 3000 hospice programs in the United States.

These important programs are greatly underutilized by African Americans. As authors note, of the nearly 1 million patients served in 2004 by hospice programs, more than 80% (81.2%) were Caucasian, while just 8.1% were African American, and just 6.2% were Latino or Hispanic.

The reasons that African Americans do not utilize hospice care are varied. Some are afraid to take on the responsibility of taking care of their loved ones at home. Many others feel that it is their duty to care for their loved ones by themselves rather than to ask for assistance, and that such a request may be viewed as weakness or that they will be deserting their loved ones by letting someone else help provide the needed care. Others may not know exactly what hospice care entails or the services that are provided for both the patient as well as the family.

Still, many may be deterred by concerns about the cost of hospice care, not knowing that there are certain programs such as Medicare that will provide hospice care services at no additional expense.

As African Americans, we have always had a rich history of caring for our own, especially in sickness and death. Hospice care should not be viewed as moving away from that tradition, but instead as an additional resource to provide the loved one and family assistance.

Hospice care should be viewed as an integral part of the continuum of care which provides the individual with the end of life care to manage illness-related symptoms and pain so that the individual can pass with dignity, quality and peace surrounded by family and friends. Hospice care provides a variety of services including pain management and symptom control; spiritual care; coordinated care; respite care; and bereavement care, to

name but a few. It can be provided in various settings, including the individual's private home, a hospital, a nursing home, or a private hospice facility. Hospice care embraces both the public health and interdisciplinary team approach, with trained professionals—such as physicians, nurses, social workers, home health aids, and clergy—who help with the end of life decisions and provide medical, emotional and spiritual support and care not only for the individual, but also for the family.

This article, **The Future of Hospice Care for African Americans: Clinical, Policy, and Caregiver Perspectives**, is timely and necessary because it is crucial to let our families know they don't have to go through this difficult time by themselves and to educate our community about the benefits of hospice care, the resources available, and how to access them. It is also important that hospice care providers be educated on the health, cultural and spiritual needs that are unique to the African American community. It is critical that trust and understanding be established between the caregiver, the patient and the family by enhancing an understanding of the dynamics of hospice care and the important role that it can play at the end of life, especially for African Americans. **This is a disparity that we can and must eliminate – the disparity of hospice care.**

Theological Perspectives on Death and Dying for African Americans: Christian & Islamic Perspectives

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Theological Perspectives on Death and Dying for American Americans: Christian & Islamic Perspectives

A CHRISTIAN PERSPECTIVE
By Reverend. Dr. Paul Smith

Introduction

Death and dying is a topic which occupies the thoughts of many people today, particularly since the horrific events of the war in Iraq, and the September 11, 2001, attack on the Twin Towers in New York City and the Pentagon offices in Washington, DC. More than 4,500 people died, making the counting of these deaths an almost daily occurrence. The evening news on all major television networks flooded the viewers with the fact of death and dying. The topic was inescapable. What goes almost unnoticed, except when some news reporter interviews a family member who has just lost a son or daughter in the war in Iraq, are the reactions to the fact of these deaths.

Furthermore, the American public watched funeral after funeral being conducted by clergy of various faiths and nationalities—a new experience for many who were watching. In particular, African American mourning and funeral services could be seen on a regular basis. The spiritual strength we witnessed from the African American community differed from that of white Americans and of other religious groups. In this paper, we will explore how two different religious (and perhaps cultural) groups— African American Christians and African American Muslims view death and dying.

A few years ago a member of my congregation said to me, "I made a living, but I never really lived." I would say many people have died who never really lived. Death and dying is a topic which is on the minds of many people today.

The fact of death often leaves us cold and wanting. Death comes unannounced and without regard to persons. We don't like death, because it snatches children from the arms of their mothers and fathers. Death tears down the little empires we have built and crushes our hopes. We fear death, and rightly so, for we cannot fathom its mystery. When the storms of death rage and batter us against the rocks of despair, we search for clues that will give us some understanding of why things are happening.

Death is the one time in life when we as Christians believe we are totally dependent upon God. Death is inescapable. Yet, for African American Christians, as it was for their forefathers in slavery, there were three major sources of raw materials in which the slave placed the alchemy of his desiring and aspiring, "the world of nature, the stuff of experience, and the Bible, the sacred book of the Christians."[1](p13)

The Bible

The Bible continues to be a major source of understanding and mystery for African American Christians. The Bible proclaims in the four Gospels of the New Testament and, in particular, I Corinthians 15:3–7, the life, death, and resurrection of Jesus.

> For I delivered to you as of first importance, what I also received, that
> Christ died for our sins in accordance with scriptures, that he was
> buried, that he was raised on the third day in accordance with the
> scriptures ….[2]

The Bible is the story about God and his people, and how God delivers his people from any kind of bondage, including death. The story of Lazarus being raised from the dead is a familiar passage of scripture used during funerals and with African American Christians facing death.

If God raised Lazarus from the dead, God could certainly raise those facing illness and death. There is a direct connection between this passage of scripture and resurrection theology for African American Christians. Resurrection theology is the belief that God has the final say over any of life's vicissitudes, especially the final say over death.

James Weldon Johnson in his poem, *Go Down, Death,* affirms the importance of the Bible for African American Christians and their understanding that death does not have the final word for those who believe in God.

> Weep not, weep not,
> She is not dead;
> She's resting in the bosom of Jesus.
> Heart-broken husband-weep no more;
> Grief stricken son-weep no more;
> She's only gone home.
>
> Day before yesterday morning,
> God was looking down from his great high heaven,
> Looking down on all his children,
> And his eyes fell on Sister Caroline,
> Tossing on her bed of pain.
> And God's big heart was touched with pity,
> With the everlasting pity.
>
> And God sat back on his throne,
> And he commanded that tall, bright angel
> Standing at his right hand:
> Call me Death!
> And that that tall, bright angel cried in a voice
> That broke like a clap of thunder:
> Call Death! - Call Death!

Theological Perspectives on Death and Dying

And Death heard the summons, and he
Leaped on his fastest horse, ...
Up Death rode to the Great White
Throne, and waited for God's command.

And God said: "Go down, Death, go down,
Go down to Savannah, Georgia,
Down in Yamacraw,
And find Sister Caroline.
She's borne the burden and heat of the day,
She's labored long in my vineyard,
And she's tired_ she's weary_
Go down Death, and bring her to me."

While we were watching around her bed,
She turned her eyes and looked away,
She saw what we couldn't see;
She saw Old Death. She saw Old Death.
Coming like a fallen star. But Death didn't
Frighten Sister Caroline;
He looked to her like a welcome friend.
And she whispered to us: I'm going home,
And she smiled and closed her eyes.

And Death took her up like a baby,
And she lay in his icy arms,
And she didn't feel no chill.
And Death began to ride again_
Up beyond the evening star,
Out beyond the morning star,
Into the glittering light of glory.
On to the Great White Throne.
And there he laid Sister Caroline on the
Loving breast of Jesus.

Theological Perspectives on Death and Dying

And Jesus took his own hand and wiped

Away her tears,

And he smoothed the furrows from her

Face, and the angels sang a song,

And the angels sang a little song,

And Jesus rocked her in his arms,

And kept saying: "Take your rest,

Take your rest, take your rest.[3]

This funeral sermon and poem by James Weldon Johnson captures the importance and the significance of the Bible's story of God and His Son Jesus in the lives of African American Christians. The Bible's imagery and focus upon death as a friend and not as some grim reaper is reassuring. The same God, who gave us his son Jesus, is the same God who comes to us in a time of trouble and dying. In death, the individual is rewarded with the resurrection. In the case of Sister Caroline, she puts herself at peace, because she sees death as a friend. The element of fear is removed, and she is rewarded with God's personal messenger, Old Death, who has been a friend of Sister Caroline for all of her life.

Sister Caroline has been a faithful member of the church, perhaps even a deaconess in her church, and she is dying, and the family and friends are gathered around her bed. In my mind's eye, I can see Sister Caroline's Bible on the table beside her bed. Perhaps, songs are being sung as family members feel their own tears gently streaming down their faces. Yet Sister Caroline, who has believed all of her life in the Bible and the stories about death and resurrection, has no fear. She sees what the family members cannot see. She is as comfortable as she can be, because she knows she is going home to be with God. And how does she know? The Bible has told her so.

The Stuff of Experience

The late Arthur Ashe, tennis professional and humanitarian, is another example of how one's life experiences shape your understanding of death and dying. Arthur grew up in a Presbyterian church in Richmond, Va. He understood what it was like to enter a professional sport dominated by white people. He received blow after blow of racial injustices on and off the tennis court. It was during his training and development on the segregated playgrounds of Richmond, Va, that his life's experiences were formed. Arthur lived the way he died. As Arthur encountered racist governments in South Africa and Europe, these life's experiences sustained him when he contracted HIV/AIDS, and as he faced his own death.

One's experiences of daily living are important to one's understanding of life and death. Experience is what shapes the African American Christian's understanding of the death and dying—experience which is revealed in story of the death of Saul Thurman, Howard Thurman's father. Saul Thurman's job was away from his home in Daytona Beach, Fla. From Monday morning through Friday evening, he would join his coworkers at an industrial plant miles away. Here these men would encounter the wrath of the white overseers and the tyranny of the idle white men who sat around the plant. There were also times of laughter and fun, as the day came to a close as these African American men sat around. Lynchings were commonplace, and therefore, death was always imminent.

One day Saul came home early, signaling something had happened. He looked tired and his body was covered with sweat, indicating he was not feeling well. It soon became clear to the Thurman family that Saul was dying, and they needed to prepare themselves. Saul's wife, Alice, managed to ask him, "Saul, are you prepared to die?"

He replied, "Alice, all of my life I have been a man, and I am not afraid to die?" He was not a religious man, nor was Saul a member of any of the small churches in his hometown of Daytona Beach, Fla. As a man negotiating the hurdles of living daily with his back against the wall of segregation, Saul had managed to remain a man. It was the stuff of his experience, of living each week away from his family, and learning how to deal with the injustices of his time that enabled him to say to his wife Alice, "I have always been a man, and I am not afraid to die."

When I was serving as Arthur's spiritual adviser, we often spoke about his ability to not allow the negative experiences of life to shape his belief system. When his illness became public, Arthur received several letters from several well wishers each offering ways of dealing with his illness. The Bible and its references to the "resurrection" of Jesus, and how God always makes a way out of no way, became the mantra for Arthur as he faced the fact of his death. Throughout our conversations, Arthur almost always relied upon his understanding and experiences of hearing the Gospel preached. Arthur Ashe lived the stories of the Bible and looked to the Bible as a source of strength as he faced death. He was not afraid of death. He wanted to die the way he had lived. And soon one morning, death came creeping into Arthur's room. And death was not a stranger. And with a thumbs-up gesture, as he was being wheeled into the hospital, Arthur embraced death the way he had lived.

Jean Young, the late wife of Ambassador Andrew Young, relied heavily upon the stuff of experience as she marched to her death in 1993. As the wife of a well-know civil rights activist who was directly attached to Dr. Martin Luther King Jr., Jean knew her husband could die at any moment.

Jean was a very religious person and an accomplished teacher and social worker and mother, Jean relied upon her mother wit and training as the basis for her strength. As she brooded over her children and the work of her husband, Jean developed a strong faith.

She read and listened to classical music. Mahalia Jackson's and Andre Crouch's music enabled her to withstand anything that might happen to her or to her husband, including his death. Jean became centered as she watched and read about the activities of her husband. As Jean neared death and encountered almost unbearable pain, she never once feared death. She embraced her own death through her life's experiences. It was no surprise to any who knew her, when in her own words, on her memorial program, she simply said, "What to remember about me? 'Now, That Was a Woman.'"

My own experience of sitting with people facing death has shaped my ministry and my theological perspective of death and dying. As an African American minister serving a multicultural, diverse, and inclusive congregation, I have come to rely upon the knowledge I have learned from the members of my congregation. It was a result of my experiences pastoring a racially diverse congregation that I realized I was living in two racially diverse worlds. One was African American and the other was white. I remember how my boyhood minister preached the deceased into heaven. Those sermons were beautiful and poetic, memorable, and deeply moving. The families of the deceased felt comforted and renewed as they listened to the black preacher.

I was able to connect with the poetry of Langston Hughes and James Weldon Johnson as I listened to funeral sermons in my home church. I grew up believing that heaven was just on the other side of the Jordan River. That sentiment continues to be expressed in African American churches today.

My experience in the black church stayed with me through college in Talladega, Ala, Here I was exposed to Negro spirituals, beautifully arranged by the college choir. Here I learned about drama, dance, and art, all incorporated into the life of worship in my college chapel. Although the student body of Talladega College was practically all black, the faculty was both white and black. For the first time, I was exposed to worship and religious experiences that included both black and white people. My circle of experience was beginning to be challenged and to expand.

Consequently, I began looking at life in the African American community through another lens. My blackness was being challenged by the knowledge of the white Christians. I was being taught and influenced by black authors and composers I had never heard of before. I was exposed to speakers, both black and white, who came to speak in chapel service four times a week, and Sundays. Never before had I experienced such racial diversity, even in my non-segregated community of South Bend, Ind. The joyful music I heard during funeral services and Sunday service in the church of my youth began to change. The preaching was quite different in the chapel of my college from that of the preachers in the church I grew up with. I was expanding and growing, and being challenged theologically, which attracted me to considering the ministry as my vocation.

Upon graduation from Talladega College and before heading to seminary, I was asked to serve as the minister of a small black church in Athens, Ala. I was just out of college and had little experience other than my college training of leading a congregation. Here I learned rather quickly how the black church was changing, and this would eventually influence my ministry. One of my first duties as the minister of this small church was to preside at the funeral of the city's most distinguished African American citizen, and daughter of the local undertaker.

I had only been in town three weeks and in my life had never conducted a funeral. Yet the family had confidence in me, because I was a graduate of the same college attended by the daughter of the deceased. The family wanted something "dignified, calm, quiet and spiritual." Clearly, these elements were not traditionally present in the black churches of Athens, Ala. All eyes were upon me, and I was also very nervous. Yet, I realized the experiences at college had prepared me for just a moment as this one. I was able to not only conduct the service, but I managed to inspire a community of people who only knew me as this new young minister who had only been in town for three weeks.

I have conducted many funeral and memorial services since that day in 1957 in Athens, Ala, but the stuff of my experiences in the multicultural and diverse setting of Talladega College gave me what I needed as I conducted the funeral in Athens that hot summer day in 1957. The spirituals I had heard and learned from the college choir and the prayers offered by distinguished white and black clergy from around the country were of great value to me. The new rural culture I had been thrown into was of tremendous value to me, and I remembered the wisdom of the people who had brooded over me. The stuff of my experience continues to guide my ministry in Brooklyn, NY, today.

Theological Perspectives on Death and Dying

The World of Nature

Nature was a constant companion for the African American slaves. Moon and stars, wind and rain, and mountains and valleys are all mentioned in the Bible. The world of nature was a place for spiritual discernment and understanding. When the brutality of slavery became unbearable, the slaves would retreat to mountain ranges or to the "hills from whence cometh our help."[2] They would find refuge in the cool waters of a river. Their music, the early Negro spiritual, often portrayed the influence of nature in their existence. *Gonna lay my burdens down; Down by the Riverside; There's a Star in the East on Christmas Morn; Rise up Shepherd and Follow; Go Tell It on the Mountains;* and *Deep River, My Home Is Over Jordan* to name but a few of these spirituals. There is something mysterious and spiritual about nature, and those mysteries brought comfort to the slaves.

The spiritual *Deep River, My Home Is Over Jordan* is often sung at funeral services in the black church. African Americans identify with the river because it is always moving and always flowing. African Americans attribute the flowing and ebbing of the river to life and death. The river is the bearer of salvation. The Jordan River, in particular, expresses the theology of eschatology. Death occurs on one side of the Jordan. Resurrection occurs on the other side. Jordan is often equated with heaven as well. Eschatology is defined as the doctrine of last things. The Old and New Testaments talk about eschatology, particularly the Book of Revelations. Eschatology involves dreams and visions of a better place or a better life. Thus many Negro spirituals are eschatological in form. The slaves sought a better life, a better place, and better circumstances for themselves and their families.

The world of nature was a refuge for African Americans. Poetry, dance, music, and song are the stuff of the world of nature. Just as Jesus retreated to the mountains before he began his public ministry, so do African Americans. In many of the slave narratives, reference is made to the slaves "stealing away" to the mountains or to the rivers, where they could talk to Jesus. There is something very spiritual and comforting about lifting up prayers to God while the full moon is visible. I remember as a boy how I sat at the top of the stairs in my childhood home whenever something was weighing heavily upon my mind. A full moon was the route to freedom because it provided light in the darkness of the evening. My spiritual development began by acknowledging the influence of the moon and the stars. There is something very deeply moving about nature and that something continues to inform me to this day.

The world of nature provides the spiritual awareness and awakening necessary when life is waging war against one's spirit. Howard Thurman writes in his autobiography, *With Head and Heart,* how he would row himself out on the Halifax River in Daytona Beach, Fla, in order to make his connection with God. He said he found comfort and strength not only in the river but in the stars and moon, which were more visible from his boat. Looking up at the stars in times of trouble and despair became a spiritual exercise for Howard Thurman.

There appears to be a mystical element about the world of nature. For example, the comparison of life to the river is an interesting metaphor for Howard Thurman. In his book, *The Negro Spirituals Speak of Life and Death*, Thurman equates life to the river.

The fascination of the flowing stream is a constant source of wonder and beauty to the sensitive mind. It was ever thus … the relentless movement, the hurrying, ever-changing stream has ever been the bearer of longings and yearnings of mankind for a land beyond the horizon where dreams are fulfilled and the deepest desires satisfied. The river, in the first place, has a very simple beginning. It increases in momentum, in depth and breadth, in turbulence as it makes it journey down the broad expanse of America, until at last it empties itself into a larger body of water. Life is like that. It has its flood times. The river that was once quiet and peaceful has times of drought and times of flood.[1(p66)]

Life is like the river for many African Americans, especially when it comes to the matter of suffering. Suffering is an ever present companion when death and dying are around. Suffering is also a part of the experience of life. It was so for Jesus of Nazareth. How does one handle the experience of suffering? Is suffering a natural part of life? Do some people suffer more than others? These questions and more are on the minds of those who are faced with death and dying. The Bible, the stuff of experience, and the world of nature are instructive here as well.

I have yet to mention prayer in this writing, but I do so now against the backdrop of the Bible, the stuff of experience, and the world of nature. I have always believed that the power of prayer is one of the most meaningful ways one can communicate with God. I am aware that others may prefer to direct their prayers or even meditations to what they refer to as a higher power. Through prayer one brings all of the resources—the Bible, experience, and nature—he can muster. African Americans are a praying people and their clues for prayer are taken directly from these three sources. Prayers offered in the hospital by the bedside where a loved one is near death or has died are extremely important. Again, Howard Thurman says "the issue of prayer is not the prayer; the issue of prayer is God."[4]

In his book *Meditations of the Heart*, Howard Thurman refers in one of his poems to "The Strings in my Hands." He says:

> One thread is a strange thread,
> It is my steadying thread;
> When I am lost, I pull it hard and find my way.
> When I am saddened, I tighten my grip
> And gladness glides along its quivering path;
>
> When the waste places of my spirit
> Appear in arid confusion,
> The thread becomes a channel for newness of life.
>
> One thread is a strange thread- it is my steadying thread.
> God's hand holds the other end.[5]

African Americans are steadied by the good news from the Bible which affirms that God is always holding the other thread of our lives. Our personal experiences and encounters with the unjust conditions of this world become building blocks for survival. The steadying thread is held tight when death looms over us and our community; yet we are sustained always by remembering that there is in God sufficient strength, whatever our needs may be. We find our places in the world of nature where we might go to pray and let the dust of life settle, just long enough for us to remember that whether we live or die, we are still with God.

In the Name of Allah, the Beneficent, the Merciful

AN ISLAMIC PERSPECTIVE

By Shaykh Ibrahim Adbul Malik, EdD

Introduction

I would be willing to hazard a guess that some readers of the compelling words of my colleague, Dr. Smith, might have found themselves either saying, or wanting to say "Amen" time and again. And why not? He took you along with him on his personal journey of discovery and transformation and of spiritual service to a growing community of committed believers. And along the way, he took time to minister to persons who were marching to the beat of a different drummer but whose concerns as they approached their final exit paralleled those of their believing brothers and sisters.

Death is a fact of life. None of us, believers or non-believers, can escape it. And indeed, when it comes knocking, there is no place to hide. But for Muslims, that is only a part of the story. It is in the rich details of the full Qur'anic account that Muslims find justification for their attitude toward death, for their approach to life and living, and for their certainty about the hereafter.

I will soon reveal many of these rich details. Let me, though, first establish a few fundamentals of Islamic belief. To know these is to understand why Muslims may express certain attitudes about their life experiences that many of their Christian friends and colleagues may consider unusual.

Islam

1. *Allah is a God of Mercy*. Undoubtedly, Allah, the Creator of the universe, Omniscient, Omnipresent, Master of the Day of Judgment, is also known by many other names. But the attributes which Allah, Himself,[6] emphasizes over and over are "*Ar-Rahman*" (The Compassionate) and "*Ar-Rahim*" (The Merciful). In the first two quotations that follow, Allah is speaking.

> With MY punishment, I visit whom I will. But *MY mercy extendeth to all things*. That (Mercy) I shall ordain for those who do right, and practice regular charity, and those who believe in OUR signs. (Qur'an 7:156)

> I am indeed *the Oft-forgiving, most merciful*. (Qur'an 15:49)
> *Allah has willed upon Himself the law of grace and mercy.* (Qur'an 6:12)

2. Islam is a religion, established, and named by Allah.[7] But equally, Islam is a way of life. Hence, a righteous Muslim declares, (as Allah instructed Prophet Muhammad):

> Behold, my prayer, and all my acts of worship, **my living** and **my dying** are for
> Allah [alone], the Sustainer of all the worlds. (Qur'an 6:162)

3. Islam teaches that everything about this world is temporary and delusive, and our limited time on earth is ultimately a preparation for the much more enduring and important life to come.

> Know, O men that the life of this world is but a play and a passing delight, and a beautiful show, and [the cause of] your boastful vying with one another, and [of your greed] for more and more riches and children…. But [the abiding truth of man's condition will become fully apparent in the life to come: *either* suffering severe, *or* God's forgiveness and HIS goodly acceptance. ***For the life of this world is nothing but an enjoyment of self-delusion***. (Qur'an 57:20)

In his moving description of how Sister Caroline faces her last moments on earth, Dr. Smith wrote, "She 'sees' what the family members cannot see. She is as comfortable as she can be, because she knows she is going home to be with God. And how does she know? *The Bible has told her so."* [emphasis mine]

Just as Christians find comfort and guidance in the Bible, Muslims also turn to their Holy Book, the Qur'an, for their comfort and guidance.[8] So what does Qur'an tell us about death and dying? Let us explore together.

The Qur'an Says

We die only when Allah wills it.

> And no human being can die save by God's leave, at a term pre-ordained… (3:145)

Death is the lot of every one of us, as decreed by Allah.

> WE[9] have [indeed] decreed that death shall be [ever-present] among you. But there is nothing to prevent US from changing the nature of your existence, and bringing you into being [anew], in a manner [as yet] unknown to you. (56:60–61)

***When it is our time*, we cannot avoid death.**

> O you who have attained to faith! Be not like those who are bent on denying the truth, and say of their brethren [who die] after having set out on a journey to faraway places, or gone forth to war, '***Had they but remained with us, they would not have died***,' or, '***they would not have been slain***'; for God will cause such thoughts to become a source of bitter regret in their hearts, since ***it is God who grants life and deals death….*** (3:156)

When it is time, delays are not possible

> Never does God grant a delay to a human being when his term has come....
>
> (63:11)

There is no hiding place when death comes knocking

> Wherever you may be, death will overtake you, even though you may be in towers raised high….
>
> (4:78)

Allah instructs that both our lives and our deaths are in HIS control.

> O prophet, tell them: ***"It is Allah who gives you life, and later causes you to die***. Then it is HE who will gather you all on the Day of Resurrection, about which there is no doubt. But most human beings understand it not." (45:26)

So much for part one of the story! As one author put it, "[Death] is the first stage of the Hereafter…. It marks the entrance into that realm."[10]

And indeed, Qur'an confirms for us over, and over, and over again, the truth of the author's statement. There is more to look forward to beyond death—much more. But what that will be for any one of us will be greatly determined by what we do before we are summoned. I will let Qur'an speak on the matter.

Allah is the supreme ruler of all the universe, and the ultimate destiny of us all is to return to HIM *for judgment* on the Day of Reckoning

HE [Allah] governs all that exists from the Celestial space to the earth. And in the end, *all* shall ascend unto HIM [for judgment], on a Day, the length whereof will be [like] a thousand years of your reckoning. Such is HE who knows all that is beyond the reach of a created being's perception, as well as all that can be witnessed by a creature's senses or mind, the Almighty, the Dispenser of Grace. (32:5–6)

The Day of Reckoning is a surety, because Allah says so.

And in the end HE will gather you together on Resurrection Day, [the coming of] *which is beyond all doubt*. (45:26)

I [Allah] call to witness the Day of Resurrection.[11] (75:1)

On that Day, Allah will raise up all who are in their graves.

On the Day, when the summoning voice will summon [man] unto *something that the mind cannot conceive*, *they will come forth from their graves*, with their eyes downcast, [swarming about] like locusts scattered [by the wind]. (54:6–7)

Out of this earth have WE created you, and into it shall WE return you, and out of it shall WE bring you forth again. (20:55)

On that Day, you are on your own. No parent will be able to help his/her child. No child will be able to help her/his parent. Only Allah knows when.

O men, be conscious of your Sustainer, and stand in awe of the Day on which *no parent will be of any avail to his child, nor a child will in the least avail his parent*. . . . Let not then the life of this world delude you, and let not [your own] deceptive thoughts about God delude you. Verily *with God alone rests the knowledge of when the last hour will come*…. (31:33–34)

Even our body parts will witness against us on that Day.

On that Day, WE shall set a seal upon their mouths, but their hands will speak unto US, and their feet will bear witness to whatever they have earned [in life]. (36:65)

After the cataclysmic events of the Last Day, Allah declares that HE will "create a new earth and heaven," just as HE created the one with which we are familiar.

> On that Day, WE shall roll up the skies as written scrolls are rolled up. And as WE brought into being the first creation, so *WE shall bring it forth anew*—a promise which WE have willed upon OURSELVES. For behold, WE are able to do all things**....** WE laid it down in all the Books of divine wisdom, that MY righteous servants shall inherit the earth**.** (21:104–105)

On That Day, Allah, Himself, promises absolute fairness to all

> But WE shall set up just balance scales on Resurrection Day, and no human being shall be wronged in the least. For though there be [in him but] *the weight of a mustard seed* [of good or evil]*, WE shall bring it forth.* And none can take count as WE do**.**

> And yet, whoever does [the least] of righteous deeds, and is a believer, withal*, his endeavor shall not be disowned. For behold, WE shall record it in his favor***.** (21:47, 94)

Allah promises full, *fair* **rewards, even to those who cared only about the things of this life.**[12]

> As for those who care [for no more than] the life of this world and its bounties*, WE shall repay them in full for all that they did in this [life], and they shall not be deprived of their just due therein***.** [Yet] it is they who, in the life to come, shall have nothing but the fire—for in vain shall be all that they wrought in this [world], and worthless, all that they ever did. (11:15–16)

Allah promises special mercy to believers who live righteously and pay zakaah.[13]

> *… I will ordain special mercy for those who do righteous deeds, pay zakaah and believe in our revelations***.** (7:156)

Allah rewards your good deed tenfold, and your evil deed, one-to-one.

He that doeth good shall have *ten times as much to his credit.* He that doeth evil shall only be recompensed according to his evil. No wrong shall be done unto (any of) them. (6:160)

Allah lays out the punishments for the wrongdoers and the naysayers.

WE have ordained that [in the Hereafter]*, hell shall close upon all who deny the truth*.

[But] one day, WE shall summon all human beings, [and judge them] according to the conscious disposition which governed their deeds [in life]. . . . *Yet, none shall be wronged by as much as a hair's breadth*. (17:8,71)

WE shall save [from hell] those who have been conscious of US. *But WE shall leave in it the evildoers, on their knees*.

WE shall record what he [*who continually denies the truth*] says, and *WE shall lengthen the length of his suffering* [in the Hereafter]**.** (19:72, 79)

Qur'an has spoken—elegantly. How is it possible for a righteous Muslim to read these magnificent words of assurance from Allah and not be moved to action? From HIS unequivocal declarations that we will all return to HIM, and that the Day of Reckoning is absolutely coming—"a fact about which there is no doubt," HE gives us a detailed preview of what we can expect—the good and the bad. And even though HE is describing a "realm beyond the reach of human perception,"[14] we cannot help but be affected by the images of our imperfect human imaginations.

In the first part of this paper, Dr. Smith presented some profiles typical of African American Christians. While it is true that Christianity and Islam differ in some important theological matters, beyond their common Abrahamic connections, they also share the fact that African American Muslims are sociologically very like African American Christians, which Dr. Wright observes in the third part of this paper. And yet, as they operate within the theological framework of Islam, many of the traditions they share with the African American Christians necessarily must be expressed differently.

In the matter of prayer, for example, African American Muslims, as all Muslims, are obligated to perform the formal prayers (*salaat*)[15] five times a day, seven days a week, three hundred sixty-five days a year. No comparable obligation exists for Christians. Still, as Dr. Smith observed: "African Americans are a praying people," whether Christian or Muslim. Beyond the formal prayers, Islam also encourages Muslims to pray informally, whenever, wherever, however they feel the need to do so. You can be sure that African American Muslims pray just as often and hard as their Christian brothers and sisters, when faced with death and dying.

Here again, Allah is most reassuring in two critically important ways for all of us who pray. HE declares that HE is *always* with us, and that HE hears our supplications.

> It was WE who created man, and WE know what dark suggestions his soul makes to him. For *WE are nearer to him than (his) jugular vein*. (50:16)

> And if my servants ask thee about ME, behold I am near. *I respond to the call of him who calls, whenever he calls unto ME.* (2:186)

As a Muslim, I am doubly encouraged by these statements. First, the message itself would be enough, so compelling is the assertion that the Creator not only hears my pleas, but is closer to me than one of my internal organs. But when the message comes in the first-person language of Allah, "*WE* are nearer…" and "*I* respond…"—well, what more could I ask?

The answer to that rhetorical question is nothing. But what I am feeling is overwhelming gratitude and a deep desire to acknowledge the dual gifts of divine assurance. And formally, at least seventeen times every day, I get the chance to acknowledge. During the salaat, practicing Muslims recite, in affirmation of Allah's declaration: "*Sámi Alláhu limán hámidah*" (Allah hears the person who thanks HIM).

Prayer is so central to the Islamic way of life, that many Muslims actually plan their daily activities around their prayer lives. Humans being humans, even the most devout among us can benefit from reminders. This verse from Qur'an both instructs and reminds that we pray *only* to Allah, who is the ultimate truth[16] and that prayer without faith is futile.

> *For HIM (alone) is prayer* in Truth. . . . For *the prayer of those without Faith is nothing but (futile) wandering (in the mind)*. (13:14)

It is unlikely that a righteous Muslim would knowingly violate the first reminder—pray to Allah alone. But we can all take to heart the second warning about empty prayers, and be ever mindful, when we do pray, to infuse our words with the essence of our faith. And surely, if there is any single time when we truly need Allah's help to deepen our faith, it is when we are facing the challenges of personal tragedy and/or adversity.

CONCLUSION

Thus far each of us has focused almost entirely on how our particular religious tradition instructs and influences its devotees in their understanding of and responses to the realities of death and dying. This was not only our assignment but a very proper approach, consistent with the relationship between a person and his/her religion. But we would be missing a God-given opportunity, if we did not also advance the cause of greater mutual understanding and productive collaboration across religious boundaries.

In calling for "greater mutual understanding and productive collaboration," we are doing more than simply following the dictates of survival politics. We are in fact echoing the invitation which Prophet Isaiah brought from God to the disobeying people of Judah: "Come now and let us reason together,"[17] and the words which Allah instructed Prophet Muhammad to speak to those who disputed his message: "O people of the Book, let us come to an agreement on that which is common between us."[18] In both instances, God is urging a collaborative process which is far more likely to bring about understanding and mutual respect, than continuing in a state of ignorance and mutual suspicion.

The most obvious example of "that which is common between us" is what we have been writing about throughout the paper:

> We are African Americans (and all that that implies),
>
> We all experience the pain and anxiety of death and dying,
>
> We believe in the power of prayer,
>
> We believe in Life after Death,
>
> We are all people of the Book.

But typically, we remain isolated from each other, wrapped in the fabric of our own scriptures, unmindful of the ways in which they overlap, focused, instead, on the perceived, often misrepresented differences between us, unresponsive to the more compelling truth that binds us—our shared humanity, the gift to each of us from our Creator.

We already have examples of influential leaders, religious and non-religious, Christian and Muslim, who have taken steps towards rapprochement. It is now for us, individually, to follow their lead, to reach out to our neighbors across the religious divide and invite the kind of respectful dialogue that can foster understanding, even lead to joint activities for mutual benefit.

We pray that our Creator God give us the grace to speak kindly to those with whom we may have differences in matters of religion: Let there be no argument between us! God will unite us, and the journey is to God.[19]

THEOLOGICAL REFLECTIONS ON DEATH AND DYING
Christian and Islamic Perspectives
By Reverend, Dr. Jeremiah A. Wright Jr.

I come to this task as a practicing Christian minister. I was ordained to the Christian ministry in 1967, and I have been pastoring the Trinity United Church of Christ in Chicago, Ill, since 1972.

I also come to this task as a student of F. Rahman, one of the nation's leading Islamists at The University of Chicago and the Oriental Institute in Chicago, back in the 1970s. My area of concentration while studying Islam in West Africa was the Tijaniyyah among the Bambara, the Fulbe and the Tukolur.

At Chicago I studied Islam in West Africa for six years under Rahman, and as a historian of religions, I studied for six years under Dr. Charles H. Long. These studies did not make a practicing Muslim, but they do give me a perspective on Islam that the ordinary Christian would not have.

My years of experience as a pastor and my close friendships with Sunni Muslims and members of the Nation of Islam in North America have taught me that the theological perspectives of the "people of the Book" are wide and diverse—far from monolithic—when it comes to issues of death and dying. The sacred texts of Christianity and Islam teach a great deal about life after death; but the degree to which the average African American believer embraces those beliefs varies from community to community and, almost, from believer to believer.

The gap between what is written in the sacred text and what is in an individual's heart and mind is the subject of revelation and history in the Christian Bible, both Old and New Testaments.

My primary professor of Judaism at The University of Chicago Divinity School, Dr. Jonathan Z. Smith, taught us our introductory courses to Old Testament and the History of Israel in a very exciting and refreshing way. His methodology helps practicing Muslims and Christians in the twenty-first century understand the difference between what is written in the sacred text and what is lived in the everyday lives of the people of faith.

What the Bible shows us, for instance, is that in the Old Testament the sacred text teaches (and preaches) ethical monotheism. The *shema* became the mantra of the Jewish faith and the Christian faith: "Hear O Israel, the Lord our God is one God!"

The teaching of one God and one God alone became the foundation upon which the faith of Israel, the faith of Judah, the faith of Judaism, the Christian faith (and many would say the faith of Islam) were constructed. That there is only one God is understood as what the doctrine of the faith teaches. What the people of faith practice, however, is something quite different.

In the Book of Genesis, for instance, Jacob (the grandson of Abraham) practices the faith of monotheism. One of his wives (Rachel), however, steals the household idols of her father, Laban, as she and Jacob leave Laban's home to go back to Jacob's home. His wife believed in more than one God. She worshipped the gods whom the household idols represented.

In the Book of Judges, Gideon is cut from the same monotheistic cloth. When God calls him into service and he accepts God's call, the first thing he is instructed to do is to tear down the male and female gods of fertility (Baal and Asherah) that are in his father's backyard. His father (also a practitioner of the monotheistic faith) worshipped the Canaanites gods of fertility in addition to the God of Israel.

All throughout the books of prophecy, the prophets are railing against the practices of the people of faith because they are worshipping several gods. They say with their mouths, "Hear O

Israel, the Lord our God is one Lord!" They recite their creeds of monotheism, but they practice a faith of polytheism.

A cursory examination of the Book of Kings shows the same gap between preachment and practice. The kings of Israel, starting with Jeroboam, set up false gods—idols and gods made out of gold—and they ordered their citizens to worship those gods. The history of the kings of Israel is one long list of kings who strayed away from the faith of David and who worshipped gods other than Yahweh, Elohim or the God of the Covenant.

In addition to all of the problems that exacerbated these kinds of practices in New Testament Christianity, there is still the twenty-first century practice of Christians professing with their mouths an acceptance of Jesus Christ as their personal savior, which means that everything in their lives has changed. Every Christian embraces II Corinthians 5:17, which says, "If anyone is in Christ Jesus, they are a new creature, *old things* have passed away. Behold. *All things* have become new."

While professing this with their lips, however, the majority of twenty-first century African American Christians can tell you what zodiac sign they are born under. Claiming that they are Aries, Gemini, Virgo or Libra negates II Corinthians 5:17. They are saying that being born under a certain sign in the zodiac gives them certain fixed characteristics that not even Jesus Christ can change.

The sacred Scriptures of the Christian and the Muslim faiths—both the Bible and the Quran—are full of passages that talk about life in *Sheol*, the soul going back to God from which it came, life in the hereafter, the resurrection of the dead, and life in paradise or life in heaven. Those are passages that give the "official party line" of what the Christian faith and the Muslin

faith say about death. When practicing Christians and Muslims, however, face death, it is a different story altogether in terms of what many of them believe.

There is no monolithic black Christian or Muslim belief. The theological perspectives of Christians and Muslims cover a wide spectrum of beliefs. When death comes knocking at a believer's door, everyone does not go as easily as the black women James Weldon Johnson and Sterling Brown describe in their poems about death.

Many believing Muslims and Christians go kicking, fighting and screaming. Even Jesus as he faced death quoted Psalm 22. He cried out in a loud voice: "My God! My God! Why hast thou forsaken me?"

Jesus the human person had some problems with life's greatest mystery, which is death, and so do we. Having said that, I do not intend to put Jesus down or to put any believer down. Human beings are human beings. We are both dust and divinity.

That means that we have fears and faith, doubts and assurances, and some questions for which there are no answers. We have some anxiety in our belief system and our "doubts and fears" are interspersed with hope and ultimate trust.

Hope and trust are not the only beliefs we have, and those are not the only set of emotions that rush through believers' hearts and send thoughts into their heads when they are faced with death and dying. When we as believers have to watch our loved ones suffer and die, the wide range of emotions that we experience, and the incredible rush of thoughts that flow and fly through our heads are just as diverse.

As an historian of religions whose field of study was West African religions, I know the carryovers from the African culture into the African American experience are incredible. They are almost too numerous to mention. (See Henry Mitchell's *Black Belief*.)

What African Americans believe about the living dead, the ancestors, life after our breath has left our bodies, the presence of the spirits of the ancestors, and those whom we love who no longer live among us in the flesh is an important part of the framework for understanding end-of-life care and death and dying in the African American community, in the African American faith community and the theological worlds which make up Christianity and Islam in North America among African Americans.

In West Africa libations are poured to the living ancestors, and it is to those same ancestors that Jesus was talking when he ascended the Mount of Transfiguration with Peter, James and John.

My approach, therefore, in talking about the theological perspectives on death and dying from an African American perspective, is to hold in tandem what it is our members *actually* believe when it comes to the *lived* experience as contrasted and compared with what the doctrinal texts and axioms of our faith say we *should* believe.

The way John describes heaven in the Book of Revelation and the way the Quran describes the virgins waiting in paradise for a Muslim man who has lived a good life are eschatological descriptions and beliefs. What black Christians and Muslims believe "on the ground," however, does not always square with the written text or with the eschatology taught by both faiths.

I give you this background to help you understand the difference between what it is people say with their mouths as they embrace a faith and what it is they do in their daily practices as they live out their faith. As this is the truth I have encountered among practicing Christians in my 34 years of pastoral experience, I would suggest to you that the same is true with Islam in West Africa and Islam in North America.

Theological Perspectives on Death and Dying

African traditional religions are not abandoned or forgotten when people embrace Islam or Christianity in Nigeria, Ivory Coast, Senegal, Liberia, or Ghana. The beliefs about life after death, death as a part of life, death as a "friend" and death as "the final enemy" are all found among Africans on the continent and Africans living in the North American diaspora.

Practicing Christians of African descent in the Americas also find almost no difficulty in mixing the *Orisha* of Yoruba and Christianity. In Cuba it is called *Santeria* and in Brazil it is called *Candomblé*.

The African traditional religions, and, indeed, all of African culture, teach that the soul lives on after death. They also teach that an individual's spirit stays among its people while traveling back and forth between the land of "the living dead" (*Sheol*) and the familiar places it used to traffic in while it was in the flesh. Some of the practices of Africans living in the diaspora in the Deep South and throughout the Americas demonstrate that these beliefs live.

Henry Mitchell in his book, *Black Belief,* gives dozens of examples of African practices that are still extant among African Americans who live in North America. Many of the beliefs have to do with death, dying, the preparation of the corpse, and the freeing of the spirit of the deceased. Mirrors are still covered, for instance, in some places in the Deep South to keep the spirit of the deceased person from being trapped in the house where he or she lived.

As a pastor I have had hundreds of members who have talked to me in my three decades of ministry about visitations of their loved ones who have come to them following their deaths. Sometimes the loved ones have talked to them. Sometimes they have simply let their presence be felt. At other times they have sat down on the bed and the member who was sharing with me could feel them actually sit on the bed, while at still other times the departed loved one was just seen passing through the house.

Theological Perspectives on Death and Dying

This strong belief in life after death—not just in heaven or with God, but in the spirit world—makes the playing field quite uneven when it comes to understanding the attitudes and the theology which inform the belief systems of African Americans in the Christian and Islamic communities in the United States of America.

Realizing that I run the risk of making broad, sweeping generalizations and lumping widely disparate people together, let me try to give those of you who will minister to persons of faith some general guidelines based on the experiences that I have as a pastor and as person.

There are some Christians of African descent who take the Bible literally. They believe in bodily resurrection. They are adamantly opposed to cremation or to organ donation because they believe that their physical bodies are going to be raised "on the day of Resurrection" and they want those bodies intact.

These Christians look at I Corinthians 15 where Paul says "the dead in Christ shall rise" and they completely ignore the fact that Paul has said that there is a spiritual body that will be raised (and not a physical body). They discount the reality of the decomposition of the flesh and they think that their physical bodies are going to be raised just as they were when they were embalmed.

The Christian Scriptures teach that at death the body goes back into the ground from whence it came and the spirit goes back to God from whence it came; but many African American Christians lean over the casket to kiss their loved ones' remains as if their loved ones are still with them in that body.

They completely ignore what the Word of God says about that "house" that the soul lived in. They think that "house" that they are looking at in the casket is the actual person and they kiss that house goodbye as if they are really kissing their loved ones goodbye.

Other African American Christians understand completely the writings of Paul in a different way. They see nothing wrong with cremation and they heartily endorse organ donation.

Some Black Christians understand terminal illness. They understand incurable cancer. They understand HIV as a biological issue, not a theological one, and they realize that once they get the virus their immune system has been compromised irreparably.

Those same Christians understand that once a person gets full-blown AIDS there is no cure and the "house" in which their soul resides is going into the ground. They look at Paul's writings in II Corinthians 5 and understand that they have another building "eternal in the Heavens" in which their soul will live.

The building in which their soul lives right now, however, is crumbling and will be destroyed. I have found the same to be true with many Christians who understand inoperable brain tumors, pancreatic cancer, liver cancer, and other terminal diseases in the same fashion.

Some Christians face death confidently because they know they have another building. Other Christians who love the Lord just as much go kicking and screaming. Because they have never experienced death they are afraid, and as a pastor I have had to reassure them of the fact that fear is natural. Fear is normal. Fear is nothing to be ashamed of, but fear is not the final answer.

Reminding Christians whose faith is strong and who embrace death confidently that God is with them even at their dying hour is an easy task. Reminding Christians who are, however, dying and afraid that the same God who has been with them in life is with them now in death is not that easy. It is what we are required to do as believers and as ministers of a God who has never made a promise that He has not kept.

Theological Perspectives on Death and Dying

I have had members ask me to explain to their families that death is not final. Death does not have the final word. Those members have been told that they have an incurable disease and/or a terminal disease, and they want to die with dignity. They want to enter hospice care so that they can die in peace.

Their family members, however, who go to the *same* church, who pray to the *same* God, who sing the *same* songs and who have heard the *same* Gospel refuse to hear what their loved one is saying. They have whipped guilt trips on their loved one by saying, "If your faith was strong, you wouldn't give up like this!"

The televangelists—the Benny Hinns, the Fred Prices, and the "Word of Faith" preachers—have had a tremendously negative impact on many African American Christians. I call their impact "negative" because it makes Christians feel as if their faith is defective if they get sick. It makes those same Christians think that something is wrong with them if they do not just "have the faith" in a God who has the power "to cure all of their diseases."

I have had members quoting, with no understanding whatsoever, Psalm 103 while dying of liver cancer. They believe that God will heal all of their disease as Psalm 103 says, and they take the words of that Psalm literally.

If God does not heal them, they reason, it means that their faith was not strong enough. Their family members undergird that kind of distorted teaching, and it makes ministry very difficult while trying to represent a God of love, a God of power, a God of hope and a God who gave His Son that we might have everlasting life.

In addition, many of the families with whom I have done ministry across the years are in different places when it comes to understanding hospice care, palliative care and end-of-life care, which can make the final stages of a person's earthly journey as pleasant and as joyful as it can

possibly be. Some families are open and receptive to what God does through the persons working in those professions.

The families that are in denial, however, do not want to talk about palliative care. Families who cling to false hope do not want to talk to hospice chaplains or hospice care people because they think that to say yes to hospice care is giving up of life, giving up hope and/or showing a lack of faith in God.

Once some church members are in hospice care, moreover, I have found them to be afraid of OxyContin. They say they do not want to become drug addicts so they deny themselves of the very medication that will ease the pain and suffering that they are experiencing.

In addition to my pastoral experience, my four years as a cardiopulmonary technician at the Naval Hospital in Bethesda exposed me to many Christians and Muslims who were dying. They knew what their sacred texts said, and some of them faced death triumphantly and joyfully. Others however were afraid. Others were angry. Others were in disbelief and still others were in denial.

What my combined experiences as a cardiopulmonary technician and as a pastor taught me was not to prejudge any situation, any illness, any family or any individual. More than not prejudging, however, my combined experiences taught me not to judge—at all.

Every person faces life's greatest mystery on his or her own terms and in his or her own way. There is no right way, and there is no "wrong way." There is an individual's way in which he or she must find for themselves. Those of us who do ministry with people of faith have to keep that in mind as we try to represent God, represent Christ, or represent Allah in that individual's life.

Theological Perspectives on Death and Dying

In addition, knowing the various stages of grief is very helpful when it comes to ministering to the dying and their families. Knowing those stages helps the pastoral counselor to understand better what stage it is that an individual is passing through as they withdraw from their loved ones, as they express anger—whether free-floating anger or anger with God—and as they express feelings of being lost in a world they do not understand.

Understanding how an individual can move in and out of the different stages of grief at different times as they are dying is also important. It helps the pastoral counselor (whether minister or imam) to be present with the dying believer in whatever stage they happen to be in on any given day.

It has been my experience to do ministry with persons of strong faith who have shown emotions that are at opposite ends of the "faith spectrum." Their faith is strong that Jesus is coming to get them just as He promised in John 14. Their faith that they have another building waiting for them (the mansion that Jesus promised) and their faith that they will have everlasting life is unwavering.

At the same time, however, when the physical pains of terminal illnesses such as cancer hit them, the words that come out of their mouth make them sound more like Jesus on the cross of Calvary than Stephen in the Book of Acts. I have heard strong saints asking God, "Why?"

I have heard them say, "But you promised me, Jesus!" They do not understand why the contradiction. Their lives have been lives full of contradiction as African Americans living in a culture of white supremacy. Then they get down to their dying moment, and they discover that instead of pat answers there are even *more* contradictions through which they must die just as there were contradictions through which they had to live.

Theological Perspectives on Death and Dying

Understanding that God is present even when God is silent is crucial for one who would seek to do ministry with those who are dying and their families. Getting a dying person and his or her family to understand that God is present even when they cannot feel God's presence becomes very important—especially if the wavering has carried the dying individual into a zone where they are now questioning God as Jesus questioned Him while hanging on the cross of Calvary.

Reassuring that individual that the answer to their questions and their fear is God's very presence then becomes one of the most important gifts that a minister or an imam can give to a dying individual in his or her family. Quoting verses of the Quran and verses of Scripture that remind the dying person and his or her grieving family that God is present and that God does care even as they are leaving this life become important acts of ministry that will never be forgotten.

Not praying "impossible prayers" or asking for God's miraculous intervention to stop the dying process are just as important in providing ministry as is the minister or imam's presence in the dying person's life and in the dying person's death room as they are leaving this life.

Staying there until the end as John stayed with Jesus and as those who loved Jesus stayed with Him is also an important task for those who would call themselves doing ministry. A person who is dying withdraws sometimes from their families and their loved ones. They pull off into themselves and go to a place that the living cannot reach.

The minister or the imam who stays right there by their side, however, showing them and their families that God's promise is true and that Allah's presence is constant will provide a "ministry moment" that will never be forgotten by the family members of those who watch their loved ones slip away.

Theological Perspectives on Death and Dying

Offering prayers of thanksgiving for the life and the labors of their loved ones and offering prayers of thanksgiving for the victory given through Jesus Christ put an exclamation point at the end of that person's life that will never be forgotten by those who gather around the remains of that loved one.

Reminding those who mourn of the words of faith found in the sacred texts becomes a finishing touch on the masterpiece of mercy that is needed in the life of those who are asking God to have mercy upon them as they are dying.

* * *

I hope that these reflections will empower those of you who attempt to do ministry or to provide palliative care, hospice care, and end-of-life care with, to, and for those who need you, God, or Allah the most as they end their physical lives. More importantly, I hope that these reflections will remind you of God's presence in your life as you seek to be a presence in the lives of others.

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2. *New English Bible.* New York, NY: Oxford Press; 1976.

3. Smith P. *Facing Death: The Deep Calling to the Deep.* Kearney, Neb: Morris Publishing Co; 1998:37–39.

4. Heard in conversation with Howard Thurman during a visit to his home in San Francisco, Calif, 1975.

5. Thurman H. *Meditations of the Heart.* Boston, Mass: Beacon Press; 1951:127.

6. The name "Allah" is the Arabic word meaning "The God." Both Muslims and Arabic speaking Christians address God as Allah. *The use of the masculine pronoun for Allah is only for linguistic convenience and not to ascribe a gender to Allah.*

7. "This day have I perfected your religion for you, and completed MY favor unto you, and have chosen for you as religion AL-ISLAM." The words of Allah, as found in Qur'an 5:3.

8. The Qur'an is the accumulated Revelations which Prophet Muhammad received from Allah through Angel Gabriel. The word Qur'an means recitation.

9. Many times in Qur'an when Allah is speaking, HE uses the first person plural: "WE," "US," and "OUR." In many other places, HE uses the usual "I," "ME,"

and "MY." Pronouns referring to the Creator are written in upper case letters.

10. Wadud A. *From QUR'AN and WOMAN*. Oxford University Press; 1999:45.

11. By calling it to witness, i.e., by speaking of the Day of Resurrection as if it had already occurred, Allah is conveying the certainty of its coming.

12. But those rewards will be outweighed "by their refusal to believe in resurrection and the life to come." Quoted from Asad, note 27, surah 11. *The Message of the Qur'an.* The Book Foundation; 2003:354.

13. Obligatory tax which is used for charity and know as "a loan to Allah." See reference 17.

14. Qur'an 19:61.

15. Salaat is one of the five pillars of Islam. The other four are declaration of faith (*shahaadah*), obligatory tax used for charity (*zakaah*), fasting during Ramadan, and pilgrimage to Mecca (at least once in a lifetime).

16. If we worship anything other than Allah (whether it is idols, stars, powers of nature, spirits or deified men, or self, or power, or wealth, science or art, talent or intellect) our worship is both foolish and futile. From Y. Ali, note 1822.

17. Isaiah 1:18.

18. The Holy Qur'an 3:64. The phrase, "people of the Book," refers to the people of the three Abrahamic faiths: Jews, Christians, and Muslims.

19. The Holy Qur'an 42:15. Cleary T, trans. Starlatch Press; 2004:239.

The attitude towards death, from the perspective of African American Christians, is theologically rooted in the Bible. In my own book, *Facing Death: The Deep Calling to the Deep,* I believe with Howard Thurman that death is not regarded as life's worse offering. I believe that if we live as though death is the worst thing that can happen to us, we lose the zest for living. I still believe in the relevancy of this, as African Americans weave a path through the corridors of death and dying.

Family and Psycho-Social Dimensions of Death and Dying for American Americans

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African Americans have been shaped by a unique cultural and historical experience in America. That uniqueness also is reflected in the way African Americans confront and cope with a universal reality—death. Death is an inevitable part of the life experience that all families must face. African Americans' social and psychological response to death is resultant from several factors, among which are the special oppression they experienced through slavery and subsequent racial discrimination as well as the imprint of their African legacy. Religious and spiritual influences, too, play a central role in shaping the African American family's response to the changes and challenges that death may bring. It has been through the reservoirs of strength and adaptation garnered from religious, spiritual and cultural life that the African Americans have successfully confronted and coped with the social and psychological challenges and changes that death presents.

Family and Psycho-Social Dimensions of Death and Dying for African Americans

INTRODUCTION

Regardless of our culture, all of us must eventually face at least two fundamental issues. First, we face the realization that life is finite—we will not go on, at least in our present form, forever. Second, the world has no built-in scheme that gives it meaning. It is, at the moment of birth, a meaningless world. We must give our existence meaning.[1(p40)] In addition, what defines death as an event may vary from culture to culture. Although death is universal, cultures vary in how participants in a culture conceptualize death—what will be done and how it will be done. Death is defined here as the irreversible cessation of life. From an Afrocentric perspective this article will address the psycho-social dimensions of death and dying in relation to the African American family. The term "family" in this discussion is inclusive of the extended family and church family.

DEATH AND DYING

Death is a subject of relevance to everyone. It is the one fact about the future that can be counted on for certain.[2(p441)] Indeed, death is a universal, natural, persistent, inescapable, unavoidable, and undeniable fact of life. Death's impact on human behavior does not take place in isolation; It takes place in a given social context. In other words, a person's behavior is a dynamic interaction between the person and the social context in which he or she lives. The social context for this article is the United States, with consideration given to a co-culture of this context—that of African Americans.

Freeman states that there are four types of death, and each type has implications both for the dying and for those left to grieve the loss.[3] The first is *social* death, which represents the symbolic death of the individual in the world he/she has known. For the person dying and for the survivors, socially and interpersonally, the world as it was known begins to shrink. A second type of death is *psychological* death. This refers to the death of aspects of the dying individual's personality. How dying persons move through the grieving process and deal with their losses may bring about changes in the person's personality. Changes may also take place as a result of the disease process and/or medications. Psychological death may precede biological and physiological death and may be one of the several death losses the bereaved suffer. A third type of death is *biological* death. With biological death, the organism as a human entity no longer exists. For instance, biological death may be evident when a person suffers a heart attack severe enough to damage the heart beyond repair, causing it to stop functioning. Although the person is biologically dead, advances in medical science allow organs to be kept alive and functioning by means of artificial life support. *Physiological* death takes place when there is a cessation of the operation or function of all the vital organs.[3 (p3ff)]

CHANGING CULTURAL CONTEXT OF DEATH AND DYING OVER TIME

Culture is the total behavior, beliefs, and values of a group of people. Or to define this term according to Brislin in its broadest sense, culture refers to the worldview, values, norms, and behavior patterns shared by a group of individuals.[4] Culture profoundly impacts behavior and the family. It basically shapes how persons make meaning out of illness, suffering, and dying.

When we fail to acknowledgement culture's power, we may find it challenging to care for, instruct, and learn from those with significantly different cultural experiences from our own.

Culture is vital at all stages of life, so it is just as critical at life's end. It provides meaning to events, objects, and people. In death, we witness the end state of the physical body. Yet,, what we believe about the meaning of death, how death should be faced and what we believe happens after physical death varies according to our culture and its associated religions.[5]

In our culture, dying, in the popular mind, is associated primarily with old age. However, medical advances and increased life expectancy have demonstrated that old age does not directly cause death. Nonetheless, it is increasingly the old who die, making death predictable as a corollary of the aging process. The leading causes of death of Americans 65 years of age and older are: 1) heart disease, 2) cancer, 3) cerebrovascular disease (stroke), 4) lung diseases, 5) pneumonia and influenza, and 6) diabetes. The association of dying of old age has caused death to be regarded as the completion of the life cycle in old age.[6] The process of dying and the prospect of death are universal reminders of our mortality and vulnerability to physical decline.

In discussing culture, we must remember that the African worldview is the means by which individuals interpret and act upon reality. The African worldview that African Americans have handed down to their descendants, though greatly modified, still forms to this day the underpinning of African American society.[7 (p6)]

ATTITUDES TOWARD DEATH

As indicated earlier, death is an inescapable, universal, and natural fact of life. Yet, in our society, the fear of death brings an ongoing anxiety into daily living. We fear the inability to predict what the future might bring and the process of dying, particularly of a painful death, more than death itself. Studies show that older adults tend to select quality of life in their end-of-life decision-making, while younger adults tend to choose quantity of life. Older African Americans, however, are less likely to employ advanced directives and more likely to want life-saving technology.[6] cites some factors from Robert J. Lifton's work on the survivors of Hiroshima that clarify why there are greater challenges within our modern cultural contexts in dealing with death. He offers the following four points as reasons why the process of dying has become more removed and distant within American culture:

1. *Exclusion of the aged and dying.* The movement to segregate the aged and dying away from the general population into nursing or retirement homes causes their societal exclusion. The exclusion factor creates fear of abandonment in the aged and dying, making death even more ominous.

2. *Advances in medical technology.* Medical technology has hastened individuals' sense of control over their lives and death. These advances have also helped increased life expectancy. Death becomes, then, less frequent as terminal illnesses become chronic instead. Advances in medical technology have served to compromise our ability to view death as a natural part of human life.

3. *Movement toward the nuclear family.* The movement toward smaller and nuclear families leaves more individuals without extended family to reduce their vulnerability and limited support following the death of a loved one. Modern American society offers limited opportunities to experience the act of dying with aged relatives as a natural part of the life cycle.

Howard Thurman noted that we are all participants in the modern conspiracy to reduce immediate contact with death to zero except under the most extraordinary circumstances. To many of us, death is gruesome and aesthetically distasteful as a primary contact for our children and ourselves.[8 (p18)] In pre-industrial societies, the majority of deaths took place in the home with the entire community often involved in rituals surrounding the death. By the 1930s, the hospital had become the main setting for death. Today, approximately 75 percent to 80 percent of all deaths occur in institutions (hospitals and nursing homes), where aggressive treatment is common and with only a few friends and relatives present.

Even though a number of persons express the preference to die at home and without pain, the older a person is when he/she dies, the more likely that death will take place in a nursing home setting. This leaves death removed from most individuals' daily lives. Though our sense of personal loss may be great, our primary relationship with death is frequently impersonal and detached. We shrink from direct personal contact with death.[8 (pp18,19)]

SOCIAL DIMENSIONS OF DEATH AND DYING

As indicated earlier, social death represents the symbolic death of the person in the world they have known. The world the individual has known begins to contract socially and interpersonally. Freeman states "the dying may experience social death as a result of anticipatory grief by friends and or family. Separation of the dying individual from others might result in magnification and preoccupation with the malady and grieving for the losses to come."[3] [(p3)]

The AIDS epidemic provides numerous examples of social death. A young adult male dying with AIDS in an African American family may experience social death as a consequence of anticipatory grief by friends and family. Although dying may be viewed primarily as a solitary event, the act of dying has wide implications within a dying individual's circle of relationships. The isolation produced by social death can be quite painful for the young adult male dying with AIDS due to the societal stigma that has often hastened the sense of alienation for AIDS patients. While families of AIDS patients may have genuine concern about the health and welfare of these dying young adults, family members' experiences with death and dying under more "normal" conditions may be quite limited. The limited exposure to death and dying hastens social death for AIDS patients. Social death restricts the oxygen of relationships by removing the dying individual from the comfort zone of familiar and positive social contacts. The young adult male with AIDS, then, often loses the very conditions that might enhance his health and well-being at a critical point.

Social death also has implications for the bereaved survivor. The caregiver for the young adult male with AIDS may be a spouse, mother, friend, or partner. As his condition worsens, increased demands are placed upon the caregiver.

Freeman observes that "the losses associated with social death may begin with decreased contact with friends or organizations as they (caregivers) care for the dying person."[3 (p3)] Social death reminds us that few occurrences in life take place in isolation. The physical act of dying produces social implications that impact the dying individual's circle of relationships and, sometimes, beyond.

PSYCHOLOGICAL DIMENSIONS OF DEATH AND DYING

Psychological death is the death of aspects of the dying person's personality. This type of death may occur due to a traumatic brain injury or stroke, a consequence of medication or a disease process, or how the dying individual handles his/her grieving process. "Psychological death leaves a person permanently psychologically altered or in a vegetative state. The person, though alive, is not the person the bereaved have known and loved.[3 (p4)] Norman Cousins may have had psychological death in mind when he noted that "death is not the greatest loss in life. The greatest loss is what dies inside us while we live."[9]

AFRICAN AMERICAN APPROACH TO DEATH AND DYING

To give this discussion a historical perspective, Nancy Boyd-Franklin suggests four main areas where the experience of African Americans in this country has been unique from other ethnic groups[10 (pp7–11)]: 1) African legacy, 2) the history of slavery, 3) racism and discrimination, and 4) the victim system.

Consideration of African Americans' African legacy incorporates such concepts as family kinship and collective unity, the role of religion, and the African philosophy of life.

In order to fully appreciate how African Americans understand death and dying, some principles of African philosophy must be considered. Dr. John S. Mbiti points out that "many words are used all over Africa concerning the act of dying. People refer to dying as returning home, going away, being called away, becoming God's property, and so on. All these words show the belief that death is not a complete destruction of the individual. Life goes on beyond the grave. Therefore, people combine their sorrow over the death of someone with the belief that that is not the end and that the departed continue to live in the hereafter."[11 (p119)]

Dr. Mbiti also notes that individuals are quite sensitive to how things are done when a death occurs in the family. As death indicates the physical separation of the individual from other humans, death signals a dramatic change, so the funeral rites and ceremonies serve to draw attention to this permanent separation. African customs generally require that meticulous care be given to funeral rites to avoid undue offense to the departed.[11(p119)] Psychologically, funerals in the African American co-culture have come to represent a posthumous attempt to achieve dignity and esteem denied and limited in a larger culture in which people often are treated with minimal respect. Thus, African American funerals represent attempts to affirm the self and achieve some measure of positive self-identity, if only posthumously.[12 (p37)]

Sullivan adds additional principles of African philosophy that provide relevant background as to how African American families understand and experience death and dying. Sullivan offers these related principles of African philosophy[13]:

Family and Psycho-Social Dimensions of Death and Dying

1. The principle of dual unity serves as a core concept. With dual unity, polarities are opposites. As examples, day and night, dead and living are viewed as having reciprocal and unifying functions, rather than dichotomous ones. Dual unity means that although death represents the soul leaving the body, death is still inherently related to life, as opposed to representing the opposite of life. Death is a different dimension of the same phenomenon.

2. The second principle is related to the first. This concept asserts that *spirit and matter cannot be separated*. In traditional African philosophy the material world is seen as a manifestation of the spiritual world. Thus, life and death—the spiritual and material—are not dichotomous.

3. *The family* is also key to understanding African culture. Africans generally include a larger circle of individuals in their family membership compared with families of European origin. Traditional African societies include children, parents, grandparents, uncles, aunts, brothers, sisters, and the offspring of these relatives. Departed relatives remain in the family circle as the living dead. The living dead remain "alive" in the memories of their surviving families.[14 (pp138, 139), 13(p161)]

According to African philosophy, an individual becomes conscious of his/her own being and responsibilities towards self and others through connections to other persons. In this sense, what happens to the individual happens to the entire group, and whatever happens to the whole group happens to the individual. Mbiti points out that the individual can only say, "I am, because we are; and since we are, therefore I am."[14(pp.138–141)]

For Sullivan the three stated principles weave throughout the African American experience of death and dying with spirituality as a core facet to both life and death.[13] A core belief from African cultures that still influences and directs African Americans' approach to death is that death is a continuation of life.[15]

DIVERSITY AMONG AFRICAN AMERICANS

Although cultural beliefs from Africa do influence and direct African Americans' approach to death and dying, other factors also affect African Americans' end-of-life behaviors and rituals. The cultural diversity of society in the United States impacts African Americans. In the United States, there are increasing contacts with new immigrants, and co-cultures continue to grow in number.

There is also a great deal of cultural diversity within and between African American communities due to social economic status, educational background, and religious belief systems. Boyd-Franklin asserts that "given the heterogeneity of cultural variables that are present in Black families and communities, it ought to be patently clear that there is no such entity as *the* Black family. The great diversity of values, characteristics and lifestyles that arises from such elements as geographic origins, level of acculturation, socioeconomic status, education, religious background and age reveals such categorization to be inaccurate. Black people in this country are not a monolithic group."[10(p6)] African Americans are a quite diverse group of people.[16]

The diversity of African Americans within the United States means that contemporary approaches to death and dying among African Americans should examine the influences of America's cultural mélange.

R.K. Barrett points out that contemporary African American funeral rites and practices reflect a fusion of traditional African and Western psychocultural influences. West African influences, in particular, permeate the attitudes, beliefs and values that African Americans reflect in their rituals for the dead. It should be noted that the stronger the African American's sense of cultural identity (positive sense of African American consciousness), the greater the tendency to adopt traditional attitudes, beliefs, and practices toward death and funeral rituals.[17 (pp80, 81)]

Not only religious and spiritual beliefs, but the dying person's personality and temperament, the primary caregiver's personality and temperament, the family's resources, as well as other factors, will influence the manner in which African Americans approach death and dying.[15(pp148,149)]

In summary, then, African Americans bring their unique perspective to issues of death and dying. African Americans' uniqueness has been shaped by their African legacy, their ancestors' slave experiences, their individual encounters with racism and discrimination, and what Boyd-Franklin calls the victim system.[10] Their perspectives are a reflection and synthesis of the African and American aspects of their character development.

THE AFRICAN AMERICAN FAMILY

"Call it a clan, call it a network, call it a tribe, call it a family. Whatever you call it, whoever you are, you need one. You need one because you are human. You didn't come from nowhere."[18(p123)] In this, Howard emphasizes the importance of the family unit in our existence as humans. The African American family is an intimate connection of individuals of African descent that are linked in a variety of ways.

These links may be through blood, marriage, formal adoption, informal adoption, or by appropriation. However, the commonality of individuals in the African American family, regardless of the type of ties to a family unit, is the history of common residence in America with lineage traced to Africa and slavery.[19 (p28)]

The primacy African Americans give to the extended family versus the nuclear family is a signal feature carried over from traditional African family patterns. Beyond the nuclear family of parents and children, the extended family embraces grandparents, aunts, uncles, cousins, nieces, nephews, and even more distant relatives, as well as some friends and neighbors.[14,19]

In addition to espousing the importance of the extended family to the African American family, some researchers of the African American family broaden the definition of the African American family to include the concept of church family. The inclusion of the concept of the church family recognizes that for a number of African American families, a church that serves persons of African American ancestry functions essentially as another extended family. Boyd-Franklin points out that after the family and extended family, the church becomes the most common source of assistance for African American people.[10]

In summary, extended family, friends, church members, neighbors, and fictive kin constitute complementary sources of informal support for African Americans.[20 (p439)] This extended network of family, extended family and church family can be considered part of the African American family's "African legacy."[10] As Mbiti emphasized, the African American's ideas of marriage and family life are firmly rooted in African thinking.[14]

Researchers on the African American family have provided the consistent reminder that although African Americans are a diverse people, they share a common cultural heritage linked historically to African culture.

STRENGTHS OF AFRICAN AMERICAN FAMILIES

In his classic research on African American families,[21] Robert Hill emphasized that the large percentage of women and adolescents who, through the years have had to work outside the home long before careers for women became more acceptable in society, necessitated the extraordinary versatility in family roles in African American families.[10] Role versatility, as well as extraordinary perseverance and persistence during difficult times, are strengths of African American families that succeed in spite of challenging circumstances.

Langston Hughes' poem, *Mother to Son,* captures the voice of an African American mother's struggles as she challenges her son to face life's difficulties with perseverance, persistence, and hard work—three strengths of African American families that succeed in spite of economic and social obstacles. The African American mother in Hughes' well-known poem knew all too well that her life and her family's lives had been an uneven journey, but that life's obstacles necessitated diligence and a steady, attentive "hand to the plow of life." As a fitting tribute to African American mothers and the importance of their roles in African American families, Hughes' poem echoes the strength and dignity of African American women in providing resilience to African American families and their communities:

Well, son, I'll tell you:

Life for me ain't been no crystal stair.

It's had tacks in it,

And splinters,

And boards torn up,

And places with no carpet on the floor -

Bare.

But all the time

I'se been a-climbin' on,

And reachin' landin's,

And turnin' corners,

And sometimes goin' in the dark

Where there ain't been no light.

So boy, don't you turn back.

Don't you set down on the steps

'Cause you finds it's kinder hard.

Don't you fall now---

For I'se still goin', honey,

I'se still climbin'

And life for me ain't been no crystal stair.[22]

This poetic tribute is a fitting recognition that African American mothers have been significant strengths to African American families and their communities. Billingsley[19] also notes that evaluating the strengths of African American families should take into account each particular family's "religion, education, money or property, jobs, family ties, and other community-centered activities…[as] the chief ingredients of strong family life."[23(p100)]

Religion and spirituality are sources of strengths for African American families. The influences of the African continent are evident through the important role of the congregational minister, belief in the supernatural, audience participation during worship, hand-clapping, the rhythms of songs, spirituals and funeral rites.[23(pp112,113)] Historically, African Americans' belief systems have played an important role in shaping attitudes, values and beliefs. Sharon Hines Smith's study[24(p17)] of end-of-life issues also indicated that religious beliefs are important resources during critical periods, such as end-of-life decisions for African American families.

Finally, Hill observed that five factors contributed to the stability, survival, and progress of African American families.[21] These factors are: 1) adaptability of family roles, 2) strong kinship bonds, 3) strong work orientation, 4) strong religious orientation, and 5) strong achievement orientation. Boyd-Franklin cautions that Hill's five strength factors should be viewed as inherent within African American culture.[10(p16)]

THE FLUIDITY OF ROLES

In the family life cycle, there are differences and similarities between African American families and other majority and minority families. As has been stated earlier, a unique factor of African American family life is fluidity of roles.

Even though the institution of slavery attempted to destroy kinship ties, slaves adapted to this attack by broadening their kinship groups to include non-blood relationships. The pattern of inclusion of pseudo-family members and other relatives in varied family roles continues to this day among many African American families.[25]

When death claims a family member and creates a void in the family system, fluidity of roles allows the African American family to reach equilibrium by enabling the family to function, at least in the interim period of early bereavement. Hill pointed out that when the roles in an African American family are flexible, the family appears more likely to cope effectively with changes in circumstances.[21]

AFRICAN AMERICAN SPIRITUALITY AND RELIGION

Historically, religion and spirituality have played significant roles in the lives and experiences of African Americans. Though the majority of African Americans may adhere to a Christian belief system, this does not indicate that all persons of African American ancestry regard death from a religious perspective. This latter point, again, points to the diversity within African American communities.

Recognizing that religion has a quality of universality, that is, all peoples mark the spiritual in some aspects, Mbiti has stated that for persons of color, "it is as if African peoples do not know how to live without religion."[11(p194)] Researchers who study African American families have repeatedly pointed to the central role of religion in these families.

These families' spiritual beliefs provide important coping and survival resources, especially during critical end-of-life periods, and religion and spiritual beliefs offer adaptive and supportive roles in enhancing the mental health and well-being of African American adults.[10,19,26,20,24]

The unique and colorful character of the African American church derives from the African American interpretation of the Western church. As with traditional West African funeral rites, the African American church serves as the wellspring that feeds the African American community its African-inspired religious rituals.[17(p81)]

When death occurs in the African American community, the African American church generally serves as the central gathering place for bereaved families. It is not uncommon to find the African American church providing comfort to families that have experienced loss, though the deceased may have been "unchurched" or lacked regular church attendance or membership. If the deceased person's family members are churchgoers, especially the parents, grandparents, or siblings, enough of a tie may remain for the African American church to extend its collective fellowship and support to the bereaved family. As Sullivan points out, African American churches are major caretakers by serving as both a community and spiritual family.[13]

The importance of religion and the spirit in African American families permeates daily conversations in homes. In child rearing, a parent might be heard to say, "Just 'cause folks do bad to you don't mean God wants you to do bad to them!"[21]

What is seen of death is the finality of the physical body. But what is believed about the meaning of death, how it should be faced, and what happens after physical death varies by culture and beliefs.

Though Christianity was seen by slaveholders primarily as a vehicle to control slave behavior and to keep slaves submissive, slaves adapted and reinterpreted Christianity and its music to aid in coping with the vicissitudes of their distressing conditions. The reinterpretation brought forth numerous Negro spirituals.[27]

African Americans' inherent spirituality throughout life and death can be evidenced in the music and lyrics of slave songs. The late theologian, Howard Thurman, who was also a philosopher, mystic and spiritual mentor, provided his insights about African American spirituality as expressed through music in his work, *The Negro Spiritual Speaks of Life and Death*.

Thurman "examines the Negro spirituals as a source of rich testimony concerning life and death, of a people for whom the cup of suffering overflowed in haunting overtones of majesty, beauty and power.[8(p12)]

Thurman suggests that Negro spirituals spring from three sources: the world of nature, the African American experience, and the Bible.[8] The reality of death, as expressed through song, occurs within a particularized context. The slave was regarded as chattel property, a tool, a commodity, but not a person. Death always loomed as an ever-present threat. Thurman poignantly writes that "he (the slave) was faced constantly with the imminent threat of death, of which the terrible overseer was the symbol. If a slave were killed, it was a property loss, a matter of bookkeeping."[8(p14)] The situational context of the slave robbed death of any dignity, with the attitude toward death profoundly influenced by life's experiences.

African Americans as slaves cause these questions to be raised: What were the slaves' attitudes toward death? How important was death in their thinking? Was death viewed as the worst of all possible things that can happen to a person? Thurman offers his response to the African American slaves' attitudes and response to death in this familiar spiritual refrain:

> Oh, Freedom! Oh, Freedom!
> Oh, Freedom, I love thee!
> And before I'll be a slave,
> I'll be buried in my grave,
> And go home to my Lord and be free.[8]

Of course there are additional spirituals that also reflect the message from the slave song above. The point here is that death was not viewed as the worst thing that can happen to an individual. As the slave song suggests, death would be preferred over slavery because, at least, through death, the captive slave would know freedom. For African Americans, there are some things in life that are worse than death.[8(p15)] The historical refrains provided by some African American spirituals inform us that death and dying have loomed heavily in the African American consciousness since the earliest days of Africans on North American shores. The slave songs provide an important window into African American spirituality and beliefs about death and dying.

THE FAMILY TASKS OF GRIEF

A family's cultural roots can deeply impact family members because each family member is part of a family system. Families are systems because of the linkage of the various family members.[16(p35)] The African American family unit is a dynamic and interactional system. Though death and dying are natural and universal, these events often occur as solitary events within the family unit. Death brings a profound impact on the family unit that can result in disequilibrium and adversity that reduce the family's proper functioning. Researchers on the family have repeatedly indicated that the death of a family member is one of the most powerful emotional upheavals that families ever face.[3] How each family responds to death in the family will, of course, vary. The range can be from non-adaptation to extraordinary resilience.

Freeman summarizes the task model of family grief that closely follows that of Worden and Moos. Families' grief work is an extension of individual grief work. The five tasks of family grief are as follows[3]:

Family and Psycho-Social Dimensions of Death and Dying

1. The first task of family grief is the need for family members to *openly acknowledge the death* at both cognitive and emotional levels. This requires communication and conversation about the deceased, as well as family members, sharing feelings about the death and surrounding events.

2. The second task of family grief is to *allow mourning to occur.* The pain of mourning necessitates that family members cooperate in aiding other family members in the grieving process.

3. The third task of family grief, according to Freeman, is the process of *adjusting to an environment in which the deceased is missing.* The deceased remains in the family's consciousness, though the family must now adapt to life without the deceased.

4. The fourth task of family grief is the *realignment of intrafamily roles.* Responsibilities have to be redistributed and roles readjusted with the family unit. Role adjustment faces each family member at some level.

5. The fifth task of family grief is the *realignment of extrafamily roles.* Family members now face the task for establishing new types of relationships with old acquaintances and making new acquaintances without the deceased family member's presence or input.[3(p145)]

CONCLUSION

As said previously, death is a universal, natural, and inescapable fact of life. Regardless of our culture, every individual must face the fact that life is finite: We will not go on in our earthly form forever. The loss of a family member can be a devastating emotional experience for a family to face. This discussion addressed the psycho-social dimensions of death and dying in relation to the African American family. Consideration in this discussion was given to the changing cultural context of death and dying over time, the psycho-social dimensions of death and dying and the African American perspective on death and dying. Death in the African American community can be viewed as a celebration of life and as a statement of the fact that life's journey has been completed.

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Key Topics on End-of-Life Care for African Americans

Family and Psycho-Social Dimensions of Death and Dying for African Americans

Commentary by Andrea King Collier

Now I lay me down to sleep, I pray the Lord my soul to keep. If I should die before I wake, I pray the Lord my soul to take.

This was one of the first prayers I was taught as a child. Is it any wonder that I am not an insomniac to this day? Or for that matter I think it explains why so many of us wrestle with the mere concept of death and dying. But funny, as I have gotten decades older and seen various people I love and respect die in a host of ways, it is now a prayer of comfort. I like the idea of going to sleep one day, like any other day, and not waking up. No long disabling illness, no chemo. No pre-planning, no big decisions to be made on my behalf. No one needs be a hero. No pain or palliative care required—just a good long sleep.

But the reality is that as many people as there are on this earth, there are as many ways and stories about the way we die. As I heard Richard Payne, MD, say in a speech once, "The single biggest indicator of mortality is being born." He's right. We all leave here. And no matter how we try to prolong it, the result is the inevitable, so it is best to live well and to love well.

Growing up, I never had much experience with death. My grandmother and caregiver was a volunteer at the church. Her job was to read the obituaries at the funeral services. She would take me with her, and I would sit quietly in the back of the church, listening and critiquing her delivery and watching the families.

For a long time I didn't really understand that there was finality to this death stuff. And when I grew old enough to understand, I was still quite removed from it. My personal reality is that I was in my late twenties before death personally touched me in any way. Or maybe the truth is I ran from death's touch until absolutely necessary.

I am one of the people that sociologists call the sandwich generation. I was sandwiched between the care of two small children and the care of a terminally ill parent. The sandwich was a thin one, as I had no skills or training to deal with this. The ongoing sense of inadequacy in wondering if I was just failing everyone or doing a passable job for anyone seemed to overwhelm me.

Once we got further and further into my mother's advancing disease, my own prayer was that she wouldn't ask me to help her end her suffering. And every day that advanced without that request was a good one. I look back on that time and wonder where was the handbook that everyone should get to explain the end of life. I wonder who thought that I was smart enough or capable enough to be the sole caregiver for someone at the end of their life. It is still one of my life's mysteries.

As is suggested by Dancy and Davis, it has always appeared to me that black folk are miraculous with the rituals of homegoing. We know how to send a person off. We also know how to stretch the time between death and the funeral out for days, often weeks, until our relatives can come from across country to say goodbye (which has always puzzled and dismayed me). Yet we are not so good at dealing with illness and the transition itself. We struggle with cancer, Alzheimer's, and stroke. Every day we are learning more about and getting better at utilizing the community and familial support that is required to care for those with life-threatening illness.

Even though it is getting better every day, it is hard work. These kinds of illnesses either bring about the best in families or it picks away at the frayed, fragile edges in them.

When my mother called me to tell me that the doctors thought she had some kind of cancer, I knew in my bones, in my DNA, that what we were embarking on was the end of her life and the end my life as her daughter. When I think about that time, even now a decade later, I picture her and me on a rollercoaster and immediately think that we should get off. But of course, you cannot. You must ride until the rollercoaster stops.

We were fortunate, blessed, or both. My mother had great health insurance. She had me as her relentless health care advocate who never took no for an answer. She had the best doctors. And I had the luxury at the time of being her caregiver. I understand that our situation was not typical for many families of color. Nor did it affect the ultimate outcome of my mother's diagnosis of ovarian cancer.

That was 13 years ago, and in some ways not much has changed. There are more resources, but it feels like so few people of color know about them. And those who do know about them have a nagging distrust of "the system" that provide those resources. When we were offered hospice care, I didn't know anybody who had ever utilized it. There was no one to give me an idea of what to expect. It was a grand, uncomfortable experiment.

But for our family hospice was absolutely a godsend. It made her transition easier for us. Hospice helped me understand death and dying better. And it gave me the support that helped to make up for the missing handbook. But I also know that there are many people of color who are not using hospice.

Commentary on Family and Psycho-Social Dimensions of Death and Dying

In the black community, we are opening ourselves up to the supports available at the end of life. We are learning more about living wills and advance directives. We are watching to see how this country speaks to those who cannot speak for themselves. We are learning from what experts as Drs. Dancy and Davis have to say about culture and death. We are benefiting from what experts are teaching our community about caring for those who are transitioning.

In the two years since my book, *Still With Me… A Daughter's Journey of Love and Loss,* was published, I have gotten a chance to talk to hundreds of individuals and families about living and dying well. I have heard the most touching stories of caregivers and families navigating care. I have seen the look of helplessness when there is just so little help available. I have seen what a heart breaking looks like and have felt my own heart breaking because I couldn't do more.

I used to say that I am the angel of death, because I have spent so much time talking about my family's death experience and how we reached out for hospice support. A friend who sought out support in her community because of our experience always corrects me. She says I am one of the angels of *good* death. This is something I do not take lightly. For me it means that I can reach out and inform and share with others who are desperate or nearly at the end of their ropes in the need for quality pain and palliative care.

If there is any take-away message in the work of Dancy and Davis, or in my own book, I suggest that it is that we must make a priority of understanding the processes of dying as well as we work to understand the processes of living.

As Black Americans, we must continue to grow to support each other as individuals, families, and communities in the full-circle business of living and dying with dignity.

Andrea King Collier is a freelance journalist. Her book, *Still With Me… A Daughter's Journey of Love and Loss*, was published in 2003. Her new book, *Because We Love You…Black Men's Health for Black Women*, is coming soon from Warner Books.

Key Topics on End-of-Life Care for African Americans

An intellectual discourse derived from The Last Miles of the Way Home 2004 National Conference to Improve End-of-Life Care for African Americans

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Working Together: Organizing the Community to Effect Change in End-of-Life Care for African Americans

Community: *A group of people living in the same locality and/or having common interests.*

Introduction

It is the common interests of communities, whether it be education, economics, safety, or the health and well-being of a community that drives organizations, associations or faith-based groups to support and speak out for those who may not be able to speak for themselves or who often times are simply not heard—underrepresented and underserved communities, including the African American community.

These organizations and associations may offer opportunities for health care providers to develop and nurture networking relationships and partnerships to work together for the betterment of underserved communities. As with any social movement that has longevity and reach within communities of color, it has been vital to build strong bridges and partnerships with grassroots organizations, community-based coalitions and of course, the religious community. The movement to provide access to quality end-of-life care to the unserved and underserved African American communities around this country is no exception.

In this segment, we will address the lessons learned to date about working with the African American community to increase awareness of and access to end-of-life care. The authors of this manuscript will highlight three innovative and successful community-based initiatives designed to promote better care for African Americans. They are: VITAS Innovative Hospice Care, a national organization that provides direct hospice services; Trinity United Church of Christ, a large church congregation in Chicago that ultimately partnered with VITAS to begin the work of providing direct hospice care services in their congregation and community; and the Center for Practical Bioethics (formerly Midwest Bioethics Center) which is working with members of local hospital ethics committees to address end-of-life care of the communities it serves.

This paper will illustrate the type of creative partnerships and dialogues that are happening in communities of color around the important health issue of end-of-life care. While the work of these three organizations is helping to set the standards for outreach within communities of color, they by no means stand alone. With significant support from local and national foundations, more than 300 community coalitions around the country have worked to:

- Improve pain management
- Promote advance care planning
- Support palliative care education for physicians, nurses, and social workers
- Advocate for better psycho-social and spiritual support
- Increase utilization of hospice care

The Challenges of Progress

Even with the numbers of community groups working to make inroads serving people of color, hospice remains underutilized across all segments of the population. Like almost every aspect of health care access and utilization, statistics indicate a disproportionate underutilization of hospice care among minority populations. All of the authors represented here have learned that there are nuances in working in the community around issues of health and death. Before a health care provider can work in outreach to external groups in various communities, there are internal matters to consider. Because there may be complexities in caring for culturally diverse patients, it is important when caring for communities of color that there is an understanding of their cultural values and spiritual beliefs. To gain knowledge about these communities of color, there has to be a genuine interest in these communities and a willingness to engage them. There has to be an assurance that providers and organizations are truly committed to outreach efforts. For example, they may want to consider implementing the following.

- Developing a formal diversity infrastructure within the organization that will focus on these communities
- Incorporating diversity training for all staff, including management, which will focus on the beliefs and cultural traditions of the communities identified for service Once this is established, then it may be time to look at reaching out to the community. Consider:
- Researching and identifying the community groups in the area
- Establishing a trusting and mutually respectfully relationship
- Hosting focus groups regarding end-of-life care issues with local churches and various community leaders
- Identifying local leaders with good standing that will advocate for communities of color
- Developing an action plan as to how and to whom to implement outreach efforts
- Developing and building relationships with community agencies that may have particular focuses on end-of-life care
- Building ongoing and sustainable relationships within communities once they have been established.

One essential way to reach the community at large is through the support and assistance of the black church and other religious institutions or faith-based organizations. African Americans have a spiritual heritage that is deeply rooted in community worship. Given that the key to working with the churches is through their leadership, it is important to bring clergy and various community leaders together. It is imperative to work with them to form collaborative partnerships so that communities can be educated and thereby

empowered to better understand and make informed decisions regarding available end-of-life care services. There is tremendous potential and opportunity to work within communities to increase awareness and utilization of hospice services and, most importantly, to help affect positive change in end-of-life care for African Americans.

AN EXEMPLARY TRIAD OF COMMUNITY ACTION
VITAS Innovative Hospice Care: A Company's Commitment

Sharon R. Latson
Senior Director of Access Initiatives

Diane Deese
Director of Community Affairs

Headquartered in Miami, Florida, VITAS (pronounced VEE-tahs) operates 40 hospice programs in 15 states (Arizona, California, Connecticut, Delaware, Florida, Georgia, Illinois, Kansas, Missouri, New Jersey, Ohio, Pennsylvania, Texas, Virginia, and Wisconsin) and the District of Columbia. VITAS is the largest hospice organization in the United States . The company is fully committed to improving care for the seriously ill and dying throughout the nation. VITAS has always been aware, however, that there is a huge divide between the percentages of white and non-white patients receiving hospice care. In 2004, more than 1 million people utilized hospice services, yet only 8.1 percent were African American.

Looking at those statistics and knowing what percentage of families could and should receive hospice services; VITAS set an ambitious goal to increase the overall utilization of hospice services by African Americans. To accomplish this goal, VITAS made a firm commitment to reach out to underserved populations through its community-focused Access Initiative. Since 2001, VITAS has worked tirelessly with key grassroots organizations across the country, as well as with various high-profile national organizations, to develop programs and establish relationships that will help to educate individuals, families and larger networks of people of color to the benefits and services that hospice care provides to patients and their families.

The VITAS Team

None of this happens without the commitment of individuals. VITAS first set out to build a team that would work with and within the communities it hopes to serve. The VITAS Senior Director of Access Initiatives manages and directs the VITAS Access Initiative and is responsible for the development and growth of national initiatives to expand awareness of and access to VITAS services in underserved and unserved communities of color. The Senior Director also serves as a national spokesperson for VITAS on access initiatives in both national media relations and public policy activities. A vital role of the Senior Director of Access Initiatives is to work with the VITAS communications/marketing department to develop and create culturally relevant educational presentations and resource materials that complement and reflect the diverse

communities VITAS services. Finally, the Senior Director partners with all 40 of the local VITAS programs to lead strategic development of local access initiatives.

The VITAS Director of Community Affairs works closely with all VITAS programs to provide guidance, support, and continuing development and expansion of the Access Initiative. Additionally, the Director of Community Affairs works to establish and build on-going partnerships with professional organizations, community agencies, the political community and healthcare organizations within communities across the country.

In summary, the goal of the Director of Community Affairs is to provide guidance in promoting the hospice philosophy as well as to increase access to and utilization of hospice services within the African American community and other underserved communities

To access and serve diverse communities, VITAS, in several key states (Illinois, Ohio, California, Florida, and Georgia) where a large African American population and community is established, instituted the position of community liaison. The liaison's role and responsibility is to reach out to local churches, community organizations, political and community leaders, and community-based physicians to offer educational workshops and informational seminars. These liaisons are vested in the communities they serve, and they establish and maintain ongoing, trusted relationships within these communities.

By working together with community partners, VITAS has been able to reach out to communities in broad and sustainable ways. Some of the noteworthy successes:

- Established relationships with African American radio talk shows, which led to the airing of informational spots and discussions on end-of-life care issues with show hosts and listening audiences
- Placed feature stories and periodic informational pieces in African American publications throughout the regions VITAS serves
- Conducted memorial services at hospitals, nursing homes, in-patient hospice facilities, community centers, and churches for family members to pay homage to their deceased loved ones
- Provided ongoing hospice educational seminars and workshops at hospitals, medical centers, and nursing homes for the professional staff
- Established key and long term relationships with renowned national African American organizations and institutions
- Conducted end-of-life care seminars and workshops at national African American health care conferences
- Worked in partnership with churches to provide an array of supportive services to the ministries, which has helped bring awareness to the congregation members on matters related to end-of-life care

In addition, as a very important part of its work to increase awareness and to build partnerships, VITAS appointed a Director of Hospice Education for Rainbow/PUSH to help inspire and educate the leadership of the One Thousand Churches Connected

initiative regarding the benefits of hospice care. Additionally, the Director of Hospice Education for Rainbow/PUSH is responsible for introducing the VITAS Hospice Ministry Program, which provides education on end-of-life care to the clergy and church leadership as a whole, and also provides various spiritual care volunteer initiatives to black church congregations across the country.

The Director of Hospice Education spearheaded several community-focused programs under the Access Initiative and in collaboration with the Duke Institute on Care at the End of Life. Under the hospice education directorship, the Black Church Community Assessment Tool was created to evaluate the knowledge and attitudes of church leaders and other key community leaders in the African American community with respect to end-of-life needs; the survey assesses the knowledge and attitudes of members of the African American community. The information is used to inform policy agenda and to redefine educational programs and curricula for health care professionals providing care and services to African American patients and their families.

The Samuel Dewitt Proctor annual conference brings together African American clergy leaders and lay persons to strengthen networks within the African American faith community and the capacity of its leaders to address the diverse needs of the community it serves. The conference initiates and develops collaborative partnerships that maximize the skills, assets, and models of engagement of the black church and its outreach into the communities locally, nationally and globally. The conference is also a conduit to identify and disseminate critical information between its partner churches and lay leaders locally, nationally and globally.

In 2005 the leadership of the Samuel Dewitt Proctor conference, the Access leadership team from VITAS, Duke Institute on Care at the End of Life, and the Duke Divinity Office of Black Church Studies developed the Proctor Covenant Statement on End-of-Life Care. The covenant serves as an initial pledge signed by faith leaders from across the country to support initiatives to improve end-of-life care in the black church. The Proctor Covenant Statement will be finalized at a future time as a theological statement on quality care at the end of life and will become the defining statement, standard and guide for African American clergy. One of the more significant and successful VITAS partnerships developed under the Access Initiative to date is with the Trinity United Church of Christ, which is presented in the next segment.

AMANI - The Story of One Faith-Based Initiative Rooted in the Community
Rosalyn Priester
Director, Amani Care Program

Trinity United Church of Christ (Trinity UCC) is a mega-church serving African Americans on the Southside of Chicago, Ill. Under the dynamic, 34-year-long leadership of the Rev. Dr. Jeremiah A. Wright, Jr., Senior Pastor, Trinity UCC has moved in the progressive mission of being an African-centered church which is "Unashamedly Black and Unapologetically Christian." Trinity UCC is "In the heart of the community . ever seeking to win the community's heart."

More than 20 years ago, one very important part of Pastor Wright's vision for Trinity UCC was that the church would provide hospice care. Earlier attempts to establish hospice care had been made but had not come to fruition. In 1998, Pastor Wright called on a group of three members to again investigate hospice for the church. That group became a task force whose efforts resulted in a three-stage growth plan for hospice ministry at Trinity UCC. The task force members were Ms. Freddye Smith, Deacon Francis Priester, and Deacon Rosalyn Priester.

Stage One

Our hospice task force wondered aloud why our pastor had chosen us, since none of us were in the health care field nor knew what hospice was. We came to understand much later in the process that he had chosen us because he had seen us providing what amounted to hospice care for one of our beloved deacons before his death. Between us, we provided spiritual care; attention to and advocacy for his physical needs; connectedness to his church community, even when he became too ill to attend services; attention to his financial and legal concerns; and ministry of presence and the love, care and affection of an extended family in the absence of his own. We were to learn that these were the fundamental tenets of hospice: that no one dies in pain and that no one dies alone. We also knew that within the African American community, extended family care and nurturing has always been at the heart of who we are as a people—communal. Connecting this way of "being" to the concept of hospice and end-of-life care, however, had not been done.

As the task force became educated about the end-of-life journey and the specifics of the concept of hospice over the course of the next two years, we sought to better understand our connectedness to our African heritage around death and dying. We enlisted the assistance of the Rev. Dr. Iva E. Carruthers, a brilliant sociologist and member of Trinity UCC. Dr. Carruthers researched and consulted with a fellow theology student from Kenya who introduced us to the African concept of "Amani," a Ki-Swahili word which means "healing, wholeness and peace (at oneness—atonement) with God." What was most important to our understanding was that healing, wholeness, and peace is not just for the passage of death into eternal life, but the healing, wholeness, and peace is for the *fullness* of our *life's journey* , of which death is only one chapter. Therefore, the meaning of Amani spans both life and death. It was this understanding that led Trinity UCC to rename our health corporation Amani~Trinity United Community Health Corporation, and our task force became Amani Trinity United Church of Christ Hospice Task Force.

After the Amani Trinity UCC Hospice Task Force had explored which direction to take for hospice care to become a reality at Trinity UCC, Pastor Wright determined that we would not succeed in moving forward without a staff person dedicated to this effort. In mid-2001, at Pastor Wright's request, I joined the Trinity UCC staff, first as Coordinator of Hospice Care and later as Director of the Amani Care Program.

Culminating this first formative stage was the commencement of hospice ministry work under the title of the Amani Care Program. In 2002, we began a two-fold approach to

educate the community about end-of-life care and hospice while forming and training a cadre of hospice care volunteers.

To accomplish this, we held educational forums at Trinity UCC and at other churches entitled: *End-of-Life - A Sacred Journey* . Members of our congregation as well as the community were invited. At these forums we featured guest presenters from various hospices in and around Chicago to answer the questions "what is hospice," "how and when do I use it," and "who pays for hospice care?" Most importantly, each of our forums began with a pastor setting the tone of our African history and heritage, our African-centeredness as a people of God, and our Christian beliefs about death and dying.

Since we know that we are all living in a death-denying society, it was important to "go there" in the beginning so as to open a safe space to talk about death and dying. As African Americans in this Christian body, we believe that there is eternal life after death. In our African American community of faith, a death is celebrated as a home going. That still does not, however, mean it is easy to talk about preparing for the death of a loved one or for one's own death. These forums became a safe place for and a way of opening the conversation about death and dying, a sacred journey.

Concurrent to the hosting of educational forums, the Amani Care Program began training volunteers for hospice care. Since we were not a hospice, we went to the experts, the "full" Medicare hospices, to be trained. Thus, we benefited from the same presentation of the hospice concept as that received by those being trained to be actual hospice workers. Our plan was to expose our trainees to the full concept of hospice so that when the day came that Trinity UCC had its own program, we would not have missed a step. To date, we have trained more than 90 hospice care volunteers.

Stage Two

We wanted to become licensed to provide hospice care for our church and community. So we next set out to accomplish this goal. Throughout 2002-2004 we continued hosting our educational forums on end-of-life care and training volunteers. We also added educational forums on advance directives. Early on, Amani Care Program became familiar with the "Five Wishes Ò," a living will publication of Aging with Dignity, and we ordered customized copies for our forum attendees and anyone we could interest in advance directives. We continue to provide these copies upon request from within our church and the larger community.

From our earliest days as a task force, we had heard about volunteer hospices as a category different from full (Medicare) hospices. Our first entrees into pursuing this type of hospice were, at best, discouraging. We were told that volunteer hospices were a thing of the past—that they had once existed, and were, in fact, the primary model of hospice care when it originated in this country in the 1970s but now were illegal. Then, by an act of grace, we saw an article in a hospice publication referencing volunteer hospices in various parts of the United States, and one of them—Fox Valley Hospice—was geographically close in Geneva, Ill. This hospice and their executive director and staff

became our mentor. While it is true that there are now very few volunteer hospices still in existence around the country, Fox Valley Hospice stands out with a 25-year-plus history of providing hospice care. They have more than 800 volunteers and are still growing. With their mentorship and support, we worked diligently with the Illinois Department of Public Health division that licenses all hospices. We were successful in forming our advisory board, identifying and hiring the necessary staff (registered nurse, licensed clinical social worker, and spiritual/bereavement care credentialed counselor), and meeting all other requirements. We were proudly licensed as a volunteer hospice in July 2004 with the name Amani Volunteer Hospice Care Program. For the next eighteen months, we were embattled in a fight to keep the category of "volunteer hospice" as part of the Illinois regulations. In the end, our coalition of six volunteer hospices of Illinois, led by Fox Valley Hospice, was successful in our legislative efforts. However, the page was turning for the Amani Volunteer Hospice Care Program as we were moving on to stage three.

Stage Three

Our pastor had always desired that Trinity UCC be able to provide full hospice service. We explored that possibility and in the first quarter of 2006, we entered into a new initiative agreement with VITAS Innovative Hospice Care Ò . This joint initiative is the Trinity Amani Hospice Care Team with VITAS. We offer members of the African American community and other communities of Greater Chicago end-of-life care that is enriched with spiritual healing, wholeness, peace and dignity. These enhanced services are available through the partnership of VITAS' provision of individualized, patient-centered, quality hospice care, combined with Trinity/Amani's ability to enrich that care through a greater emphasis on cultural and spiritual integrity, sensitivity, and compassion. This is a brand new model of a faith-based entity partnering with a for-profit hospice to provide full hospice care. As of this writing, while the "Trinity Amani Hospice Care Team with VITAS" team is not yet fully formed, we are moving steadily in that direction. We presently have two Trinity UCC positions providing volunteer, bereavement and education/advocacy services, and the remainder of the hospice circle of care (registered nurses, certified nurse assistants, social worker, chaplain, physician, and team manager) is supplied from an existing team of VITAS' Chicago Central Office. The goal of this initiative is for Trinity UCC to be able to provide the full range of hospice services to members of our congregation and the surrounding community, and for the VITAS Chicago Central Office to learn firsthand from an African American church how to better approach, work within, help to educate and service the African American community in the area of end-of-life care.

Trinity UCC is working faithfully in this relationship to see how we can together serve our congregants and community who either know little about hospice and/or who presently underutilize hospice services. To accomplish this will achieve our ultimate goal by putting in place the basic tenets of hospice—that no one die in pain and that no one die alone.

The Center for Practical BIOETHICS: Learning From Different Cultures
Myra Christopher
President and Chief Executive Office
Center for Practical Bioethics

Greater Kansas City is a metropolitan area of diverse racial and ethnic groups, and although "cultural diversity" has been one of the Center for Practical Bioethics (formerly Midwest Bioethics Center) organizational goals for many years, it was within the context of a three-year initiative, *Pathways to Improved End-of-Life Care: A Community's Approach* , in the late 1990s, that we began working with diverse segments of our community in a strategic way. In this paper, we will describe three projects that specifically targeted African American populations among other diverse co-communities in the Kansas City metropolitan area in an effort to improve end-of-life care for *all* Kansas Citians:

- "Compassion Sabbath"—an initiative to provide support and training for clergy to improve spiritual care of the dying.
- "Trusting Our Differences"—an *active listening* project where members of our hospital ethics committee consortium learned about end-of-life experiences from African American, Latino, Vietnamese, and poor whites.
- "EPEC" (Education for Physicians on End-of-Life Care)—a training program for health care professionals caring for people of color at the end of life.

We will also share with readers what we, as a predominantly white staff, learned from our interactions with African Americans in these three projects that not only strengthened our *Pathways* initiative but also the overall work of the Center.

Compassion Sabbath

Various studies inform us that, at the end of life, having one's spiritual needs addressed is as important as having our physical needs addressed through competent clinical care. Therefore, one of our key *Pathways* strategies was to engage clergy leaders in efforts to improve care of the seriously ill and dying. Knowing the role of the church in our African American community, we believed this was a critical strategy to address the needs of African Americans this important population in our community. However, as a secular, freestanding bioethics center, we were not certain how willing clergy would be to engage with us in this endeavor.

Our first step, therefore, was to invite two prominent clergy, one white and one African American, to provide leadership and credibility to this project. Both were affiliated with the Center in volunteer leadership roles. After several initial meetings, each invited a handful of close colleagues to join a steering committee to develop strategies to accomplish our goal. Eventually, using a peer-to-peer approach, a very strong diverse steering committee of more than three dozen prominent clergy developed *Compassion Sabbath* .

Data was collected from clergy in one-on-one interviews, focus groups and pencil and paper surveys. We engaged an outside research firm and were able to gather statistically valid information. Interestingly, across faith traditions, race, and educational variations, clergy reported that ministry to the seriously ill and dying as among their "high" to "highest" callings (nearly three-fourths). Although they indicated that they felt they were better at ministering to the seriously ill and dying than were others in their congregations clergy did not feel that they did a very good job. The reasons given for this self-proclaimed inadequacy closely mirrored those given by physicians in various studies, i.e., their seminary curriculum did not address these issues. Moreover, they were unaware of resources available to them to shore up or improve their skills.

Based on the experience of steering committee members and the data we collected, a comprehensive multi-faith initiative was developed that the group named *Compassion Sabbath* .

Components of this program included:

- A day-long leadership conference for clergy only.
- A resource manual that provided sample sermons, homilies, prayers, poems, songs, and religious text from a variety of religious traditions.
- A workshop for clergy and lay leaders on end-of-life care, providing information about advance care planning, pain management, conflict resolution within health systems, etc.
- A prayer breakfast.

Each clergy who attended the leadership conference was asked to make a personal commitment, including participation in *Compassion Sabbath* weekend. On a highly publicized designated weekend, clergy across our community who had participated in *Compassion Sabbath* were asked to speak from the pulpit about their duties and obligations and those of their congregation to the seriously ill and dying from their specific theological perspective.

Careful attention was given each step of the way to involve highly regarded local and national African American clergy in leadership roles. For example, we hosted Dr. Gardner C. Taylor who *Ebony* named one of America's greatest preachers and who one of our co-chairs referred to as the "dean of American preachers" to lead the prayer breakfast, and Dr. Wallace S. Hartsfield, a highly revered Kansas City clergyman and former chairman of the Congress of Black Churches, to be the final speaker at the *Compassion Sabbath* leadership conference. The outcomes were well worth the effort.

On *Compassion Sabbath* weekend, more than 80,000 people in Kansas City heard their clergy talk about the importance of spiritual care of the dying. As one clergy said, "That's as many people as saw the Chiefs play that weekend at Arrowhead Stadium." In Kansas City, that's a lot of people.

More importantly, we saw faith communities, including a significant number of African American congregations, take action and develop 9/ongoing efforts. The impact of this program was significant, for example:

- The percentage of faith leaders in Kansas City who thought their congregation ministered "very effectively" to the seriously ill and dying increased by 33%.
- The number of congregations who had programs or other means of teaching members how to minister to the seriously ill and dying increased by 48%.
- The median number of members involved in ministry to the seriously ill and dying in Kansas City congregations increased by 60%—from five to eight in one year.
- The percentage of faith leaders who rated the overall quality of their congregation's ministry to the seriously ill and dying as better than the previous year increased by 50%.

Not long thereafter, we took on another project specifically attempting to understand the experiences and perceived needs of African Americans, Latinos, Vietnamese and poor whites at the end of life. We called this project *Trusting Our Differences* .

Trusting Our Differences

The Kansas City Area Hospital Ethics Committee Consortium celebrated its twentieth anniversary in January 2006. We believe it to be the oldest continuously functioning ethics committee network of its kind in the United States . It has also been a powerful driver of many successful Center projects, and members of the consortium were instrumental in helping our staff to develop the three-year initiative, *Pathways to Improve End-of-Life Care: A Community's Approach.* Members of the consortium are chairs of ethics committees or their designees and reflect the composition of ethics committees across the United States, i.e., they are, generally speaking, not people of color. However, early in the planning of *Pathways* , we realized the necessity of engaging and learning from all members of our community.

Our immediate goal was to "seek to understand differences in knowledge, ideas, and attitudes among persons of diverse cultural backgrounds to improve communication regarding health care decision making at the end of life." Our long-range goal was to elevate the importance of learning about diverse cultures in programs for improving end-of-life care by building and enhancing relationships with leaders from diverse communities in the Kansas City area. We also wanted to develop and test the effectiveness of a cultural diversity intervention targeted at ethics committee members.

We wanted to provide a forum in which to "confront the dilemma of difference," and our hope was to "transcend the difficulties difference implies." We wanted to persuade clinical leaders "to listen actively and ask questions that would help them learn about cultural diversity."

To better employ the active listening model, we hosted a series of panel presentations over several months with participants from diverse ethnic, racial, and socioeconomic backgrounds. Each panelist was asked to tell one or more personal or professional stories about end-of-life care and to dialogue with consortium members about their experience. The idea was to provide a forum, literally a "safe place," where local ethics committee leaders could engage in open, honest dialogue about issues that made them feel inept, uncomfortable, or awkward when treating patients with different cultural perspectives.

Flaws in the plan were apparent almost immediately, and significant modification was necessary. Consortium members were extremely uncomfortable because it "felt like our visitors were being objectified." The conversations did not distinguish cultural relativism from ethical relativism, and, although some wanted to have an intellectual/analytical discussion about these theories, others thought the discussion appeared confrontational and even hostile toward our guest panelists.

Imagine the Center's distress: some participants believed that the process was damaging the personal or professional relationships they already had with panelists and organizations they represented. In hindsight, providing a clearer rationale for participation could have mitigated these tensions but no such plan had been established. For nearly six months, Consortium members and Center staff struggled with the plan. As the divisiveness of the project increased among Consortium members, we realized that another strategy was needed. Nevertheless, the experience actually strengthened the Center's resolve to address cultural diversity in the context of the project.

"If at first you don't succeed, try again." This adage, often taught to small children, became the mantra of staff working on cultural diversity; and, in 1999, we began the project anew, retaining the "active listening/learning" model, but with a smaller task force (members of the Consortium, rather than the entire group), and with clarified goals and objectives.

The methodology was also refined to take us outside the confines of the Center to places where diverse groups live and work. Volunteers from local social service organizations to were asked to develop a set of diverse end-of-life narratives and tools to facilitate active listening and ethical discourse. The narratives would then be used to develop a set of recommendations for how ethics committees can address cultural issues as a way to improve the care of seriously ill and dying people.

In the process, we hoped to learn how individuals from various cultures define "dying well" and about institutional or systems barriers that they think makes dying well either difficult or impossible to achieve. We hoped to learn how they derive their knowledge and the sources they turn to for advice and support. We also wanted to learn about variations in orientations to the self and family and willingness to talk about dying and death.

Assembling the task force took tenacity and salesmanship. Membership recruitment was much more difficult for this task force than for many others that the Center has

established over the years. Many potential members said the project was too time consuming or that they did not have the "expertise" necessary to participate. We also came to realize that many long-time Center volunteers were not comfortable in the role we were asking them to assume.

These difficulties notwithstanding, we eventually assembled a task force of eleven highly-motivated volunteers, including three physicians, four nurses, a chaplain, and two social workers. Ultimately, nine people participated in the interviews as "active listeners." Ten Center staff members including, among others, a physician/ethicist who had practiced medicine in the county, an attorney, and a social worker also participated in the program.

A nurse with formal training in ethics, agreed to manage the project. Her interpersonal and communication skills were outstanding, and she was excellent at building relationships and doing effective community outreach. Perhaps most important, she was a good listener and was willing to take on a difficult project. We knew that we needed a project manager who would be morally courageous and willing to work with many people to accomplish the goal. From the outset, we knew that we were on "terra incognito." We were, in effect, following maps like those that guided the ancient mariners to lands unknown. As the early sailors were warned, so also were we: "You are now entering uncharted areas; 'here be dragons.'"

An advisory committee was assembled that included both local and national experts in cultural diversity. The advisory committee met once as a whole, but members of the committee consulted with staff and several contributed to publications about the project. Advisory committee members were culturally diverse, multidisciplinary, highly skilled, and professional. Its members included a physician; professors of nursing, sociology, and ethics; a Holocaust educator; and a civic leader.

A medical anthropologist was also enlisted to provide technical assistance and advice to the task force through calls, emails, and written recommendations. The task force met frequently to receive reports from the small groups and to share their experiences. We also read and discussed the literature related to cultural diversity and supported one another emotionally.

The initial assignment for taskforce members and Center staff was to identify four diverse communities on which to focus and to find partnering agencies in those communities. By size, African American and Latino communities were at the forefront of our project; our other two choices were less obvious. After much discussion, we agreed that demographically the Vietnamese, Hmong, and Lau communities were significant, and we agreed on the Hmong. We also decided, after much debate, to focus on Caucasians of low social and economic status as the fourth group. We wanted to interview people who might be especially vulnerable for reasons of their culture, ethnicity, race, or class.

We divided into four work groups, each group focusing on one community. The initial responsibility of each group was to secure a partnering agency. We began by calling on social service agencies that served individuals in the designated communities. At a snail's pace, agreements were made, participants were identified, and a series of panels or interviews were scheduled.

For the purpose of this paper, we will focus on our experience in the African American community. It took some time to identify an African American organizational partner for this project. Even though the Center has a good relationship with Kansas City 's Black Healthcare Coalition and has often relied on our relationship with them for similar projects, our funding placed geographic limitations on us that precluded the Coalition as a partner. Fortunately, an African American nurse on the task force made contact with a long-time nursing colleague who assisted us in forming a relationship with a large African American church. Based on her relationships, six members of the church agreed to share their stories.

Their pastor more than 25 years told about his wife, who died eight years earlier, after being diagnosed with ovarian cancer. Her cancer had spread to the lining of her stomach, aorta, and liver. From the time of her diagnosis until her death was only four weeks.

She had surgery and was in and out of the hospital frequently during that time. At her last admission, she was told that her cancer "was in her bones" and that she had only a few days to live because her "platelets were being eaten up."

While in the dying trajectory, medical students were brought in "to drill in there to get this bone marrow." The pastor said they had been through a lot and his wife was in pain. A medical student who attempted the procedure failed and was instructed to by the attending physician to "try again." The pastor said, "I told him to get the best person here. Hit it. Get it. And not be experimenting. I think sometimes there's a lot of experimentation going on. I don't want to sound . like I am dealing with racism. I don't know that they wouldn't have done the same thing, but we're not welfare recipients, we're paying. And I want the best medical, and I'm willing to pay for it, and I don't want anybody experimenting at that time.. So, that was a problem for me."

Another participant, a 40-year-old African American intensive care nurse told about the unexpected death of her husband who was a paramedic. Because of a debilitating cardiac condition, he had been moved to a "desk job," and while attending a professional conference out of town, he was found dead in his hotel room.

When she and her family went to identify his body, the morgue was closed. They were told they could not see his body that they would have to wait until they got back home to see him. She said she "tried to push it way back into the back of her mind, but the only thing they had to identify who we were was that all of us were black. So, I kept thinking that they wouldn't do this to a white person.. Maybe if I had walked in with my nursing license?"

Along the way, it became clear that we needed to modify our agenda. We were asking about cultural or anthropological ideas regarding death and dying, but those we interviewed were more interested in describing what we began to refer to as their collisions with the health care entities. Everyone we talked to had a story about the difficulties he or she had experienced with health care providers. .

What started out to be a research project exploring cultural preferences at end of life evolved into a collection of personal stories that revealed the ineptness of providers and organizations to communicate with, and to care for, individuals who were different from them. It also revealed distrust and skepticism among African Americans about the motivation of health care professionals. Some even questioned our the Center's intent. Unfortunately, we heard similar stories from the other designated populations. The task force members felt guilt and angst.

We had not anticipated this turn of events. Therefore, the struggle to provide a framework for these findings presented a new and more challenging task. The project director asked the program team and the task force to meet together to probe the issue face-to-face. In that meeting, each person was asked to recommend how we could best use the stories we had heard. Their suggestions varied from passionate comments like, "I just want to tell the truth" to compiling a list of recommendations for all ethics committees regarding vulnerable and diverse patients. Motivation to do something significant was high, but no clear plan had yet emerged.

As staff read and reread the reams of narratives, we recognized that we were becoming more aware of our own biases and shortcomings related to cultural, ethnic, and class issues. The act of listening had been a transformative experience for the task force members and ripples of that transformation were still being felt. Out of the ferment, a solution began to take shape. Why, we asked, couldn't we develop a tool that would help others have a similar experience?

We chose a dozen excerpts from the narratives that seemed to have a potential for prompting self-reflection. The task force and staff reflected on these excerpts and took them to the larger group, the Kansas City Area Hospital Ethics Committee Consortium. Finally, eight excerpts were chosen as the basis for a cultural diversity tool.

The task force and program staff met again. Working in small groups, they asked introspective questions based on their reading of the narratives. These questions were subsequently revised and edited many times by Center staff with input from the participating agencies and expert advice from the advisory council. Additionally, program staff completed a list of recommendations for ethics committee members whose responsibilities included helping organizations do ethics in culturally diverse situations. These recommendations and the cultural diversity tool appeared as special supplements in an issue of *Bioethics Forum* .

As a finale to this project, the Bioethics Center held a summit in February 2002 to discuss cultural diversity — the discoveries that were made and their implications for our

community. More than 200 thought leaders participated. Without question those who attended comprised the most diverse group of people the Center had ever convened.

The Center and its community partners remain committed to searching for new ways to hear and see who we are, collectively and individually, and how we can ease the ethical tensions in the health care experiences of persons who are especially vulnerable because of cultural, ethnic, or class distinctions.

Based on the stories we heard in the *Trusting Our Difference* project, we knew that health care professionals needed additional education and training to provide good care at the end-of-life and that there was a need to specifically address needs of African Americans and other people of color.

EPEC (Education for Physicians on End-of-Life Care)

The American Medical Association had developed and distributed an outstanding end-of-life care curriculum commonly referred to as EPEC (Education for Physicians on End-of-Life Care) and hosted several train-the-trainer faculty development programs. The Center took applications of local physicians and served to facilitate and coordinate EPEC trainings in Kansas City with a goal of presenting EPEC to 10% of all physicians in the metropolitan area. We achieved this goal without difficulty. However, when we took a look at who had attended these sessions, African American physicians were underrepresented.

To remedy this problem, we went to the Black Health care Coalition and asked them to partner with us to do an EPEC training specifically targeting African American health care professionals. We agreed together to identify and financially support a highly regarded African American physician and nurse to become EPEC trainers.

We also agreed that the Coalition would be responsible for recruiting African American clinicians to attend and that the Center would pay the Coalition to do recruitment. Together we agreed that we would invite Dr. Richard Payne, a nationally recognized palliative care physician then at Sloan Kettering in New York and now Director of the Institute on Care at the End of Life at Duke University's School of Divinity, to serve as the keynote speaker.

[Ultimately, Dr. Payne served as principal investigator for a Robert Wood Johnson grant, to develop an addition to EPEC called APPEAL (A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End)].

Once again, by making this commitment and investment, the Center for Practical Bioethics learned a great deal and strengthened our resolve to enrich our understanding of care of the seriously ill and dying by working with African Americans and other diverse populations.

What We Learned

- Nothing is as important in relationship building as is face to face communication. Letters of invitation are necessary but not sufficient. Finding intermediaries who are willing to "broker" relationships can be very helpful
- Commit to honest communication with all parties even when it feels risky. Learn to actively listen and to apologize when mistakes are made. Be willing to be vulnerable. The views and perceptions of others may be different than your own and sometimes are hard to hear. Don't attempt to refute or explain away the experiences of others that are in conflict with your own.
- Make a commitment at the beginning of a new relationship between individuals or organizations to engage in reciprocal relationships that you hope will lead to genuine engagement.
- Identify and involve leaders from communities with whom you wish to work in planning the project. Good intentions can be easily misunderstood. Don't develop a project and then try to "sell" it to others. Together, develop and agree upon clearly stated goals, strategies, and rules for participation. Be prepared to compromise and to include in the agenda a broader scope of concerns than your own.
- Even if you are a secular organization, recognize the importance of clergy in the African American community. Respect and appreciate the significance for many who are "trying to understand God's will."
- The majority white population in our country tends to value and primarily rely upon written communication. Understand the importance of an oral tradition. Learn to actively listen and to value story telling and narrative.
- Be tenacious. Making a commitment means sticking to it even when situations are complicated and relationships may be strained. Remember the power of saying, "I'm sorry" and "thank you."
- Don't go away when the project is over. Build on the relationships that have been established. Don't imagine that your organization should always be in the lead.

Although national health policy and Medicare and Medicaid impact care that people across this country receive, health care is fundamentally a local enterprise. Providers such as physicians, nurses, pharmacists, and hospitals are licensed by state boards. Psycho-social/spiritual care is provided by families and faith communities. And the institutional policies of the local hospital, nursing home, and hospice have a direct impact on care people receive. Very few Americans ever travel more than 150 miles in their lifetime to receive care.

End-of-life care is community centered. The authors believe that death and dying happen in a social context and that our communities and the partnerships we form in those communities can significantly increase and improve care of at the end of life for African Americans.

Key Topics on End-of-Life Care for African Americans

The Case Study

"African Americans have been caring for their loved ones at home since the beginning of time. It was never called HOME CARE. They have cared for their dying relatives equally as long. It was never called HOSPICE. Relatives come home from various parts of the country to relieve the caregivers, and it was never called RESPITE CARE. They come to give relief to mama, papa, sisters, brothers, aunts, uncles, cousins, grandma and grandpa. They talk with each other, share experience[s] and give advice and counsel. It is never called NETWORKING. Last, but not least, they serve as volunteers in their own communities, in their own churches, and on their own streets. They wear no uniforms, record no hours and receive no awards. Nor do they expect to be rewarded. It is family caring for family, neighbors caring for neighbors and communities caring for each other."

—Bernice Catherine Harper, MSW, MSH, PhD

The Last Miles of the Way Home, a National Conference to Improve End-of-Life Care for African Americans, was held in February 2004 in Atlanta, Ga. The powerful climax of the conference was the Town Hall Meeting moderated by renowned journalist Mr. George Strait. Mr. Strait designed a role-playing scenario in which a group of distinguished national experts and conference participants engaged in theatrical dialogue about an African American family facing end-of-life care decision making. The Town Hall Meeting, **"Bringing the Message Back Home: Taking Action, Making Changes,"** examined how one African American family moved quality end-of-life care from concept to reality.

Moderator:

- **George A. Strait Jr.**
  Assistant Vice Chancellor, Public Affairs, University of California, Berkeley, CA

Panelists/Performers:

- **Beny Primm, MD**
  Director, Addiction Research & Treatment Corporation

- **Gwendolyn London, DMin**
  President, London & Associates

- **Glenda Hodges, PhD, JD, MDiv**
  Director, Program in Spirituality and Medicine, Howard University College of Medicine

- **Richard Payne, MD**
  Director, Duke Institute on Care at the End of Life

- **LaVera Crawley, MD**
  Medical Ethics Researcher and Lecturer, Stanford University

- **Aranthan Jones**
  Former Senior Health Advisor
  Congresswoman Donna M. Christian-Christiansen, MD
  US Virgin Islands

- **Darryl Crompton, JD, MPH**
  Vice President, Research and Program Development
  MasiMax Resources Inc.

The Road Home: A Father and Daughter's Journey

Mr. Beny Primm is a successful 75-year-old African American business owner and widower with one child, daughter Gwendolyn, who is a registered nurse. Mr. Primm lives alone in the home he shared with his wife of 52 years; she passed away several years ago. He is a very independent, spiritually rooted man who has been an active member of his community for more than 40 years.

Mr. Primm is a well known and highly regarded individual in his community and his home church. Mr. Primm has developed and maintains a strong relationship with his former classmate and attorney, Darryl Crompton, and his long-time pastor, Rev. Glenda Hodges. Mr. Primm regularly seeks their legal counsel and spiritual guidance.

Mr. Primm has a loving relationship with his daughter; however there are strained periods in their interactions on a daily basis. Recently he is feeling vulnerable about his loss of control over his life and concerned about his overall quality of life. Gwen is feeling the stress of having to support and deal with issues related to her father's care, while raising her three teenage daughters. Gwen's husband runs the family business started by her father.

Mr. Primm is forgetful and has experienced some lost of function over the past few years. After his third car accident in a year's time, his daughter confiscated his car keys. Since his last car accident, Mr. Primm has moved in with his daughter and her family.

Mr. Primm has developed an intermittent palsy on his left cheek, and he is aphasic at times. He is on blood pressure medication but does not like how the medication makes him feel. Mr. Primm also suffers from diabetes and has recently had his left leg amputated.

Over the course of the last six months, Mr. Primm has been diagnosed with a rare blood disorder; his health is declining rapidly. Dr. Payne, the family physician of more than 20 years, has informed Mr. Primm and his daughter that the disease can only be treated with an expensive bone marrow transplant.

Although Dr. Payne and his colleague, Dr. Crawley, passionately advocate on Mr. Primm's behalf for the transplant, Mr. Aranthan Jones, director with the Center for Medicare/Medicaid Services has emphatically denied the request for the transplant. Dr. Payne has informed Mr. Primm and his daughter that based on the progression of his illness and Medicare's decision, he should consider other options of care, such as hospice.

While Dr. Payne would like to refer Mr. Primm to hospice immediately, Mr. Primm and Gwen are still very reluctant to give up the fight. At this stage, the family meets with the principals in Mr. Primm's life (his pastor, doctor, and attorney) to discuss his options for care. Gwen is concerned about the quality of her father's remaining time. As a nurse Gwen is very familiar with the under treatment of pain and the reports that pharmacies in predominately Black and Hispanic communities are not stocking the proper pain medications. As Mr. Primm's illness advances, Gwen would like his cultural preferences acknowledged and respected. Because of the conflict that has developed between the two of them, Gwen would also like to be reassured that his psycho-social concerns are met.

In previous conversation with Rev. Hodges and Dr. Payne, Mr. Primm revealed that his primary concerns are that he will be in severe pain, weak and addicted to pain medications as his condition progresses. He also states that it is important that he not become a burden to this daughter. He expresses that hospice care means giving up and that his quality of care will decrease once he submits to hospice. Mr. Primm is also worried about his life-long business and he wants to make sure that everything "is in order" for his son-in-law to fully take over the business once he relinquishes control of the company.

Gwen strongly expresses her frustration and anger to Rev. Hodges and Dr. Payne that she was not brought into the conversations about her father's health earlier on given that she is his primary caregiver. Dr. Payne and Rev. Hodges acknowledge Gwen's frustration, and they reassure her that the lines of communications will be open to her regarding her father's continuous medical and spiritual care.

Rev. Hodges informs Gwen and Mr. Primm that hospice care will allow them to have the quality time they are both seeking and not overburden Gwen with his daily medical and personal care. Gwen states in no uncertain terms to Rev. Hodges and Dr. Payne that in considering hospice care for her father it does not mean that she giving up her role as his primary caregiver. Rev. Hodges informs Mr. Primm that hospice is comfort care and that accessing the services does not mean giving up; she assures him that his unquestionable faith and spiritual beliefs will guide him through his journey.

Because the hospice program is run by their church, Rev. Hodges informs Mr. Primm and Gwen that his home church is an extension of his family; members of the church and the community will be at his side throughout his need for care. Rev. Hodges states that the church fully recognizes the cultural norms and perspectives of the community they service; it is vowed by Rev. Hodges that should Mr. Primm and his daughter elect to utilize hospice services, his cultural needs and preferences will be honored and respected. In addition, Rev. Hodges tells Gwen that hospice will also address her father's psycho-social and spiritual needs. Rev Hodges comforts Mr. Primm with song and prayer during their meeting together.

Mr. Primm's attorney, Mr. Crompton, suggests that Mr. Primm give his daughter power of attorney over his legal and financial affairs and reviews the advance directive document with Gwen and Mr. Primm. He also discusses the legal matters Mr. Primm will need to attend to in the very near future concerning his company. Mr. Primm is comfortable with his attorney's advice and he agrees that all legal matters relating to his medical care and financial business should be taken care of immediately with his daughter and son-in-law by his side.

Mr. Primm and his daughter reviewed their options for care together, affirming and reaffirming the full conversations. At the end of the meeting, confident that they have exhausted all options for curative measures and that their questions and concerns were fully acknowledged and addressed, they requested that Dr. Payne refer them to hospice care services.

* * *

The two-hour session provided a stimulating and insightful view into how an African American family addresses the end-of-life care issue for a family member. Mr. Primm and his daughter Gwen wanted their concerns to be heard and questions responded to before making any final decisions about beginning hospice care. In the end, Mr. Primm and his daughter took the action and made the change to ensure that Mr. Primm's final journey home was one of comfort, dignity, and respect and that his cultural preferences, spiritual needs, and psycho-social needs would be met.

During the theatrical scenario, the panelists/performers explored various topics such as:

- Understanding the cultural needs and preferences of diverse populations seeking end-of-life care

- Acknowledging the traditions of care for African Americans from its historical and cultural perspectives

- The importance of listening to the patient and family member(s); addressing their concerns and fully answering their questions

- The role of the church in the spiritual care of the patient and their family members

- The fear that the patient will be in severe pain and that pharmacies in predominately African American neighborhoods will not stock proper pain medications

- Addressing the misconceptions about hospice care

Questions for Discussion

1. Why do you think it was important to have a meeting with Mr. Primm and his daughter? How likely is this scenario to be played our in a real life situation**?**

2. How were the principals involved in assisting Mr. Primm and his daughter with making decisions regarding his care? What were their individual roles and why was each of them important to this meeting**?**

3. What were some of the major issues that needed to be addressed?

4. There is an underutilization of hospice care with African Americans. Can you identify some of the reasons Mr. Primm and his daughter were initially reluctant to consider hospice as a viable option for his care?

5. Do you think this situation would have been different if this were not an African American family? If so, how do you think it would have been different?

Key Topics on End-of-Life Care for African Americans

Ibrahim Abdul-Malik, EdD
Shaykh
Center for Empowerment and Personal Growth, New York, NY

Ibrahim Abdul-Malik, is director of the Center for Empowerment and Personal Growth. Dr. Abdul-Malik is also a certified master practitioner of both Neuro-Linguistic Programming and Ericksonian Therapeutic Hypnosis and a member of the World Health Community of NLP Practitioners.

After earning his doctorate at Harvard University in 1971, Dr. Abdul-Malik continued his work in education with the New York City school system. He served as science adviser for UNESCO in the Republic of Maldives, S.E. Asia, where he organized the first junior college in that country and became its first president. He also served as adjunct professor at The City College and Baruch College, parts of the University System of New York City. For 10 years, Dr. Abdul-Malik taught school-aged actors on Broadway and in television, particularly "The Cosby Show."

Dr. Abdul-Malik has just completed his third book, entitled: *The Joys and Rewards of Prayer- A Guide for Beginners, A Reminder for Believers.* He is currently preparing the young person's edition of this book. Shaykh Abdul-Malik is general secretary of Imams Council of New York, whose members provide religious leadership for more than 100 Masjids throughout the New York metropolitan area. He also is an elder of the Admiral Family Circle Islamic Community, an arm of which, the Malik Shabazz Human Rights Institute, is accredited to the United Nations as a non-governmental organization, with special consultative status.

Fay Burrs, RN, BSN
Director of Access and Diversity
National Hospice & Palliative Care Organization (NHPCO), Alexandria, VA

Fay Burns is the former Interim Director of the Foundation for Hospices in Sub-Saharan Africa (FHSSA) and directed the Offices of Access and Diversity at the National Hospice & Palliative Care Organization in Alexandria Virginia. She shared the responsibility of assisting and educating providers regarding issues of cultural competency and sensitivity to the uniqueness and diversity of patients that may impact end-of-life-care. Her role as Interim Director for FHSS focused on supporting organizations in Africa and the United States to provide hospice and palliative care and support services in sub-Saharan Africa. With more then 27 years of experience in various areas of health care Ms. Burrs has committed the last 15 years to hospice and palliative care.

Ms. Burrs received a Bachelor of Science from Columbia Union College and is currently pursuing a graduate degree in health administration. She is an experienced international and national speaker and lecturer on end-of-life care issues, cultural diversity, cultural competency and program development. She was nominated for Nurse of the Year award and her past leadership of the nurse section for the National Council of Hospice Professionals. Ms. Burrs also received recognition from the National Black Nurses Association (DC Metro) and Washington area and the Women's Ministry for the development of Community Health Programs.

Key Topics on End-of-Life Care for African Americans

Kelvin Calloway, D.Min
Pastor
Second A.M.E. Church, Los Angeles, CA

Reverend Kelvin T. Calloway, D.Min, was born in Herlong California. Educated in the Mobile County (AL) public school system, he received the Bachelor of Science (Business Administration) degree from Texas Southern University (Houston, TX) in 1975. One year later, Calloway earned a Master of Business Administration (Organizational Behavior and Marketing) degree from the University of Illinois - Champaign. Further studies resulted in the Master of Divinity degree from Alabama Interdenominational Seminary (Mobile, AL) and a second MDiv - along with the Doctor of Ministry (Ethics and Preaching) degree - from the Southern California School of Theology at Claremont in 1988.

Dr. Calloway has varied business-related experiences. He has been employed as an Industrial Engineer with Ingali's Shipbuilding, Pascagoula, Mississippi, a Financial Services Representative with the Metropolitan Insurance Company, a Commerical Investment Specialist with Century 21 Real Estate Corporation, Adjunct Instructor in the Department of Business Administration, S. D. Bishop State Community College, Executive Director of Strongly Oriented For Action (a church sponsored social service agency) La Jolla, California. Additionally, he served as visiting Professor of Preaching and Ethics, St. Paul School of Theology, Kansas City, Missouri and a member of the National Advisory Committee for The Robert Wood Johnson Foundation's Last Acts Campaign.

Dr. Calloway was ordained an itinerant deacon in the Central Alabama Conference of the Ninth District of the A.M.E. Church in 1984 and an itinerant elder in the Southern California Annual Conference of the Fifth District of the A.M.E Church in 1986. He has pastored rural, urban and suburban churches in Alabama, California and Kansas. Dr. Calloway is the recipient of numerous honors and awards. Among them are Outstanding Young Men of America, 1979, Who's Who of La Jolla, California 1989, and the Wilshire Preaching Award, Claremont, California 1988.

Key Topics on End-of-Life Care for African Americans

Congresswoman Donna Christian-Christensen, MD
United States Virgin Islands

The Honorable Donna M. Christensen continues to distinguish herself as a leader in the United States Congress. As a member serving her fifth term, she is the first female physician in the history of the U.S. Congress, the first woman to represent an offshore Territory, and the first woman Delegate from the United States Virgin Islands.

In the 109th Congress, Delegate Christensen serves on the following House Committees, Subcommittees and Caucuses: the Committee on Resources, which oversees territorial and public land issues, the Committee on Small Business, which oversees entrepreneurship and business activities and the Homeland Security Committee which oversees preparing the nation to prevent and withstand attack.

Delegate Christensen is a Member of the Congressional Black Caucus and chairs the Congressional Black Caucus' Health Braintrust, which oversees and advocates minority health issues nationally and internationally; is a Member of the Congressional Caucus for Women's Issues; Member of the Steering Committee of the Congressional Travel and Tourism Caucus; Member of the Congressional Rural Caucus; Member of the Coastal Caucus; Member of the Congressional Fire Caucus and additionally, a Member of the Congressional National Guard and Reserve Caucus.

She earned a Bachelor of Science from St. Mary's College in Notre Dame, Indiana and an M.D. from George Washington University School of Medicine in Washington, D.C.

Christensen began her medical career in the Virgin Islands in 1975 as an emergency room physician. She served as staff physician at the Maternal & Child Health program, Medical Director of the Nesbitt Clinic in Frederiksted, Director of the Frederiksted Health Center, Director of Maternal and Child Health and Family Planning, served as the Medical Director of the St. Croix Hospital and rounded out her medical career as the Territorial Assistant Commissioner of Health and as the Acting Commissioner of Health.

Christensen is a member of the National Medical Association, the Virgin Islands Medical Society, the Caribbean Studies Association, the Caribbean Youth Organization and the Virgin Islands Medical Institute.

Key Topics on End-of-Life Care for African Americans

Myra Christopher
President and Chief Executive Officer
Center for Practical Bioethics, Kansas City, MO

Myra Christopher became president of the Center for Practical Bioethics in December 1994, and continues to serve as its executive director, a position she has held since the Center's inception in 1985. In addition to providing oversight to the Center, Christopher served as the national program officer of the Robert Woods Johnson Foundation's National Program Office for State-based Initiatives to Improve End-of Life Care. These roles allow Christopher to continue her lifelong mission to improve care for seriously ill people and their families. An author and frequent speaker on bioethical issues, Christopher has made presentations to such prestigious national organizations as the American Hospital Association, Group Health Association of America, the National Health Lawyers Association, AARP, and the American Philosophical Association.

Because of Christopher's involvement with the Nancy Beth Cruzan case, Senator John Danforth sought her assistance in drafting and introducing the Patient Self-Determination Act. In 1991, she was appointed vice-chair of the Kansas Commission on the Future of Health Care by the governor and served in that capacity until 1994. She also consulted with the Joint Commission on the Accreditation of Healthcare Organizations on patients' rights and organizational ethics standards.

Christopher is currently a member the National Advisory Board for the Duke Institute for Care at the End-of-Life, the expert panel for the Rosalynn Carter Institute for Human Development and the advisory board for the Federation of State Medical Boards. She is formerly a member of the American Bar Association Commission on Law and Aging,

She has been named an honorary member of Alpha Sigma Nu, Rockhurst College and the 1996 Alumnus of the Year for the College of Arts and Sciences at the University of Missouri – Kansas City. Christopher was nominated for the Gleitsman Foundation's Citizen Activist Award for 2000 and in that same year was chosen one of the "Top 150" citizens of Kansas City in celebration of its sesquicentennial.

Recent honors include the prestigious 2004 Marian Grey Secundy SANKOFA award for her "deep commitment and outstanding work to improve palliative and end-of-life care for African Americans," and the 2003 National Association of Attorneys General President's Award. In 2003 she was recognized as an Honorary Alumnus of the KU School of Nursing.

Andrea King Collier
Freelance Journalist and National Health Care Advocacy Consultant, Lansing, MI

Andrea King Collier is a freelance journalist and a national health care advocacy consultant. Her new book, The Black Woman's Guide to Black Men's Health will be published in February, 2007. Her work in health care advocacy is guided by her own personal experiences and years of interviews with everyday individuals who strive for access to quality care.

She is the author of *Still With Me...A Daughter's Journey of Love and Loss.* She has written for More, Women's Day, Family Circle, Ladies Home Journal, Essence, Chicago Tribune, the Lansing State Journal, the New York Times and others.

Key Topics on End-of-Life Care for African Americans

LaVera M. Crawley, MD
Medical Ethics Researcher and Lecturer
Stanford University School of Medicine Center for Biomedical Ethics, Oakland, CA

LaVera Crawley is a medical ethics researcher and lecturer at the Stanford University School of Medicine Center for Biomedical Ethics. She is the recipient of a five-year National Cancer Institute Career Development Award to study the effects of trust and perceived racism on cancer prevention practices among blacks. Dr. Crawley received the Soros Faculty Scholars Award (1999-2001) for the Open Society Institute's Project on Death in America, which supported her project on developing and implementing a series of continuing education programs on end-of-life care to educate African American physicians.

A graduate of Meharry Medical College, Dr. Crawley completed a residency in family medicine at the University of California, San Francisco, and a research ethics fellowship at Stanford University. She also participated in the Harvard Medical School Center for Palliative Care Education Program. During the current 2003-2004 academic year, Dr. Crawley is on educational leave from Stanford to complete her master's degree in public health at the School of Public Health, University of California at Berkeley.

Dr. Crawley served as the first executive director of the Initiative to Improve Palliative Care for African Americans and sits on its board of directors. She is the lead author of several articles on the subject of palliative and end of-life care for African Americans. She also serves on the executive board of Americans for Better Care of the Dying and is an adviser to the Alta Bates Summit Ethnic Health Institute End-of-Life Decision-Making Project in Oakland, California.

Joseph Dancy Jr., PhD, MDiv, ThM
Professor
Ethelyn Strong School of Social Work at Norfolk State University, Norfolk, VA

As a gerontologist, Dr. Dancy is a professor in the Ethelyn Strong School of Social Work at Norfolk State University in Norfolk, Virginia, where he also served as interim dean of the School of Social Work. He earned his Bachelor of Arts degree from Virginia Union University in Richmond, and his master of divinity degree from the School of Theology at Virginia Union University. He earned his master of theology degree from Princeton Theological Seminary in Princeton, New Jersey.

In addition to his theological training, Dr. Dancy received his doctorate in educational gerontology from the University of Michigan. In 1995, he completed an intensive bioethics course at Georgetown University. In 2002, he completed a sabbatical in bioethics that focused on such topics as medicine, law, ethics and spirituality through Michigan State University's Center for Ethics and Humanities. In the area of bioethics, Dr. Dancy has served on the Internal Review Board (IRB) for Eastern Virginia Medical School in Norfolk. He also has served as a consultant to the Center for Bioethics at Tuskegee University in Alabama and is a participant in The Robert Wood Johnson Foundation-funded project on end-of-life issues.

Dr. Dancy, a native of Brooklyn, NY, is the author or co-author of articles and books related to his areas of interest: spirituality and aging, caregiving and grandparents raising grandchildren. His book, *The Black Elderly: A Guide for Practitioners,* was published through the University of Michigan Press. He has served as a board member of the Southern Gerontological Society.

Key Topics on End-of-Life Care for African Americans

Willie Davis, PhD
Director
All Around the African World Museum and Resource Center, Lansing MI

Dr. Davis is the Director of the All Around the African World Museum and Resource Center. He is an Adjunct professor at Davenport University and Lansing Community College. In addition, Dr. Davis has taught courses in Black Studies, Human Services, Social Work, Sociology, Education, Psychology and Interdisciplinary Studies, Diversity, and Racial and Ethnic studies and conducted Seminars and Workshops at the College and University levels and for professional groups in areas of Aging, Diversity, Health, Education, and Business. He has traveled extensively through the inhabited continents.

He currently serves on the board of directors of El Hajj Malik El Shabazz Academy; a charter elementary school and retains active membership in many African and African American organizations including A Progressive Palliative Educational Curriculum for th Care of African Americans at Life's End (APPEAL), the National Association of Black Social Workers, National Black United Front, Association of Classical African Civilizations, and the Black Data Processing Association and APPEAL. Recently Dr. Davis has served as Co-Chair of the Ghana Committee of the Lansing Regional Sister City Commission which has established Sister City Relationship with the Aquapim South District in Ghana in West Africa and a Information and Technology project in Dar Es Salaam, Tanzania.

Dr. Kweku (Willie) Davis is also President and CEO of DIANEX LTD. an investment and international trade firm and The Davis Complex of which he is president and specializes in the area of Cultural Sensitivity and Health Consultation and the Business incubation process.. He is also a member of and one of the founders of the Greater Lansing Minority Business Association and a past member of the Chamber of Commerce. Dr Davis has recently retired from the State of Michigan as the Program Manager of the Medicaid Managed Care Ombudsman Program for the Michigan Department of Community Health. In addition, he co-founded the Potter/Walsh Neighborhood Association and he is past-president of Neighborhood Youth and Parent Partnership Program. Writings include many articles on community organizing.

Diane Deese
Community Affairs Director
VITAS Healthcare Corporation, Chicago, IL

Ms. Deese has over 15 years of experience in the operational, marketing and public relations of hospice programs. She is currently the community affairs director for VITAS Healthcare Corporation. Ms. Deese has professional affiliations with the African American AIDS Memorial Service, is a member of the task force on access to hospice care by minority groups for the National Hospice and Palliative Care Organization. She is also a member of the National Association of Black Health Executives, a board member for Kupona Network (first African American AIDS Agency in Chicago) and a faculty presenter for the APPEAL project, an educational program funded by The Robert Wood Johnson Foundation to train health care professionals providing palliative and end-of-life care to African Americans. In November 1999, Diane Deese was an award recipient of "Fifty African American Women Making a Difference" in Chicago. These women were recognized for their outstanding career achievements and dedication to the African American community. Ms. Deese is a trained emergency medial technician and is continuing her studies in the areas of marketing and business management.

Key Topics on End-of-Life Care for African Americans

Michelle Grant-Ervin, MD, MHPE, FACEP
Medical Director
VITAS Innovative Hospice Care, Washington, DC

Michelle Grant-Ervin M.D., is a graduate of the Abraham Lincoln School of Medicine at the University of Illinois class of 1981. She completed her residency training at Cook County Hospital in Chicago in 1984 and holds board certifications in Internal Medicine and Emergency Medicine. Dr. Grant-Ervin was inducted as a Fellow of the American College of Emergency Physicians in1989 and in 2002. Her experience in emergency medicine includes serving as Chair and Residency director of Emergency Medicine at Howard University Hospital from 1993 – 2003.

Additional training and education achieved by Dr. Grant-Ervin include:
A masters degree in Health Professions Education (MHPE) from the Department of Medical Education at the University of Illinois conferred in 1995, a fellowship in Bioethics at the MacLean Center for bioethics at the University of Chicago from 1996 – 1997, and a faculty scholar appointment with the Project on Death In America funded by the Open Society Institute. Dr. Grant-Ervin presently serves on three advisory boards which are: Iona Senior Services in Washington DC, Center to Advance Palliative Care Studies (CAPC) at Mount Sinai Medical Center in New York, and President-elect for the national advisory board for the American Alliance for Cancer Pain Initiatives.

Currently Dr. Grant-Ervin is Medical Director for the Greater Washington office of Vitas Innovative Healthcare Corporation and is faculty in the Department of Emergency Medicine at the Georgetown/WHC Emergency Medicine residency program.

Dr. Grant-Ervin speaks locally, regionally, and nationally on issues of quality care at life's end, access to health care and a broad spectrum of issues impacting the navigation of care from the Emergency Department thru our complex health network.

Key Topics on End-of-Life Care for African Americans

Harold P. Freeman, MD
Founder and Medical Director
Ralph Lauren Center for Cancer Care and Prevention, New York, NY

Dr. Freeman is founder and medical director of the Ralph Lauren Center for Cancer Care and Preven- tion in Harlem, New York. He is currently a Senior Advisor to the Director of the National Cancer Insti- tute (NCI). He holds the academic rank of Professor of Clinical Surgery at Columbia University College of Physicians and Surgeons. Dr. Freeman is one of the foremost international authorities on *Interrelationships among Poverty, Culture Social Injustice and Cancer* and is the leading voice on cancer disparities.

For twenty-five years (1974–1999), Dr. Freeman was the Director of Surgery at Harlem Hospital Center. For a five year period ending in September 2005, he held the position of an Associate Director of the NCI and Founding Director of the NCI Center to Reduce Cancer Health Disparities.

Dr. Freeman served as National President of the American Cancer Society (ACS) where he was the chief architect of their initiative on *Cancer in the Poor* and was influential in making the health concerns of the poor and underserved a national priority. In recognition of this contribution, the ACS established the "Harold P. Freeman Award" which is given annually by various ACS divisions throughout America to individuals who have made outstanding contributions in the fight against cancer in the poor.

Dr. Freeman served as Chairman of the United States President's Cancer Panel (PCP) for eleven years. He was appointed for four consecutive three-year terms to the panel first by President Bush in 1991 and subsequently by President Clinton in 1994, 1997 and 2000.

Dr. Freeman pioneered the "Patient Navigation Program which has proved to be a successful model to reduce disparities in access to diagnosis and treatment of cancer particularly among poor and uninsured people. Based primarily on the Patient Navigation model created by Dr. Freeman in Harlem, "The Patient Navigator, Outreach and Chronic Disease Prevention Act" was enacted by The Congress and signed by The President in June 2005.

Dr. Freeman received an AB Degree from Catholic University of America and an MD Degree from Howard University. He was elected to the Institute of Medicine of the National Academy of Sciences in 1997.

Key Topics on End-of-Life Care for African Americans

Bernice Harper, MSW, MSH, PhD, LLD
Former Medical Advisor, Department of Health and Human Services
Centers for Medicare and Medicaid. Washington, DC
Former Board President, Foundation for Hospice in Sub-Saharan Africa

Dr. Harper was the Medical Care Advisor to the Health Care Financing Administration in Washington, DC. Her career, which has progressed to this most influential Federal level, has focused on the area of health care and health care policy formulation. She has practiced in varied settings and personified the values and ethical standards of the social work profession even in the most difficult and highly charged political environments.

Harper earned her MSW degree from the University of Southern California in 1924 and an MPH from Harvard University in 1959.

She was instrumental in developing long term program policies which highlight continuity-of-care, including community and institutional care, and stresses the importance of psychosocial components. Her commitment to the long term care of those in need has served to demonstrate the best of the best for the profession and for those in need. Her insight and commitment to professionals, especially social workers, who are under both personal and professional stress as they work with patients in the final phases of their lives, combined with her perspective, academic, and practice skills with their families, motivated her to produce a definitive publication on death and the special needs for professionals to cope with their related stress. The book, Death: The Coping Mechanism of the Health Professional was in advance of the interest now placed on this area. Harper identified and labeled specific stages of coping with death that are important to understand, especially for professionals living through the process with clients.

Harper's work at the City of Hope in California as Chief Social Worker and her practice with leukemia victims sustained her interest in the important needs of those with chronic and long term illness. She is nationally recognized for her work and is sought after for training workshops and conferences.

Bernice Harper has consistently been referred to as the professional's professional. Harper has been able to represent social work values and bring them into policy statements. She is a personification of social work's value base and has sustained that consistency in the Washington scene through multiple and changing administrations as well as political appointees. She has not compromised the long term health care needs of those in the country. She has also worked with multiple government organizations around minority services and activities for professional as well as other educational needs.

Harper has been active and served in leadership positions at NASW and the International Conference on Social Welfare. She was the first recipient of the Knee/Wittman Outstanding Achievement in Health/Mental Health Policy Award. As an international advisor Dr. Harper visited South Africa and Zimbabwe as a member of the first western seminar to share and explore hospice concepts with African countries.

Key Topics on End-of-Life Care for African Americans

LaVone V. Hazell, MS, LED, FT, CFT
Project Director
Palliative Care Training and Education Program, New York, NY

LaVone V. Hazell is a New York State licensed funeral director, a certified funeral service practitioner with the Academy of Professional Funeral Service Practice, and is certified in thanatology as a fellow (FT): Death, Dying and Bereavement, by the Association for Death Education and Counseling (ADEC). She was the designer and project director of The Palliative Care Training and Education Program for Caregivers in Minority Communities (PTEP), sponsored by North General and Memorial Sloan-Kettering hospitals. With more than twenty-five years o f training experience, she has developed curricula for mental health, religious, educational and AIDS institutions.

Ms. Hazell was a member of the board of directors of ADEC for two consecutive three-year terms, and is mortuary officer for the United States Federal DMORT Region 2 Disaster Team, a founding member of Homeland Security, a board certified expert in traumatic stress (designate diplomate), with the American Academy of Experts in Traumatic Stress, an instructor for, and member of the Faculty Council of the American Academy McAllister Institute of Funeral Service, Inc., a member of the advisory board for the African American Church and Community Perspectives for End-of- Life Care, and a member of Phi Delta Kappa Honor Society. She has also published numerous academic articles and book chapters in the field of thanatology.

A graduate of Howard University and Fordham University, Ms. Hazell holds a Bachelor of Science degree in psychology, a Master of Science degree in adult education and human resources, and is a certified family therapist. Ms. Hazell is presenting as an online faculty member of AAMI. Her major interest is the influence of culture on death rituals and the comparison of various minority groups' practices relating to end-of-life events.

Karla FC Holloway, PhD
Duke University, Durham. NC

Karla FC Holloway, PhD, is the William R. Kenan Jr. Professor of English, Law, and Women's Studies at Duke University. She is the author of six books, including *Passed On: African-American Mourning Stories* (Duke University Press, 2002*). BookMarks—Reading in Black and White—A Memoir*, will be released this fall. She currently is at work on a project on bioethics, race, and law. Dr. Holloway is an affiliated faculty member of Duke University's Institute on the Care at the End of Life. She also serves on the Greenwall Foundation's Advisory Board in Bioethics, the Center for Documentary Studies at Duke, and the Princeton University Advisory Council: Program in the Study of Women and Gender. Dr. Holloway received her AB from Talladega College, her MA and PhD from Michigan State University, and her M.L.S. from Duke University Law School.

Key Topics on End-of-Life Care for African Americans

Camilla Hudson
Patient Advocate, Chicago, IL

Camilla Hudson is a freelance interior designer living in Chicago. Ms. Hudson attended the University of Illinois in Urbana, Illinois and made a career change from the hectic, corporate world into the design field partially due to assuming the role of primary caregiver to her aging parents. As the demands upon her time increased, she found it necessary to have better control over her work schedule in order to fulfill her obligations as their caregiver. Ms. Hudson is the mother of one child and two adopted dogs, one of which is a Hurricane Katrina survivor. As a result of her personal experiences with regard to end-of-life issues, Ms. Hudson has become an active and vocal advocate of advance directives. She is committed to increasing public knowledge and awareness of all end-of-life matters, particularly within the African American community.

Bethsheba Johnson, MSN,CNS.GNP-BC
Luck Care Center, Chicago, IL

Bethsheba Johnson is a board certified gerontological nurse practitioner. She received her Bachelor of Science in Nursing degree from Chicago State University and went on to complete her Master's of Science in Nursing at Rush University as a Clinical Nurse Specialist. In 1997, Ms. Johnson completed her post Master's certificate as a Gerontological Nurse Practitioner. Her experience covers surgical nursing for patients with head and neck cancer, surgical intensive care and pulmonary medicine. She has also been certified as an APPEAL (**A P**rogressive **P**alliative Care **E**ducational Curriculum for the Care of **A**frican **A**mericans at **L**ife's End (APPEAL) and EPEC (Education for Physicians at End of Life Care) trainer.

Ms. Johnson currently works for the Southside Health Association at the Luck Care Center, an HIV/AIDS Primary Care Ambulatory Center. The Luck Care Center's 200 patients are primarily African American and underinsured. The center provides HIV primary care, dietary consulta-tion, substance abuse counseling, mental health counseling, bioelectric impedance analysis, peer educators, support groups, clinical trails, complimentary therapies, prevention case management, adherence case management, and HIV case management.

She is also clinical faculty for the Midwest AIDS Training and Education Center located in the Jane Addams College of Social Work at the University of Illinois at Chicago. She was appointed by Mayor Daley of Chicago to the Chicago HIV Planning Services Council and received an award with her husband in 2002 from the AIDS Legal Council of Chicago as Provider Advocates of the Year. In 2005, she was chosen as one of the recipients of The Body's HIV Leadership Award in the Outstanding HIV/AIDS Nurse Category. In 2005, Bethsheba received the Excellence in Health Sciences award from Chicago State University. Ms. Johnson has traveled to South Africa with her husband to provide consultation to hospices caring for patients with HIV/AIDS. She is also shares a membership position with Dr. William Johnson on the Board of Directors for the Foundation for Hospices in Sub-Saharan Africa. In 2005, she and her husband have been featured in the July/August edition of Positively Aware Magazine. Ms. Johnson has recently been approved by the Clinton Foundation's International Center for Equal Healthcare Access (ICEHA) to Provide HIV/AIDS and Operational Training to Local Healthcare Providers in Ethiopia.

Key Topics on End-of-Life Care for African Americans

William Johnson, MD
Medical Director
VITAS Healthcare Corporation, Chicago, IL

William A. Johnson, MD, is medical director of the Chicagoland Central program for VITAS Innovative Hospice Care®. In this role, Dr. Johnson provides and oversees expert palliative care and symptom management for a 300+-patient hospice program.

In addition to his responsibilities at VITAS, Dr. Johnson maintains a private practice, is attending physician for several area hospitals, assistant professor of internal medicine at Rush Presbyterian-St Luke's Medical Center, and medical director of the Luck Care Center, an HIV/AIDS primary care clinic in Chicago. He also is affiliated with several professional organizations including the Cook County Physician's Association, the American College of Physicians and the National Medical Association.

Dr. Johnson dedicates much of his time organizations, such as the American Academy of HIV Medicine and the Infectious Diseases Society of America, and to the relief efforts of organizations such as the Foundation for Hospices in Sub-Saharan Africa (FHSSA).

Board certified in internal medicine and in hospice and palliative medicine, Dr. Johnson began his career as a pharmacist, earning a Bachelor of Science degree in pharmacy at Purdue University in West Lafayette, Indiana. He received a medical degree at the University of Chicago, Pritzker School of Medicine, where he attained honor status, and completed his residency in internal medicine at Rush Presbyterian-St. Luke's Medical Center.

Sharon R. Latson
Senior Director of Access Initiatives
VITAS Healthcare Corporation, Chicago, IL

Sharon Latson is the Senior Director of Access Initiatives for VITAS Healthcare Corporation. Ms. Latson is responsible for development of national programs and initiatives to expand awareness of and access to VITAS hospice services in diverse and underserved communities.

In her previous position Ms. Latson coordinated the professional and community outreach campaign for the 2000 PBS broadcast of *On Our Own Terms: Moyers on Dying* series. Ms. Latson secured funding from The Robert Wood Johnson Foundation and served as the director for The Last Miles of the Way Home: A National Conference to Improve End of Life Care for African Americans. Ms. Latson also directed a national project for the development of a culturally sensitive end-of-life curriculum for health care providers titled, *A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End* (**APPEAL**). The APPEAL project was recently awarded a *Quality of Care* grant from the Aetna Foundation.

Ms. Latson, is the co-principal investigator on the Key Topics on End-of-Life Care for African Americans project with the Duke Institute on Care at the End of Life. She also directed the full publication of the eleven articles addressing end-of-life care for African Americans. She serves on the board of directors of the Foundation for Hospices in Sub-Saharan Africa; Women Living with Pain Initiative and the Intercultural Cancer Council.

Ms. Latson holds a Bachelor of Arts degree in Marketing and Communications from Columbia College in Chicago, IL and is currently pursing a Masters in Communications.

Key Topics on End-of-Life Care for African Americans

Gwendolyn W. London, D.Min
London & Associates, Silver Spring, MD

Gwendolyn London, D.Min, was the Interim Director the Duke Institute on Care at the End of Life. Prior to her position at Duke Dr. London had a 20-year tenure with Blue Cross and Blue Shield of the National Capital Area, Dr. London left the field to pursue a career in direct services to patients and families. She has been involved in the field of end-of-life care since 1982 when she became a volunteer at Hospice of Washington, the first inpatient hospice facility in the United States.

Previously employed at the DC Partnership to Improve End of Life Care, Dr. London was the first executive director of the Robert Wood Johnson Foundation Community State Partnership organization, where she directed the activities of a coalition of over 60 organizations involved in the care of the dying. A long-term advocate of improved end-of-life care, she has a strong commitment to the need for policy initiatives, public education, professional education and research in this area.

Dr. London has extensive experience as a practitioner, educator and administrator and has held various positions related to the care of the dying. She has worked as a Hospice Chaplain, Hospice Bereavement Coordinator, Hospital Chaplain and Associate Minister at a 1700 member urban congregation. In each of these positions, she did extensive work with patients and families from diverse cultural backgrounds.

Key Topics on End-of-Life Care for African Americans

Richard Payne, MD
Esther Colliflower Director
Duke Institute on Care at the End of Life
Duke Divinity School, Durham, NC

Richard Payne is an internationally known expert in the areas of pain relief, care for those near death, oncology and neurology, and is the Ester Colliflower Director of the Duke Institute on Care at the End of Life at the Duke Divinity School. The Institute seeks to create knowledge and rediscover wisdoms about life's end through interdisciplinary research and scholarship, teaching, and community outreach.

Prior to his appointment at Duke, Dr. Payne led the Pain and Palliative Care Service at Memorial Sloan-Kettering Cancer Center in New York City. During this time at Memorial Sloan-Kettering, he held the Anne Burnett Tandy Chair in Neurology. Dr. Payne directed the program's clinical and rehabilitation services as well as research and training programs. He also served as Professor of Neurology and Pharmacology at Weill Medical College of Cornell University.

From 2003-2004, Dr. Payne was President of the American Pain Society. He is certified in hospice and palliative medicine by The American Board of Hospice and Palliative Medicine, in neurology & pain medicine by The American Board of Psychiatry and Neurology, and is a diplomat of The American Board of Pain Medicine. Dr. Payne was Chief, Pain & Symptom Management Program, Department of Neurology, M.D. Anderson Cancer Center, Houston, TX from 1992-1998.

Currently, Dr. Payne serves as the chair of the board of Foundation for Hospices in Sub-Saharan Africa (FHSSA) of The National Hospice and Palliative Care Organization and is also a board member of the National Coalition of Cancer Survivors. He co-chairs the Palliative Care Steering Committee of the National Quality Forum (NQF) and is a member of the Long Term Care Commission of the NQF. He has published over 250 peer-reviewed papers, articles and opinion pieces.

Dr. Payne received his B.A in molecular biophysics and biochemistry from Yale University, 1973 and his M.D. from Harvard University, 1977. He completed post graduate training in medicine at the Peter Bent Brigham Hospital in Boston, MA, in neurology at the Cornell Campus of the New York Presbyterian Hospital, and a post- graduate fellowship in neuro-oncology and pain medicine at Memorial Sloan-Kettering Cancer Center.

Key Topics on End-of-Life Care for African Americans

Rosalyn Priester
Director
Amani Care Program of the Trinity United Community Health Corporation, an affiliate of the Trinity United Church of Christ, Chicago, IL

Deacon Priester is director for the Amani Care Program.   The program offers members of the African American community and other communities of Greater Chicago end-of-life care that is enriched with spiritual healing, wholeness peace and dignity.

Decon Prister has been a member of Trinty United Church of Christ since 1982 and served actively for the deacon ministry for the last 13 years. From 1996-98 she completed a clinical pastoral care practicum with emphasis on hospice ministry; and in 1999 she completed a hospice management certificate program at the University of Illinois. She is board member of the Chicago End of Life Care Coalition.   Deacon Priester works closely with the HIV/AIDS support ministry and provides staff support for education, prevention, testing and treatment programs at Trinity United Church of Christ.

Beny Primm, MD
Executive Director
Addiction Research & Treatment Corporation, New York, NY

Beny Primm has been the executive director of the Addiction Research & Treatment Corporation (ARTC) of Brooklyn, New York, since its inception in 1969. As one of the largest minority non-profit community-based substance abuse treatment programs in the country, the ARTC provides a multimodality service and treatment program for approximately 2,300 men and women, primarily members of severely underserved populations. Since 1983, Dr. Primm has served as president of the Urban Resource Institute, a non-profit organization that provides supportive social and medical services to critical populations within New York City. Among them are multiservice shelters for battered women and their children, intermediate care facilities and other services for mentally challenged individuals as well as outpatient alcoholic treatment services.

In recognition of his authority on the Human Immunodeficiency Virus (HIV), addiction and AIDS, Dr. Primm was appointed to the Presidential Commission of the Human Immunodeficiency Virus Epidemic in 1987. Dr. Primm is known internationally for his commitment to substance abuse treatment and the treatment of the psychological, social and economic ills that fuel that disease. In 1989, Dr. Primm was appointed by the Secretary of Health and Human Services to direct the federal government's Center for Substance Abuse Treatment (CSAT), formerly known as the Office for Treatment Improvement (OTI). In that capacity, Dr. Primm was responsible for the development of programs, policies and initiatives relating to the treatment of addictive disorders and the improvement of the quality and effectiveness of substance abuse treatment as well as treatment capacity expansion for the United States and its territories. Dr. Primm is widely published in treatment of drug abuse and related disorders in peer journals and textbooks.

He is the recipient of numerous awards and in November 2000, was granted the Surgeon General's Medallion for U.S. Public Health Service for his lifetime of leadership in mental health and substance abuse treatment in the battle against the AIDS epidemic. Dr. Primm earned his medical degree from the University of Geneva, Geneva, Switzerland.

Key Topics on End-of-Life Care for African Americans

Gloria Ramsey, JD, RN
Director, Community Outreach and Information Dissemination, Silver Spring, MD

A registered nurse and attorney, Gloria Ramsey is known for her work in bioethics; in particular, her research has focused on questions concerning end-of-life care, decisional capacity in the elderly, and legal and ethical issues for individuals and families with HIV disease and AIDS. Currently, she is the director of Community Outreach and Information Dissemination at the Center for Health Disparities Research and Education at the Uniformed Services University of the Health Sciences. In that role she directs community outreach efforts to reduce and eliminate health disparities among African Americans, Hispanics and the Military. Dr. Ramsey's prior research examined reasons why African Americans do and do not complete advance directives and is working with investigators from Duke University Center for End of Life Care to develop and implement the didactic content for, APPEAL, 'A Progressive Palliative Care Educational Curriculum for the Care of African-Americans at Life's End,' a project funded by the Robert Wood Johnson and Aetna Foundations. Gloria Ramsey was the former director of a program funded by The Teagle Foundation, Inc. entitled, "Building Academic Capacity in Bioethics and Nursing" at New York University.

Dr. Ramsey's clinical interests include ethical issues in clinical practice, ethics education and consultation and the unique ethical and legal issues that arise in nursing practice. Dr. Ramsey was the founding author of an online column for The Nursing Spectrum Career Management resource for RNs, "Ask the Experts," entitled "Law & Ethics."

In addition, she is involved in a variety of professional organizations and as a member of the American Nurses Association (ANA), she served from 1996-2001 as a member of the ANA Code of Ethics Project Task Force, reviewing and revising the Code of Ethics. She is also past secretary of the American Society for Bioethics and Humanities (ASBH) Nurse Affinity Group.

After graduating from Felician College, Lodi, NJ (AAS, Nursing) and Jersey City State College (BS, Nursing, the National Dean's List), Gloria completed a JD in 1992 at Seton Hall University School of Law. In May 1996, she completed a Certificate in Bioethics and the Medical Humanities from Columbia College of Physicians & Surgeons and the Montefiore Medical Center/Albert Einstein College of Medicine.

Prior to joining NYU, Dr. Ramsey worked as a law clerk for Honorable Carol A. Ferentz, Superior Court of New Jersey, Law Division, Civil Part, Newark, NJ. She is a member of the Health Law Section of the New Jersey Bar Association, the New York City Bar Association Bioethics Committee, and the American Association of Nurse Attorneys. Additionally, she is a member of a number of boards and is published in the areas of nursing ethics education, research and clinical practice.

Key Topics on End-of-Life Care for African Americans

Kevin Sanders
Editor
Ohio University College of Osteopathic Medicine, Athens, OH

For the past eight years, Kevin M. Sanders has been editor/writer for the Ohio University College of Osteopathic Medicine. There he directs a number of areas, including the medical school's Web and print news. He also was the managing editor for the college's alumni publication, *The Ohio D.O.* Under his tenure as editor, *The Ohio D.O.* won three awards for "Best Article or Feature Story" and one for best print publication from the American Association of Colleges of Osteopathic Medicine's annual communication competition. Prior to that, he was the assistant director for the university's Institute for Applied and Professional Ethics. Mr. Sanders is a graduate of the university's E.W. Scripps School of Journalism at Ohio University

A native Chicagoan, Mr. Sanders worked in the securities industry (Chicago Board Options Exchange and Pacific Coast Options Exchange) for 15 years before becoming a journalist. In Chicago, he helped to launch the magazine, *Chicago AfterHours*, and was its managing editor for two years. He has an extensive background in desktop publishing, philosophy, and politics.

Pernessa C. Seele
Founder and CEO
The Balm in Gilead, Inc. New York, NY

In 1989, Pernessa Seele founded The Balm In Gilead, Inc., a non-profit organization whose mission is to mobilize churches to become centers of compassion, education and prevention in the struggle against the devastation of HIV/AIDS in the Black community. The Balm in Gilead's pioneering achievements have enabled thousands of churches to become leaders in preventing HIV by providing comprehensive educational programs for the community and offering compassionate support to those affected by HIV and AIDS.

As founder and CEO of The Balm In Gilead, Ms. Seele has conceived and implemented several innovative programs that are being used both nationally and internationally. This includes The Black Church Week of Prayer for the Healing of AIDS, the premier program of The Balm In Gilead, and now the largest AIDS awareness program in the US targeting African Americans since its inception in 1989. Ms. Seele is an advisor to the Congressional Black Caucus' Health Brain Trust and a consultant to the Mailman School of Public Health at Columbia University.

Ms. Seele received a Master of Science degree in immunology from Atlanta University and a bachelor of science in biology from Clark College. She is a native of Lincolnville, South Carolina.

Key Topics on End-of-Life Care for African Americans

Paul Smith, D.Min
Pastor
First Presbyterian Church, Brooklyn, NY

Paul Smith is the pastor of First Presbyterian Church in Brooklyn, New York. Under his caring and pastoral administration, high-church ceremony has disappeared. His sermons have a strong emotional appeal based on his deep commitment and his personal experiences of faith. He transfers his conviction to the congregants simply and directly.

Dr. Smith's sermons contain symbolism from a multitude of different cultures. The service music encompasses gospel, rock, jazz, and traditional hymns, sources that reflect both the growing multicultural membership and the Presbyterian reform tradition that opens the door to new ideas and approaches within the church.

Dr. Smith is passionate about outreach to the community as well as to the larger communities of New York City and the world. In 1997, he preached at the Presbyterian Church of Southern Africa in Johannesburg, South Africa, to mark its centenary. He has brought sensitivity training to the local police precinct in Brooklyn, introduced a lunch program for the homeless and has brought many famous leaders to the pulpit to speak for social causes including the Dalai Lama, Ambassador Andrew Young, Arthur Ashe and former House Speaker Tom Foley. The Reverend is guided and inspired by his late mentor, Dr. Howard Thurman, whose life and beliefs embraced the philosophy of inclusion. Dr. Smith's sincerity and religious fervor have brought enthusiasm for all spiritual aspects of life to the First Church.

Robert A. Washington, PhD, MDiv
Minister
Montgomery Hospice Service, Washington, DC

During his 29-year career, Dr. Washington, a licensed clinical psychologist and minister, has held various administrative positions in mental health including commissioner of Mental Health Services for the District of Columbia and executive director of the William Wendt Center for Loss and Healing. For the last 18 years, he has specialized in grief counseling -working with those who are ill, dying and/or bereaved, and training others to do likewise. As a result of this work, Dr. Washington developed a strong interest in the interface of psychology and spirituality. He retired from mental health administration to pursue a second career in ministry. An ordained minister in the United Church of Christ, Dr. Washington currently works as a chaplain for Montgomery Hospice.

Key Topics on End-of-Life Care for African Americans

September Williams, MD
Physician, Filmmaker and Clinical Medical Ethicist
San Francisco, CA

September Williams' cross-disciplinary clinical background encompasses internal, family, emergency, refugee and palliative care medicine. Her clinical base is in palliative care and geriatrics at the San Francisco VA Medical Center, while her film base remains at Ninth Month Productions in Santa Fe, New Mexico, devoted to cross-cultural competency.

Dr. Williams served as a part of the inaugural team opening the Tuskegee University National Center for Bioethics in Research and Health Care as the National Center's consulting clinical medical ethicist and communications specialist. Williams' career as a screenwriter and filmmaker emerged when she began to explore film's impact on people's autonomy and expectations of medicine, particularly for her African American community, when she was the Lowell T. Coggleshall Fellow at the University of Chicago Center for Clinical Medical Ethics (1990-91). She subsequently learned the filmmaking craft in the screenwriting and directing MFA program at Columbia College, Chicago and in the MS program in screenwriting at Boston University. Along with feature film scripts and shorter pieces, she is the writer/director of the medically based short films, *Shared Decisions* and *A Conversation on Moral Intuition,* and the feature-length documentary film, *When We Are Asked,* the source material for The Robert Wood Johnson Foundation APPEAL project (A Progressive Palliative Care Educational Curriculum for the Café f African Americans.

She is a co-editor of Bioethics Research Directions and Concerns for African Americans, and a contributing editor for the landmark bioethics volume, It Just Ain't Fair. Additionally, Dr. Williams has been a consultant in areas of bioethical, medical and cross-cultural competency to a number of filmmakers and television directors, producers and writers. She was a National Endowment for Humanities Fellow in Black Film at the University of Central Florida's Zora Neal Hurston Institute.

Dr. Williams has appeared in, and provided research for films and television broadcasts including "Frontline," "AIDS Report" and "Nightline." She has consulted with organizations from the Center for Disease Control and the Harvard AIDS Institute to the Initiative to Improve Palliative Care for African Americans and *Last Acts Partners.* In 2002, Williams was the Elizabeth Layton Memorial Lecturer at the Midwest Bioethics Center. Dr. Williams was the bioethics and medical voice for the Health Rhythms Radio (healthradio.org), America's first health radio program reflecting diversity and concern for ending health care disparities.

Dr. Williams is currently the attending physician in internal medicine, geriatrics, palliative care and clinical ethics at Laguna Honda Hospital and Rehabilitation Center in San Francisco, CA

Key Topics on End-of-Life Care for African Americans

Kristy Woods, MD, MPH
Director
Maya Angelou Research Center for Minority Health, Winston Salem, NC

Kristy F. Woods, MD, MPH, is professor of medicine, Department of Internal Medicine and was named the inaugural director of the Maya Angelou Research Center on Minority Health at Wake Forest University School of Medicine in June 2003. Dr. Woods' primary interests are in health care delivery, utilization patterns and health outcomes for underserved and minority populations with chronic diseases. She has extensive clinical and research experience in sickle cell disease, having served as director of education programs, Medical College of Georgia Sickle Cell Center and the director for, Meharry Sickle Cell Center.

Prior to joining Wake Forest University, Dr. Woods held faculty appointments at the Pritzker School of Medicine at the University of Chicago, Medical College of Georgia in Augusta, Georgia and Meharry Medical College and Vanderbilt University School of Medicine in Nashville, Tennessee. Dr. Woods has served as principal investigator or co-investigator on a number of National Institute of Health supported studies.

Dr. Woods received her Bachelor's Degree from Oberlin College, Ohio, her medical degree from Tulane University School of Medicine in New Orleans and her Master's Degree in Public Health from Tulane University School of Public Health and Tropical Medicine.

In addition to her role on the Blue Ribbon Advisory Board, Dr. Woods serves on the board of directors of the Urban League of Winston-Salem.

Jeremiah Wright, Jr., D.Min
Senior Pastor
Trinity United Church of Christ, Chicago, IL

Jeremiah A. Wright Jr. takes seriously not only the call to worship but also the call to take action as mandated by the Gospel. Under his leadership, Trinity adopted the motto "Unashamedly Black and Unapologetically Christian" and has set out to make activism within and on behalf of the African American community a key aspect of the church's mission. An outspoken community leader, Wright has been vocal in making once-taboo issues, such as AIDS, a priority within the African American church leadership and service. His commitment to political activism, coupled with his dedication to the African American sermonic tradition, has made him a highly sought-after speaker nationally and internationally.

The Reverend Wright is the recipient of numerous awards, including three honorary doctorates and three presidential commendations. An accomplished musician and author, he has written four books, numerous articles, countless sermons and was named one of *Ebony* magazines's top fifteen preachers.

Wright has been the pastor at Chicago's Trinity United Church of Christ since 1972, seeing its membership grow from 87 adult members to a congregation of nearly 10,000. Wright's early education took place in Philadelphia's public schools. From there, he went on to earn a BA and an MA from Howard University, an MA from the University of Chicago and a doctorate in divinity from United Theological College, where he studied under the eminent Samuel DeWitt Proctor. In addition to national and international ministry, the Reverend Wright serves on several boards of directors and committees.

Key Topics on End-of-Life Care for African Americans

Resources

APPEAL-**A P**rogressive **P**alliative **Care E**ducational Curriculum for the Care of **A**frican **A**mericans **at L**ife's End
Contact: www.iceol.duke.edu
Housed at the Duke Institute on Care at the End of Life, APPEAL is a curriculum to educate health care professionals with essential clinical competencies and practical skills needed to provide culturally appropriate palliative and quality end-of life-care services to African American patients and their families.

Association of Black Cardiologists
www.abcardio.org
Founded in 1974**,** the **Association of Black Cardiologists, Inc**., (ABC) is a nonprofit organization with an international membership of over 600 health care professionals. The ABC is dedicated to eliminating the disparities related to cardiovascular disease in all people of color. Today, the ABC's public and private partnerships continue to increase the impact in communities across the nation.

Balm In Gilead
www.balmgilead.org
The Balm In Gilead is a not-for-profit, non-governmental organization with an international mission to stop the spread of HIV/AIDS throughout the African Diaspora by building the capacity of faith communities to provide AIDS education and support networks for all people living and affected by HIV/AIDS . The Balm In Gilead's pioneering achievements have enabled thousands of churches to become leaders in preventing HIV by providing comprehensive educational programs and offering compassionate support to encourage those infected to seek and maintain treatment.

Congressional Black Caucus
www.cbcfinc.org
In January 1969, newly elected African American representatives of the 77th Congress joined six incumbents to form the "Democratic Select Committee. The Committee was renamed the Congressional Black Caucus and the CBC was born in 1971. The goals of CBC is to positively influence the course of events pertinent to African Americans and others of similar experience and situation, and to achieve greater equity for persons of African descent in the design and content of domestic and international programs and services. While the CBC has been primarily focused on the concerns of African Americans, the Caucus has also been at the forefront of legislative campaigns for human and civil rights for all citizens.

Duke Institute on Care at the End of Life
www.iceol.duke.edu

The mission of the Institute is to create and promote the growth of knowledge and to encourage the application of that knowledge in caring for the whole person at life's end. The Institute is conceived as a dynamic organization, fully engaged in the intellectual lives of the university and the larger community and driven by interdisciplinary scholarship, research and practical application.

Key Topics on End-of-Life Care for African Americans

Georgia State Medical Association
www.gastatemedicalassoc.org
Georgia State Medical Association, Inc., (GSMA) is the state affiliate of the National Medical Association (NMA). The association was founded in 1893.Founded as an organization to give a voice to African-American and other minority physicians in the state of Georgia; Georgia State Medical Association is a non-exclusive organization which works to represent its membership in all medical, scientific, legislative, public health and related affairs.

The association is represented on special committees in all area of State government affecting medical practitioners in Georgia, some of which are the Department of Medical Assistance, the State of Georgia Health Planning Agency, the Georgia Drug Utilization Review Board, the Georgia Medical Care Foundation. Members of Georgia State Medical Association serve on the faculties of all medical schools in the state of Georgia -Morehouse School of Medicine, Emory University School of Medicine, the Medical College of Georgia, and Mercer University School of Medicine.

NAACP
www.naacp.org
The mission of the National Association for the Advancement of Colored People is to ensure the political, educational, social and economic equality of rights of all persons and to eliminate racial hatred and racial discrimination.

National Association of Black Journalists
www.nabj.org
The National Association of Black Journalists (NABJ) is an organization of journalists' students and media related professionals that provide quality programs and services to advocates on behalf of black journalists worldwide.

National Black Nurses Association
www.nbna.org
The NBNA represents approximately 150,000 African American nurses from the USA, Eastern Caribbean and Africa, with 76 chartered chapters nationwide. The purpose of the association is to provide a forum for collective action by African American nurses to "investigate, define and determine what the health care needs of African Americans are and to implement change to make available to African Americans and other minorities health care commensurate with that of the larger society." NBNA is committed to excellence in education and conducts continuing education programs for nurses and allied health professionals throughout the year. The association provides annual scholarships for students.

National Association of Black Social Workers
www.nabsw.org
The NABSW was founded in May 1968 in San Francisco. The organization was formed in response to issues relating to providing human care in the Black community, educating social workers for effective services in the Black community and providing opportunities for participation of Black social workers in the social welfare arena.

Key Topics on End-of-Life Care for African Americans

National Medical Association
www.nmanet.org

The National Medical Association (NMA) is the largest and oldest national organization representing African American physicians and their patients in the United States. The NMA is a 501(c) (3) national professional and scientific organization representing the interests of more than 25,000 African American physicians and the patients they serve. NMA is committed to improving the quality of health among minorities and disadvantaged people through its membership, professional development, community health education, advocacy, research and partnerships with federal and private agencies. Throughout its history the National Medical Association has focused primarily on health issues related to African Americans and medically underserved populations; however, its principles, goals, initiatives and philosophy encompass all ethnic groups.

National Resource Center on Diversity
www.nrcd.com

NRCD is an information and technical assistance resource for coalitions and community leaders reaching out to diverse populations. The center provides information, materials, training and networking opportunities to improve end-of-life care for Latinos, African Americans, Native Americans, Asian Americans and others. NRCD works with coalitions and community-based organizations around the country to strengthen local efforts to reach minority audiences. We support community awareness efforts that explain how to reach diverse communities and encourage the development of community-based end-of-life care programs that are sensitive to a community's multiracial and multicultural members.

Rainbow/PUSH Coalition
www.rainbowpush.org

The Rainbow/PUSH Coalition is a progressive organization fighting for social change. The Rainbow/PUSH Coalition is a combination of a grassroots and political organization merged together in 1997, which seeks to protect, defend and gain civil rights and to even the economic and educational playing fields in all aspects of American life and to bring peace to the world. RPC is the merger of Operation PUSH (founded in 1971) and the National Rainbow Coalition (founded in 1985).

VITAS Healthcare Corporation
www.vitas.com

VITAS Innovative Hospice Care®, is a pioneer and leader in the hospice movement since 1978, it is the nation's largest provider of end-of-life care. Headquartered in Miami, Florida, VITAS (pronounced VEE-tahs) operates 40 hospice programs in 15 states (Arizona, California, Connecticut, Delaware, District of Columbia, Florida, Georgia, Illinois, Kansas, Missouri, New Jersey, Ohio, Pennsylvania, Texas, Virginia and Wisconsin. VITAS is developing innovative programs to increase the awareness and utilization of hospice services to diverse populations.