

## Commentary

### End of Life Care Decision-Making: Race Matters

Chester A. Robinson, D.P.A.<sup>1</sup>

<sup>1</sup>Jackson State University

#### Abstract

The advances in medicine over the past six decades have increased our capacity to prolong life (and postpone death) in circumstances that were not previously possible. These advances, however, have also sparked increased public policy debate regarding the quality of the extended life these modern therapies bring, issues of social equity, and concern over the cost of care. Making end of life care decisions in advance is intended to improve the quality of life for patients during the final months before death, as well as, reduce the cost of high technology and medical services. Prior research has shown that African Americans are less likely to make these decisions in advance than White Americans. Factors contributing to this difference in decision making include religious or cultural considerations, lack of awareness, differences in the availability of health care, and a lack of trust in a White dominated medical system. The objective of this study is to explore the impact of these factors on end of life care decisions by African Americans. The study uses a holistic perspective of the nation's diverse constituency to reveal insights into different needs, wants, and cultural diversities, which play key roles in fashioning the delivery of public services. This article examines disparities from this multidimensional perspective and offers insights for changes in public policy.

**Key Words:** end-of-life care decisions, hospice, advanced directives, health disparities

#### Introduction

Until well in the 20<sup>th</sup> Century in the United States, how we prepared for our 'final journey' was virtually the same for everyone, regardless of race or ethnicity. Death came in its own time, in its own way. Death was as unique as the individual who was experiencing it (Lewis, p.20). The appropriate place to die was a foregone conclusion: by social expectation and practice, it was at home, surrounded by family and friends (Rothman, 2014).

As Harlem Renaissance author, poet and playwright, Langston Hughes (1902-1967) once said, 'There is no color line in death'. My maternal grandmother, Fannie Ross, echoing similar sentiments that death is the great equalizer, said 'No matter how high or how low we are in life, we've all got to go'. Both of these sage commentaries indicate that however we reach the end of life, our mortality is universal – there is no color line in death (African American Outreach Guide, 2008).

The shift from the typical death being located at home to a hospital was not immediate. In the 1940s, most Americans still died at home. In 1949, only 40% of persons older than 65 years of age died in the hospital. But over the next several decades, as the hospital increasingly monopolized acute care delivery and its reputation for curative care soared, the trend toward hospital death accelerated. By the 1970s and early 1980s,

more than half of U.S. deaths occurred in hospitals and the proportion occurring at home dropped to 15% (Rothman, 2014). Moreover, given the success of modern medicine and treatments, the cause of death is now most often the culmination of years with chronic illness, such as dementia, congestive heart failure, or cancer. Most people dying from these causes often suffer debilitating symptoms, delirium, or severe pain in the process.

During this timeframe, broad scale concern also began to rise about the traditional problem-cure model of health care that emphasizes life-enhancing therapies, but falls short of guiding quality in end of life care. The growing discrepancy with what is generally perceived as a ‘good death’ and other concerns redirected the nation’s attention toward a closer examination about our attitude and perception of a death with dignity. Elizabeth Kubler-Ross’ (1969-1981) groundbreaking and widely debated work on the dying process set the stage for this national introspective examination. The outgrowth was an increased emphasis on dying as a time of personal growth and profound spirituality. Kubler-Ross maintained that by accepting death’s inevitability, dying persons can live meaningfully during their final days, come to terms with key life decisions and accept who and where they are.

A number of operational initiatives designed to help individuals face death on their own terms through better planning and decision-making arose from these discussions. Examples cover a continuum of both legal and personal health mechanisms to help a dying person ‘settle their affairs’: advance directives, medical power of attorney, palliative care, hospice care, euthanasia (in the State of Oregon), various public policies designed to give the dying person a ‘Bill of Rights’, and others.

Promoting quality end of life care planning and decision-making has become an important societal goal, as well as for individuals. Making a decision to forgo or to sustain life with artificial treatment is a complex process that brings various individual, economic, educational, social, and cultural traits into play. The literature is replete with evidence identifying significant disparities between African Americans and Whites in using these end of life planning mechanisms. This extends across a broad spectrum of end of life care planning. The intent of this paper is to yield additional insights that can be used to design programmatic interventions that address particular needs of African Americans and promote informed public policy decision-making. The paper advances discussion on three main questions:

- How has the African American community been uniquely impacted by historical developments in end of life care?
- Where are African Americans today in terms of their negative views (or misperceptions) that commonly lead to disinclination toward advanced end of life care decision making?
- What signposts are emerging that can help the African American community navigate through the end of life care planning terrain?

Studies that focus on racial/ethnic differences in end of life care planning are significant because who we are and our perception of a ‘good death’ are the products of generations of core religious beliefs, culture, and a variety of socio-economic factors. These broad contextual influences have a significant impact upon an individual’s end-of life care decision-making. While it would be improper to consider these elements as simple predictors of behavior, it is critical to have a full understanding of their influence in decision-making at life’s end. If African American elders want greater access to end of life care services but face barriers in doing so, from a public policy perspective, it is important to understand and address these barriers. If African American elders have access to these services but; service providers cannot accommodate their preferences in receiving

care, or if public programs are not adequately equipped to accommodate these preferences, then these limitations could serve as barriers to receiving care; and, therefore, need to be examined.

## Methodology

Public policy can be analyzed in many ways and from a variety of theoretical and ethical perspectives. Therefore, it is useful for the researcher to first consider policy analysis in terms of the results the study is designed to generate. This study assesses the underlying pinning of decisions by African Americans concerning end of life care decisions. It analyzes representative samples of the literature to identify prevailing explanations for end of life care decision making. The study analyzed existing literature and data sources. It drew freely upon an accumulated multidisciplinary stock of knowledge: books, professional journals, research studies, government documents, expert opinion, and media reports.

In examining these resources, emphasis was placed on the complexity of decision-making processes and attitudes toward end of life care decisions. Three paradigmatic taxonomies were formed: including (a) demographic, economic and social explanations (b) the impact of governmental programs (i.e., Medicare), and (c) religious-cultural explanations. Each makes explicit and implicit assumptions about why people behave as they do in end of life care decisions. However, no single definitive answer exists that entirely explains decision-making behavior or disparities. Each of these taxonomies is discussed in turn below.

## Death and Dying: Viewed Through Multiple Lenses

A common assumption in the U.S. is that everyone desires to have a peaceful death, one that is marked by advanced planning and settlement of one's emotional, family, and financial affairs. End of life care planning is a process of communication between an individual, his or her family members, and health care providers to ensure end of life health care is consistent with the patient's treatment preferences and values. This process typically results in a written instructional advance directive (or other legal procedure) executed by a competent person in the event the person becomes incapacitated. Although end of life advance care planning offers individuals the opportunity to express their health wishes, these wishes are left unspoken for 70% of Americans (Hilliard, 2013).

Studies involving culturally diverse patient's responses to end of life care planning began to appear in the 1990s. They have consistently demonstrated that there are significant disparities in planning and how and where we die among population groups. These differences persist despite extensive efforts to provide information and greater access to end of life planning options. The answer to the basic question of 'Why these differences persist?' has varied over the past six decades. A recent PEW survey (PEW, 2013) demonstrated that African Americans differed from non-Hispanic Whites in their willingness to complete advance directives and their desires about life-sustaining treatment. Both earlier and recent studies have found that significantly more African Americans and Hispanics wanted their doctors to keep them alive regardless of how ill they are, while more whites agreed to stop life-prolonging treatment under some circumstances. The literature suggests that support for a common notion of a good death that could provide structure for end of life care is lacking, particularly for African Americans. Invariably, we are lacking a comprehensive understanding about how the concept of a good death might vary across relevant populations or different cultures (Wicker, 2012). These studies offer descriptive explanations which are useful, but fail to provide insights for the underlying causes. In many instances, we are left with suppositions about religious, cultural, and socio-economic differences.

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Despite our many improvements in end of life care service options over the past two decades, many problems remain. Until we gain more insights, patients will continue to die prolonged and painful deaths, receive unnecessary, expensive, and invasive care that only contribute minimally to extending life, its quality, or preferred death experience. Much remains to be learned about effective means to incorporate patient preferences and to accommodate cultural differences at the end of life. At this article's conclusion, we outline steps to take us beyond normative data which helps to illuminate who is impacted to explaining why and how to design changes in our social and institutional support systems.

## Demographic Disparities

Health disparities across U.S. population groups are not a new phenomenon. So, it comes as no surprise that this is also the case with end of life care decisions. Since the early 1960s, our Nation has conducted major efforts to identify and address health care disparities. This arose out of social justice concerns and reflects genuine efforts by both the public and private sectors to reduce health disparities. Although the term is often interpreted to mean racial or ethnic disparities, many other dimensions of health disparities exist. Regardless of the definition, the underlying conclusion is that systematic differences in population health status or delivery are inherently unfair. Moreover, the assumption is that these 'inequalities' do not occur naturally, but are attributed to some social or economic conditions (Unnatural Causes, 2008).

The field is replete with scholarship documenting the extent of health disparities in the U.S. and the contributing demographic factors. Similarly, differences in end of life care decisions are well documented in income, education, environmental, economic conditions, health behaviors, life style patterns, access to care, as well as differences in the levels of quality care received. End of life care disparities have also been observed by geographic location, age, gender, and disability status (Atrash, 2003).

A common linking thread behind these disparities is that U.S. minority groups experience poorer access to medical care and services than their White counterparts. For example, even after adjusting for socioeconomic status and access-related indicators, African Americans are less likely than Whites to have primary care providers. Although previous research has shown that these factors create real barriers to care and services, they do not tell the whole story (Welch, 2005).

In May 2006, Caring Connections, of the National Hospice and Palliative Care Organization (NHPCO), conducted two African American end of life focus groups in St. Louis, Missouri. Group participants discussed their general feelings and issues regarding end of life thinking and planning. Most participants were unaware of the true meaning of advance planning, using it interchangeably with end of life care, which they connected with life insurance and funeral planning. Many misinterpreted the materials they were given, and thought that advance care planning referred to an agency or organization where all advance directives are stored. It was noted that there was significant distrust in the focus groups that even if preferences are specified in writing, that the medical professional in charge would not honor them (African American Outreach Guide, 2008).

Many African American remember the days of segregation, Jim Crow laws, and violence towards their people. Many African Americans are deeply distrustful of the government and the health care system, a distrust that is rooted in both historical and present day experiences. For example, the Tuskegee syphilis experiment was an infamous clinical study conducted between 1932 and 1972 by the U.S. Public Health Service to study the

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natural progression of untreated syphilis in rural African-American men in Alabama. They were told that they were receiving free health care from the U.S. government while purposely left untreated. Similarly, there is the case of Henrietta Lacks (August 1, 1920 – October 4, 1951), an African American woman who was the unwitting source of cells from her cancerous tumor which were cultured to create the first known human immortal cell line for medical research. This is now known as the HeLa cell line.

The literature is clear that there are historical and present day obstacles to reaching all population groups equally. There is considerable anecdotal evidence supporting the conclusion that working-class people, who constitute the majority of African Americans, feel more uncomfortable and less prepared in dealing with middle- and upper-status professionals than they do in dealing with persons of equal status. Moreover, poor people, as a class, frequently mistrust traditional bureaucratic institutions that have "mistreated" them, or lack confidence in their ability to communicate their concerns and problems in terms understood by doctors (Smith, 1997). C. P. Jones (2000) has proposed a framework for understanding how social class and social conflict influence health outcome on three levels: (1) perceptions of adhering to institutional processes in the face of need, (2) differential assumptions about the abilities, motives, and intentions of others based on race or status, and (3) the internalization by the under-privileged of concepts of 'whiteness', self-devaluation, resignation, helplessness, and hopelessness.

## **The Growth of Hospice Care: Understanding the Medicare Impact**

Medicare data over the past 50 years have shown that having equal health insurance coverage does not necessarily solve the disparity problem. Racial and ethnic minorities have lower utilization than whites, even when insurance status, income, age, and severity of medical conditions are comparable (Smedley, Smith, & Nelson, 2002). Among Medicare beneficiaries, for example, significant disparities persist in health care despite the clear intent of the law to provide equal access to medical care, regardless of race, income, or location of residence. Upon reaching age 65, virtually all Americans are eligible for Medicare, making it uniquely a universal medical insurance program. Medicare also provides the same benefit package to all beneficiaries. Further, the vast majority of health care providers and institutions participate in the program, which in theory, should help ensure that minority beneficiaries have equal access to services (Eicher, 2005).

For Medicare hospice patients who have a prognosis of no more than six months of life, covered services range from in-home care, to stand alone centers, to special wings in hospitals. The program does nothing to artificially lengthen or shorten life, focusing mostly on a patient's comfort. People on Medicare account for the vast majority of U.S. deaths and care in the last year of life. This care accounts for roughly one quarter of Medicare's budget (Sedensky, 2009; Riley, 2010).

Indeed, the Medicare program has significantly improved access to end of life care services for all segments of the elderly population, especially for African Americans. In the 1980s, the National Hospice Organization (NHO) Task Force on Access to Hospice Care by Minority Groups, determined that there were no significant national studies about access to hospice care to non-white groups. The most significant hospice research available was the National Hospice Study, conducted by Brown University (Mor, et.al 1988). This research was part of a study mandated by the U.S. Congress to compare the cost and quality of hospice care to that received by similar patients in conventional care settings. While not providing patient racial or ethnic characteristics, it did describe the racial makeup of primary care givers and volunteers. According to the study, only 8.1 percent of primary

caregivers in home health agency-based hospices were non-white, as were 5.3 percent in hospital-based hospice, and 2.7 percent of all hospice volunteers (Harper, 1995).

Since then, hospice care has grown from about 25,000 privately funded patients in 1982, when Congress approved coverage under Medicare, to 1.45 million people in 2008. As of 2010, hospice use was highest among White Medicare decedents (41.8%) followed by Hispanic (32.9%), African American (30.8%), Native American (29.8%), and Asian American (24.5%) ethnicity. Medicare hospice use grew substantially among all these groups between 2000 and 2010 (MedPac, 2012).

Even with Medicare's historic achievements in extending greater access to health consumers, marked disparities persist in treatment and health status. For example, the 2002 Institute of Medicine report, *Unequal Treatment*, found that minority beneficiaries fall short of Whites on many measures of health status. Blacks have shorter life expectancy at age 65 than Whites (by 1.8 years), and African American and Latino beneficiaries are more likely than Whites to have chronic conditions, such as hypertension and diabetes (Arias, 2012). These lingering differences are pointed to by social-cultural theorists as indications of wide diversity in cultural, environment, community, and other factors that are not readily apparent in aggregate Medicare program data.

At first glance, America is making great strides toward a medical and cultural shift in its approach to end-of-life care: More and more health care providers are recognizing the benefits of hospice, more people are dying at home, and many health care organizations are institutionalizing the discussions between providers and patients that would help patients formalize their wishes for end of life care (PEW, 2013). But, pull up the curtain on these statistics and the drama that unfolds tells a very different story. End of life continues to be characterized by aggressive medical intervention and runaway costs. While fewer individuals are dying in hospitals than in the past and more are receiving hospice care, more patients are receiving care in an intensive care unit in their last month of life and a growing number are shuffled around between different care sites in their final three months (Adamopolos, 2013). This has led many analysts to conclude that these existing patterns of care do not meet the needs and preferences of terminally ill patients.

## Religious and Cultural Explanations

Much of what we have learned about death and dying is informed by the fields of anthropology, sociology, and psychiatry. Death is a process that involves an interaction among individuals and group behaviors. The social context is illustrated by the fact that all cultures develop beliefs and practices regarding death in order to minimize its disruptive effects on the social structure. These cultural practices influence how members of a particular society react to their own death and that of others (Hooyman, 2011).

Religious beliefs are also key factors that interact with age and cohort to affect attitudes toward death. For instance, in all age groups, individuals who hold the strongest beliefs in an afterlife have less anxiety about dying. Religious people are less fearful about the unknown and view death as the doorway to a better state of being. Those most fearful about death are irregular participants in formal religious activities or whose belief systems may be confused and uncertain (Cicitelli, 2006). Religion can either comfort or create anxiety about an afterlife, but across cultures, it offers one way to try to make sense of death.

From Africans initial embrace of Western religions, while retaining elements of their own native traditions, the evolution of the Black church into today's modern religious practice remains the backbone of



African American communities (African American Outreach Guide, 2008). In African American faith communities, members seek out everything from spiritual guidance to relationship counsel, to adult vocational education programs, to guidance in voting in political elections. Each African American religious denomination takes great pride in its ability to hold together its congregation even in the gravest of times, as exhibited in the 1960s civil rights movement. As noted by famed Mississippi author, Clifton Taubert:

*'It was closer to our hearts than our homes – The Colored Church. It was more than an institution; it was the very heart beat of our lives. Our church was all our own, beyond the influence of whites, with its own societal structure.'*

A number of studies have indicated that religious beliefs have a significant influence on African American decisions and practices during the end of life. In some cases, African Americans perceive advance directives and palliative care measures as 'giving up hope' or not respecting their religious or personal values. For example, African American elders are more likely than Whites to believe that God is the ultimate decision maker regarding the time, manner, and place of death, and to have religious prohibitions against limiting life sustaining treatment (Johnson, 2005).

Clearly, the role of the church in the broader African American community can yield insights into the personal preferences about end of life treatments. Most White mainline Protestants (72%), White Catholics (65%) and White evangelical Protestants (62%) say they would stop their medical treatment if they had an incurable disease and were suffering a great deal of pain (PEW, 2013). By contrast, most African American Protestants (61%) and 57% of Hispanic Catholics say they would tell their doctors to do everything possible to save their lives in the same circumstances (PEW, 2013). On balance, African Americans and Hispanics are less likely than Whites to say they would halt medical treatment if they faced these kinds of situations.

## Conclusions

Is it a utopian dream to believe that, at some point, in our multicultural-racial society differences in end of life care preferences, as well as other health disparities, will be fully understood and addressed? Perhaps not! We clearly have learned that many of these problems reflect core political, economic, and social-cultural factors, some of which our society and leaders are not eager to take on. This does not mean, however, that there is little or nothing that can be done. This examination of the current state of knowledge suggests that end of life care decision-making is multidimensional and any attempt to explain disparities must approach it from multiple perspectives. In doing so, we can better assemble the mosaic of the population being served. This is a 'picture' where the population's needs, wants, deficiencies and cultural diversities are pieced together in an interlocking way in developing more effective programs.

The essential steps in making this a productive process first requires that scholars use mixed research methodologies to examine the impact of religious behaviors and other social-cultural factors on end of life care decision making by African Americans. Both qualitative and quantitative techniques should be employed for collecting and analyzing information. The overall strategy should follow a Community-Based Participatory Research approach (CBPR), which uses a partnership to research. It equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process and in which all partners contribute expertise and share decision-making and ownership. The aim of CBPR is to increase knowledge and understanding of a given phenomenon and integrates the knowledge into interventions, public policy, and social change to improve the health and quality of life of community members (Wikipedia).

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Second, though initiatives have been implemented in some areas, more culturally sensitive education is needed to increase awareness of end of life care services and its benefits. Some studies suggest that cultural diversity among hospice staff may influence diversity among hospice patients (Rhodes, 2006). As we become an increasingly diverse society, we need to bolster current educational efforts to improve cultural competence among health care providers. Overcoming the health disparity gap will require better patient education, better tools for patient engagement, and increased provider awareness of population-specific barriers to care. Providers will need to improve the skills required to care for patients from dissimilar backgrounds and languages. Admittedly, the effectiveness of cultural-competence training remains to be fully tested, but its potential benefits should not remain unexplored (Peterson, 2009). Ann C. Klassen and her colleagues captured it well when they conclude that “..... Caregivers cannot undo a patient’s past experiences, but they can be aware of the influence of those experiences on current decisions and well-being” (Klassen, 2002).

Third, many public and private efforts frequently focus on persuading people to change their behaviors and perceptions of end of life care to make it more ‘logical’. This approach fails to challenge the medical and social structures and place primary responsibility on individual choices. This is particularly so with African Americans who have encountered discrimination (both overt and covert), mistreatment, and suffered inequalities. These have been powerful and frequently systematic experiences that have been woven into cultural experiences and are not easily dispensed. Moreover, given the powerful influence of our environment, people cannot be expected to change patterns of decision-making through individual behavior alone. Rather, any solution that public policy officials test must also consider changing community environmental situations (Lavery, 2005).

Fourth, we need to develop more sensitive criteria for defining disparities. Definitions of racial and ethnic disparities fall along a continuum from differences with connotations of simply being different to those that result from discrimination. Where along this continuum does one decide that a racial difference becomes a disparity is subjective? The most recent evidence suggests that the magnitude of the injustice is generally proportional to how much control a person is perceived to have over the root cause of the difference. The degree to which one sees environmental factors and the social context as shaping choices has important implications for the measurement of disparities and ultimately for directing efforts to eliminate them (Hebert, 2008).

Fifth, the research spectrum needs to be broadened. Older Americans also often provide elder care. Most frail adults who need help with basic activities live in the community, not in nursing homes, and receive care from family members, not from paid helpers. Older adults with disabilities who receive family care are substantially less likely to become institutionalized. African Americans, those in excellent or very good health, and those with frail spouses or parents are especially likely to engage in care-giving activities. Nearly seven in eight adults age 55 and older with frail parents serve as family caregivers (Johnson, 2005).

Finally, despite the political uproar about ‘death panels’ that occurred in the 2009 presidential campaign, some private insurers have begun to bypass the political process, and begun reimbursing doctors for ‘advance care planning’ conversations as interest in them rises along with the number of aging Americans. People are living longer with illnesses. Many want more input into how they will spend their final days, including whether they want to die at home or in the hospital, and whether they want full-fledged life-sustaining treatment, pain



relief, or something in between. Some states, including Colorado and Oregon, recently began covering these sessions for Medicaid patients (Belluck, 2014). But far more significant; however, Medicare may begin covering end of life discussions if it approves a recent request from the American Medical Association (AMA), the country's largest association of physicians and medical students. One of the AMA's roles is to create billing codes for medical end of life conversations and submit them to Medicare. If Medicare adopts the change, its decision will also set the standard for private insurers, encouraging many more doctors to engage in these end of life care conversations.

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