

International Perspectives

Death and Dying in the Black Experience:

An Interview with Ronald K. Barrett, PhD

*In this interview with Innovations Associate Editor Karen S. Heller, PhD, Dr. Ronald K. Barrett, PhD, an expert on African American funerary customs and practices, as well as the ways in which people of African ancestry in other countries traditionally cope with death and dying, comments on how health care professionals might be more helpful to black people when a loved one is near death or has died. [Citation: Barrett RK, Heller KS. Death and dying in the black experience: An interview with Ronald K. Barrett. *Innovations in End-of-Life Care*. 2001;3(5), www.edc.org/lastacts]*

What sparked your interest in studying the traditions associated with death and dying in the African American community?

I became interested when I taught my first Death and Dying course and noticed little or no information in the literature about African Americans. I thought that was odd.

Growing up as a child within the black experience, funerals were very much a part of my life and my earliest memories. I remember the experience of people dying, of many funerals, and the importance of family gathering for funerals. When someone died, my mother and grandmother became very preoccupied with preparing meals, which they were going to send to the neighbors, or to whomever it was who had suffered a loss. One of my earliest memories, when I must have been about six years old, involved a traditional wake I attended with my family. The casketed remains were set up in the living room of someone's house. I can vividly recall the emotions of that experience. I can also recall on many occasions my mother and grandparents having to leave us to travel great distances to go to funerals.

Even though it was a part of my cultural experience, there were many things about black funerals that I didn't quite understand. I didn't understand the emotionalism or the priority that blacks gave to funerals. I can remember, throughout my school years, learning about how white middle-class funerals were done, and contrasting that with my own experience. I felt I had to reconcile the differences between the ways funerals were depicted on television and in the majority culture, and what my own experience was of black funerals. As I began my research into black funerals, I was able to understand and become much more at ease with my own experience. I was able to understand the historical origins and appreciate the sociocultural significance of many of the elements of black funerals. I have now spent the last ten years researching the funeral rites of African Americans and people of African ancestry in other parts of the world, including the Caribbean and West Africa.

The Diversity of "Black" Experience

Through my research, I have grown to appreciate that African Americans are only one slice of the

black experience. I find that it's helpful to make a distinction in terminology –"blacks" can be defined as all persons of African descent, whose genealogical connection is to Africa, and in particular West Africa. "African American," on the other hand, is a term that has become much more politically correct to use in referring to blacks in the United States, people whose sociocultural roots are in the North American experience, but who are of African descent.

I think it's an important distinction to be made because blacks who reside in other parts of the world, on the African Continent or in the Diaspora, have different and distinct histories and cultures. For example, Jamaican blacks are very distinct from African Americans in the United States; their experience is deeply rooted in a culture that's very different from that of African Americans. Jamaicans have a strong sense of nationalism and don't want to be confused or lumped together with all blacks, nor do people from Guyana, Trinidad, Barbados or elsewhere want to be identified inappropriately as coming from another country. So, generalizing about "culture, race, and ethnicity" with regard to black experience overall is very difficult, if not somewhat misleading. It is important to recognize and honor those national and sociocultural distinctions.

In an article I wrote about contemporary African American funeral rites, I spent a lot of time trying to answer the questions, "What are some general ways that blacks respond to death and dying? What are some general things that can be said about funerals? What are some general things that can be said about attitudes, beliefs, and values?"¹ I found that question very difficult to answer stereotypically because there's much heterogeneity within the black experience. Although in general, blacks share many core beliefs, in Jamaica, Barbados, many of the Caribbean islands, and in other parts of the world, you will find different funeral rites and idiosyncratic ideas about death and dying. For example, in West Africa, the bereaved want to participate in bathing the body and other funeral rites. Similarly, Jamaicans insist on assisting with closing the grave, whereas African Americans have grown accustomed to delegating these chores to the funeral directors, and the bereaved play a more passive role.

Thus, in considering which aspects of funeral rites and beliefs about death are common across black experience, I find it helpful to use what I call an "inferential model," which looks at the relative influence of three variables: cultural identification (the extent to which a person identifies with traditional black values, and embraces their cultural roots in Africa), spirituality, and social class.²

When communicating with blacks in the United States about end of life care, it is important for health care providers to elicit from patients (and their family members) how they define their cultural heritage, and other factors which may influence the degree to which they are loyal to their cultural traditions, such as the length of time an individual or their family has lived in the United States, the region they are living in, and whether they are living in an urban or rural setting.

I tend to think that our formative experiences may be more enduring, and may have a stronger impact on our choices, conscious and unconscious, than our later experiences. So, in trying to understand the values of particular patients and families that bear on particular medical decisions near the end of life, it may be helpful to learn not just what the patient's religious and cultural affiliation is now, but what were the beliefs of the family of origin. Health care professionals might want to ask, "How were you raised? Were you raised Catholic? Baptist? In the Islamic tradition?" Those early experiences may greatly shape people's values, and may strongly influence their choices.

Research has shown that social class also influences the degree to which blacks follow traditional funeral practices. The affluent tend to move away from their communities of origin, and to become less traditional, whereas the poor are more likely to follow traditional practices.^{3,4}

Attention to Spirituality is Key

Blacks who are Afrocentric and traditional are likely to have a profoundly spiritual approach to dying. When someone dies, they might choose to hold the old "sit-ups" or wakes, and they would probably have what contemporary African Americans call the "home-going service," meaning that the deceased is "going home" to the spirit world.

The belief in an afterlife is a very common and fundamental aspect of death and dying in the black experience. But they also believe that the dead are not in a distant heaven, but rather still among us. Blacks generally believe that in times of crisis or need, and sometimes in times of joy, departed loved ones are smiling down on us, looking out for us, and assisting us. Thus, even though it is stressful to have a loved one die, people find comfort in the belief that loved ones who may not be physically present are spiritually present.

I think that the spiritual aspects of caring for people who are dying have been neglected in medical settings, and attention to spirituality is particularly important in caring for people of color. So much emphasis is placed on the physical care of the dying that spirituality is often overlooked, and health care providers do not always recognize that this should be an integral part of the continuum of care.

I was recently involved in a situation in which a member of my family was in the hospital, dying, for over a week, yet there was no attention at all paid to the patient's or the family's spiritual needs. At first, I politely waited to see when the chaplain was going to show his or her face. Then, I became indignant and angry and had to ask. Only then did someone on the health care team say, "Oh, yes, we can do that." Involving the hospital chaplain should not have come as a second thought. It would be ideal to involve clergy from a person's own faith community, but if that is not possible, then certainly make sure that the hospital chaplain calls or visits and is an integral part of the care team.⁵

For people of color, particularly for blacks, I would say that attention to spiritual needs should be a *necessary and essential* part of the continuum of care that is provided at the end of life. It is almost unthinkable that you can have an honest, intelligent discussion about death and dying, unless you deal with the centrality of spirituality in the black experience. It is a fundamental part of how black people process and reconcile the experience of death. So, it's very important to be sensitive to the centrality of spirituality, and to acknowledge and honor that in working with blacks and other people of color. Health care professionals need to allow for and affirm the diversity of experience surrounding death and dying and encourage people to do those things which are comfortable for them.

Given the sociocultural and economic heterogeneity among blacks in this country, and the risks of stereotyping, is it helpful for health care professionals to be aware of any widely held, traditional beliefs or practices that may come into play when a loved one is dying or has died?

As I've said elsewhere, generalizations about beliefs and practices may offer helpful guides, but "the map is not the territory" and stereotypes are not helpful.⁶ Each individual is unique, so even though I can make some generalizations, health care professionals need to find out about the particular family and patient in their care by eliciting information from them about their particular background and beliefs. That said, some generalizations may be made, which may serve as "landmarks" on a rough map of black experience related to dying and death.

Belief in the Sanctity of Life

Blacks as a group generally believe in the sanctity of life. They generally operate with the traditional belief that life is to be preserved at all costs. Belief in the sanctity of life would suggest that, in general, blacks would not be inclined to discontinue life-sustaining treatment, once it was started, if they perceived that decision as causing death. However, it is difficult to generalize about this; decisions about use of life support would differ from case to case. Similarly, blacks are not likely to be in favor of any artificial means of terminating life, such as assisted suicide, which they are likely to view as being sacrilegious.^{7,8}

In any event, such decisions would be arrived at through family consensus, in which many people would have to give their opinion and reach a comfortable conclusion about what is to be done.

Importance of Consensus in Decision Making

Black culture, overall, places a strong value on the collective. In collectivist cultures, people value "community," as a good in itself, and they believe in honoring members of their immediate community, especially the family. Thus, to make decisions without at least respectfully listening to and honoring other people's input is considered to be disrespectful.

Given that people may not always have the luxury of time in making medical decisions about gravely ill people, individual family members may be placed in a position of having to make these decisions on their own. However, not being able to consult with other people who are important to them often places greater emotional burdens on those individuals asked to make decisions about a dying relative. It's not that people don't want to take the weight, and don't want to decide. Rather, it would be considered offensive to other family members if just one of them rushed into decision making without at least considering what others thought and felt.

Health care providers often do not appreciate that these important decisions cannot comfortably be made until the family gathers and everybody has made their views known, and arrives at a comfortable position regarding the decision at hand. When caring for black patients and families, health care providers might build trust if they honored this approach to decision making, by anticipating and arranging for, when possible, many family members to be included in discussions and reaching decisions.

Gathering of the Family at the Time of Death

Typically, blacks feel a *very* strong sense of obligation to gather at the time of a death. So, when someone is dying, generally there is a call for anybody and everybody who can do so to get to the bedside as soon as you can. Elders and other members of the family gather for a prayer vigil, often physically encircling the dying person and giving them as much comfort as possible in making the transition to the next life.⁹

Death as Transition

The term "transition" is traditionally used by blacks to refer to dying. Only rarely would people say "the person died." Saying "the person transitioned," means they have "gone to the next life" and implies that the person has not left us; they have simply changed form. They're no longer physically present, and they've spiritually "passed" into the afterlife. The term "passed" also is frequently used to express this transition.¹⁰

Circle of Life and Death

Having said all that, I think that in general, blacks may be characterized as having a holistic view of

death and dying, in that birth and death are understood to be part of a cycle or continuum. In 1995, in a foundation piece that I wrote about blacks and death and dying, I contrast the cyclical view of life and death with the European/Western view, which is a much more linear model.¹¹ In the European/Western view, you are born and eventually you die. In the traditional black cultural experience, you're born, you die, and then you continue to exist in other realms. The circle is very commonly used in African art symbolically to represent life and is very common in figures referred to as cosmograms, which represent the continuance of life.

Death-accepting Versus Death-denying

Because they believe death is a natural part of the rhythm of life, blacks as a group also may be characterized as being death-accepting.¹² During my travels and studies in West Africa, I was fascinated to learn the way in which an ancient Ashanti folk tale explained the origin of death. The Ashanti, a people of the central region of Ghana, have a cultural tradition that goes back thousands of years. In their folktale, they tell that there was a time in which people lived forever. During that time, when there was no death, there also were no births. The people were very fascinated with the idea of being able to bear children, however, and they appealed to the gods and asked, "Can we bear children?" The gods refused, but after the people continued to beg and plead, the gods finally submitted, and said, "On one condition." The people said, "Oh, anything, we would do anything!" And the gods said, "Well, on one condition, that is, with every birth, there must be a death." And the people agreed, and so it was.

Interestingly, it is a very common belief among blacks today, regardless of where they are in the world, that when someone dies, a baby will be born.

So, believing in the cyclical dynamics of life and death, death is seen as part of the natural rhythm of life and may be more acceptable for that reason. Now, that does not mean that people are not going to pursue every option possible to survive and live long lives. But when death occurs, it is accepted as natural.

Nobility of Suffering

For many blacks, there's almost an acceptance, if not the glorification, of suffering as a good thing, that suffering is somehow noble.^{13,14} If Christian, they identify with Christ's suffering on the cross as being the most noble of experiences. This has relevance for how black people may report their pain and how accepting they may be that pain should be controlled well at the end of life. I've certainly heard discussions at many funerals about how people fought the good fight, and fought without the assistance of pain medication, just white-knuckled it. And there's somewhat of a glorification of that as being somehow a better way to go than people who have been medicated and thereby have chosen a "softer" way. Among blacks and other people of color, depending upon the particular theology that people believe in, there are some people who really identify the dying process and the critical moment of transition as being times of *necessary* suffering. Care providers need to be sensitive to that and help patients and their family members realize that pain and suffering may not be a necessary or desirable part of dying.

Please comment on how the history of discrimination and denial of full access to medical care, which blacks and other minorities have experienced, affects their willingness to trust that health care providers are acting in their best interests when they discuss the goals of care for a dying patient.

There has been such a history of betrayal, in which corporate interests have taken precedence over

looking out for the best interests of individuals and communities. We've seen it time and time again where corporations will deny the presence of toxic chemicals in communities, and then later we find that, in fact, they knew of risks and ignored them in the interest of their bottom line. Another example is the tobacco companies and the years and years of denial that cigarettes were dangerous to our health, have just recently come to the point of admitting that cigarettes may be detrimental to one's health.

On top of that, there are painful cultural experiences particular to blacks, most notably the Tuskegee syphilis experiments. As you may know, from 1932 through 1972, the US Public Health Service deliberately allowed a sample of 399 black men infected with syphilis in Macon County, Alabama to go untreated, even after effective treatments were available, in order to learn about the natural history of the disease.¹⁵ In 1972, a front-page article about the study in the *New York Times* caused a public outcry and an Ad Hoc Advisory Panel was formed to review the study. They found that the study was unethical and should be stopped at once. It was stopped one month later, and the following year, the National Association for the Advancement of Colored People (NAACP) filed a class action lawsuit, which ended with the US government giving more than \$9 million to the study participants, as well as free medical and burial services to all living participants. Four years later, in May 1997, President Bill Clinton issued an apology for this shameful piece of government behavior.¹⁶

This kind of experience, in which the government and health care institutions were complicit in the neglect of black health or contributed actively to it, is at the root of black mistrust of health care professionals and institutions. Blacks know that care providers, such as these nurses and doctors in the US Public Health Service at that time, have not always been trustworthy to make decisions in our best interest.

Cultural mistrust, it must be acknowledged, affects interactions between health care providers and most people of color, including blacks, Hispanics, and Native Americans, and most poor people, including some poor whites. It's not just simply the mistrust of whites and white institutions—although that's a big part of it—but it sometimes extends to mistrust of blacks and people of color who represent those institutions because of the cultural, historical legacy of stories and accounts that suggest you should certainly be careful with these people.¹⁷

The cultural mistrust of institutionalized systems of care is also complicated by the fact that most of those institutions are seen as "white," and many of those institutions have historically denied access to blacks and other people of color. Racism and racial prejudice is a reality in the history, cultural memory and present experience of many blacks and people of color. Personal accounts of being victimized abound in the black experience and make it difficult to trust or assume that others can and will treat you fairly or have your best interest at heart. A recent empirical study reported in *The New England Journal of Medicine* documents that blacks suffering from the same illnesses as whites often do not receive the same level or quality of care in many medical institutions.¹⁸ In my experience, it is productive for clinicians in such institutions to acknowledge these perceptions and feelings of being victimized and treated differently as the reality of blacks and other people of color.

Presently, a number of "white" institutions are involved in an unprecedented outreach to people of color, yet are finding their efforts less than fruitful. Since blacks have had unequal access to these institutions in the past, now many blacks may suspect their motives: Do these institutions have our interest at heart or are they reaching out simply because it is politically correct to do so? The irony is that in most cases, these institutions seem perplexed by this reaction. There may be a "credibility gap" in many of these institutions because although most say they welcome blacks, few have

identifiable black administrators, doctors, nurses, social workers, chaplains, or other health care providers, and few have blacks representing the institution to the community. In addition, the lack of attention to black culture and aesthetics in the institutional environment, including design, art, and food menus, in many health care institutions can contribute to a black person feeling unwelcome in those settings.

So it's about building trust. And the burden of proof is on the institutions, not the people of color they aim to serve. My own research and professional experience suggest that trust is hard to establish, yet easy to lose and destroy in human relations. People who have had a history of abuse, betrayal and discrimination will have a learned disposition to be guarded, distant, or mistrusting.¹⁹ In many ways, their mistrust serves to facilitate their survival.²⁰

What can you tell health care providers about how to build trust and be sensitive to dying patients and family members from minority populations?

Attention to emotional and spiritual needs would be very helpful, because it would show some attempt by these institutions to be more culturally sensitive. It would help if institutions were more flexible in order to accommodate the cultural practices of black families when a loved one is ill. For example, restrictive policies, such as "only two visitors" allowed to visit patients at one time create a barrier for families who are gathering around a dying family member. For black families, that kind of policy feels like an insult, because then families are left to choose: Who are the two most important people? It creates a conflict.

When my mother was dying in a critical care unit in which they had this policy, my family and I decided to pay it no mind. I'm tremendously grateful to the evening nursing staff for their sensitivity in allowing a collective of about 20 family members to gather in my mother's hospital room during her final hours. We made a prayer circle around her bed, held hands, and prayed for her. Then, we disbanded, so that we didn't disrupt the unit. Within a period of about 20 minutes, we were able to provide meaningful closure for everybody who was there because they allowed us to perform that rite. When the death did occur, we were tremendously relieved in feeling that we had been there, and had done everything that we could. We felt that even though she was comatose, my mother was able to feel our presence.

So, providing something as simple as allowing large numbers of family members to visit at once does tremendous honor to the cultural group and to the traditions of the people involved, as opposed to an institution saying, "I'm sorry. The rule is only two people, and you can only stay ten minutes."

"Keep It Real"

I am often asked by white health care providers if they can or should reach out to blacks in crisis. My answer is "yes," even though I believe that connections occur more easily between people of like backgrounds. However, because of the shortage of black care providers across the health care system, all professionals need to develop multicultural competence in working with an increasingly diverse population.²¹

I tell individual clinicians and those representing health care institutions that they should not take it personally if they are not received with open arms when they reach out to black patients and families in crisis. They will have a better chance of building trust for resolving situations that occur in end of life care if they lay the groundwork earlier, in all their dealings with people of color, through patience, persistence, and unquestionable sincerity. As brothers and sisters from the "hood" say

today: "Keep it real."

Like most victims of discrimination, blacks are keenly aware of prejudice in others and can tell instantly if someone is patronizing and lacks genuine sincerity about their welfare or well being. However, regardless of race or ethnicity, caregivers who are sincere and can connect on a human level during times of need can be effective in communicating with people of color. Both my professional and personal experience tell me that in times of crisis or need, people care most about being comforted by people whom they believe genuinely care.

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