PERSPECTIVE

The Importance of Spirituality in African-Americans' End-of-Life Experience

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A profound and moving spirituality provided emotional and psychological support for most terminally ill patients at Grady Memorial Hospital. The authors were able to trace the roots of these patients' spirituality to core beliefs described by African-American theologians. Truly bedrock beliefs often reflected in conversations with the patients at Grady included the providence of God and the divine plan for each person's life. Patients felt an intimate relationship to God, which they expressed through prayer. Importantly, almost all patients were willing to share their beliefs with the authors in long bedside interviews. This willingness to share indicates that physicians can learn about and validate such patients' spiritual sources of support.

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Crossing the cultural divide that separates many African-American patients from their physicians may be difficult, but is a pressing need when a patient is dying. The physician may envisage spirituality as likely to be powerfully important to such patients, yet be reticent to raise the topic. Some physicians may hesitate to bring up spirituality because of sensing their cultural distance from African-American patients, while others may feel that spiritual beliefs are highly personal and outside of the domain of medicine, or beyond their expertise. Our experiences with African-American patients at Grady Memorial Hospital led us to believe that discussions of spirituality could greatly enhance the doctor's ability to support a patient at the end of life.[1] When 2 of us, both white physicians, simply sat for a time and respectfully and attentively conversed about end-of-life care with 23 terminally ill patients at Grady Memorial Hospital in Atlanta Georgia, almost every patient willingly brought up spirituality. Taking the time to establish trust and a human-to-human bond with the patient naturally led to spirituality becoming a part of the conversation.[1] In these terminally ill patients, we think the human-to-human bond overcame cultural barriers that otherwise might inhibit such conversations. Our patients' words were poetic, and their beliefs were providential in time of need. We wish to share with other physicians what our patients told us.

We describe our patients' views from our own perspectives, those of 2 white physicians and 1 African-American chaplain. Although we ourselves come from somewhat different religious and cultural traditions, we believe that to understand and show respect for patients' spiritual views in the context of the patient doctor relationship are keys to providing excellent palliative care.

Every patient's spiritual beliefs may be unique in some way. But understanding may benefit from having a starting point. For us, the concept of core beliefs developed by Cooper-Lewter and Mitchell[2] provided the framework that fit our experience. As they describe in their classic book on African-American spirituality, core beliefs are "bedrock attitudes."[2] They are "most authentically expressed when uttered spontaneously in crisis situations." These authors describe themes that are present in African-American culture and that cut across both religious and socioeconomic lines. Some physicians may understand the core beliefs of African-Americans because they share this common cultural and racial heritage, while others may learn about these beliefs through study and relationships with individual patients.

As we searched the words of our patients for common themes, we found acceptance of illness was especially prevalent. Almost invariably, acceptance became possible through religious faith. Their acceptance emerged from 2 bedrock beliefs of African-American spirituality, belief in the providence of God, and belief that God is intimately present in each person's life. This encompasses the belief that whatever happens is part of God's plan. As one patient said, when told about a serious illness:

> To be honest, I thought about it for a few minutes and then I just talked to the Lord about it and I put it in His hand and took it out of mine. And that's a worry off of my mind. You know, you just sit there and worry about it. What are you going to do about it? Ain't nothing you can do about it.

Another patient described the role of faith in coping with adversity:

> I know that without faith I couldn't have come this far . . . Faith is very important to me because of the simple fact that without faith I probably wouldn't be (here) right now, without hope and faith and trusting in the Lord.

Belief in the providence of God has 2 key aspects: belief that God is in control and belief that God is the giver of all good things.[2] Our patients expressed both of these concepts. Many patients voiced the belief that God would decide their future, including their time of death:

> Up there, everybody has got a number that says when you will die. Believe in it. When it's time for the Lord to call you, it's time for you to go.
>
> We just got to keep going, going, going day-by-day. You don't think about dying . . . you know it's all up to God.

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This faith was comforting. It provided a sense of peace and an acceptance of the present. For many it also included belief that death was not the end, and greater things were to come in the next life:

> I don't actually fear death as I did in the past, because I know that's a deliverance. Death is a deliverance. Like this world outside of what we live in, it's about time for me to go somewhere else anyway. On another journey.

The belief that God is the giver of all good things as articulated by Cooper-Lewter and Mitchell[2] says that for every evil there is a counterbalancing good, or that God will "squeeze from the evil itself a literal blessing." Despite having a terminal illness, one patient listed her blessings:

> . . . let's put it to you this way, I know a lot of people who aren't here today. I know a lot of situations I had myself in and I'm still here. I've got all my limbs, I can speak clearly, my brain is still functional, I've got no holes in my body. I've got other stuff but hell, it could've been much worse. So my faith is here.

The theme of suffering has been noted in African-American spirituality[3]; however, our patients did not reject medical care because of their acceptance of illness or belief in the providence of God. Others reported that African Americans wish for more aggressive interventions than most other patients at the end of life.[4–7] Our patients seemed to find no contradiction between their spirituality and receiving care. One patient expressed her wish for life while yet accepting God's plan:

> I know I want to live a life—a long life. I'm seventy four now. I want to get that age again. Seventy four again . . . we'll see, ain't nobody want to die. You know nobody want to die. I can't understand people wanting to die. I want to live as long as the good Lord lets me live and you do too.

In addition to the powerful belief in God's of providence, African-American theologian Howard Thurman[8] proposed a second concept essential to faith: experiencing an intimate relationship with the divine. Our patients articulated this experience as well. One patient approaching death described a religious awakening:

> God is telling me something. Somebody is telling me something and I'm not listening. So I'm like . . . wait a minute . . . now, the other day I could barely see my mother and brothers and all of them came down from different places because they thought it was the end. And you know my eyes just opened. And just that night I was on my knees just praying and crying. I prayed . . . just cried and prayed. It just seems like something was in this room just lifting me. I changed spiritually.

Prayer was the primary means by which our patients practiced their faith, and also reflected their personal connection to God.

> I just pray every night and every morning. I just thank the Lord for letting me live to see another day, you know, and thank Him for, you know, for letting me go to sleep, thank him for waking me up and just thank him for everything, you know thank God I am still here, you know. I love Him, I love Him.

So acceptance through faith benefited our patients. It did not deter them from wanting to live or seeking medical care. But it provided meaning to the lives of persons, who were often materially impoverished. Terminal illness may bring forth anger and depression. We think faith in God's plan and the sense of an intimate connection to God helped patients to tolerate, sometimes overcome dark moments, like these:

> I would say well you know I've accepted this, you know, Lord you said that there was nothing too strong in His power that He could not do for me. At the same time I'm still ill, ill, ill, ill and you know I get angry behind it, but at the same time I knew that hey, no matter what, you have to accept this in your heart and know in your heart that it's going to be okay and that's what gave me a peace of mind.

These are the words of a few individuals, with particular life circumstances and a particular cultural context. We quote their words not to provide a generalization that fits all people of a particular race or culture, but to be a starting point in understanding the spiritual journeys of our African-American patients.

In our experience, for doctors to discuss spirituality in this depth is unusual even with dying patients. We think that establishing the human-to-human bond that facilitated these conversations reflected several elements. Out previous research at Grady Memorial Hospital suggested that a physician's honesty, kindness and patience were the main qualities that promoted trust.[9] These qualities relate closely to another core belief identified by Cooper-Lewter and Mitchell[2]—the equality of persons—the belief that every person is unique and worthy of respect. Demonstrating respect for a patient sometimes means to speak honestly, from the heart. This may be as important to building trust as a doctor's qualifications.

Understanding a patient's spiritual core beliefs could greatly facilitate the doctor's ability to honor the patient's wishes for end-of-life care. Additionally, bearing witness to a patient's faith is often a therapeutic act, whether or not the physician shares these beliefs. If comfort is derived through belief, the doctor can bear witness to this comforting nature of the patient's spirituality. Speaking to us about the providence of God and experiencing closeness to God seemed to aid our patients as they approached the end of life.

We acknowledge that physicians may not share the religious worldview of many patients. The physician may feel it is inappropriate to readily make offers, such as praying with the patient, that could be interpreted as an insincere effort to share someone else's faith. Remaining true to one's own beliefs is an aspect of integrity. Furthermore the training of physicians, while it ideally teaches them to be excellent listeners, does not prepare them to be spiritual guides. A physician could potentially harm a patient if she/he attempts to provide spiritual guidance with little training or experience.

A physician who wants to understand a patient's spiritual views may therefore feel tension between the desire to be fully present with the patient, and the desire to be true to oneself and one's appropriate role as a physician.[10]

For us, it is important to resolve this tension when caring for patients who derive support from a religious worldview and personal connection to God. We believe authentic, respectful understanding will be most supportive. *Authentic* means that one expresses feelings and beliefs that are congruent with one's personal values. More than an outer demeanor, it is an inner attitude. Being *respectful* honors the patient's dignity and is not intrusive.

With this in mind, the doctor may formulate a therapeutic solidarity: "It has helped me to understand how prayer is a comfort to you. I want to be sure that our medical treatments are always consistent with your beliefs and wishes." Or, if this is authentic, "We doctors may be a small part in the larger scheme of things, but I don't want you to suffer. I can make you more comfortable." Thus, the physician authentically and respectfully communicates within the context of the patient's spiritual beliefs, but without claiming to share them.

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