Concordance

How does a physician who is neither black nor white decide when race is a factor?

by Alok A. Khorana

As I write this, my patient K.W. is dying in a private room on the sixth floor of the medical center. This is his second week in the hospital. K.W. is eighty-two, and, by all accounts, he has led a full life. The other identities he has possessed (amateur musician, Mets fan, preacher, foster parent, horror movie buff) have dropped away, and to my eyes at least, he is defined as the patriarch of a large and supportive family. There's always someone in the room with him when I do my rounds: usually a son, sometimes a granddaughter, and on weekends, his daughter.

K.W. suffers from metastatic rectal cancer, and I have been his sometime oncologist over the past six months. I say “sometime” because K.W. has never received chemotherapy for his disease. His cancer was metastatic when first diagnosed, and his initial surgery was complicated by a wound infection. This took several courses of antibiotics, and several weeks of nursing care provided by his foster son, to heal. During the past months, his family brought him in three or four times to discuss starting chemotherapy, but each time there were complicating circumstances, and we never got around to starting. In the meantime, his overall condition deteriorated, and he reported increasing tiredness. More and more he stayed at home, pushing himself only to make it to church each Sunday. Over the last few weeks prior to being admitted, he stayed mostly in bed, eating very little. When he was finally brought into the emergency room by his family some days ago, he was delirious, with high fever and a cough, and appeared to be dehydrated.

The team of admitting medical residents, mindful of my admonition to treat metastatic colorectal cancer as a chronic disease rather than a terminal state, did not discuss a Do-Not-Resuscitate (DNR) policy. Mindful as well of my other admonition not to emphasize race, the staff identified him on his admission note not as an “80-year-old African American male” but simply as a “pleasant but cachectic 80-year-old gentleman.” During his first few days in the hospital, we identified a pneumonia in his right lung, likely caused by aspiration. Worse, we found that his metastatic lesions had progressed significantly compared with the last scan performed just a few weeks ago. We administered intravenous fluids and antibiotics. K.W.'s condition improved, but only to an intermittently awake state. Most of the
time he lay listlessly in bed, his eyes barely registering the images as his foster son flicked between BET and CNN on the overhead television. Over the next few days, I realized that it was highly unlikely that KW could improve much more, and I had misgivings about our ability to make him healthy enough to return home. Much as I hated to give up the idea of starting chemotherapy, I knew that my responsibility now lay in providing appropriate end-of-life comfort.

Making The Tough Decision

I had known the family for some months now, and over the past few visits had discussed the hospice option. I thought I had prepared them well for this final step in decision making for KW. I arranged for a family meeting and was pleasantly surprised to see the entire family show up: sons, daughter, foster sons, granddaughter. I discussed, openly, how gravely ill KW was and how unlikely he was to improve enough to be able to receive chemotherapy. I recommended hospice. The family listened, asked questions, discussed the issues back and forth, agreed in principle, but asked for some time. Since KW was still on antibiotics, I felt it reasonable to give them another couple of days to decide.

This was a mistake, as I discovered over the next few days. As I had feared, KW’s condition worsened, and he lapsed into longer and longer periods of unconsciousness. I repeatedly tried to arrange for a follow-up family meeting. It took three missed appointments—the son showed up for one meeting and the daughter for the other two; both refused to make a decision without the other being present—before I realized that this family was having trouble making a decision. One of the nurses on the floor finally figured out what the problem was: The family was fine with transferring KW to the hospice program, but they were unable to commit to a DNR order. This was not surprising. I had heard anecdotally about the difficulties of approaching African American patients and families regarding DNR orders, although I had previously taken care of several such patients without encountering this problem. A quick MEDLINE search led me to several studies documenting substantially lower rates of DNR orders in black patients. One large, communitywide study found that 18 percent of hospitalized white patients had DNR orders, compared with only 9 percent of blacks.

I have worked in the U.S. health care system now for less than a decade, but that has been time enough for me to become acquainted with the issues surrounding race and health care disparities in what is arguably the premier health care system in the world. I know, for instance, that African Americans and Hispanics constitute more than one-fourth of the U.S. population, but just over 5 percent of physicians and less than 10 percent of nurses. In my chosen subspecialty, oncology, the numbers are even more stark. The American Association for Cancer Research identifies just about 2 percent of its members as African American. Patients from these ethnic minority groups are therefore far more likely to be treated by health
care professionals from a different ethnic background: what researchers describe as a race-discordant physician-patient relationship.

I began to wonder if race discordance was important to my relationship with KW’s family. The Institute of Medicine (IOM) report Unequal Treatment (2002) described racial and ethnic disparities in health care in great detail. Although several factors are responsible for U.S. health disparities, the IOM report suggested that “bias, prejudice, and stereotyping on the part of healthcare providers may contribute to differences in care.” Presumably, such factors would be less likely in a race-concordant physician-patient relationship. They might also affect decisions about advance directives. Indeed, in a study of AIDS patients, nonwhite patients with a nonwhite physician were four times as likely as those with a white physician to discuss resuscitation preferences. This might be related to better interpersonal communication in race-concordant physician-patient relationships. In a study of audiotaped physician-patient conversations, race-concordant visits were found to be slightly longer and led to higher patient satisfaction.

Neither Black Nor White

As I read more, trying to gain some perspective, I discovered a big problem with the race-concordance literature: It didn’t apply to my situation. I am neither black nor white. I am brown, but not Hispanic. I am also not alone. International (or “foreign”) medical graduates (IMGs) account for one-quarter of this country’s physicians, an increase of 160 percent since 1975. IMGs also account for more than one-quarter of current physicians-in-training. IMGs are important when discussing race concordance: One-fifth of physician IMGs and fully one-fourth of trainee IMGs are Indian, as am I. The next seven most prevalent nationalities are Filipino, Cuban, Pakistani, Iranian, Korean, Egyptian, and Chinese. The only predominantly Caucasian nationality on this top-ten list is German (just 2 percent or less of IMG physicians and trainees). IMGs are also of importance when discussing health disparities, because 40 percent of primary care programs depend on immigrant physicians, and two-thirds of IMG residents serve in hospitals providing a disproportionate amount of care to the poor. In other words, a black patient is far more likely to encounter a nonwhite IMG physician than a black physician. In certain Veterans Affairs and county hospitals, one is more likely to encounter a nonwhite IMG physician than even a white physician. Also, consider this: Given the disproportionate number of Indians in the physician workforce as compared to the general population, every physician-patient relationship that I (and other nonwhite, nonblack IMGs) participate in is,
by definition, race-discordant. I found little in the evidence-based literature to help me understand the issues facing K.W.’s family because much of the literature analyzing race concordance specifically excludes nonwhite, nonblack physicians and patients. There is grim irony in the fact that well-intentioned researchers—including IMGs themselves—scientifically probing issues of race and health care are treating as invisible an entire subset of providers and consumers.

This was remarkably frustrating for me. From my readings, it appeared that mistrust of a predominantly white health care system, based on historical precedent, and poor communication were the biggest stumbling blocks to DNR among African American patients. Yet neither applied to me. I had been communicating well with the family for some months now, and I was confident that they trusted my medical judgment. Although indeed part of the medical system, my accent and skin color distanced me enough from historical acts of prejudice. Or, at least, so I thought. Was I wrong? Had I internalized the health care system’s prejudices? Did this family perceive me to be making medical decisions based on K.W.’s skin color? Worse, were they right? Did they think of me as if I were, well, white?

A Simple Rearranging Of Words

Finally, with K.W.’s condition worsening and my inability to guide his family to an appropriate end-of-life setting, I threw up my hands in despair and asked for help. The hospital where I work has recently developed a palliative care service, one of whose primary functions is to help families through difficult end-of-life decisions. Yesterday I called the palliative care team and explained the situation, expecting multiple family meetings before a satisfactory resolution. But only a day later, the white nurse practitioner on the palliative care service paged me to inform me that K.W. was now DNR and in comfort care and that she had already placed the orders in the chart.

I was shocked. How could she have helped the family transition to hospice so (seemingly) effortlessly, when I had been unable to do so for nearly two weeks now? “I called the son last night,” she said. “I knew him from a previous admission, and he was fine discussing issues with me over the phone.” But how did he make the decision? “Well, I helped him by not asking him to make the decision. I told him that his father was dying, that from my prior conversations with him I knew that his father wouldn’t want to be put through ultimately futile aggressive cardiac and respiratory resuscitation. He agreed, but asked for more time to discuss things with his sister”—the same temporizing measure that he had used with me.

She continued, “I met with him earlier today. I asked if he had spoken with his sister the night before, and he had. But then he started to stammer and gazed at the floor. It hit me then. He couldn’t bring himself to say it. So I gently said that we were going to recommend that his father be made DNR and have his primary team try and keep him comfortable, and I asked him if he had any objection to that, and,
of course, he didn’t.” A simple rearranging of words, and an emotional burden is lifted from a family that is having a hard time dealing with a decision.

Had she used a similar approach for black patients and families before, I asked. “Oh, we use it for a lot of the families we see that are struggling with this, black or white,” she replied. “If it’s emotionally difficult for the family, I never make them sign the DNR; I just obtain verbal approval. They think that by signing they are deciding life and death, when you and I know the disease is doing that.”

So there you have it. After all my hand-wringing and ruminating on race and race concordance, race was, in this case at least, a red herring. In trying so hard to not let this be about race, I had made it about race. For me, this revelation provided solace. There is no doubt in my mind that greater minority participation in the physician workforce is essential. But is moving toward greater physician-patient concordance a laudable goal? Race is, after all, a sociocultural construct. Should my sociocultural identity (immigrant, physician-scientist, Indian, bibliophile, Bollywood/Coldplay/Jay-Z buff) preclude me from taking care of patients like K.W., or L.F. (farmer, ex-veteran, white, Brooks and Dunn fan)? Should we start assigning our black patients to black physicians, immigrant patients to immigrant physicians, gay patients to gay physicians? Which sociocultural identity should be assigned priority when arranging for concordance? When F.G. (antique dealer, Caribbean American, gay) calls for an appointment, to which physician (black, immigrant, or gay) should our office staff assign her?

There are many, too many, problems of health disparities and discrimination in twenty-first-century America, but do we not close the doors to self-examination and self-improvement if we espouse concordance as a goal? I refuse to let go of my hope: Physicians are, if nothing else, educable. As health care providers and researchers, we are equally humanists and scientists; we betray both sets of principles if we are unable to move beyond our prejudices. We fail our craft if we cannot bring ourselves to look past the skin color or sexual orientation of a patient or, for that matter, the skin color or nationality of a physician. Zora Neale Hurston could have been speaking of an ill patient when she said:

I was and am thoroughly sick of the subject [race]. My interest lies in what makes a man or woman do such and such, regardless of his color. It seemed to me that the human beings I met reacted pretty much the same to the same stimuli. Different idioms, yes. Circumstances and conditions having power to influence, yes. Inherent difference, no.

Postscript

K.W. LIES UPSTAIRS. Tonight, or early tomorrow, he will die, or so the nurse taking care of him tells me. I have learned to listen to the nurses when they tell me such things. But he will die in comfort, and with dignity. Dying is never easy, but it can be made easier, and for K.W., we have made it easier. And he will die surrounded by family; a family relieved, semantically but also emotionally, of the burden of a difficult decision. There is solace in all of this too, is there not?