Race, Ethnicity, and the Patient-Caregiver Relationship

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ABSTRACT

Shortly before his death in 1995, Kenneth B. Schwartz, a cancer patient at Massachusetts General Hospital (MGH), founded The Kenneth B. Schwartz Center at MGH. The Schwartz Center is a non-profit organization dedicated to supporting and advancing compassionate health care delivery, which provides hope to the patient, gives support to caregivers, and encourages the healing process. The center sponsors the Schwartz Center Rounds, a monthly multidisciplinary forum where caregivers reflect on important psychosocial issues faced by patients, their families, and their caregivers, and gain insight and support from fellow staff members.

Racial discrimination is a pervasive problem with multiple damaging effects. It is naïve to believe that medicine is somehow immune to race-based practices, but there is a growing literature detailing poorer disease-specific outcomes in minority populations for a range of illnesses. A recent study in the New England Journal of Medicine has implicated physician prejudice as a significant contributing factor. The March 1999 Schwartz Center Rounds sought to explore the influence of ethnic bias on the patient-provider interaction and the quality of health care delivery. Using a different format with a current affairs video clip and an interactive panel discussion, participants were encouraged to identify the often subconscious racial prejudices which may undermine their relationships with patients. Staff members were challenged to think creatively about how institutions and individuals might promote “cultural competence” and a more equitable health care environment. The Oncologist 1999;4:325-331

CASE PRESENTATION
(from Nightline: “America In Black and White”)

The following case was taken from a March 1999 ABC Nightline News Special Report profiling institutional racism within the U.S. medical system. The report was motivated in part by a provocative study revealing racial and gender prejudice in physicians’ recommendations for cardiac catheterization. Published in the February 25, 1999 edition of the New England Journal of Medicine, the investigators observed a 40% reduction in catheterization referral rates for blacks versus whites despite controlling for cardiac risk factors, type of angina, stress test results, and other relevant variables [1]. Indeed, the discrepancy persisted even after adjusting for physicians’ estimations of each patient’s probability of coronary artery disease.

Reporter: Brenda Nixon is about to discover she needs emergency treatment to save her life. Ms. Nixon is also diabetic. She had been feeling fine until today, when she found out that the disease has virtually destroyed her kidneys.

Physician addressing Ms. Nixon: You now have to make a decision as soon as possible as to when you can identify how you want to be dialyzed and whether you want to move quickly to be transplanted.

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Schwartz Center Rounds

Reporter: For more than a year, while she was managing her day care center, Brenda Nixon's kidneys were failing. But her doctor never mentioned that she might need a transplant until a few weeks ago. Scared and angry, she came to see transplant surgeon Clyde Calender for a second opinion.

Ms. Nixon: I never felt I was that sick. I mean, because I honestly felt that if I had reached the stage of transplantation that I would have had that discussion by now. Suddenly, I find out that I needed to be on dialysis tomorrow!

Reporter: Within an hour, she had an operation to prepare her for dialysis. The next afternoon, she was hooked up to a machine that will keep her alive until she gets a kidney transplant. Dr. Calender says Ms. Nixon should have been put on a transplant list years ago. Waiting so long complicated her care.

Reporter addressing Dr. Calendar: How unusual was that case?

Dr. Calendar: Well, unfortunately, I think that this is typical. And I think that this is just the tip of the iceberg. She is an excellent example of the dynamics which result in blacks waiting for transplants twice as long as other ethnic groups. The fact is that we don’t treat black patients the same as we treat white patients.

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The Scope of the Problem and the Need for Cultural Sensitivity

Panelist: I am a transplant nephrologist here. I also direct the Office of Multicultural Affairs, formerly known as the Office of Minority Health Professions. One of the goals of our program has been to enhance sensitivity among the staff here as to what represents the appropriate standard of culturally competent care at our medical center. The community surrounding MGH is becoming increasingly ethnically diverse, and therefore, for us to be a cutting-edge medical center, we have to continuously improve our skills for delivering sensitive and competent cultural care. Virtually all of the colleagues that I have worked with here at MGH and across town at the Brigham and Women’s Hospital would say that we at the Harvard Teaching Hospitals deliver care that is blind to color and culture. They would say the standards across the board apply to people no matter what their ethnicity, gender background, or sexual preference. I think that one of the things that is clearly illustrated in this video clip is that there are blind spots—pockets of blindness that probably befall all health care providers. We all arrive at the bedside with certain inherent biases that we might not be aware of. The conclusion of the New England Journal of Medicine study is really quite striking. This is happening in medical centers that pride themselves on delivering excellent standards of care. To be aware that there might

A panel of five Boston clinicians was assembled to stimulate discussion. Four were persons of color. The panel consisted of the director of the Massachusetts General Hospital (MGH) Multicultural Affairs Office and the director of the Diversity Office at the Dana Farber Cancer Institute. Also present was a staff oncology nurse at the MGH Cancer Infusion Unit and a Medical Fellow interested in issues of racial bias. Discussion was facilitated by a social worker who serves oncology patients and their families at the MGH.

The discussion followed viewing of the Nightline headline story on ethnic bias in medicine from which the case was drawn. It is also succeeded by a description of a February 1999 New England Journal of Medicine article suggesting ethnic and gender bias influence physicians’ recommendations for coronary arteriography. Although Schulman et al.’s study and its reporting in the media have been criticized for poorly represented and overstated data, racial bias clearly exists [2].
One of the people who was asking the questions (she happened to be a white nurse) looked at her and said, “Oh I have not seen dreads before. Your hair doesn’t smell.” This was to someone the nurse was trying to get information from! I wouldn’t have said anything to the nurse after that. The person happened to be an attorney with a Masters of Public Health degree. She chooses to wear dreads.

**Panelist:** I agree with your point about helping people to think about how it affects not just their medical decisions or the actual options they might present, for instance, but also how it affects the art of medicine and how it affects one’s bonding. What kind of response can one expect someone to make when you are put in a position like that? Having worked in the field of child abuse, when I am out in a grocery store and I see somebody starting to slap her kid around, I think nobody asked me to come in here as a social worker to tell the customers how to act. Yet, “Lady, you need to be made conscious of what you are doing here and that other people care about it.” The question is: “How do you develop an atmosphere in which either the subject of the discrimination or the observer of the discrimination can clarify what is going on?” because nobody is going to change unless something is pointed out to them.

### Conscious and Subconscious Barriers to Cultural Awareness

**Nurse:** I think a lot of times we do things and think things because of ignorance, and I am always challenged by how we learn about our biases, because they are often so unconscious, and I don’t know the best way to uncover them. I don’t know what we can do as professionals or as a health care organization to understand what it is we might be thinking about a specific group. I remember taking care of my very first patient ever in nursing. He was a black man who was dying of lung cancer, and I was supposed to do a bed bath. I remember draping the patient, as I was taught, and I was trying to wash his arm. The washcloth was dirty every time I rinsed and I thought, “My God! Nobody has done anything with this patient!” I think I tried to wash his arm about ten times. It was stupid, but I didn’t know better. And I think that is the kind of thing that happens to people without being malicious in their intent. But as an organization, how do you get people to understand their biases?

**Doctor:** I think part of the problem that we have is that most of us focus on our job and what we’re doing, and dealing with subconscious things like racism is kind of hard. We ought to get up and say, “I’m a recovering racist!” or something like that. I certainly was raised in
Patient Bias Against the Care Provider

**Audience:** What would you do if the reverse happens, when the patient tells you that they don’t want you to take care of them because of your skin color? This happens, and it puts you in a very difficult position.

**Panelist:** I actually experienced it on the Infusion Unit, so I can relate to this. Someone’s i.v. pump was beeping, and I fixed it and told the other nurse that I had. When the other nurse went and finally got over there and was taking care of her patient, the patient said, “You know that aide was playing with my pump. I don’t know what she did.” The nurse corrected her and said, “No, she’s an RN and I asked her to do that for me.” She said, “Well, I don’t want her doing anything with it anymore,” and the nurse replied “Well, she’s a nurse, and if she needs to do something with you, if I’m not around it is going to happen the same way.”

**Panelist:** I think that’s a particular problem where the institutional mechanisms can play an important role. That’s the kind of thing that you offer up to a nurse manager or nurse administrator or the people who are in charge of running the unit. It needs to be addressed in no uncertain terms. I, for one, think such patients should be spoken to and told what kind of institution this is, what kinds of values this institution is invested in, what we represent and our mission statement. We deliver a certain standard of care, but it requires a certain investment and a commitment from our health community to be rendered in a good way.

**Panelist:** I was kind of taken aback because the person that was in charge at that point put the patient in an area where she was taken care of by the ethnicity that she wanted. I thought this was wrong because it encouraged prejudiced behavior. It shouldn’t be encouraged; it should be dealt with and not accepted.

**Panelist:** I absolutely agree with that idea that shaping care to someone’s bias is really very dangerous for the morale of the ward, as well as sending a message that this kind of thing is reinforced and OK. If you come here and you don’t want to be taken care of by women who deliver care services, then it is OK for you to have all-male care providers. I think that is a wrong response. I think this is an opportunity where we ought to have more systematic ways to educate all of our staff as to what is appropriate in terms of standards of care, particularly with culturally sensitive materials. I think looking at this tape and listening to the conversation that has ensued devolves into a discussion of race in America. The discussion addresses our comfort level about this dialogue and how we broach the barriers that are impediments to our having honest discussions that are not going to fly off in some angry direction. I think there are a number of opportunities for teaching and training on the unit that the staff ultimately grows from. And I think there is an even more generalizable concept that the institution as a whole ought to have seminars and workshops wherein we can all learn about how to have comfortable conversations about race.

Fostering Sensitivity in the Workplace

**Panelist:** I would like to raise the question that when an elderly patient comes into the hospital we treat them one way. We would think of ourselves as poor care-givers if, when a 35-year-old came into the hospital we treated them exactly the same way, or if a 5-year-old had come in after splitting their head open and treating them the same way. We take all the nuances of particular ages into account. I think that recognizing if you
have an 85-year-old African-American in front of you, you don’t call her by her first name and expect to get the same sort of information: this will help in her care. So you have to understand that and know that without that information it impedes your doing a good job.

**Panelist:** I think that as caregivers we need to hold each other accountable. We witness racism all the time, and I think when you witness the very subtle ways that it encroaches upon health care, you need to speak to that person, pull them aside and let them know, “Do you know what you just said?” or “What did you mean to say?” I think just making people aware because a lot of times people say things and they have no idea that they may have really offended someone. I think this would really help.

**Audience:** Have you tried that and had responses? I don’t mean to put you on the spot. I’ve been on the spot like that and was wondering whether you think it should be done but haven’t found a way to do it yet.

**Panelist:** Yes, sometimes I do let people know, and they act very surprised.

**Audience:** Oh really? And then where do you go from there?

**Panelist:** I usually say, “Don’t you think it would have been better?” or “Don’t you think this person would have responded better to you if you had done this?”

**Audience:** And then it gets better?

**Panelist:** Yes, I think it helps people out a lot, because it is very unconscious, as we were saying, and I’ve had really positive responses.

**Panelist:** I wonder if I could just give you one other example of an institutional way of making our hospital a little more comfortable for patients from all backgrounds. My administrative assistant went to the Cancer Resource Room, which is advertised as “the place where cancer patients and their families get in touch with information and resources.” She went through a number of books and articles and brochures, and they were all very informative and asked the coordinator if there were any bilingual materials or ethnically focused materials. What she got in response was “Well, we think they are in the back closet.” So my assistant went and did a net search on amazon.com, and I have about 15 titles here of ethnically-geared appropriate materials, both bilingual and based on a particular race and background. They might, in fact, address directly some of the issues—for example, the patient with breast cancer who happens to be an African-American woman. But I think, again not to disparage the Unit, but that lack of preparedness and resource provision sends the message to folks who are consuming care here that they are not as valued as consumers who are majority folk.

**Concluding Suggestions**

**Panelist:** Ask yourself, in any patient interaction, “Am I considering what this patient would want done?” Or conversely, “Would I want what I’m doing to this patient?” I think that will enhance one’s own humanity regardless of whether or not it changes the outcome of a particular interaction, and I think also, as was so eloquently mentioned, to keep your colleagues accountable to the way that they treat patients. We do it in technical aspects of care; we should also do it in this aspect of care.

**Panelist:** I would like to reiterate that this is an excellent beginning, and I think the fact that people are willing to sit here, though it is an uncomfortable topic, means a lot. None of us need to beat up on ourselves for not being where we would like to be in terms of giving patient care.

**Moderator:** I think the thing that has been made so clear to all of us—black, white, Asian, or whatever your background is—we all look at people and consider race, and we all have racial biases regardless of background. What I’ve learned is that we don’t wake up in the morning with thoughts of wanting to do racist things. These were ingrained in our behavior and are reflected in our decisions in practice. I think the issue is that all of us are capable of these same biases and it’s impossible to say, “It’s somebody else’s problem.”

**Discussion**

Racial discrimination is endemic, as is the injustice of being labeled the “wrong” color [3]. Although ethnic inequalities in health care are widespread, the preceding discussion clearly reflects a positive desire among health professionals to address personal biases and attempt to optimize patient care.
Disparities in Health Care

Studies have often been flawed by being poorly controlled for other factors that influence outcome. However, an increasing number of studies clearly demonstrate the large disparities in health care outcomes. Parham et al. reported from the National Cancer Data Base, comparing African-American women and non-Hispanic white women having epithelial ovarian carcinoma treated at the same hospital [4]. Controlling for age, stage, and residential income, African-American women were twice as likely as white women not to receive appropriate treatment and had a poorer prognosis.

It is all too easy for a disadvantaged minority to suffer from inadequate consent and suboptimal treatment. A succession of studies has also revealed the tendency of health care providers to stigmatize patients from different cultural backgrounds. Such patients are often perceived as nonparticipatory, uncooperative, poor historians, and reluctant to accept therapy. This is compounded by the fact that they are also blamed for this stereotype [1, 5, 6].

Awareness of Cultural Identity: One’s Own and Others

In its broadest sense, cultural identity is an integral aspect of distinct groups that are recognized by race, geography, age, education, gender, income, sexual orientation, taste, or character. It is typically associated with judgement and separation; “One tends to apply the term ‘culture’ to others and not to oneself” [7]. Despite this, defining one’s own cultural context is central to developing cultural sensitivity and intercultural awareness. Your relationship to your own culture, as well as to the dominant culture in which you work, influence your perspective. Whether blatant or subtle, there is an effect on the interpretation of symptoms, the meaning of disease, and the delivery of health care. These assumptions serve as the platform from which other ethnic groups and cultures are evaluated. Beyond language barriers, cultural nuances influence understanding, beliefs, and responses.

In addressing the problem, there are a number of helpful, cross-cultural strategies that can assist the health care provider to establish more effective and insightful interactions with patients. There is a growing literature which provides an empiric basis for understanding differences in culture. For example, understanding the Hispanic cultural notion of “simpatìa” improves physician scores reflecting positive interactions with Hispanic patients [8]. More traditionally oriented Latinos tend to conceptualize themselves as subject to nature, while Caucasians tend to see themselves as manipulators of nature [9]. Patients with a traditional orientation would emphasize strict gender role differences, rather than more flexible boundaries and stress strong family identity and loyalty, while modern-oriented cultures frequently emphasize individual autonomy [10]. Being flexible and matching one’s cultural style to that of the patient and attention to these details can create a reassuring sense of congruence and enables the sensitive delivery of care. Consulting culture-specific literature allows the health provider to move beyond broad generalizations about cultural differences, focusing instead on particular behavioral and social constructs. Patients and health providers sometimes hold widely divergent beliefs about the causes and treatments of disease [11]. These differences can affect health outcomes and need to be understood.

In the past, disease- and system-based learning have dominated medical education. However, in cross-cultural interactions, the inductive, or patient-centered, approach is often valuable. In this model, the patient, rather than the theory, is the starting point. This requires that the health care professional become a skilled observer of patient behavior in clinical settings. Sensitive exploring a patient’s understanding engenders a more complete sense of the values, assumptions, and expectations patients hold and effectively affirms patients’ dignity and intrinsic worth [12, 13]. Decisions are then based primarily on the patient and family, secondarily on the patient’s immediate social and community context and their wider ethnic identity. Stereotyping “culture” as “the rare, quaint practices of unsophisticated peoples” [14] and using outdated and inaccurate generalizations while attempting to be culturally sensitive are likely to reinforce negative biases [15]. Likewise, attributing correlates of social class and education to culture may also reinforce ethnic bias. Indeed, in studies of ethnic differences that controlled for socioeconomic status, many group differences previously explained by culture disappeared [16].

Challenging Discrimination

Discrimination is difficult to admit and difficult to change. The greatest thing that facilitates a change is...
tolerance of the differences between people. Health care providers must learn to ask themselves, “What are my biases and assumptions about individuals with this cultural background? Is my knowledge of this culture superficial or deep? Is my understanding personal, or theoretical and academic?” In essence, providers must honestly consider issues of racism and prejudice and face their own ignorance [17].

Tacit disapproval is too frequently misinterpreted as condoning unacceptable views and behavior. Frank prejudice can be isolated if there is a managerial will to challenge abusive discrimination. Political statements, professional codes of conduct and legal precedent clearly support action. Courteous containment is not enough [18].

CONCLUSIONS

Alarming disparities exist between the health outcomes of minority and non-minority populations. Ethnic bias among the providers of health care contributes to this effect, and such bias can be addressed. The first step toward dispelling racism is to realize that even the most well-meaning clinician can be affected. The sort of compassion that draws people into the medical profession together with careful patient observation and a willingness to learn can help a provider interpret a patient’s cultural framework and engender mutual understanding. Providers can constructively hold their colleagues accountable in the worthy pursuit of equitable health care for all. Personal awareness, education, and accountability make for an enriched experience of ethnic diversity and recognize cultural diversity as a strength in our institutions.

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REFERENCES