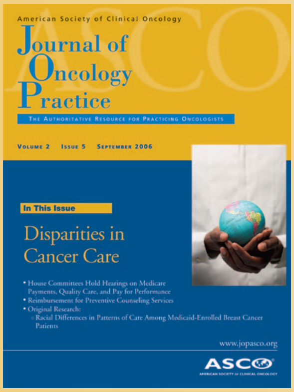

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# Disparities in Cancer Care

Two days before Christmas in 1971, then president Richard M. Nixon signed the National Cancer Act. It declared "the conquest of cancer a national crusade." Among other steps, the Act authorized the National Cancer Institute (NCI) to create a three-member National Cancer Panel, which would report directly to the president on the progress of this "crusade."

More recently, in 2004, the secretary of the Department of Health and Human Services (HHS) convened a group of leading experts to study an issue tightly bound to any effort to minimize cancer's impact on America—inequalities in Americans' access to cancer prevention and treatment measures. This group issued its report: Making Cancer Health Care Disparities History. It stated that "the president of the United States and the secretary of HHS have made closing the gap in health disparities a top priority for our nation." These two advisory bodies have had a major impact on informing the discussion of disparate access to cancer care among racial and ethnic groups.

Though the message of these bodies has been unambiguous, "what has been done is a different question," points out Harold P. Freeman, MD. He chaired the President's Cancer Panel (1991 to 2002), served on the HHS expert panel that studied disparities, and is the president and medical director of the Ralph Lauren Center for Cancer Care and Prevention in New York, New York. LeSalle D. Leffall Jr, MD, a professor of surgery at Howard University, is chair of the National Cancer Panel as a 2002 appointee of President George W. Bush.

The National Cancer Panel focuses on one theme each year. In 2005, the theme was the challenge of translating research findings into improved care; in 2004, it was survivorship. Under Freeman in 2002, the National Cancer Panel examined special cancer issues faced by American Indians of the Pacific Northwest. In 2001, the Panel called its report Voices of a Broken System. That report summarized the many barriers to care faced by millions of Americans, including those who belong to underserved minorities. Whatever the focus, says Leffall, "the issue of disparities is so important that it undergirds everything that we do." He adds that reducing disparities is a priority for "every major cancer group" and that, "you see this emblazoned on the headlines of nearly every program related to cancer."

Central to the issue of disparate access to and outcomes of care is the classification into a minority or racial population subgroup. The current literature, and the social constructs relevant to disparities across cancer, has imperfectly defined ". . .how individuals are routinely categorized in research studies. For example, most clinicians and researchers understand that the concept of race [or minority group membership] is a rather complex social construct that incorporates nonbiologic effects that have been poorly delineated in the United States," point out Olufunmilayo Olopade and her colleagues in their Overview of the May 10 issue of the *Journal of Clinical Oncology*. "With completion of the Human Genome Project (http://www.genome.gov/10001772) comes an understanding that human beings are 99.9% identical, but that the 0.1% difference may explain individual differences in cancer risk and response to therapy. . .Using self-identified race or ethnicity as a variable in research studies that identify genetic differences with respect to disease status or outcomes without a proper definition. . .could lead to spurious results that have the potential to propagate stereotypes."[1] This Review issue of the *JCO* was "devoted to developing ideas for achievable, practical solutions to reduce health disparities and to identify opportunities for research. Important articles explore the genetics and epidemiology of disparities in care and the disparate responses to cancer therapies.[2,3]

The present article surveys certain key themes related to the problem of disparities in cancer care and discusses governmental support for steps to address the problem. It will also relay the stories of several community oncologists who care daily for patients from traditionally underserved populations. These physicians will describe the challenges and rewards that come with serving members of diverse ethnic groups.

## The Poverty–Minority Group Cancer Connection

According to the NCI's Center to Reduce Health Care Disparities, "the burden of cancer is too often greater for the poor, ethnic minorities, and the uninsured than for the general population. Many ethnic minorities develop cancer more frequently than the majority of the US white population." Masses of reliable data illustrate that members of those minority groups not only develop cancer disproportionately, they also do far worse with regard to accessing quality care and surviving the disease. The data also support the role of poverty and poor education as being highly predictive for the disproportionate development of cancer and for worse outcomes.

Epidemiologist Nancy Krieger, PhD, questions the traditional viewpoint that focuses on the ways in which each person's individual "web" of risk and protective factors determines their risk for poor health in general, and for certain specific illnesses. Krieger, professor in the Department of Society, Human Development, and Health at the Harvard School of Public Health, advocates focusing on the larger forces that set those mechanisms into play. She looks for "the spider" that spins the web. The basic idea is that the immediate causes of illness (bad diets, smoking, and inactivity) are driven by larger forces such as poverty, discrimination, stressful jobs, and poor housing.

According to the 2000 US Census, African Americans constitute this country's largest "racial" minority. (The Census does not consider Hispanic origin a racial category; 12.5% of those surveyed self-identified as Hispanic.) African Americans accounted for 12.3% of the US population in the 2000 census, with Asians next at 3.6%, people reporting two or more races combined at 2.4%, American Indians and Alaska Natives combined at 0.9%, and Native Hawaiians and other Pacific Islanders at 0.1%.

The NCI reports that "African American males develop cancer 25% more frequently than white males" and face a 43% higher mortality rate compared with white men for all cancers combined. Furthermore, states the Center for Disease Control and Prevention (CDC), African American men "have more cancers of the lung, prostate, colon, and rectum than do white men. Overall, African American men have more malignant tumors and are less likely to survive cancer than the general population."

Likewise, notes Freeman, while "death rates for breast cancer have decreased over the last 10 years for both white and African American women, the comparatively higher death rate in African American women compared to whites has not diminished. I liken this to a car. The car may go faster but the back wheels cannot catch up with the front for structural reasons."

Hispanic women were significantly less likely to have ever had a mammogram than either black or white women, states the CDC.

Some ethnic groups experience a lower incidence of certain kinds of cancer than most Americans do. In many other cases, "some specific forms of cancer affect other ethnic minority communities at rates up to several times higher than national averages," according to the NCI. Here are some more illustrative findings:

- The overall cancer mortality rate among all American Indians and Alaska Natives (161.4 per 100,000 population) was lower than that for all racial/ethnic populations (205.5) between 1994 and 1998. However, cancer rates for American Indians and Alaska Natives varied greatly by region. For instance, those rates were higher in Alaska (248.9) and the Northern Plains regions (291.7) than in the United States overall. In those two regions, lung, colorectal, liver, stomach, and gallbladder cancers were the main contributors.
- According to the NCI, "American Indians experience the lowest cancer survival rates of any US ethnic group. Much of the disparity in cancer outcome is a reflection of type, timeliness, and continuity of cancer care rather than the disease itself."
- Asian American females are the first American population to experience cancer as the leading cause of death. Cancer has been their number one killer since 1980. One major problem among Chinese American women diagnosed with breast cancer is that about 22% of them rely upon herbal remedies for treatment. Significant numbers of Korean American women have never heard of the Pap test. Cervical cancer incidence rates are five times higher among Vietnamese women than white women. Korean American men have stomach cancer rates five times that of white men.

## Barriers Take Several Forms

The CDC states that "limited access to health care services and language and cultural barriers are primary reasons for the low rates of screening and treatment" for many minority groups. Although complex, "disparities are driven by three major forces," explains Freeman.

### 1. Lack of Resources

"Any poor person experiences a broad spectrum of problems that are universal issues for people of low income," says Freeman, "As doctors, we tend to look at the medical manifestations of being poor but that is incomplete. When you are poor, you not only have diminished access to medical care and treatment, you have poorer housing, less social support, and a risk-promoting lifestyle, with a greater likelihood of smoking."

"People who are very poor have different survival priorities," Freeman explains, "If you are worried about food, shelter, and avoiding crime, you are not going to think so much about getting a mammogram, especially if you can't pay for it."

"Poverty is the carcinogen," he says, "Poverty causes people to die early. It causes cancer and cancer can cause poverty if you need to get treated." He explains that today "the number one cause of bankruptcy in America is failure to pay your medical bills."

### 2. Cultural Issues

"These have to do with lifestyles, attitudes, and behaviors, as well as belief systems and traditions. If you live in a culture that is risk promoting, that will drive disparities," Freeman says, adding "your culture might shield you from risk, like Seventh Day Adventists. They don't smoke or drink and they're vegetarians. You don't have to join a religion to do these things though."

### 3. Social Injustice

"We don't have a fair society in every respect. Inequities, whether they are based on race or economic status, are strongly entrenched health care disparities," says Freeman.

Freeman explains that while race does matter as a determinant of inequities in health care, it is *not* a significant biological factor predisposing members of minority communities to worse cancer outcomes. "We have to look beyond categories at the real causes of the disparities," he says. "Why do blacks have a disproportionately high death rate from cancer? Twenty-five percent of blacks are poor compared to 8% of white Americans. So whatever poverty means is disproportionately affecting black Americans."

Freeman also mentions the considerable research that shows that even at the same economic level, "race somehow matters in how people get treated." A 2002 report by the Institute of Medicine (IOM) was titled "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care." In it, the IOM found that race is "in and of itself a determinant" of the quality of care.

### Equal Access to Prevention and Screening of Paramount Importance

Leffall and Freeman agree that the first step toward addressing disparities, the one with the greatest potential for impact, should be improved delivery of basic preventive and care measures to communities that have not enjoyed equal access to these measures. Leffall says, "If we can employ what we already know about women getting Pap smears and mammograms and men and women getting colonoscopies, we can eliminate many of the disparities." Freeman says, "I have personally suggested that we concentrate on areas where people are dying at higher rates from cancer and provide special education and access to screening; that we go where the real problems are."

## No Lack of Proposed Solutions, Little Government Funding

Despite all the official conclaves, Freeman states, "I don't think you can be serious about eliminating disparities without doing something dramatic to fix the health care system. It's not realistic." He cites the 46 million Americans with no health insurance and the 35 million with inadequate coverage. He believes that the most promising approach to creating some system of universal coverage will combine private and public coverage, as is happening in the state of Massachusetts.

Freeman maintains that from a cost-benefit point of view, cancer disparities cost this country tremendously. Virtually everyone who develops cancer will get treated, and it costs much more to treat those who come in with late-stage disease. "You can make an argument with the economically inclined that it makes sense to pay for early diagnosis through screening and treating people as early as is possible," says Freeman, "We are, however, far from that [situation]" today.

President's Cancer Panel member Lance Armstrong has stated that "with the record number of uninsured and underinsured Americans and increasing budget strains on Medicare and Medicaid, the cost of quality cancer care continues to divide those with access to the best cancer care from those left out of the system altogether. That's unacceptable."

He adds, "We are a country of ambition and resources and we know what is working. We must get information about prevention, detection, and treatment to everyone, regardless of where they live, how much they earn, or what they do for a living. Right now we are failing millions of Americans who cannot benefit from the knowledge and tools we already have." (Michelle Milford, Lance Armstrong Foundation, personal communication, July 3, 2006.)

## Physicians Enjoy Caring for Diverse Patients and Strive to Help Them Overcome Hurdles

Below, three oncologists who care for diverse patient populations describe their own experiences and insights. Although the groups that the physicians help vary, certain key themes emerge. One is that monetary issues loom large for these patients and cry out for resolution on a national scale. Another is the need for oncologists to allow extra time and attention for many patients from minority backgrounds.

Discussing the Native American patients who form a large part of her practice in New Mexico, Barbara McAneny, MD, says, "One of the hardest things for me is to slow down my normal pace so I'm not rushing them. I have to accept the fact that I'm not going to get anything done in a 15-minute office visit."

Sarah May, MD, cares for many Caribbean and Asian patients in the Boston area. She, too, finds that "when you're working with minority patients who have language issues, and also with other underserved populations, you need to take extra time. I used to frustrate myself trying to see patients with these issues in 15 minutes. It may take half an hour. Rather than getting upset anymore, I prepare for that."

## Awareness of Gifts Given and Gifts Received

*Sarah May, MD, Commonwealth Hematology Oncology, Quincy, Massachusetts*

Sarah May, MD, spends nearly a third of her time caring for patients from different cultures—in her case, people from the Caribbean and from Asia (primarily Vietnam). She received, she says, "zero training" to prepare her for working with diverse patient populations, though she has figured out certain key things.

One is that she will often have to expend extra time and effort addressing language difficulties and practical concerns, such as finances and transportation. For translation, her office generally uses paid translators or translations provided by a patient's relatives. "In general," she says, her Vietnamese patients' families "prefer to use a professional interpreter. They think that it's better care, and it is better care." The reason is that a patient who is reticent about discussing certain sensitive areas may feel even more reticent when a relative, often a younger person, is doing the translation.

"Cancer care is time intensive and complicated even when a person has all kinds of resources," May says, adding that it is doubly challenging when a person does not. Community oncologists treating diverse populations need to educate themselves and their staffs about resources that less affluent patients of any background may need. "If I didn't think about these issues, I might write a prescription for a person without prescription coverage. I also need to know if they have transportation" to come for treatments.

### Cultural Divides Can Complicate Care

May has found that caring for the whole person can be especially challenging when she faces a cultural divide. "It has surprised me when I've missed something," she says, mentioning one Vietnamese patient who was depressed. May referred her to a mental health provider, but the woman would not go. "She didn't want to talk about that kind of thing in that kind of setting. It's hard enough to talk about your emotions and it's even harder when English isn't your first language." In the end, another physician, an internist who is also Vietnamese, "picked up on her struggle and her need" and was able to help the patient with the depression.

### Special Challenges, Special Rewards

May finds certain special rewards in her work with patients born abroad. From her Vietnamese patients, she has learned about the war fought there, and even about life as a prisoner. "If you are curious, you can learn so much. I think that taking an interest in the place a person comes from and their traditions, is a gift to them." In return, she says, "I have felt very touched when they have traveled back to their country and thought to bring me a gift."

She also notes how rewarding it is to care for patients who deeply appreciate the cancer care that they receive. "Many of my patients see it as such a privilege; they don't take it for granted."

## Absorbing Native American Culture, Adapting to Help

*Barbara McAneny, MD, CEO, New Mexico Oncology-Hematology Consultants, Ltd., Albuquerque, New Mexico*

In New Mexico, the ethnic mix is complex. "Hispanics are the largest group here, non-Hispanic Anglo Americans are second, and then we have 18 Indian tribes. Ten percent of the state's population is Native American," explains McAneny. This rich mix of peoples drew her to New Mexico originally, and her patient population mirrors the state's demographic.

Like other oncologists with diverse patient populations, McAneny stresses that language barriers, while important, are only one contributor to a cultural divide that can greatly impact the kind of care a person receives. Other factors, relating to culture and worldview, play an equally important part in creating significant barriers.

### The Power of Language

"Among Native Americans, language is viewed as powerful. Certain things simply are not spoken of," she says. "If you speak the words 'breast cancer' and 'mammogram', they will often interpret that to mean that you are wishing that problem on them." They may also believe that the action of going for screening tests will draw cancer to them.

"You can't accept that viewpoint and drop the idea of screening, though," she says. To overcome such barriers, she has adapted her own way of interacting with Native American patients, and her practice employs people of the tribes who can successfully straddle the cultures. "We try to explain or have [the Native American employees] explain that our goal is to find the disease while it is early and fixable."

With words being viewed as wishes, the process of obtaining advanced directives from Native American patients can also pose a challenge. "If I say, 'Your grandfather has advanced lung cancer that is very widespread' and ask about how to handle his death when it comes, a relative may ask me, 'Why do you wish him to die?' That's their cultural translation of my questions."

By being flexible, McAneny has found an approach that helps her obtain the decisions she needs in a way that respects her patients' sensitivities. She uses storytelling. "I might say, 'When some people have cancers this bad and life just isn't good anymore, they only want to be comfortable and not to have a lot of machines attached to them.' Then the person might answer me, 'I think a person ought to do everything they can to live,' or they might say 'When it's your turn to go, you might as well just seek comfort.'"

Such decisions often fall not only to the ill patient or to his immediate relations, but also to tribal elders. "The tribe decides what is best together. Then my job is to carry out their wishes as best I can."

At times, she cannot find a meeting ground with patients. "If someone asks me to prescribe an herbal remedy for cancer, I say, 'No. That isn't what I do.' You don't have to abandon your principles."

Still, finding common ground whenever possible is her goal. She and her colleagues are now building a clinic in Gallup, New Mexico, which is the cultural and health care center for the Navajo nation. There, the oncologists are cooperating with native healers to incorporate both traditions. She gives an example of how the two healing practices can act synergistically. Patients often need to drive long distances for a prolonged period to undergo radiation treatments. They often undergo half the treatments and then just stop. They feel too discouraged by the long costly commutes. They dislike being in an Albuquerque motel, and they feel dislocated from home and family.

"We are building a traditional hogan in front of our new center. It's a dwelling for the medicine men to do their traditional healing rituals. If I can offer these comforting rituals to my patients instead of just telling them to come lay in a scary machine for 15 minutes, I can probably do a lot better for them."

### Seeing Each Patient As an Individual

"I try to hear what each person wants in terms of their own situation. I try not to pigeonhole folks in terms of their culture," says McAneny, pointing out that her Hispanic patients are as diverse as any group of Anglo Americans might be. "If you are a PhD physicist from Sandia National Labs, you are going to react like a PhD physicist whether you have Hispanic or Irish blood. On the other hand, if you're a rancher from a rural area and you haven't interacted a lot with the big health care system, you're going to be equally nonplussed whether you are Spanish speaking or an Anglo."

"I take what I am handed by each person and deal with them as an individual. Religion, culture, your grandparents. . . . Those things go into the mix for every single human being."

"The major impediment to getting patients adequate care is money and the fractured insurance system. A lot of my patients have Indian Health Insurance (IHS). The IHS depends on grants from Congress, and they never give enough. In New Mexico, we have 21% to 26% uninsured."

## Comfort for Patients When the Doctor Is "One of Them"

*Pedro Sanz-Altamira, MD, Commonwealth Hematology Oncology, Methuen, Massachusetts*

A native of Spain, Pedro Sanz-Altamira, MD (who often goes by "Dr Sanz") practices oncology in a Boston suburb. Almost half of his patients come from Latin America, mainly Puerto Rico and the Dominican Republic. He also sees one or two patients from Vietnam each week.

Sharing a common language and certain cultural ties helps him address the needs of his Latin patients. On the other hand, being of a different culture from his Asian patients creates certain challenges for him. "I don't communicate easily with them, and it is much more than a language barrier. They have a mentality that is hard for me to understand. I understand where the Dominicans are coming from but I can't relate the same way to Asian patients' thoughts about end-of-life issues, chemotherapy. Vietnamese people are often shy. And then it may just be my ignorance of their culture."

He speaks of two main issues that arise in dealing with patients from diverse backgrounds—culture (including language) and money.

Although Sanz didn't seek out a practice with many Hispanic patients, he says, "I am happy to be working with them and, although I don't know if it's true that I can help them more

### To Learn More

Finding information online to help with patient care for ethnic populations poses problems. As *JOP* Associate Editor Terry Mulvey, MD, says, "There is no one source to get patient information that is language specific and culturally sensitive at the present time. It is all hit or miss."

**To learn more about specific patient populations**

- The Vietnamese American Cancer Foundation: www.ungthu.org
- Native American Cancer Research: www.natamcancer.org
- Women's health site, www.maclearinghouse.com/catalogue, has limited breast cancer information in English, Spanish, Portuguese, Chinese, Creole, and Vietnamese

**To learn more about cancer care disparities**

- Search the CDC Web site for cancer care disparities: www.cdc.gov
- Read the IOM Report, Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care: www.iom.edu/?id=16740
    - The following page speaks directly to health care providers: www.iom.edu/CMS/3740/4475/4175.aspx
- Read the report issued by the HHS expert panel called Making Cancer Health Disparities History: www.**hhs**.gov/chdprg/pdf/chdprg.pdf

because we share a language, they feel that that is the case. They say things to me like, 'It's easier for me to tell you things that sometimes I don't tell to the other physicians.' They find the different languages cumbersome."

The sense of comfort and familiarity rests on more than language, Sanz says. "I understand a little bit of their habits and goals," he explains. He has observed that compliance with certain treatment plans sometimes proves harder for his Hispanic patients. "Some of it may be language related; some not. They may not think that certain things are so important. Maybe they are a little less strict in these matters. Or someone may have called to remind them about an appointment, but no one in the household spoke English and no one passed them a message. These kinds of things can limit the totality of the treatment."

Although a significant number of his Hispanic patients are comfortably well off, more of them have economic difficulties. "The money issue is important," he says. "It influences whether they are willing or able to pay for certain copays, for medications that aren't covered, for transportation. . ."

As do Leffall and Freeman, Sanz believes in focusing efforts to help poorer populations on proven methods to improve outcomes. He believes that the single most important thing we can do to reduce cancer is to support smoking cessation efforts and programs. Screening for cancers such as breast, cervical, and colon comes next on his list of priorities. And third, he says, are programs to improve access to the treatments themselves.

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