FEATURE STORY

Are Minorities Benefiting From Prevention Priority?

EDITED BY JO CAVALLO

Cultural differences, suspicion about the health care system, and lack of access to good medical care impact how cancer affects minority groups.

During the past decade, there's been somewhat of a shift in cancer—treating the disease now shares the spotlight with prevention. No one can pinpoint the exact moment the movement occurred, but today, cancer prevention and control programs are on the rise.

More hospitals are putting funds toward research projects and outreach programs, and more nonprofits, like the American Cancer Society, Susan G. Komen for the Cure, and the American Society of Clinical Oncology, are actively educating and facilitating change among the general public and health care professionals.

But with this new focus on prevention comes questions about the reach of the message—particularly its reach across ethnicities. Prevention in minority populations has been met with challenges unique not only to each group's cultural beliefs, but also to language, socioeconomic status, and other factors. Now, nonprofits, hospitals, and average citizens are taking the prevention message straight to minority communities.

What's the Real Barrier?

Cancer incidence in the general population has remained stable over the past decade with a steady drop in mortality rates observed during the same time. But for minority populations, incidence and mortality rates remain disproportionately high overall for certain ethnic groups in specific cancers, making prevention critical in these areas.

"There's no question that a substantial number of cancer cases can be prevented," says Robert C. Young, MD, chancellor at Fox Chase Cancer Center in Philadelphia who also created the center's comprehensive cancer prevention program. "Smoking cessation and tobacco use of all kinds being the major player, but by no means the only one. [Health screenings] and early diagnosis, exercise programs, and dietary management all play a significant role."

A general mistrust in the medical system is often cited among the top reasons

why African-Americans and other minorities don't take advantage of cancer prevention strategies or participate in prevention studies. A cultural belief that individual choices don't influence disease outcome is also a barrier in prevention strategies. For many, it comes down to money and social circumstance.

"If you're struggling to make ends meet, prevention seems like a luxury compared to some of the necessities," says Derek Raghavan, MD, PhD, director of the Taussig Cancer Institute at the Cleveland Clinic and co-chair of ASCO's Health Disparities Task Force. "I personally believe that the biggest factor is competing interest for their time. So a woman who's struggling to keep it together doesn't have time to get to the mammogram place. If she has time, she may not have the money."

The biggest stumbling block to eradicating the disparity in minority groups, say some experts, is the lack of a national health care system.

"Academics and public health officials are getting better at crafting messages that are more meaningful [to minorities]," says Deborah Erwin, PhD, director of the Office of Cancer Health Disparities at Roswell Park Cancer Institute in New York. "Poverty and the lack of comprehensive health care are bigger issues than our communication problems, because you don't see these [health] disparities in Canada, where there is a very diverse population [and universal health care]."

Despite the various economic barriers, advocates say it all comes back to education. "We recognize that economics is only part of the formula," says Ysabel Duron, founder and executive director of Latinas Contra Cancer, an organization that has developed creative ways to reach and educate the Latino community about cancer. "One of our major goals is to try to think of a way to educate the community that meets their needs and meets them where they live, work, and worship, instead of waiting for them to come to us."

Tailoring the Message

When Ullyses Wright, 56, of Olathe, Kansas, heard an advertisement on his car radio about a prostate cancer prevention study, he thought about his college fraternity brothers who had started dying from the disease and knew it was something he should participate in. Although no family member had been diagnosed with prostate cancer at the time of his enrollment in 2002, his father has since become a prostate cancer survivor.

"I'm one of nine males in a family of 11 children, and as we age this is something we'll probably have to confront," says Wright. "And I thought that participating in the study was a good way to give back to society."

Ullyses Wright joined a prostate cancer prevention study after friends started dying from the disease. Photo by Aaron Lindberg

Stunned after reading that African-American men were more than twice as likely to die from prostate cancer as white men, Wright says he wondered, "Why are we the only ones? I think we can change those statistics if we can get men on the

grassroots level talking to other men about getting screened and putting these numbers in front of them."

Virgil Simons, founder of The Prostate Net, is doing just that with a program he started in 2004 called Going to the Barbershop to Fight Cancer. Designed to promote prostate cancer screening among African-American and Latino men, barbers participate in educational sessions with doctors and pass along not only what they've learned, but also coupons for free prostate screening at a local hospital.

"[Barbershops are] like the country club—a place where guys go to talk to their friends," says Simons. "It's where minority men, regardless of socioeconomic status, are on an even playing field." The program, which also targets white men, has led to more than 30,000 prostate screenings in 21 states, says Simons.

Programs from Latinas Contra Cancer reach across tumor types. Its cervical health initiative targets Latinas at mother-daughter rallies to promote the HPV vaccine and Pap screening. And through bingo health cards covering breast, prostate, cervical, colorectal, and lung cancers, the group hopes to educate Latinos about each disease and dispel common myths.

Duron says that by doing more than 2,000 breast health bingos, they learned that a quarter of women under 40 were confusing clinical breast exams with mammograms. "They assumed they were getting a mammogram," Duron says. "Now when we ask if they've received a mammogram, we ask them to describe it," which, Duron says, starts the conversation.

During the game itself, participants communicate fears and beliefs about cancer, providing a supportive environment for education. The health bingo program has been so successful in the San Jose community that Latinas Contra Cancer plans to expand it nationwide, says Duron.

More than 100 mothers and daughters took part in Latinas Contra Cancer's cervical health rally in Gilroy, California. Photo courtesy of Latinas Contra Cancer

Going a step further, Latinas Contra Cancer will host the first National Latino Cancer Summit this summer, inviting researchers, health policy experts, oncologists, and advocates to San Francisco to discuss ways to increase clinical trial participation, improve cancer care, and decrease cancer health disparities for Latinos.

Asian-American organizations, including the Asian American Health Coalition in Houston and the Center for Asian Health at Temple University in Philadelphia, have made breast cancer screening and smoking cessation, among others, prevention priorities.

Advocates and researchers are also working to curb the rate of liver cancer-causing hepatitis B among Asian-Americans, who have higher rates of infection than any other ethnic group in the United States. A five-year project funded by the National Cancer Institute's Center for Reducing Cancer Health Disparities through 2011 has University of California researchers looking at

hepatitis B screening and intervention (promoting vaccination of uninfected individuals and anti-viral treatment and screening of infected individuals) among Vietnamese, Hmong, and Korean adults.

For American Indians and Alaska Natives, whose languages don't include a word for cancer, translations are thought to contribute to fear and misunderstanding about the disease. Prevention may be further hindered because, according to findings reported by the NCI, many tribes believe talking about a disease will bring it about, or that when one is healthy, he or she should not look for illness (in regards to screening). So health care professionals and advocates are trying to confront these cultural taboos with cultural sensitivity—for example, having tribal members as part of the research team—to make preventive strategies relevant and meaningful.

In addition to the right communication, the right setting for direct education is also crucial to facilitate trust. The Witness Project uses churches to raise cancer prevention awareness. An educational and community faith-based outreach program sponsored by the Arkansas Cancer Research Center's Cancer Education Department at the University of Arkansas for Medical Sciences in Little Rock, The Witness Project began locally in 1991 and is now in 22 states. The program uses the personal stories of breast and cervical cancer survivors to give "witness" about their experiences.

"Through their story-telling narrative, survivors impart messages to counter issues relating to the fatalism experience of so many minorities and the importance of early detection," says Roswell Park's Erwin, a cofounder of The Witness Project. Using a spiritual or religious setting helps dispel a belief by some African-American women that talking about negative things can "talk them" into existence, according to Erwin's research.

"One message we often hear is that everything causes cancer and you can't do anything about it," says Erwin. "The Witness Project is important because it offers direct education from trusted messengers, so the similarity of the women telling the stories to the women they're talking to is extremely important. It's like it can happen to me." A pilot program for Latino women is in the testing phase.

Although The Witness Project has resulted in an increase in breast self-exams and mammography by women in participating communities, says Erwin, the prevention message still isn't getting to enough women. "For the past year we've done The Witness Project for over 500 women in Buffalo, but how many African-American women are there in Buffalo? There are still a lot of women we're not reaching."

But creating heightened awareness of the disease and offering screening isn't enough, says Simons. "There's still a chasm in being able to act upon the knowledge. We created a safety net for men brought into the [barbershop] program who test positive [for prostate cancer]," which includes coverage for all diagnostics and care, a condition to which doctors and hospitals involved in the program must agree.

Prevention on Trial

Because African-American men have a higher risk for prostate cancer, Elise Cook, MD, of M.D. Anderson Cancer Center's clinical cancer prevention department, says she paid close attention to recruiting these men into her prevention study, including a recruitment focus in cities with high African-American populations.

Called the Selenium and Vitamin E Cancer Prevention Trial (SELECT)—the study in which Ullyses Wright enrolled—volunteers take either the vitamins and/or placebos daily for up to 12 years and have follow-up exams every six months. Still haunted by the Tuskegee Syphilis Experiment, which ended in 1972, Wright says taking over-the-counter vitamins and not an experimental drug was what he found most appealing about SELECT.

While SELECT reached its recruitment goal of 32,400 volunteers two years earlier than expected, it fell short of its target to enroll 20 percent African-Americans, with just 15 percent joining the trial. Latinos and Asian-American/Pacific Islanders have 5 percent and 1 percent representation, respectively.

As minority participation in prevention trials lags, what may encourage greater participation is more accurately identifying who's at high risk for specific cancers and establishing outreach programs in those communities.

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> —Dale Sandler, PhD

Last year, when Edith Joyner, 61, saw her doctor for a routine checkup, she was given a brochure about a nationwide breast cancer prevention trial called the Sister Study, the largest observational study to date looking at breast cancer risk factors. Still grieving the death of one sister from breast cancer, and helping another one in her battle against the disease, Joyner wanted to do something to honor both women.

"The brochure had photos of African-American women on it, and it said that this was a special invitation to African-American women to join the Sister Study," says Joyner. "I was so impressed I called that day and signed up." Joyner has also become a volunteer to help recruit more African-American women in the study.

Launched in 2004, the Sister Study is enrolling 50,000 sisters of women diagnosed with breast cancer to investigate the environmental and genetic causes of the disease. Currently, the study has recruited more than 46,000 women, although only 7,000 are from minority groups, despite greater community attempts to spread the word about preventive care.

"Some of the barriers, the taboos about talking about breast cancer and the family are breaking down," says Dale Sandler, PhD, lead investigator of the Sister Study

and chief of the epidemiology branch of the National Institute of Environmental Health Sciences. “Various partnerships have developed, and groups are working with beauty parlors and churches to encourage [health] screenings, [so] the word is slowly getting out.”

Even if some cancers can be prevented through lifestyle changes and health screenings, the question remains, why are some cancers, once they do develop, so much more deadly in minorities than whites? Biology may be one answer, say experts.

“While prostate cancer is rampant throughout the population, it has its highest frequency in African-American men, and if you look at [disease] stage and economic group to economic group, black men still have worse outcomes,” says Dr. Raghavan. “So even black men who present early still have a different outcome, so there’s a difference in biology there.”

Others disagree. “Whether there is a real biological difference in cancers in minority populations is a debatable point,” says Dr. Young. “What isn’t debatable is that any cancer that is diagnosed at a later stage will affect the ultimate outcome. I think [disease outcome] has to do with the importance of early screening.”

Dr. Young points to studies in military populations, for example, that show no difference in cancer frequency, stage, or outcome in minority groups managed in military systems. “That’s because they have access to the same screening at the same time,” he says.

Finding a Solution

Recognizing greater effort must be made to eliminate cancer prevention disparities in minority populations, the medical and advocacy communities are coming together on a national level to combat the problem on several fronts. But Dr. Raghavan says immediate progress must begin on a smaller level.

“I think communities need to take responsibility for themselves. In my view, an individual physician in his region or his state can do way more than a national body because it takes a while to move things forward,” Dr. Raghavan says.

The major teaching hospitals in Ohio are developing a program with educational buses explaining why screening is important and why diet matters, he says. “And then we’ll split into teams so each of the major hospitals will have screening vans. We’re getting some of the black athletes to do public service announcements.”

While more must be done, doctors are seeing the stages at diagnosis going down in minority groups, says Dr. Young. “In some instances, depending on the year you look at them, the drop is greater in minority populations than it is in Caucasian populations. Now part of that is because they have further to go, but those are encouraging figures.”

And the big payoff may be yet to come.

According to Dr. Young, “To the extent that minority populations don’t either avail themselves or get access to some of the early diagnosis and screening

programs that currently exist, one might anticipate that the impact [of prevention strategies] would be even larger [than in the white population]."