Cancer Control Efforts Reach Out to “Culturally Isolated” Groups

Many cancer prevention control outreach efforts are redefining “special populations” in a way that expands outreach efforts and tailors messages to reach previously overlooked or newly emerging demographic groups.

One such community partnership effort, led by Detroit’s Barbara Ann Karmanos Cancer Institute, involves an outreach program to bring breast cancer early detection and treatment information to that city’s Arab community — the world’s largest outside of France and the Middle East.

“There is often very little available information about these kinds of communities and their health needs,” said William Stengle, director of the National Cancer Institute-supported regional Cancer Information Service, based at Karmanos. “We’ve really had to start from scratch in this community.”

Diverse Communities

A small grant from the Michigan Department of Community Health’s Cancer Section helped the CIS gather information about several distinct Arab-American communities in Detroit including Muslims with ethnic ties to Yemen, Lebanon, Palestine, Jordan, Syria, and Egypt. There is also a large community of Iraqi Christians (Chaldeans) who speak a modern form of Aramaic and practice Orthodox or Eastern Rite Catholicism.

Like many such groups, Arab-Americans are not distinguished from people of European, North African, or Middle Eastern descent by the U.S. Census nor do they qualify as official minorities under federal law. Nevertheless, in Michigan, state officials estimate that, with a population of more than 300,000, they comprise the third largest minority group in the state after African-Americans and Hispanics.

Because these groups do not fit formal government “minority” definitions, they are often ineligible for special federal programs and funding initiatives. This increases their reliance on state, local, and private support, Stengle explained.

“Although it’s always been our agenda to serve the underserved, these groups have been culturally isolated and there has been very little interest in them from funding authorities such as the federal government and large foundations. So we had to develop our own

Complexities of p53

It is one of those oft-repeated factoids at scientific meetings. The tumor suppressor gene p53 is mutated in about half of all cancers, making it the most frequent target for tumor predisposing mutation.

But there is another factoid that might be worth mentioning also. According to the latest release from the p53 Mutation Database, operated by the International Agency for Research on Cancer in Lyon, France, scientists have published on more than 9,300 distinct mutations in p53 since the gene was isolated in 1986. p53 has a coding sequence that stretches about 20,000 bases, or units of DNA, and encodes a protein that is 393 amino acids long.


Bob Kuska

Jane Hoey (left), William Stengle, and Denise Ballard.
unique partnership program tailored to their needs virtually on a shoestring," added Jane Hoey, assistant director of breast cancer community outreach and education at Karmanos.

According to Adnan Hammad, Ph.D., director of health services for the Arab American Community Center for Economic and Social Services (ACCESS), more than half of all Arab-American women may be at increased risk for breast cancer because of a close relative with the disease. In addition, many have never sought out mammography providers because a significant number lack English language skills and health insurance.

While women with health insurance are referred to private physicians, those without insurance often fall between the cracks, Hammad said. Under the Centers for Disease Control and Prevention's breast and cervical cancer early detection program, funding for only 3,000 women in Detroit is available annually, while Hammad estimates that there are more than 7,000 in need of low or no-cost mammography in the Arab-American community alone.

"In general, there is little interest from the CDC and other national public health agencies in supporting initiatives in these communities," Hammad said.

A non-sectarian, non-profit community organization, ACCESS approached state health officials for assistance in promoting mammography after learning that many low-income Arab-American women in their community were not keeping appointments for free or low-cost screening through the local health department because they lacked transportation or were ashamed of their lack of English language skills and low-literacy in Arabic.

In 1995, Michigan Department of Community Health cancer control officials paired ACCESS with Karmanos and CIS resources and awarded the group a $45,000 grant to conduct needs assessment. A twice-monthly mobile mammography and cervical cancer screening program is provided by Karmanos.

In addition, ACCESS began developing a "home visit" program in which a trained health educator visits women in their homes to assess a constellation of social and economic needs, to provide health referrals, and to teach breast health. The program is so popular that they are doing 300–500 home visits each year. Thanks to their partnership with Karmanos, ACCESS also now has a small grant from the National Alliance of Breast Cancer Organizations, New York.

While some in the public health community concentrate their efforts on expensive, high-tech multimedia approaches, this group has found the only successful way to reach communities where there are multiple barriers is the old-fashioned way: posters, pamphlets, community events, and door-to-door canvassing.

"High-tech approaches won't work in this group. Language is not the only problem, trust is essential. You really have to break the ice and help women understand that it's you and her working together. Using appropriate terminology, cultural sensitivity, and understanding the mentality of the individual is crucial," Hammad said.

"You have to be concerned enough to go out to the people. That's the foundation of our outreach program; we don't expect people to come to us," Hammad added.

Provider Sensitivity

According to Denise Ballard, outreach program manager at the Michigan CIS, Arab-American women, like those in many immigrant groups, place a strong emphasis on personal modesty and the importance of the home and extended family, which requires a traditionally "low-tech" approach to outreach.
"Some of the cultural barriers we expected turned out to be myths while we discovered others that had not been well-documented. We had to design a program that was responsive but not overstep our boundaries and alienate the community," Ballard said.

This emphasis on cultural sensitivity has also included efforts to develop training programs in "cultural competence" for area hospital staff and health care providers as well as partnerships with religious organizations.

One successful program developed by the Michigan-based Oasis Communications, Inc., involves a facilities assessment followed by a Continuing Medical Education-approved seminar for health professionals. This includes Muslim dietary requirements, developing bilingual signs and educational materials, and bioethical and religious concerns.

“Decision making that may include unrelated people, the distinct boundaries the home represents, modesty, and an approach to disease as something to be endured rather than overcome has made cancer prevention and control among these individuals unique and problematic," said M. Kay Siblani, Oasis president.

— Lou Fintor

Erratum

In an article on spirituality and medicine in the Sept. 2 News section, Christina M. Puchalski, M.D., an assistant professor in George Washington University's department of health care science and medicine, was incorrectly identified as Christina Larson, associate professor in that department.

Dr. Andrew Novick

Are Lumpectomies for Kidney Cancer Shifting Towards Acceptance?

Partial nephrectomies, if not exactly the rage, are being seriously considered for growing numbers of patients with renal cell carcinoma.

The ideal candidate for this procedure is a patient who has a single, small (less than 4-cm) tumor in one kidney and whose other kidney is at high risk for present or future kidney failure, or a patient with only one functioning kidney. In the absence of metastatic disease, a patient with cancer in both kidneys may also be considered for a partial nephrectomy.

More recently, the indications for this type of so-called "nephron-sparing surgery" to preserve renal function and to keep patients off dialysis have expanded even further. Some patients with a normal opposite kidney — at no risk of shutting down — are having a partial nephrectomy in the one with cancer. Others with the hereditary disease von Hippel-Lindau syndrome, in which their kidneys contain hundreds of tumors, are having them individually excised, leaving the rest of the kidney intact.

This change in attitude about whether the procedure should be done at all, and who is eligible to have it, has come about gradually as study results show no difference — up to around 5 years of follow-up — in outcome for selected patients who undergo either radical or partial nephrectomy.

Many of these studies were conducted at the Cleveland Clinic Foundation, which probably has the largest experience with 700 cases, as well as studies from the Mayo Clinic, Rochester Minn., Memorial Sloan-Kettering Cancer Center, New York, the University of Texas M. D. Anderson Cancer Center, Houston, and the National Cancer Institute, where there is considerable experience with patients with von Hippel-Lindau syndrome.

Andrew Novick, M.D., chairman of urology at the Cleveland Clinic Foundation, said that at least half of the estimated 30,000 new cases of kidney cancer diagnosed each year present as localized tumors. "And if the number eligible for nephron-sparing surgery is in the 30% to 40% range, which is a conservative figure," he said, "you're talking about 9,000 to 12,000 people with localized disease," who would be eligible for the less radical procedure.

Age a Factor

Novick added that people with renal cell carcinoma are usually older, and many have comorbid conditions such as hypertension, diabetes, renal artery stenosis, or some other condition that puts their remaining kidney at risk. These people also may need good kid-