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Otis W. Brawley

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Minority Accrual & Clinical Trials

by Otis W. Brawley, M.D.

A major goal of American medicine should be to make innovative treatments and technologies available to all patients. Cancer clinical trials offer the patient state-of-the art therapies. Taking patients through these clinical trials serves as a form of continuing medical education for physicians. Thus, it is fair to say that all of a participating physician's patients will likely benefit from the physician's involvement in clinical trials. Availability of clinical trials to patients of all ethnic and socioeconomic groups is critical for social fairness.

The Minority-Based (MB) Community Clinical Oncology Program (CCOP) was implemented by the National Cancer Institute in 1990 as one of several efforts to increase minority accrual to NCI-sponsored clinical trials. The program offers several advantages. While individual patients benefit from clinical trials, society also profits: A diverse population with different kinds of health care systems means that clinical findings are more valid and more generalizable. The MB-CCOPs are a good vehicle through which the patterns of minority accrual to clinical trials can be studied. They are a potential vehicle for the study of outcomes in clinical trials.

In 1990 ten MB-CCOPS were funded to put patients onto NCI-sponsored cooperative group and cancer center clinical trials. A recompetition was held in 1994, and ten programs were funded to continue an additional three years. The current ten programs involve more than 360 physicians and 48 hospitals and clinics in nine states and Puerto Rico. Over the last five years, 15.3 percent of all cancer patients accrued to NCI-sponsored cancer treatment trials were from an ethnic or racial minority group. Approximately 10 percent of all minority patients accrued to NCI-sponsored treatment trials were accrued by the MB-CCOPs. More than 70 percent of patients accrued to trials from the MB-CCOPs are from an ethnic or racial minority group.

Study of minority accrual in these programs allows for the identification of institutional and social barriers to minority patient participation in cancer clinical trials. A most important finding is that eligible African-American and Hispanic patients enter clinical trials in the same proportions as eligible white patients. This suggests that race is not a factor in the cancer patients' decision to enter a treatment trial, when treated in an environment conducive to clinical trials research. A second finding is that there are negligible differences in protocol availability and eligibility for available trials among African-American, white, and Hispanic patients.

OVERCOMING BARRIERS

The term "minority" has numerous definitions. In the United States, it most often means a member of a racial or ethnic group other than white. The term, however, can also be used to mean the impoverished and less formally educated, including poor whites. The minority patient generally has limited access to and use of health care services.

Those successful in accruing minority patients to clinical trials identify the common barriers to participation as such logistical issues as difficulties in transportation, inconvenient clinic hours, and lack of day care. Other barriers include differences in language, lack of understanding, fear of being denied care because of inadequate financial support, fear that researchers will take advantage, and not understanding the value of the research to the participant. Many of these barriers can be overcome when the patient and his or her family have trust and good rapport with the health care providers.

Institutions and health care providers that are successful in recruiting minority patients to

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Otis W. Brawley, M.D., is program director, Community Oncology and Rehabilitation Branch, National Cancer Institute, Bethesda, Md.

cancer treatment trials have demonstrated that barriers can be overcome. They succeed by having a genuine concern for their community and by providing a history of service. These institutions and health care providers are clearly influenced by the factors endemic to the communities they serve. They have a respect and appreciation for the cultural qualities that affect the health status and practices of the population they serve. They also understand that culture and needs can vary considerably. For example, the culture, needs, and concerns of African Americans in a northern industrial city differ from those of African Americans in the rural South. Using culturally specific strategies to teach about cancer and good health habits can increase understanding and are often much appreciated.

Accrual to cancer prevention trials involves a dynamic that is very different from accrual to cancer treatment trials. The referral network in place for patients diagnosed with cancer is of little help in recruiting healthy individuals to cancer prevention trials. Accrual of minority patients to the breast and prostate cancer prevention trials has been lower than desired from all NCI-supported institutions, including the MB-CCOPs. Efforts at increasing minority accrual to these trials continue.

The price of poverty is high. Minority and poor patients cannot afford the luxury of worrying about preventing problems that are not likely to be a concern in the near future. At the heart of our recruitment endeavors should be a desire to explain the importance of participation in trials and a respect for each individual's decision to accept or decline the invitation to enter the trial.

Minority accrual is important in the cancer clinical trials process and has received attention for a number of years. The MB-CCOP has become an important part of the NCI Clinical Trials Network. As these programs confront substantial challenges, they allow us to learn important lessons about involvement of patients from all parts of American society in clinical trials and demonstrate that minority accrual to treatment trials is possible given a supportive and understanding environment. ■

SYMPOSIUM FOCUSES ON MINORITY NEEDS

Cancer researchers have tried to involve more minorities in their studies but have had only limited success, according to Edward Sondik, M.D., acting director of the National Cancer Institute. He was addressing the closing session of a four-day summit meeting on minorities and cancer, held April 22-25, 1995, in Arlington, Va. The symposium was sponsored by Baylor College of Medicine, the University of Texas M.D. Anderson Cancer Center, Howard University Hospital, the American Cancer Society, the Susan G. Komen Breast Cancer Foundation, and Kellogg's.

"We are having difficulty recruiting minorities to these trials," he said, speaking of studies on prostate cancer. "We've tried mightily with minorities."

Over the course of the 5th Biennial Symposium on Minorities, the Medically Underserved & Cancer, underrepresentation of minorities on clinical trials was discussed repeatedly. Among the barriers cited to more minority participation in clinical trials are distrust of white-run research in minority communities and lack of educational materials that are relevant to the culture.

Correcting that deficiency is part of the policy agenda for the Intercultural Cancer Council (ICC), which was formally launched at a Capitol Hill policy forum during the meeting. The ICC's mission is to allow diverse groups to speak with one voice to the government on issues relating to cancer and their communities.

"There is a special need for the NCI director to mandate increased minority participation in clinical research trials and epidemiological studies," noted the ICC's policy statement. "It is also important that the director support efforts to develop researchers from minority communities and to include them in the design and conduct of the...research trials."

Although Sondik endorsed the ICC's mission, he cautioned that its realization will take a long time.

"We don't simply turn the spigot and out come researchers," he said.

Cancer Education Among Minorities

A number of research and demonstration projects examining cancer education among minorities were presented at the recent symposium. The consensus was that education and prevention materials that fail to reach their audiences, combined with deep-grained cultural attitudes about cancer, are among the reasons that cancer rates are so high among so many minorities in the United States.

About 40 of 100 cancer education materials examined, ranging from booklets to a bookmark, were rated at a 10th-grade reading level, according to a poster presented by Pebbles Fagan of Texas A&M University. Meanwhile, 22 to 24 percent of African Americans read at a ninth-grade level or below. The American Cancer Society estimates that about 120,000 African Americans will be diagnosed with cancer this year.

The good news is that the readability of cancer educational materials has improved in recent years.

Culturally relevant educational materials about cancer, however, remain scarce. Karen Johnson of Duluth, Minn., began a project on four Native American reservations to develop culturally relevant educational materials on cancer pain. The project will involve interviewing groups of Native Americans on the Red Lake, White Earth, Leech Lake, and Fond du Lac reservations in Minnesota to get suggestions on how best to deal with the topic.

Johnson hopes the material she gathers will be used in brochures and other materials, perhaps illustrated by Native American stories that will teach people on reservations about the uses of medication in controlling cancer pain.

"It will be their ideas. ...They

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will own it," she said.

But the trick will be getting people to talk about their disease. As a culture, she said, Native Americans do not like to discuss cancer, even within their own families. The fear is: "If you talk about [cancer], it will come to you."

Results of the project are expected in a year.

Increasing Cancer Awareness

The Witness Project, an outreach program of the Arkansas Cancer Research Center, works to increase awareness of breast and cervical cancer among minority women in economically depressed areas of the state. At the recent symposium the Witness Project team received the prestigious "HOPE" Award in recognition of exceptional service in the area of cancer prevention, control, and treatment in minority communities.

Witness Project volunteers—all African-American women cancer survivors—travel to churches and community centers throughout rural central and eastern Arkansas, educating groups of women about the importance of early detection by "witnessing" or talking about their cancer experiences. They stress the importance of screening and answer questions about their personal experiences, fears, and concerns. Volunteers teach breast self-examination and offer vouchers for free mammograms.

Directors of the Witness Project, Deborah O. Erwin, Ph.D., C.T.R., and Thea S. Spatz, Ed.D., conducted focus groups and interviewed rural women to identify barriers to screening. Women interviewed were unaware of screening programs in the area. (In 1988, less than 2 percent of respondents to an ACS reduced-cost mammography promotion were African American, although nearly 17 percent of the state is African American.)

Many of these women are at what Erwin refers to as a "precontemplative stage." When asked if they had ever discussed breast cancer with one or more women, about 53 percent said 'no.'

"It's a big jump to expect these women to go from never discussing a mammogram to feeling comfortable about getting one," said Erwin.


PHOTOGRAPH BY ANDREW KILGORE

Witness Project volunteers help to increase cancer awareness among women in rural Arkansas.

The Witness Project tries to reach women at all levels of awareness, not just those who are at ease with having a mammogram.

"Helping a woman to become more comfortable with breast self-examination is an important step," explains Erwin. The literature indicates that women who perform BSE are more likely to go on and eventually have a mammogram, she said.

Working with the local churches has been a very effective way for the Witness Project to reach women. A woman who would never deliberately participate in a health program is more likely to listen to health instruction after church. Local cancer survivors who lead the instruction create a dynamic and often spiritual atmosphere.

"The church is an important part of these women's lives," explained Erwin. "The message is less threatening when it is delivered in such a familiar, comfortable environment."

"Much more than an educational message, a witness program is an empowering experience," noted Erwin. "Because these women reach down into their souls and share a part of themselves, they are able to empower other women. They may quote scripture. They may ask God's help. At the end of the program, the audience feels uplifted, strengthened, and encouraged to practice breast examination and, perhaps, finally get that mammogram!"

Advocates Call for Central Clearinghouse of Funds

"Money is power," said Lovell Jones, symposium co-chair. He spoke of the need for the minority health research office to serve as a funding pool for all NIH research on minorities. Up to now that office's role has been largely advisory.

"What we would like to do is have all the monies that are directed toward minority research, just like it is in terms of AIDS," said Jones, who is professor and director of experimental gynecology and endocrinology at the M.D. Anderson Cancer Center in Houston, Tex.

He said the minority health research office should have at least as much money at its disposal as the office of women's health, which has some $700 million.

Approaching Congress to give the minority health research office more authority is high on the agenda of the newly formed Intercultural Cancer Council.