Overcoming the Barriers to Cancer Screening

In this issue of the Mayo Clinic Proceedings (pages 301 to 308), Lobell and colleagues report on the association between knowledge about cancer and anxiety in a group of 188 Mexican-American women. The investigators used sophisticated statistical modeling techniques to demonstrate that knowledge of cancer did not directly predict screening behavior and that screening behavior did not directly predict anxiety. With access to health care statistically controlled, communication skills and anxiety were predictive of screening behavior in the directions hypothesized (a higher level of communication skills was associated with increased screening, and increased anxiety was associated with decreased screening). In the authors' own words, however, "unexpectedly, knowledge of cancer was positively, rather than negatively, associated with anxiety about cancer."

Differing Perspectives

Anthropologists have long recognized that the human experience can always be observed from at least two perspectives—the perspective of the professional observer (the anthropologist) and the perspective of the observed. Similarly, the health-care experience can be viewed from two perspectives: the perspective of the health-care professional and the perspective of the patient. Health-care professionals naturally tend to view health care from the professional perspective; however, in the case of searching for barriers to cancer screening, valuable information can be gained from the lay perspective.

Although I have never worked with the Mexican-American women of Arizona, I have seen responses similar to those of the Mexican-American women by some of the Native American, Alaskan Native, and Pacific Island women with whom my associates and I have worked to try to increase these women's access to high-quality cancer screening services. The observation by Lobell and his coworkers is also consistent with the behavior of women with whom we have worked in the Minneapolis-St. Paul metropolitan area and in southeastern Minnesota. The observation that knowledge related to cancer can lead to anxiety is not surprising. One's attitudes about the value of early detection of cancer depend on what one believes will happen once cancer has been detected.

Advocates of cancer screening tend to focus on improvement of outcomes in cancer treatment, both by early detection and by sophisticated intervention. Moreover, the women who have been cured because of a screening test are differentially remembered. As health-care professionals, we also tend to think of cancer as "something that happens to someone else."

The Mexican-American women surveyed by Lobell and associates do not share our experience and therefore do not share our perspective. They do not have easy access to screening or sophisticated health care, and they are unaware of the statistics about the benefits of early detection and aggressive treatment. Most likely, these women have gained their knowledge about cancer from firsthand experience with a relative or a friend—someone similar to them. The likely scenario was probably discovery of cancer at a late stage, minimal intervention, and a poor outcome. Such experiences also reinforce the notion that cancer is something that might happen to them.

Positive Versus Negative Emphasis

Our customs about health care, death, and dying accentuate and reinforce negative conceptions about cancer. Our customs minimize the message that early detection and aggressive treatment of cancer yield better outcomes; by filtering out the information about the survivors and the successes, our customs emphasize the deaths and poor outcomes.

Fortunately for the survivors of cancer, their special status is usually invisible to others in general social encounters. In our society, women with breast cancer have access to highly effective cosmetic surgical procedures or sophisticated breast prostheses, and our rules about confidentiality of medical records protect their status as cancer survivors from the eyes of the community unless they choose to reveal otherwise. These guidelines are good for the cancer survivor, and the option of confidentiality must be preserved. Nevertheless, these opportunities and customs bias the information available to women at risk. This filtering of information means that the women at risk—that is, all women in the community who have not experienced cancer—learn about cancer mainly from the obituary column in the newspaper or from whispers in private or over the telephone.

In order to demonstrate the positive aspects of early detection of cancer, several years ago our group hypothesized that women could be recruited to have cancer screening tests if they heard cancer survivors tell their...
This sharing was achieved through a series of fashion shows. Although the concept of a fashion show tangentially became a controversial issue, the participating women were strongly positive about the event. Making use of the custom of women sharing information at informal social gatherings at which refreshments are served, we also organized a series of “teas” that were hosted by cancer survivors. These events were likewise positive experiences for the women who participated.

Rationale for Not Undergoing Screening

When we analyzed the reasons why women in our Southeastern Minnesota Women’s Health Project population sample had not been screened for cancer, the explanations offered did not seem to indicate a profound fear of cancer: “No good reason, I just have not gone,” “I have not been sick,” and “I haven’t had time” were the most common responses. Although 12% of unscreened women reported that a mammogram was too expensive, the proportion was only 6% for a clinical breast examination and 6% for a Pap test. This pattern of responses suggested to us either that the fear of cancer was buried deep beneath the conscious or that most women without up-to-date cancer screening had not participated simply because they had not experienced an action-precipitating stimulus.

In contrast to the survey responses of most women, we have encountered a few women who were paralyzed into inactivity by their fear of cancer. Therefore, we attempted to test the hypothesis that unexpressed fear is a common barrier to cancer screening for women. Dr. Julie A. Van Eck, in a project that she conducted as a medical student, identified women who had survived breast cancer for 5 years and also identified age-matched counterparts who had not had breast cancer (unpublished data). She asked both groups of women to complete a social function questionnaire; in addition, she asked the women without breast cancer to complete the same questionnaire as if they had been diagnosed with breast cancer 5 years before but were now free of disease. She found little evidence to support the hypothesis that a large proportion of women think that life after the diagnosis of breast cancer would be a profoundly negative experience.

Behavior change experts indicate that the public will be amenable to behavior change if they are convinced of the benefits of such change. They maintain that listing the cons of not changing (that is, emphasizing the “bad things” that will happen if they do not have cancer screening) will not alter their behavior. They also state that individuals learn the “correct” behavior from their social peers.

Plan of Action

What do these observations suggest about prompting women to seek and accept cancer screening? If the medical community is to help women benefit from cancer screening, we must take action on several fronts.

Financial Support.—As an initial step, we must ensure that no woman goes unscreened because she lacks financial resources. The Breast and Cervical Cancer Control Program, established by the Centers for Disease Control and Prevention, is attempting to achieve this goal, but their current level of funding can reach only a fraction of the women who need financial coverage for screening, and the program is prohibited by law from paying for the actual treatment of any cancers that are discovered.

Reminders About Screening.—We also need to create the expectation that health-care providers remind women to undergo cancer screening tests. These same health-care providers need assistance with development of the information systems that will identify women who are due for screening. In a patient survey we recently conducted in the Minneapolis-St. Paul area, almost two-thirds of the women had up-to-date results of Pap testing and mammography, but only 20% of women who were not current on mammographic screening said that they had been advised to have the test at their most recent clinic visit. The proportions for Pap testing and clinical breast examination were 28% and 15%, respectively. The clinical staff believed that cancer screening was important but simply did not have the information systems or reinforcement to determine which women were due for screening procedures.

Promotion of Benefits.—The benefits of cancer screening must be promoted to the women in the communities that we serve. This activity is happening to a limited extent, but much more effort should be devoted to helping women realize that most women similar to them undergo routine cancer screening tests. All women should be given information about the benefits of early detection of cancer by screening tests.

Through the testimony of cancer survivors, the women of our communities should learn that life after the diagnosis of cancer is usually satisfying and fulfilling. We should encourage cancer survivors to tell other women that surgical treatment, chemotherapy, and radiation therapy are tolerable and that they provide long-term benefits.

Continued Investigations.—Finally, more studies like the one conducted by Lobell and his colleagues are needed. They challenge our conventional wisdom that our patients see the world as we physicians do, and they remind us that our patients may be viewing the cancer experience from a different perspective. By increasing our understanding of our patients, these types of studies help us to accomplish our mission.
If we can ensure that knowledge about cancer includes the knowledge that tens of thousands of women of all ethnic groups continue to live rewarding and productive lives because their cancers were detected early and treated aggressively, and if we can ensure that knowledge about cancer includes the knowledge that a periodic mammography, clinical breast examination, and Pap test are routine activities for every woman, I expect that the association between knowledge about cancer and anxiety will no longer keep Mexican-American women from enjoying the benefits of cancer screening.

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REFERENCES