Screening Mammograms: When Fighting for Coverage and Quality Isn’t Enough

By Cynthia Pearson

Sometimes the work of women’s health activists is easy. We find out that a new procedure or service can help improve women’s health, we advocate for all women to have access to it, we do everything we can to ensure that it is provided in a high quality way, and then we celebrate the gains made. Sometimes it’s more complicated, though, and the case of mammography screening for breast cancer is a painful example of a complicated women’s health issue.

Mammography was originally studied as a screening tool in the 1960s. The first trial seemed to show screening saved lives: asymptomatic women were screened every year or two; smaller cancers were found than in similar, but unscreened women; these cancers were treated promptly; and fewer women died of breast cancer. This trial was followed by a large demonstration study that showed the average radiologists outside a highly structured clinical trial could identify small breast cancers. Based on these promising results, it appeared that mammography screening should be made available to all women at-risk of developing breast cancer.

This trial was followed by a large demonstration study that showed the average radiologists outside a highly structured clinical trial could identify small breast cancers. Based on these promising results, it appeared that mammography screening should be made available to all women at-risk of developing breast cancer.

In the aftermath of this early research, NWHN advocated strongly for mammography access. In the late 1980s, we lobbied Congress for Medicare coverage of screening mammograms—and being opposed by a government accountant who said that it would be “too expensive” to pay the health care costs for all the women who would live many years longer if their breast cancer was cured after being found on a screening mammogram! Thankfully, Congress expanded Medicare’s coverage even after the accountant’s dire warning.

After Medicare began to cover screening mammograms, private insurance companies followed suit, and programs aimed at reaching women without insurance began. With access expanding, NWHN next turned its advocacy efforts to quality— and found we had work to do. Provision of screening mammography wasn’t regulated back then, and the quality of machines used varied greatly, as did the training and experience of radiologists.
of technicians and radiologists. Many women received very high-quality services, but not everyone did. And, as we pointed out, a bad mammogram is worse than no mammogram at all. The Network created a guide to the important elements of high-quality mammography, and many NWHN members volunteered to check out facilities in their hometowns. When members found inconsistent quality, we took this information to Congress and sought federal regulations. Other women’s and cancer advocacy groups joined in this effort and, in the early 1990s, the Mammography Quality Standards Act was passed. We were especially proud that the Act gave women the right to get their own copy of their mammograms.

But, just when we thought we had accomplished our work, the original premise of mammography (that screening saves women’s lives) came into question. In 1992, NWHN began analyzing the benefit women really got from mammography screening. And, it turned out, the benefit wasn’t as big as originally thought, nor did it apply equally to women of all ages. NWHN dove into this work, not because we thought we were exposing a sham—we’d promoted screening mammography, after all—but because our members want to know if researchers had doubts about the effectiveness of any treatment. NWHN members have told us that they don’t want overly optimistic information or simplistic messages that are better at motivating than educating.

What we discovered in the 1990s was disheartening. In the aftermath of mammography screening’s first trial, several other trials were undertaken, without impressive results. Screening’s life-saving benefit was not found in all trials. It certainly wasn’t found in the one trial designed to show the benefit of beginning mammography at age 40. NWHN went public with this information, and in 1993, issued a position paper recommending against screening mammography for pre-menopausal women—a very controversial position. The breast cancer advocacy movement was just getting started back then, and many organizations had a hard time accepting the idea that screening mammography might not really be very effective.

We also found that many people were shocked at the very idea that screening could, in fact, be harmful. Here’s why: screening leads diagnosis, which leads to treatment. There is no treatment without risks. Treatment is often worth the risk when a condition is causing symptoms or is dangerous. But early cancer found through screening, when no symptoms are present, doesn’t always progress to life-threatening, advanced cancer. We wanted to be sure that treating everyone found to have early cancer would actually help save women’s lives. It was these considerations that led NWHN to tell women we believe that breast cancer screening should not be recommended for pre-menopausal women until it’s been well-proven to do more good than harm.

Times have changed but, unfortunately, the complicated nature of mammography screening hasn’t. The same seven screening mammography trials still generate controversy, just as they did in the early ‘90s. But the emergence of several wonderful breast cancer advocacy organizations that do their own independent analysis of science and clinical trials
now makes it much easier for women to find excellent information on this complicated subject. The Network stopped doing our own analysis of the issue a few years ago, when we realized that other organizations can follow and analyze breast cancer screening reports as well as, and often more quickly than, NWHN.

In this article, we're sharing with our readers the opinions and analysis that we respect. Take a look at the organizations' positions provided below, visit their websites, and share this information with your colleagues and clinicians. Fifteen years after the debate about the value of screening mammography first flared up, too many women (and clinicians) still don't know it's more complicated than the "early detection is your best prevention" slogan.

Center for Medical Consumers: "Mammography-detected breast cancers have the best outlook. The screening test also leads to the detection and treatment of breast cancers that would never become life-threatening. Mammography's role in the nation's declining breast cancer death rate remains unclear. At best, it appears minimal. Women are not receiving honest information about mammography's harms... For every 1,000 women who undergo mammography screening for ten years...one woman will have her life prolonged; five additional women will receive an unnecessary cancer diagnosis and treatment; and three women will have a benign tumor biopsied." Center for Medical Consumers, 2005, www.medicalconsumers.org.

Breast Cancer Action: "[Mammography:] currently it is the best screening method widely available. There has been much debate about the use of screening mammography—X-rays given to healthy women without any symptoms of breast problems. To make an informed decision about mammograms, women must be aware of the following facts: Mammograms do not prevent breast cancer...Mammography is a form of ionizing radiation...Radiation is a known cause of cancer, and the effects of small amounts may accumulate in the body...The quality of mammography screening varies widely...Mammography is an imperfect test...The benefit of routine mammograms for healthy pre-menopausal women is unproven...Clinical breast exam and self breast exam are important detection methods." Breast Cancer Action, 2004, www.bcaction.org.

Dr. Susan Love Research Foundation: "Even in older women, mammography is far from a perfect screening tool. It may help you find your cancer early, but finding a cancer 'early' is not a guarantee that your life will be saved. New data suggest that there are different types of cancers and that how quickly a cancer progresses has more to do with the type of cancer it is than when it is found...probably about 30 percent [of breast cancers] have the potential to become 'bad' if not stopped early. These are the cancers whose outcomes are affected by breast cancer screening programs and early detection. These are also the cancers that we respect. Take a look at the organizations' positions provided below, visit their websites, and share this information with your colleagues and clinicians. Fifteen years after the debate about the value of screening mammography first flared up, too many women (and clinicians) still don't know it's more complicated than the "early detection is your best prevention" slogan.

The Myth of the Baseline Mammogram

While many things about screening mammograms are uncertain, there's at least one thing that is certain: baseline mammograms shouldn't be recommended as a routine part of health care for women. There is complete agreement about this, even among organizations that disagree on almost every other aspect of mammography.

But, despite this agreement that baseline mammograms aren't necessary and shouldn't be recommended, many women tell us that their practitioners start recommending baseline mammograms at age 35. Why is this? In part, it's because American Cancer Society (ACS) spent over a decade promoting baseline mammograms as an essential part of screening for breast cancer. The ACS recommendation had no scientific evidence to support it—there are absolutely no studies showing any benefit of a baseline mammogram in women under 40—but the ACS recommendations reached and influenced the majority of U.S. physicians, nurse practitioners, and physician assistants.

The ACS received steady criticism of its recommendation in favor of baseline mammograms and finally withdrew it in 1992. The ACS did not, however, promote this change and the message still hasn't gotten out to well-meaning practitioners who continue to tell women in their 30s that its time for their baseline mammogram.

For more information about the history of the mammography debate, see:

Reference:
mammography is best at finding... Screening is still our best tool for changing the mortality rate of breast cancer. We need to take full advantage of it while working very hard to find something better.” Dr. Susan Love Research Foundation, 2006, www.susanlovedmd.com.

National Breast Cancer Coalition (NBCC): “NBCC believes that there is insufficient evidence to recommend for or against screening mammography in any age group of women... Women are told that mammography screening saves lives, but the evidence of a mortality (death rate) reduction from screening is conflicting and continues to be questioned by some scientists, policy makers and members of the public... Women deserve to know the truth — and the truth is that there is no evidence of a mortality reduction in women under the age of 50 and the evidence for women over 50 is currently unclear... NBCC believes that there are public health interventions that could save more lives and use fewer health care resources than mammography screening programs. One such intervention would be to ensure that all women diagnosed with breast cancer have access to quality health care.” National Breast Cancer Coalition, 2003, www.stopbreastcancer.org.

For more information about the issue, see the National Women’s Health Network’s position paper on mammograms which is available on-line at http://www.nwhn.org/publications/position_details.php?pid=1.

Cynthia Pearson is the NWHN’s Executive Director