

## *These Graduates Spread the Message of Breast Cancer Prevention*

**I**t was graduation day in Beaufort County, replete with diplomas, flashing cameras, and finger food. Yet the students—all African Americans over 50—had taken only one class that lasted three Saturdays. That class was in the prevention of breast cancer, a disease more prevalent among white women but more frequently fatal among African-Americans.

Proud family members and teachers crowded the room to mark the occasion. Lela King served as informal valedictorian.

She glanced at her notes, remarked on all the men in the room, then plowed ahead with her story. "It was December 1, 1983," she says. "I went to the doctor. He said I had a small lump on my left breast and told me, 'I'm going to let you go talk to the surgeon.'"

The lump the size of the tip of her little finger was malignant. Lela King had breast cancer. The surgeon recommended a mastectomy and King quietly complied. But breast cancer wasn't talked about much in this rural coastal county. King tells her classmates that she kept her surgery and her suffering largely to herself. She didn't even tell her close friends at church.

"Somehow after the operation I felt neglected and rejected," says King. "I thought that God had dealt me a bad blow. I was not even going to church anymore. I felt I was the only one in the world going through something like that, and thought, 'Why did it have to happen to me?'"

Still, the surgery was a success. King did not have to go through chemotherapy or radiation treatment. "By starting in time and catching it in time, he [the surgeon] was able to get everything done." At the 10-year mark, King's doctor found her cancer-free and pronounced her cured. "We hollered and shouted about that," she says.

King's jubilation about her own cure and her sorrow about another breast cancer case that wasn't caught in time helped her come to a conclusion. She isn't keeping quiet anymore. "I

would like to advise all women to please, keep your breasts checked," she says.

King and her fellow graduates have been charged to do exactly that. After three Saturdays of training, they are certified lay health advisers. Their job is to go out in the community and encourage African-American women to come in to local health facilities for breast cancer screening. The training came via the North Carolina Breast Cancer Screening Program—a five-county intervention to improve the inclination of African-American women to practice preventive health.

The program relies on community leaders like Lela King to get the word out among African-American women about the need for breast cancer screening. It also works with local health departments and clinics to assure that they have access to these services at a cost they can afford. Ultimately, the results in five counties—Bertie, Beaufort, Martin, Tyrrell, and Washington—will be compared with five control counties to see if the intervention has had an impact.

The N.C. Breast Cancer Screening Program is modeled on a Wilmington, N.C., program called Save Our Sisters. That program was successful in getting more African-American women to seek breast cancer screening where traditional outreach efforts had failed. These traditional efforts included a publicity campaign and free clinical breast exams at African-American churches and referrals for mammograms.

Part of the reason breast cancer is so deadly for African-American women is that they are less likely than whites to seek breast cancer screening that could lead to early detection and a cure. Indeed, researchers found a gap of 11 percent when they compared how many African-American and white women got breast cancer screening in New Hanover County in 1990.

A resulting public education campaign and series of free clinics had an unintended consequence. The gap grew to 17 percent. Even at the African-American churches, white women out-

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numbered blacks in seeking breast cancer screening.

That's when Geni Eng, a professor of health behavior and health education at the University of North Carolina School of Public Health, decided to apply some of the lessons she learned while working with another professor at the school, John Hatch. Hatch, she says, had worked with black churches in "defining and capturing that natural helping that goes on in congregations" and applying it to health issues.

Eng decided the same approach would work with breast cancer awareness. Her idea was to recruit and train natural leaders within the African-American community to spread the word among their peers about the need for breast cancer screening.

Part of the task of designing a lay-health-adviser intervention program was to figure out why black women were reluctant to seek breast cancer screening in the first place. For this, Eng turned to focus groups. The results were eye-opening.

Among the barriers teased out in focus group interviews were concerns about costs, fear of the mammogram procedure, and a pervasive attitude that preventive health care is a luxury. "They might need the money to feed their kids and clothe them and some other things," one New Hanover County focus group participant observed. Another said an African-American woman might not come in for screening, even when she feels a lump, "because she is so used to bumps and knocks and hurts until she ignores it."

Eng believes that memories of a previously segregated health care system may also have made black women reluctant to seek preventive care. "There's a history out there of a health care system during segregation," says Eng. "It wasn't the most pleasant, sincere kind of interaction during segregation, so you would only go when you were hurting. We're telling them now to go when they don't have a problem and to go and look for a problem."

To dispel these kinds of doubts and fears, Eng felt that African-American women needed

role models in the community. She advertised in the local newspaper and wound up hiring Jackie Smith as the Save Our Sisters coordinator. Through the efforts of Smith and others, 95 lay health advisers were trained to spread the preventive care message in New Hanover County and get African-American women in for screening.

So far, more than 200 women have received breast cancer screening as a direct result of SOS efforts, and countless others may have been encouraged to do so through contact with lay health advisers. The program is being evaluated to determine if older black women in New Hanover County were more prone to get breast cancer screening than those in a control county that did not have a program like Save Our Sisters.

Although the jury is still out, Smith is confident Save Our Sisters has made a difference. "You know what I think? I think the key to our success is getting lay people out into the community, and they get the word out to other people," says Smith. "I try to recruit ladies, and we coordinate the training and go around and speak to people."

But the job involves more than public speaking and sharing information about breast cancer around the kitchen table. If necessary, lay health advisers are encouraged to bring people in for services at clinics or to shepherd women to mobile mammography units deployed at housing projects and black churches.

Smith says the barriers to screening can be anything from fear of losing a breast or hair through chemotherapy or radiation treatment to inability to read and write well enough to fill out the required paperwork. Some might require a gentle nudge, such as, "Can I help you fill out that form?" says Smith. Otherwise, they might leave a clinic in frustration. "You have to be very sensitive to people," Smith says.

And sensitivity involves dealing directly with these women's fears and helping them overcome them. "I think it's the fear of finding breast cancer and the fear of losing hair or breasts, more than pain from radiation or a mastectomy," says Smith. "They're in the habit of going to the doctor for a specific problem instead of going to the doctor to look for one."



**Breast cancer survivor Lela King displays her diploma indicating she is a lay health adviser promoting breast cancer screening in Beaufort County.**

The goal of SOS, says Smith, is to build the confidence of older African-American women to the point that they demand the health services they need. Smith chuckles when she speaks of one previously soft-spoken woman who went to the doctor for screening and scolded him when he failed to feel for lumps. "She told him, 'You come back here. You didn't examine my breasts,'" Smith says. "We're telling women to take control of their bodies, and if they don't get the answers from one doctor, to go talk to another one."

The N.C. Breast Cancer Screening Program hopes to replicate the success of SOS in motivating lay volunteers in a different setting—five rural, medically underserved counties. It also will try to build on SOS by breaking down barriers such as cost and lack of capacity to serve clients. The goal is to improve by 20 percent the number of African-American women who get regular breast cancer screening and mammograms.

Unlike Smith, the coordinators of the programs for the five counties are health department employees. This strengthens the link to service providers, although Eng worries that the increased institutionalization may erode trust in the community. "Right now, the beauty of SOS is that we're all equal," says Eng.

But even with heightened professionalism, the success of the other programs will depend upon lay volunteers like Lela King, who must spread the word that the key to curing breast cancer is early detection. If they fail, it won't be for lack of enthusiasm for the mission. That's because for many of these volunteers, the problem of breast cancer awareness hits painfully close to home.

"I had a bad experience with my daughter," says King in closing her graduation remarks. "She had it a couple of years ago, and she didn't get it in time, and she passed. I'm telling my granddaughter now."

—Mike McLaughlin