



FEATURE STORY

The Comforts of Help

BY KATHY LATOUR

Women need [and are now getting] more than medical care to heal from breast cancer.

Peggy Plaisted recalls the day she was diagnosed with breast cancer in 2002 as one with lots of surprises and lots of paper. She had been tracking a cyst on her ovary and had planned surgery to remove her ovaries when her doctor recommended she have her annual mammogram, which was overdue. The doctor called her later with the news that she had a noninvasive form of breast cancer and they would remove her ovaries at the same time as a lumpectomy to remove the tumor in her left breast.

“They were giving me brochure after brochure about all the services offered for breast cancer. It was overwhelming,” she recalls. All the information left her head spinning, Plaisted says.

“I called my oncologist and told him I couldn’t get out of bed. He gave me the name of the coordinator for the support group and a prescription for an antidepressant. I called and it turned out they were meeting that night—and I was there.”

Plaisted, who was 47 when she was diagnosed, returned to the group sessions twice a month for a year because it helped her to talk about what she was going through. She still attends, but now she takes newly diagnosed women from her community, something she does to give back. She also goes to check in with the women in the group who have become her friends.

Twice she has attended an all-day breast cancer symposium at Gilda’s Club North Texas, a free support community named for comedian Gilda Radner that has numerous support groups, classes, speakers and workshops on topics that include nutrition, pain, yoga, meditation and journaling, among others.

Just two decades ago, Plaisted’s doctors probably would have told her not to talk to other women because they might give her wrong information. Or, as happened to one woman, be told by her surgeon to “stop crying” because she wasn’t going to die.

Today, thanks to insightful medical professionals and demanding breast cancer patients, the need to include emotional and social issues in the resolution of a breast cancer diagnosis has been accepted.



Peggy Plaisted found the emotional help she needed through a support group. Photo by David Gresham.

Building a Case

Research studies in the psychosocial aspects of breast cancer, which only began in earnest in the mid-1980s, have shed light on a complicated area that encompasses not only emotional and social issues, including family matters, spirituality, employment and insurance, but also supportive care issues, such as pain management, and a vast array of complementary therapies, such as exercise and nutrition.

Today, support for women with breast cancer ranges from cancer center programs that might be a support group to others where patients might find enough options to bring them to the hospital every day doing art therapy, music therapy, an exercise class, a nutrition class or meditation. Nationwide community programs include Gilda's Club and The Wellness Community, among many others.

Research in psychosocial areas explore myriad variables, including what constitutes a psychosocial issue, how to determine who needs interventions, the best solutions and when the solutions should be presented. The studies also look at why some women still do not receive adequate interventions despite their demonstrated benefit and what types of intervention are most effective for specific subgroups of patients.

Mary Jane Massie, MD, attending psychiatrist at The Breast Center at Memorial Sloan-Kettering Cancer Center in New York City, has been working in the area of psychosocial support for women with breast cancer for more than 30 years. She experienced the medical community's acceptance that treating a woman for cancer should encompass the whole person, including her mental health needs and the core issues that can cause disruption.

Dr. Massie, who recalls a time when patients weren't even told they had cancer, says in addition to medical professionals who recognized the need, it was the women themselves who demanded information and participation in what was happening to them.

"We never saw men back when I started," she says. "Women brought their mother or friend or sister. The first time I saw a husband, I ran out to the waiting area to ask if he wanted to join us. He said no, and right then decided he needed to go put money in the meter. He ran out of there. Now, there are men and the whole family, and the men want to know how it works."

Understanding the Need

Today, many women meet with support persons immediately after diagnosis and are introduced to the range of options provided by the facility. These interventions may be as casual as handing the woman a brochure or as formal as an interview to gather extensive information on her emotional and social environment.

“It’s assessing what is there for patients—family, religion, community and their cultural and professional community,” Dr. Massie says. “We need to identify those who are most vulnerable and determine how this person best receives help.”

A 2004 report from the Institute of Medicine of the National Academies presented an overview of psychosocial help for women with breast cancer. One study in the report identified women of younger age as those most likely to experience distress as well as those with a history of depression, physical health issues or inadequate social support.

Patricia Ganz, MD, director of UCLA’s LIVESTRONG Cancer Survivorship Center of Excellence and head of the division of cancer prevention and control research at Jonsson Comprehensive Cancer Center in Los Angeles, says screening of a patient’s emotional status should occur before treatment to understand the patient’s needs. “Then special attention needs to be paid at transition points: starting treatment, ending treatment. If you haven’t already assessed once, you won’t know where the patient started,” says Dr. Ganz, who contributed to the IOM report.

It’s a matter of paying attention to patients and their needs because there are no universal reactions, says Dr. Ganz, offering as an example the results of a recent study in women at the end of treatment that didn’t show the distress researchers anticipated. Instead, physical issues, such as sleep disorders and pain, were of more concern.

Dr. Ganz’s patient assessment process begins by exploring intrapersonal issues and the patient’s life history, such as how she coped with difficulty in the past and how she feels about body changes and, if appropriate, being disfigured. Then there are the interpersonal issues of relationships and work followed by discussion of physical issues like chronic pain, fatigue and sexual dysfunction.

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—Patricia Ganz, MD

Once the patient’s history has been assessed, Dr. Ganz helps the patient understand that there will be a variety of issues associated with the cancer journey and offers tools for coping. “We want to help them find a way to normalize symptoms and know that these issues go along with a diagnosis. They may not have difficulties immediately, but when we have introduced the idea that they may experience something later, they know they have a place to go.”

It’s a process, Dr. Ganz says. No one can handle it all on the first visit. For example, if a woman is going to be thrown into menopause, she should know

what symptoms to expect and where to get help.

Dr. Ganz, like many medical professionals, takes advantage of well-established programs already in place. And, for women who can't or won't be involved with people, she recommends online resources, which a 2005 study conducted by the University of Missouri at Columbia showed could provide numerous psychosocial benefits. The study analyzed 33,000 postings to an online community and showed benefits such as increased skill or ability to cope with the disease, improved mood, decreased psychological distress and strategies to manage stress. The longer women belonged to the online community, the more they reflected a positive well-being—and the more they began to share information with the group. Indeed, the study showed the longer women belonged to the group, the more time they spent online offering information to newly diagnosed women who joined the community.

Although psychosocial support services have come a long way, Dr. Ganz says they are still not on par with medical services. The breast cancer journey is individualized, and women must continue to demand support and take control of how to get support—and what that support should look like.

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