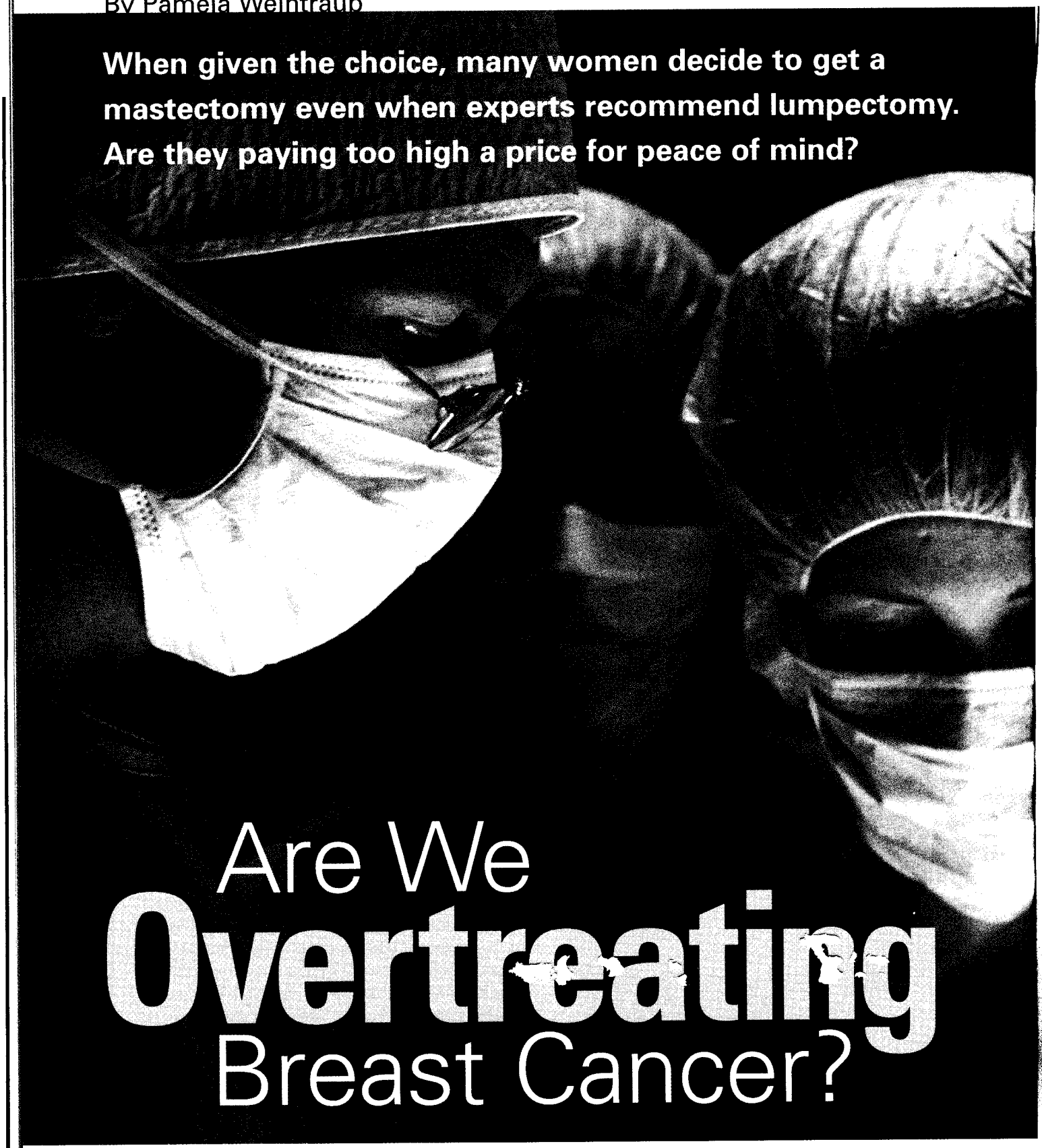
By Pamela Weintraub

When given the choice, many women decide to get a mastectomy even when experts recommend lumpectomy. Are they paying too high a price for peace of mind?



Are We Overtreating Breast Cancer?

In 1999, Beverly Flowers, a flight attendant with American Airlines, was visiting her gynecologist to see about getting pregnant. Age 45, and just recently married, she knew her biological clock was ticking. During the same appointment, Flowers' physician ordered a mammogram, which revealed a suspicious lump; a subsequent biopsy found a small ductal carcinoma—a 1.5 centimeter malignant tumor in the milk duct of her left breast, classified as stage I. Because the tumor was so small and Flowers had no family history of cancer, her surgeon recommended breast conserving surgery—a lumpectomy—followed by radiation. There was no need for Flowers to remove her entire breast with mastectomy, the doctor said, because the lighter surgery resulted in the same rate of survival, and obviously, it was much less extreme.

A natural-born skeptic and lifelong independent thinker, Flowers wasn't in a rush to commit. "Do I have some time to think about it?" she asked her doctor.

"Don't take too long," she was told.

But Flowers, who knew her tumor was small and her prognosis excellent, decided to take two months "so that I could learn all I could." What she discovered in the course of her investigation convinced her the doctor's advice was wrong, for her. Scrutinizing her medical records, she learned her personal risk was higher because her tumor was stimulated to grow with exposure to estrogen and was positive for over-expression of HER2/neu, a gene associated with cancer growth. She was especially influenced by statistics: In women with small breast cancers (two centimeters or fewer) 8.8 percent of those receiving lumpectomy plus radiation experienced recurrence in the same breast, compared to 2.3 percent of those receiving mastectomy. In other words, chance of recurrence with lumpectomy, though still small, was about four times as great.

Because recurrences were treatable, lumpectomy and mastectomy ultimately have the same long-term survival rate. But the small percentage difference in recurrence was meaningful to Flowers, causing her to reject her doctor's advice. "When I was first diagnosed, I was devastated," she explains. "I had a choice about the surgery, but it was difficult to decide. The first step

Two women, two choices

Mastectomy

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– Beverly Flowers

Lumpectomy

"After I chose lumpectomy, I had to deal with axillary node dissection, chemo, radiation, and then getting my life back. I had to move forward and did not look back."
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Flowers' choice: Mastectomy followed by chemotherapy and the estrogen blocker tamoxifen. Says Flowers, "the decision felt right."

Janet Gilsdorf, M.D., an expert in pediatric infectious disease at the University of Michigan, a medical insider with great sophistication, stands in contrast to Flowers. Diagnosed with ductile carcinoma in 2000 at age 55, Gilsdorf also had breast cancer sensitive to estrogen and was positive for HER2/neu. At 2 centimeters, her tumor was classified as stage II, conferring a prognosis less rosy than Flowers'. Gilsdorf, too, took time to review the medical literature and parse the numbers; she consulted her husband, a surgeon experienced in treating just the kind of cancer she had.

In the end, Gilsdorf preferred to look not at recurrence rates, but at the bold math of survival. For a tumor like hers, she learned, 10-year survival with lumpectomy plus radiation was 62 percent; with mastectomy, 60 percent—two percent less. As a researcher herself, Gilsdorf knew there was virtually no difference between 60 and 62 percent, statistical "chump change" that could best be explained by chance, she wrote in *Inside/Outside: A Physician's Journey with Breast Cancer*, her book about the experience. By "relying on the subjective calculator deep within my gut rather than the subjective one in my head," she found "the bigger survival number in the lumpectomy group" more comforting. She chose lumpectomy (followed by radiation, chemotherapy, and hormone therapy) and she, too, never looked back. Says Gilsdorf, "I am comfortable with my choice."

When Patients Decide

Was Beverly Flowers' decision wise or was her treatment too aggressive? Did Janet Gilsdorf's more conservative treatment decision put her at risk of recurrence? Should women embrace their doctors' advice, even if it makes them anxious? Or should they push the treatment envelope if it gives them peace of mind? Are there different ways to view the same statistics? And as for surgery, how can women decide what to do?

These questions assume importance in light of a sur-

prising fact: In the U.S., patients with early breast cancer receive many more mastectomies than their counterparts in Europe, and far more than indicated by the current standard of care. For the earliest stage of breast cancer, ductal carcinoma in situ, or DCIS, for instance, the U.S. mastectomy rate is 26 percent, a study from the University of California, San Francisco, recently found, compared to 10 percent in the United Kingdom, the figure many academic experts think appropriate here as well.

But if you think that doctors are largely responsible for our high mastectomy rate, think again. According to Steven J. Katz, M.D., a professor in the department of health management and policy at the Comprehensive Cancer Center at the University of Michigan in Ann Arbor, the aggressive approach in America is often a grass-roots phenomenon, fueled by the patients themselves. American women, it turns out, often feel more comfortable with the aggressive approach, and choose it more frequently when left to decide themselves. In Katz's study, published just recently in the *Journal of Clinical Oncology*, when the surgeon alone made the decision, only 5.3 percent of women with early breast cancer received mastectomies. When the decision was shared, that rose to 16.8 percent. Women who made the decision themselves—women such as Flowers and Gilsdorf—elected to have mastectomies 27 percent of the time. "It's misleading to compare the U.S. and the U.K.," Katz explains. "Medicine in the U.K., by nature, is more prescriptive, more one-size-fits-all. In the United States, we have more personal choice."

A Personal Choice

The goal for doctors and patients, says Monica Morrow, M.D., chairman of surgical oncology at the Fox Chase Cancer Center in Philadelphia, should be to keep surgery to a "proper minimum" so that quality of life remains high. Indeed, only a few women are excluded from lumpectomy in the early stages of disease: those in the first or second trimester of pregnancy who cannot expose a fetus to accompanying radiation; those who have had prior irradiation to the breast in question; those with multiple tumors in a single breast; and those with "positive surgical margins," where cancer cells have been found in the tissue surrounding the tumor that's been removed. For everyone else, lumpectomy is fine.

Those statistics on recurrence may not influence survival, but, it turns out, they can color daily life and prey on peace of mind. "No woman should be criticized [illegible] ting to do more, even for the earliest form of breast cancer," Morrow states. "It is most important to find that proper balance where the outcome is good and the quality of life remains high." Even though survival rates "are the same for lumpectomy with radiation versus mastectomy," Morrow notes that "those who have mastectomy are usually done with the cancer, cured."

Electing Peace of Mind

As far as Katz is concerned, these patient decisions are appropriate in meeting the womens' needs. "When peace of mind and the idea that leaving the disease behind you conflicts with recommendations, the more important thing might be the peace of mind," he says, adding that patients make these decisions intuitively, often without a deep understanding of the science or statistics. "But it is the patient, not the doctor, who must live with the idea that the cancer can return. Leaving the breast that had the tumor can drive some patients crazy, and they feel better when it's gone," he says.

"Breast cancer is a disease not just of the body but also the mind," Flowers says. "It is like a journey on a train where you see a light at the end of the tunnel but never get there. You must be watchful for the rest of your life." If she'd left the breast intact, she says, keeping watch would have been that much harder.

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"Even women with early cancers are choosing mastectomy."

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It all makes sense to Robin McILvain, an active participant in Flowers' breast-cancer support group at the Wellness Center in Atlanta and a contributor to *B.O.O.B.S.: A Bunch of Outrageous Breast Cancer Survivors Tell Their Stories of Courage, Hope & Healing*. "I've seen a real change among members in recent years," McIlvain says. "The newcomers are far more proactive. Even those with very early cancers are choosing mastectomy, and recently, bilateral mastectomy, to prevent a recurrence in either breast. They know that with mastectomy the percent of recurrence is almost nil. That is a number they can live with much more easily, day to day." With so many survivors out there, McILvain adds, word has gotten out that reconstruction can be more symmetrical if both breasts are removed and rebuilt at once.

Beverly Flowers decided on a more aggressive course than generally recommended for her diagnosis; Janet Gilsdorf embraced the more conservative recommendations her doctors and the medical journals prescribed. But each woman made an educated decision, and did what was right for her.

"Once I made the decision, I never second guess," says Gilsdorf. "After I chose lumpectomy, I had to deal with axillary node dissection, chemo, radiation, and then getting my life back. I had to move forward and did not look back."

How can patients know whether all the options have been spelled out? Katz says patients must feel that doctors have truly communicated, and that they have outlined the range of choices, not just dictated the treatment course from on high. "More face time between the surgeon and the patient before a decision is made would certainly help." Other suggestions include seeking a second opinion at a major medical center, and asking a doctor whether your disease is amenable to a less invasive approach or a more radical one, depending on what you want.

Finally, you may want a female physician. Of note, when the surgeon is male, the recommendation is more often for lumpectomy; some surgeons may tell the woman that mastectomy is not an option at all. When the surgeon is female, she's more likely to understand how the patient feels and so, more likely to present all the options and give the patient the choice.

"The women making the choice here are the ones who have to live with the cancer, and with or without the breast. They know their own comfort level, and how they will feel best," says Katz.

"It's a personal decision that every woman needs to make herself," concludes Morrow. "Even for the earliest breast cancers, labeling a mastectomy 'overtreatment' is a mistake. Mastectomy is a reasonable treatment alternative, and a legitimate way to go." ✱