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THE DOUBLE MASTECTOMY REBELLION

Defying Doctors, More Women With Breast Cancer Choose Double Mastectomies

By Lucette Lagnado

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Chiara D'Agostino, midway through a series of planned operations to remove and reconstruct both breasts.

ILLUSTRATION: ALLISON MICHAEL ORENSTEIN FOR THE WALL STREET JOURNAL

After she was diagnosed with cancer in her left breast last fall, Chiara D'Agostino turned to two holistic healers, a psychotherapist, a massage therapist, a hospital social worker, a meditation class and two support groups to help her navigate a frightening new world.

One piece of advice she doesn't plan to follow: her doctor's. The surgeon recommended a single mastectomy along with chemotherapy and radiation. But many women in the support groups argued that she should get both breasts removed.

One warned Ms. D’Agostino that her healthy breast would eventually sag while the reconstructed one stayed perky. Others, trying to be helpful, would lift their tops to show off their new figures. “I was like, ‘You are crazy. I would rather keep my breasts,’ ” said Ms. D’Agostino, a 43-year-old former Italian teacher from New Jersey. But after hearing the message for months—and discovering that her insurance would pay for the second procedure—she decided to have her healthy breast taken off and reconstructed too.

Researchers have tracked sharp increases in double mastectomies, even among women at low risk for cancer to develop in the other breast and for whom the radical procedure offers no additional survival benefits. Doctors call it a profound shift in the prevailing medical culture and some have begun to question whether the field should reconsider performing what amounts to an amputation with little evidence to support its efficacy.

“This is an epidemic,” says Dr. Ann Partridge, an oncologist at Dana-Farber Cancer Institute in Boston.

An analysis of the National Cancer Data Base revealed that 12% of women who received surgery for Stages 0-to-3 breast cancer in 2012 underwent a double mastectomy, up from 2% in 1998. Nearly 30% of women under age 45 opted to have both breasts removed in the most recent year, according to the analysis by Dr. Katharine Yao, director of breast surgery at NorthShore University HealthSystem near Chicago.



Watch the video: Follow Chiara D’Agostino as she comes to terms with her diagnosis and makes a decision about her treatment. Image: Robert Libetti/The Wall Street Journal

A constellation of factors have contributed to the surge. Most public and private insurers have been mandated since 1998 by federal law to cover reconstructive surgery after a mastectomy. The doctor-patient relationship has changed, and physicians are reluctant to

tell women what they should or shouldn't do. Advances in plastic surgery promise more attractive artificial breasts than ever before.

Then there is what doctors dub the "Angelina effect." The actress Angelina Jolie, whose own mother died of cancer, announced in 2013 that she had undergone a preventive double mastectomy after a blood test revealed that she had a genetic predisposition for breast cancer. [In an op-ed piece](#) she said, "I feel empowered that I made a strong choice that in no way diminishes my femininity."

There is a general consensus that such procedures dramatically decrease the risk of breast cancer for genetically vulnerable women like her, who represent a minuscule 0.25% of the U.S. population, according to Dr. Kenneth Offit, chief of the genetics service at Memorial Sloan Kettering Cancer Center in Manhattan. After the actress's announcement, women across the country flocked to get tested.

But doctors say they are also seeing increases in the numbers of low- or average-risk women who, when diagnosed with cancer, opt to have their healthy breast removed along with their stricken one, a procedure called a contralateral prophylactic mastectomy. "There are women who have come to think of their breasts as the enemy," says Dr. Offit.

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A mounting body of medical literature is arguing against such drastic surgery. The procedure virtually eliminates the already-tiny chance that cancer will develop in the remaining breast. But it carries its own significant risks of complications such as infections. Meanwhile, doctors say, returning cancer is much more likely to spread or metastasize elsewhere in the body, such as bones, the liver or the brain.

Dr. Steven Katz, a researcher at the University of Michigan who has published several studies on double mastectomies, said the rate of the cancer recurring elsewhere in the body is as high as 13%. "Women should be focusing on staying alive, which has nothing to do with taking out the other breast," he said.

A groundbreaking study of nearly 190,000 California women with breast cancer led by Stanford University oncologist Allison Kurian revealed that survival rates weren't any

better for women who opted for double mastectomies than those who chose a breast-saving lumpectomy with radiation. Dr. Kurian says her database study raises the question of “whether the outcome of contralateral prophylactic mastectomy is worth its costs to a woman’s quality of life and to society.”

A DRASTIC CHOICE

Many more women—especially those 45 and under—are opting for double mastectomies when fighting stage 0 to stage 3 breast cancer.

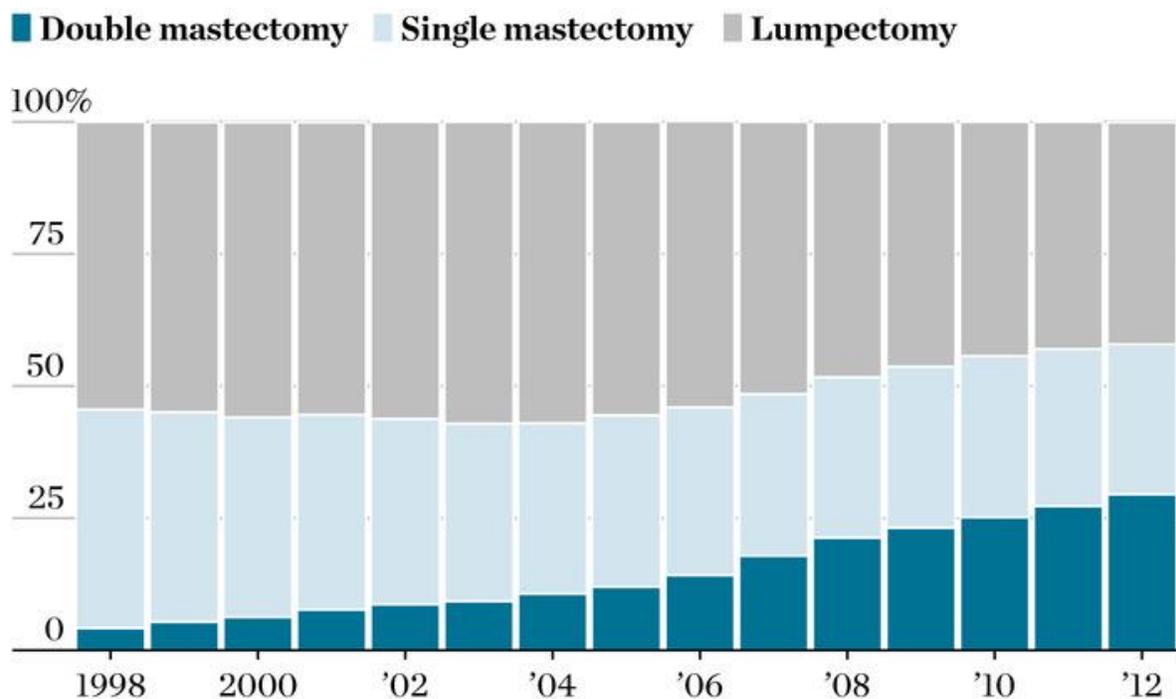


ILLUSTRATION SOURCE: ANALYSIS OF THE NATIONAL CANCER DATA BASE BY DR. KATHARINE YAO, M.D., NORTSHORE UNIVERSITY HEALTHSYSTEM

Many women who choose the surgery say any risk of returning breast cancer is too high. They say they are grateful to be free of the mammograms, MRIs and doctors’ appointments necessary to monitor the other breast and the anxiety that arises every time a test shows a possible anomaly.

“This is about living your life without looking over your shoulders,” says Jennifer Finkelstein, who was diagnosed with breast cancer in 2005 when she was 32 years old. She had a single mastectomy and reconstructive surgery. Still cancer-free five years later, she decided to have her healthy breast removed against the advice of her oncologist.

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Ms. Finkelstein said her instincts told her the surgery could protect her—and she no longer sees unmatched breasts in the mirror.

The surgeries weren't easy. She has needed by her own count five or six operations or procedures involving both breasts. One surgery left her with a tattooed nipple in the wrong place. But Ms. Finkelstein says emphatically that she doesn't regret her decision. She recently founded a New York nonprofit organization, 5 Under 40, which provides financial and emotional support for young women diagnosed with breast cancer.



Jennifer Finkelstein had a single mastectomy in 2005 after a cancer diagnosis, then chose to have her healthy breast removed five years later for peace of mind.

ILLUSTRATION: ALLISON MICHAEL ORENSTEIN FOR THE WALL STREET JOURNAL

White women, in particular younger white women, are twice as likely to undergo the surgery compared with other racial groups, according to a study by Dr. Yao of NorthShore using the National Cancer Data Base, which captures roughly 70% of newly diagnosed cancers in the U.S.

Karen Hurley, a New York-based psychologist who specializes in treating breast cancer patients says peer pressure contributes to the rise. “You see almost this proselytizing,” she says. Dr. Hurley believes women who go ahead with the surgery are often regarded as brave and in control. “At one point, empowerment was keeping your breasts, and now it is removing them.”

After Dr. Hurley was herself diagnosed with Stage 3 breast cancer in one breast, she had a single mastectomy and reconstruction but chose to keep her other healthy breast because she was familiar with the risks of complications.

Historically, women with breast cancer faced a nightmarish treatment and few options except for radical mastectomy, a surgery that included the removal of the breast, underlying chest muscles and axillary lymph nodes and often left them disfigured.

In the 1960s and 1970s, University of Pittsburgh doctor Bernard Fisher did seminal research on treating breast cancer using a lumpectomy, a delicate operation that involved removing the cancerous material from a breast along with some surrounding tissue. Dr. Fisher concluded that a lumpectomy followed by therapy such as radiation was as effective as a mastectomy in treating cancer. Dr. Fisher was hailed as a hero.

But mastectomies were still common, and women were still left scarred. In 1998, Congress passed the Women's Health and Cancer Rights Act, which mandated that most health insurers cover reconstructive surgery for women who had mastectomies. The legislation, pushed by former New York Sen. Alphonse D'Amato, helped women who couldn't afford reconstruction and combated the notion that reconstructive surgery was strictly cosmetic.

It had another effect. In an analysis using 1998 to 2011 data in the National Cancer Data Base, Dr. Evan Matros, a Sloan Kettering reconstructive surgeon, and other researchers found that as the number of double mastectomies rose, there was a correlative decline in lumpectomies and single mastectomies.

In other words, even as medicine has moved more toward minimally invasive surgeries in other arenas, many women with breast cancer have been moving in the opposite direction, said the study, which was published in May in the journal *Plastic and Reconstructive Surgery*.

The surgeries can be costly. According to data from a major private health insurer a single mastectomy—not including hospitalization—averages \$8,500; a double mastectomy costs 24% more, or \$10,500. Reconstruction of each breast costs \$10,000—or nearly three times as much as a simple cosmetic augmentation procedure, which typically isn't covered by insurance. Altogether, the average cost of a double mastectomy with reconstruction was 65% higher than removing and rebuilding one breast alone—\$30,500 versus \$18,500.

Recent years have seen significant advances in breast reconstruction, leading more women to have double mastectomies. Doctors have developed techniques not simply for better implants, but also to rebuild a woman’s breast using her own tissue taken from other parts of her body. These operations can take several hours for each side, but result in a more natural look and feel.

RECONSTRUCTION BOOM

Breast reconstruction surgeries, change from a year earlier

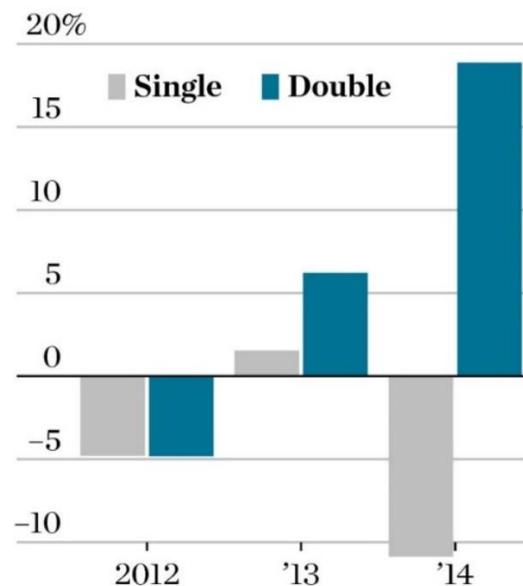


ILLUSTRATION SOURCE: AMERICAN SOCIETY OF PLASTIC SURGEONS (ONLY PROCEDURES PERFORMED BY SOCIETY-MEMBER SURGEONS)

Still, even the most attractive outcome leads to lack of sensation and often scarring. While many women want to preserve their nipples, it isn’t always possible because of the fear that the cancer could spread in the area.

Breast surgeons tend to be troubled by the trend toward double mastectomies. Dr. Michael Miller, chief of plastic surgery at the Ohio State University Wexner Medical Center in Columbus, says he doesn’t hesitate to argue with women who don’t have high risk factors yet opt to get both breasts removed. “I say, ‘Why don’t we simply remove your foot? It would make as much sense to remove your foot as to remove your breast. Either would contribute an equal amount to your survival.’ ” On the other hand, he says there is a genuine need for reconstruction among women whose cancer leaves them no choice but to have a mastectomy, and hospitals should offer it.

What's more, he adds, "It is very lucrative." In a June 2014 study that appeared in the *Plastic and Reconstructive Surgery* journal, Dr. Miller calculated that his hospital's net income from breast reconstruction surgeries grew by 7,264% from 2004 to 2012, from a very low base, while his team of plastic surgeons saw a 1,211% growth in professional net income.

While there is general consensus about the science, there are significant divisions about what doctors should do. Some want clearer guidelines that could limit the procedure and others even suggest that insurers should stop covering it except in high-risk cases. But others argue that they can't refuse a well-informed woman.

"We are no longer practicing medicine in a paternalistic fashion, and at the end of the day, it is the patient's decision," says Dr. Deanna Attai, president of the American Society of Breast Surgeons and a surgeon affiliated with UCLA Health.

Dr. Attai believes many double mastectomies are medically unnecessary—and indeed carry a heightened risk of serious complications—but thinks that since medicine can't guarantee cancer won't develop in the healthy breast, she is obligated to defer to the patient's wishes.

"The patriarchal allegation has moved 180 degrees," says Sloan Kettering oncologist Dr. Clifford Hudis. "It used to be, 'How dare you say my breast isn't important and make me lose a breast to mastectomy?' Now, decades later, the allegation is, 'Why do you care so much? It is my breast.' That is a humbling perspective."

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For women, too, the new bedside manner may be disorienting as well as empowering. Jacqueline Lowey, of East Hampton, N.Y., says all the information can be hard to take in during the terrifying moment of a cancer diagnosis. In 2012, she was told she had a Stage 0, noninvasive cancer, along with traces of a second cancer marker. She says she was

offered three options: a lumpectomy followed by radiation and the drug Tamoxifen; a single mastectomy of the affected breast; or a double mastectomy.

Doctors said that a lumpectomy would offer her the same chance of survival. But she says she was also told that the breast-sparing procedure might leave her vulnerable to a return of the disease. Thinking of her 7-year-old son and 10-year-old daughter, and unwilling to submit to radiation, Ms. Lowey asked for a double mastectomy.

“There is a lot of power given to patients, and it is overwhelming,” she said. “You want someone to tell you what to do, but basically, they lay out options, give you odds, give you all the information, and you have to make the decision.”

While some women express satisfaction with their choice, others say they didn’t anticipate the profound ramifications of a double mastectomy. On a recent April morning, Lesa Ann, a nurse in rural Ohio, watched television news shows reporting that actress Rita Wilson had decided to have a double mastectomy. Ms. Ann was furious.

Ms. Ann had a double mastectomy after she was diagnosed in 2010 with cancer in one breast. “My feeling was, I had cancer, get rid of it. I didn’t want to have that stress again.”

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But her stress increased. “The aftermath is unbelievable,” she says. The doctors told her they were unable to do a reconstruction because her smoking habit made such a procedure too complicated. Now she feels disfigured, and has since coped with “a bad self-image, depression and no sex drive,” she says.

The psychological pain has been so great that only now, five years later, is she able to come to grips with what happened. She believes that women don’t fully understand the risks and that celebrity endorsements glamorize the procedure.

“You don’t come out in your prom dress looking all happy and cheery,” she says.

Ms. D'Agostino, the former Italian teacher, had her first mastectomy, to remove the ailing breast, in April. Even in the weeks leading up to the procedure, she was still wrestling over whether to have her other breast removed.

One evening, at a support group sponsored by SHARE, a Manhattan-based breast cancer organization that she especially values, Ms. D'Agostino asked a woman who had had a double mastectomy if she still had any sensation in her breast area.

"There is no feeling left at all," Susan Levin replied.

It was a sobering experience for Ms. D'Agostino, who was saddened at the prospect of losing a key aspect of her sexuality.

Ms. D'Agostino received conflicting medical advice. One breast surgeon suggested she could have a lumpectomy and preserve her breast. But the one she chose, and another she consulted, both argued for a mastectomy. None of the surgeons suggested a double mastectomy.



Chiara D'Agostino

ILLUSTRATION: ALLISON MICHAEL ORENSTEIN FOR THE WALL STREET JOURNAL

Her surgeon, M. Michele Blackwood of Saint Barnabas Medical Center in Livingston, N.J., says that while she explains to women that removing a healthy breast doesn't boost survival rates, there are other reasons to support the decision. A woman can emerge from

the procedure feeling good about her body, Dr. Blackwood said. “She swims and she runs and she goes to the gym and she gets undressed,” she said.

After she had her mastectomy in April, Ms. D’Agostino received some promising news. The pathology on the removed breast showed chemotherapy had worked and there was no trace of cancer. Doctors decided that she wouldn’t need radiation.

During the mastectomy, her plastic surgeon inserted an “expander,” or temporary device to make room for a cosmetic implant. She has decided to wait until September to take the next step, removing the other healthy breast. After that, both will be reconstructed. She is determined to go ahead; while she waits, she is developing a blog about her experience, “Beauty Through the Beast.”

She has no illusions: She knows that the next surgery won’t improve her odds. She doubts that it will bring her peace of mind. It is about achieving “symmetry.”

“Look, I am 43 and single,” she said. “I want to feel attractive, and I want my breasts to match.”

Write to Lucette Lagnado at lucette.lagnado@wsj.com

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