Middle Eastern women once feared the stigma of breast cancer more than the disease itself. They whispered the words, keeping breast cancer secret and ignoring symptoms until the disease was so advanced it could not be treated effectively.

For many, death was less fearful than the shame of divorce or receiving treatment from a male physician – or even jeopardizing their own daughters’ marriage opportunities because of genetic concerns.

Times have changed, and today many Middle Eastern countries push public awareness through education campaigns, free breast cancer screenings and more research and collaboration. Former First Lady Laura Bush’s 2006 visit to the region launched a host of breast cancer initiatives and drew international attention to a disease that remains the leading killer of women in the Middle East.

“For some reason, breast cancer is more prevalent and it happens in a younger patient population in the Middle East,” says Dr. Aldona J. Spiegel, director and founder of the Center for Breast Restoration at Methodist Hospital’s Institute for Reconstructive Surgery in Houston. “Patients get identified at later stages.”

While physicians with a keen interest in women’s health issues want to understand the reasons behind the disparity, Spiegel says there are no existing databases to accurately address the questions. Middle Eastern women are empowered with greater awareness and earlier diagnosis, but multidisciplinary centers to treat the entire spectrum of breast cancer – including reconstruction and restoration – are often lacking here and internationally.

Many breast cancer patients still don’t get the full story when it comes to reconstruction and breast restoration. The information vacuum is not limited to countries like Saudi Arabia, the United Arab Emirates, Kuwait, Jordan and other Middle Eastern countries.

Even in the United States, where powerful organizations like Susan G. Komen for the Cure have focused attention and resources to bring down death rates and raise awareness, women still remain in the dark on major issues like restoration options after mastectomies.

Spiegel, a specialist in microsurgery, says 90 percent of the estimated 200,000 U.S. women diagnosed with breast cancer this year will undergo breast implant surgery – and most will be led to believe the implant is the only option available. Yet new procedures pioneered in the last decade offer a host of alternatives that use the patient’s own tissue, oftentimes sparing underlying muscle and preserving feeling through re-innervation or restoration of nerve function.
“That’s not to say that implants are bad,” Dr. Spiegel explains. “But the average age nowadays for breast cancer reconstruction is in the mid 40s. If you look at the statistics for long-term problems with implants versus autologous (using patients’ own tissue) reconstruction, it’s quite significant. Implants can have problems long term versus using patients’ own tissue. It’s frustrating that women don’t have more access to this information.”

At a recent U.S. conference of the National Consortium of Breast Centers, Spiegel says she was shocked to discover that microsurgery and restoration are not routinely offered at national and international cancer centers.

One of the main reasons behind this information gap is training. Microsurgery itself presents a huge learning curve. “It takes special training, it takes special focus and, I think, a passion to do this,” Spiegel says. “It takes time to get the expertise.”

In discussions at conferences around the country, Spiegel says many plastic surgeons don’t believe restoring feeling and sensation are as important as restoring patients cosmetically.

“If you talk to the patients, it is important,” Spiegel says. “The breast needs to have sensation, not for erogenous issues, but to feel like it’s a part of you. If you’re truly trying to get the ideal breast reconstruction, sensation certainly needs to be a part of it.”

One patient who lost both her mother and her sister to breast cancer underwent a mastectomy seven years ago. She learned about Spiegel’s reconstruction expertise from a news release, underwent restorative surgery last year and wrote that she is in better shape now than before surgery. “It seems to me that every woman considering breast reconstruction would choose this method if she had the choice to. Diagnosis of a serious disease is devastating enough without having to suffer through a diminishing experience of make-do reconstruction surgery.”

A Texas woman who underwent reconstructive surgery last year learned about her options on the Internet and wrote to thank Spiegel and her staff following her reconstruction surgery:

“A diagnosis of breast cancer can turn your entire world upside down. I cannot even try to describe the emotional roller coaster that I found myself riding on. Regaining my feeling was very important to me. Thank you so much for reconnecting my nerves and for making me look and feel normal again.”

The bottom line, Spiegel says, is to find the right option for the individual, and every woman is different.

Many women around the world have been empowered by their own research on the Internet. In the past year, Spiegel updated her site (www.breastrestoration.org) to include more patient education content, videos and detailed explanations of reconstruction surgery options. Plans to translate the Web site into Arabic and Spanish are under way.

She also is collaborating with colleague Dr. Constance Chen on an interactive and functional Breast Reconstruction Handbook with photos, lists, step-by-step instructions following diagnosis and other valuable information designed to guide a breast cancer patient through the process from start to finish. The book is scheduled for release in October 2010.

Along with Dr. Robert Allen, a plastic surgeon who pioneered many of the microsurgical techniques used in breast restoration, Spiegel founded the Group for Advancement of Breast Reconstruction Surgery (GABRS) and several plastic surgeons are now pooling information on their surgeries for future study and a national database. No medical certification currently exists to let prospective patients know whether a surgeon is qualified in breast reconstruction; GABRS hopes to raise the bar in the specialty and advanced techniques that eventually can replicate the original breast.

“We’re getting close,” Spiegel reports. “We’re working on sensation; we’re working on skin-sparing techniques for a mastectomy; and we’re working on minimizing donor site problems.”

Members of GABRS believe the most important facet of treating breast cancer patients is tailoring treatment to the individual. Women diagnosed later in life usually have vastly different post-surgery needs than younger women. Identifying their expectations from different perspectives – social, body image, medical and oncological – is crucial to treating the “whole” patient. For plastic surgeons, that means being able to offer everything from the simplest reconstruction to the most complex.
A diagnosis of breast cancer can turn your entire world upside down. I cannot even try to describe the emotional roller coaster that I found myself riding on. Regaining my feeling was very important to me. Thank you so much for reconnecting my nerves and for making me look and feel normal again.”

-- Patient from Texas

Spiegel and other surgeons of GABRS today have gone beyond the TRAM flap. They routinely perform DIEP and SIEA flap reconstructions in which they take only the tissue needed and meticulously separate arteries and veins from the abdominal muscle to spare it. The DIEP procedure is used in patients whose blood supply is deeper in the muscle. Patients whose blood vessels are in the fatty layer of abdominal tissue can use the SIEA flap, in which less dissection is needed. Surgeons usually make the decision on which surgery to use as reconstruction begins, since not all patients have the more superficial blood vessels that allow the less invasive SIEA flap surgery.

“Everything in plastic surgery is about allowing the tissue to have blood flow,” Spiegel explains. “The TRAM flap is routine. But we’re working to say, ‘Wait a minute. Just because you can remove the muscle doesn’t mean you should.’ I get some patients who have significant problems after a TRAM flap. They come to me because I do muscle-preserving surgery, and they think I can do something to help them. But once that muscle is gone, it’s gone.”

Another procedure surgeons like Spiegel are perfecting is an areola-sparing mastectomy in which the only part removed in the breast envelope itself is the nipple, but surgeons spare the areola. Since the ducts empty into the nipple, it must be removed in a mastectomy. In the past, the areola was taken with it and had to be tattooed onto the reconstructed breast. It never looked as good as the natural body part, Spiegel explains.

Now surgeons are keeping the original areola and reconstructing the nipple, with such natural results that Spiegel says she’s actually had to write letters to patients’ gynecologists confirming that they indeed do have a reconstructed breast and no longer need a mammogram.

As surgeons in GABRS work to elevate the aesthetic results and focus attention on reconstruction options, many breast cancer patients remain stuck in the information gap between breast cancer diagnosis and their futures. Breast cancer awareness and survival rates improve each year, yet longevity and quality of life issues are often neglected.

Spiegel’s patients formed a support group called DREAMERS to offer emotional backup and information to other breast cancer survivors. Most members learned of their options serendipitously and are frustrated by the information gap between diagnosis/cure and restoration/recovery.

They want health care to consider the whole patient and the whole spectrum of breast cancer. Their mission is to spread information far and wide so breast cancer patients know what to ask for and request what they want for their futures.
“The breast needs to have sensation, not for erogenous issues, but to feel like it’s a part of you. If you’re truly trying to get the ideal breast reconstruction, sensation certainly needs to be a part of it.”

-- Dr. Aldona J. Spiegel, Director and Founder of the Center for Breast Restoration at Methodist Hospital’s Institute for Reconstructive Surgery
I first heard of DIEP flap breast restoration for mastectomy patients in 2000 and daydreamed that some day the surgery would be available for those of us who lived with poor cosmetic results after lumpectomies. The daydream became a reality on March 29, 2004 when Dr. Spiegel and her associates restored my breast using the even less invasive SIEA flap technique.

"Thrilled" is the word that goes through my mind so many times a day. I am thrilled with the results of the surgery: I have cleavage again, am more balanced and the new tissue is soft and flexible. I can't quit smiling. Just today the receptionist at my dentist's office commented on how happy I was. I feel as if Humpty Dumpty has been put back together again. Thank you, Dr. Spiegel!

As a writer of a women's health newsletter, I learned about Dr. Spiegel's ability to use stomach fat (while sparing the muscle) to rebuild breasts and restore sensation when I interviewed one of her patients for an article on breast reduction surgery. I had no idea that less than two months later I would be diagnosed with breast cancer. In my view, the conversation was Divine intervention.

In whatever way you have come to learn about Dr. Spiegel, consider yourself blessed, too. Cancer is certainly a dark cloud, but Dr. Spiegel and her staff offer the silver lining of physical restoration to any women whose goal is to feel whole again. "Thank you, Dr. Spiegel!"

Having lost my mother and her sister to cancer in the seventies, it was still a shock to me to learn in the mid nineties that I was at high risk for breast cancer. As a fairly young woman, it was important to me to take every precautionary step to live a long life.

Years of multiple biopsies and renewed anxiety over my deteriorating condition led to my decision to have a bi-lateral mastectomy in June of 2002. An inner college press release alerted me to Dr. Spiegel as an emerging talent with a unique approach to breast reconstruction surgery. When I met with her, she put me totally at ease when she used a magic marker to spontaneously draw a picture of the surgery and technique she would use. I was delighted to find that she was able to explain it in a way I could clearly understand it.

Since having the DIEP procedure last summer, I am in better shape now than I was before my surgery and enjoy the same active lifestyle that I always have. It seems to me that every woman considering breast reconstruction would choose this method if she had the choice to. Diagnosis of a serious disease is devastating enough, without having to suffer through a diminishing experience of make-do reconstruction surgery. Dr. Spiegel has given me back my femininity and my quality of life! "Thank you, Dr. Spiegel!"