

Rethinking “Cure”

by Musa Mayer

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Once upon a time, cancer was referred to, in hushed tones, as the “C” word. Now we’re past such euphemisms. But despite this new openness, for many breast cancer survivors there is a new “C” word--cure--spoken with an edge of irony and even bitterness, when uttered at all.

“When I had my first breast cancer in 1981,” said Jacky Stopsy of Dumont, New Jersey, “I was told specifically by the surgeon that now that my breast was gone, I could be reasonably sure of being cured. In 1986, when I had my second breast cancer and my second breast was gone, my surgeon said, and I quote, ‘Now - no more breasts - no more worry about breast cancer.’ Four years ago I was diagnosed with mets to my lungs. So much for that BULL!”

Yet cure is a word that media loves to use and the public loves to hear. It’s upbeat, implying victory over a life experience fraught with fear, a comforting antidote to the anxieties women feel about this dread disease. Its calming influence encourages women to examine their breasts and get mammograms, or so the authorities on early detection would have us believe. It also helps breast cancer patients accept and justify the difficult treatments they are told they must undergo.

But over-optimistic media coverage about cure makes many breast cancer survivors angry. “Breast cancer has a very high cure rate, with 97 percent of women surviving for 5 years if the cancer is diagnosed early,” trumpeted website Yahoo! Health, in a webpage devoted to Breast Cancer Awareness Month.

“Are they saying that if you live for five years you are cured? So, if you die of breast cancer in the sixth year, you are still considered cured?” asks Tina Bucklin, from Raleigh, North Carolina, who was diagnosed with metastatic disease in May, 2000.

“I heard the same ridiculous percentages Sunday on a two hour special radio program on breast cancer,” concurs Alice Huntsha, of Hinsdale, Illinois. “I am so sick of all the whitewash.”

The five-year survival statistic is accurate but misleading. Five-year survival is not equivalent to cure. The 97 percent figure includes not only those whose cancer has not recurred, but those whose cancer has and are still alive. It also includes those whose cancer might recur but whose possible recurrences are delayed by chemotherapy and the anti-estrogen drug tamoxifen (Nolvadex). Breast cancer tends to be slow-growing and better treatments have extended life for metastatic patients. So, while 75 percent of recurrences happen within five years, fully one quarter of all recurrences occur after the five-year period. Furthermore, up to 35 percent of women with metastatic breast cancer now live five or more years following recurrence. So, as breast cancer outcomes improve over time, short-term statistics are less and less meaningful.

What do we mean by the word, cure, anyway?

Well, it depends upon who’s using the word, and for what purpose. To statisticians, it means one thing, to doctors another, and to breast cancer activists and patients, something else again.

With no entry between “curare” and “curettage,” a medical dictionary is no help, while trusty Webster’s weighs in by saying that cure “specifically suggests the elimination of a disease.” This is how I think of the word. When we are cured of bronchitis, with an antibiotic, we mean it is gone for good. If we get sick again, it’s a new episode of illness. In daily speech, cure often also has a sense of the absolute and forever attached to it.

But the medical literature on breast cancer uses the term only rarely, preferring measurable data to unfounded speculation about the future. A highly regarded (and quite weighty!) medical text on breast cancer indexes the word cure only once, referring to it with this cryptic statement: “Many patients never develop distant metastases and these may be considered cured.”

But considered by whom, and at what point in time? When Dallas breast cancer patient Esther McKenna pressed her doctor to say whether she was cured, he presented the current state of medical knowledge (or lack thereof) with a humorous twist. “If, when you are 99 years old, you die of a heart attack, you were cured,” he told her. “If, when you are 99 years old, you die of cancer, you were in remission.”

Not every doctor is as honest with patients about the vagaries of prognosis. Whether this approach derives from a misguided need to reassure a frightened patient, or is simply a throwback to an earlier, paternalistic era in medicine, women can and do feel betrayed when doctors tell them they are cured, and their breast cancer comes back anyway.

Doreen Jaskela, of Kelowna, British Columbia, who has been living for five years with extensive metastatic disease in her bones, after an initial breast cancer diagnosis in 1980, is still angry at her doctors for their misleading

initial prognosis. “I feel cheated,” she says. “I shouldn’t have been told that I was cured. It was devastating when I realized what had been happening. I would have planned my life differently.”

What most women I’ve spoken with seem to want from their doctors is the truth, presented with sensitivity, and with a sense of the limitations of prognosis. If we don’t know, we don’t know. We can handle that. But we need to feel our doctors will level with us. “I like hope,” says Julie Kelly, of Austin, Texas, diagnosed with Stage II interductal carcinoma of the breast in 1995. “But I prefer the truth to false hope. So please, no ‘cure’ for me, until you can guarantee it in writing.”

Some oncologists shade their advice on coping more subtly, and perhaps more wisely, suggesting that patients should “consider” themselves cured as an antidote to the perpetual anxiety and vigilance of living with the fear of recurrence. After her treatment, Sara McKenna’s doctor told the Surrey, England survivor, “You’ve got to *believe* you are cured.” The reasoning behind this kind of advice appears to be that living with a state of uncertainty is either impossible or intolerable.

This tip on the benefits of optimism is a point well taken, but not easily put into practice. Allan Grossman, of Battle Creek, Michigan, whose wife Deborah’s cancer was first diagnosed at Stage IV, puts it this way: “I think the impact of cancer on a family is so profound that you keep your guard up just so nothing can blindside you like that again.”

For obvious reasons, those whose have not faced recurrence find this mental discipline easier, as Sara McKenna says: “Of course I can’t be 100 percent sure that it won’t ever happen again, but I’m happy to live with the belief that I just *might* be cured, meanwhile.”

But as patients begin to comprehend the ambiguity and uncertainty surrounding their disease, and confront mortality for what is, perhaps, the first time in their lives, they often experience a certain loss of innocence. “At diagnosis I felt so out of control,” said Jan Black, of Little Rock, Arkansas. “But then I finally realized that I had never really had control. I was blissfully ignorant prior to breast cancer and felt like nothing could ever happen to me.”

Other breast cancer patients, by telling their own stories and experiences, can play a part in this disillusionment as well. The trade-off for getting information and support with other survivors is often a poignant one: isolation for anxiety; innocence for knowledge.

Slogans and Statistics

The word cure is a reminder of what we are working for, a rallying cry, a slogan. But when we speak of a cure for breast cancer, it's a distantly glimpsed ultimate objective-- an artificially unified goal, held in contrast to increasingly complex research realities. While some organizations race for the cure, drive for the cure, even shop for the cure, other organizations, it must be said, carefully avoid the “C” word. Instead they declare as a goal “eradicating” breast cancer, a word whose first meaning is to “tear out by the roots,” implying a concern with prevention as well as treatment, and embracing a goal that doesn't inaccurately imply a single method or magic bullet. As a lover of precision in language, this has always appealed to me.

Nevertheless, statistically, it seems clear that breast cancer can indeed be cured, if by cure one means that many patients treated for the disease live without recurrence for several decades.

This was not always the perception. Early studies on the natural history of breast cancer led to the belief that for the rest of their lives women who'd once had breast cancer continued to recur and ultimately die from the disease.

As recently as 1991, a large Italian study looking back at the history of more than five thousand breast cancer patients found “evidence of a persistent excess mortality”— an increased death rate from breast cancer— “even after long-term follow-up” of 20 years. The authors concluded that their findings had “provided no evidence of a ‘clinical’ cure for breast cancer patients.” Even node-negative disease--breast cancer that had not spread outside the breast at the time of diagnosis--the authors suggested, should be thought of as “a slow-growing metastatic disease.”

However, a longer-term University of Chicago study published in 1999 in the *Journal of the National Cancer Institute* found that most recurrences happened within 10 years of diagnosis, and were very rare after 20 years. After this length of time, the death rates matched those of the rest of the population, the authors concluded. A population-based study that looked at all breast cancer cases from a single urban area in Finland found 1945 to 1965 found no excess of breast cancer deaths after 27 years, excluding patients who developed breast cancer in the other breast. A similar Dutch study concluded that, “Patients who survive for 19 years may be considered cured.” And finally, a statistical analysis conducted on survival data for 13,000 women with breast cancer in Utah over a 30 year period concluded that “cure is a possible outcome of breast cancer treatment.”

The best overall statistics on long-term survival we have in the United States are from the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI), which is based on 11 representative cancer registries around the United States that include 14 percent of the entire U.S. population. These cancer registries collect data on patient demographics, primary tumor sites, stage at diagnosis, among other information. Established in 1973, since 1976, SEER has been tracking cancer mortality, as well as incidence. The NCI includes particular registries because of the quality of their data, and the fact that their communities reflect overall US demographics.

According to SEER data, for those diagnosed with breast cancer in 1976, relative mortality from the disease was 48.2 percent. That means a little more than half of patients treated in 1976 have survived their breast cancer--at least until 1997, the last year for which figures are available. But with recent advances in treatment and with earlier diagnosis, the clinical cure rate is almost certainly much higher now for women diagnosed today. Indeed, later SEER data clearly reflect improvement in survival rates.

Still, the reality is we live with uncertainty, and cure is too absolute a word. It implies a confidence we will never possess again, a recapturing of innocence lost. Cure implies permanence and completion: when you're

cured of an illness, it's done, you're restored to your former state of health.

But even if cancer never recurs, this particular disease has a way of leaving us changed psychologically, emotionally and physically. Scar tissue, disfigurement, lymphedema, premature menopause, chemobrain, fatigue, loss of sensation, and other lasting side effects of treatment make it difficult for many of us to think in terms of a cure; we struggle, instead, for a "new normal."

So what word should those of us who have completed treatment with no sign of recurrence use to describe our state of being? *Do* we have breast cancer, or *did* we have it? Present tense or past? Saying we're in remission is just the fatalistic flip-side of the cure coin, implying that somewhere within us the cancer is dormant or growing but still undetected. We can't know that, either.

Instead, many of us have chosen to label our current status just as the doctors do: N.E.D. No evidence of disease, meaning that breast cancer may be there, lurking about, or it may not. It's beyond the ability of current medical science to measure that. It's what we know now. It's all that we know, and that's good enough for me. It has to be. In a world of pink ribbons and 97 percent cure rates, we choose uncertainty. We choose truth.