

Breast cancer awareness campaigns too often overlook those with metastatic breast cancer. Here's how they can do better

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Is there anyone who isn't aware of breast cancer?

Since 1985, cancer-related nonprofits, along with pharmaceutical firms and other businesses, have sponsored an international campaign to [observe October as "Breast Cancer Awareness Month."](#) During these weeks, the public is bombarded with awareness and education messaging featuring the campaign's symbol, a pink ribbon.

A wave of pink products typically appears, too, including clothing—think about [the "Save the Ta-Tas" shirts](#)—as well as events like marches and walkathons. This onslaught has led some to term the [campaign "Pinktober."](#)

These efforts often focus on encouraging women to get screened with mammograms to increase the possibility that the cancer will be detected early. Breast cancer patients are celebrated for "beating" cancer, "winning" the battle, having survived and being cured. But these messages overlook the experiences of millions of breast cancer patients.

I am a [sociology professor](#) who specializes in studying gender as well as how having a serious illness affects identity. These themes also hit close to home for me: In 2009, I was diagnosed with [metastatic breast cancer](#)—also referred to as stage 4 on a scale from 0 to 4—which means a cancer that has spread beyond the breasts to other parts of the body. Since that time, I have participated in face-to-face and online support groups, joined retreats and met myriad health professionals who specialize in oncology while also continuing my research.

In 2019, I began a nationwide study to examine the experiences of women with stage 4 breast cancer. The first of my papers on religion's role in coping with metastatic breast cancer [was recently published](#) in the *Journal for the Scientific Study of Religion*. I am now working on research that examines metastatic breast cancer and a range of spiritual experiences.

The seriousness of metastatic breast cancer, which is the only breast cancer that kills, is rarely discussed. This leaves people with this diagnosis feeling ignored and angry—and largely invisible to most of the organizations focused on breast cancer.

A need for inclusion

Breast cancer is [the second most common cancer in women](#) in the U.S. after skin cancer. [One in 8 American women](#) will be diagnosed with breast cancer at some point in her life.

Although [women of color](#) are less likely to get breast cancer, they are more likely to die from it. [Male breast cancer](#) makes up less than 1% of all cases of breast cancer.

Nearly [30% of people with early stages breast cancer](#) will see their cancer metastasize to stage 4, which kills [about 44,000 American women and men](#) each year.

To find participants with stage 4 breast cancer for my survey, in 2019 I sent out requests through online support groups, cancer organizations and societies, and word of mouth. Ultimately 310 women completed a questionnaire about their experiences with metastatic breast cancer, such as perceived support, feelings about breast cancer organizations and the pink ribbon, and ways of coping.

I selected 33 of those women to participate in in-depth interviews to provide additional information about some of their survey answers.

Recognizing people with metastatic disease

I'm a member of several metastatic breast cancer social media groups.

For the purpose of this article, I asked people in these groups to share their thoughts about Breast Cancer Awareness Month and specifically the term "survivor." Most people who responded aren't overly excited about October: They don't find terms like survivor and related language relevant. Nor do they feel the pink ribbon represents them.

Of the women who took my original survey, the majority—at least 70%—felt that pink-ribbon events tend to minimize the seriousness of metastatic breast cancer and tend to ignore stage 4 altogether. They also believe that pink-ribbon campaigns focus too much on breasts and selling products and services, [a practice known as "pinkwashing."](#)

As one respondent in a social media group wrote, "I don't like the term survivor. That and October are aimed at early stage cancer, not at supporting people who have Stage 4 cancer. We won't survive. We aren't going to be cured. Early detection didn't save many of us. Removing boobs didn't save us. All the pinkwashing does nothing to help us."

Asking women to rate their preferences on a scale of 1 to 4, from "not at all" to "a great deal," I found that far more metastatic people prefer "patient" and "a person who has cancer" over the term "survivor."

On average, many participants also say there isn't much recognition that those with metastatic disease have a different treatment plan. Often, stage 1 to 3 patients can look forward to a treatment end date after they finish radiation, surgery—mastectomy or lumpectomy—and what are called systemic therapies, such as chemotherapy. The vast majority of metastatic patients will be in treatment for the rest of their lives.

For stage 4 breast cancer, [there is some debate](#) as to whether lumpectomy or mastectomy are effective options. The effectiveness of radiation treatment [is also debatable](#). So metastatic patients more typically receive chemotherapy and—more recently—immunotherapy,

with no surgery.

I also learned that many stage 4 [breast cancer patients](#) find it necessary to manage the diagnosis in ways that don't apply to those with earlier stages. Metastatic patients must go into treatment simultaneously hoping the drugs will calm the cancer and confronting potential end-of-life issues. They may worry about leaving their families. Some may set milestones, such as seeing their children or grandchildren graduate from school or get married.

They may also be contending with issues like how many possible treatment options are left, or maximizing both quantity and quality of life amid a range of side effects.

Overturning worn-out narratives

I surveyed participants about the degree to which they feel excluded from breast cancer organizations, and why. They firmly indicated feeling a recognition gap among breast cancer organizations and awareness campaigns. So many seem to emphasize early detection and survivorship, and leave out the concerns and needs of metastatic patients.

One respondent talked about the "early detection mantra." Another referred to the "ringing of the bell," a common celebratory ritual when one is done with chemotherapy or radiation. I've been known to use the phrase "that damn bell" to express frustration that I will always be on treatment and won't get to ring that bell.

People echoed these same sentiments when I posed my question in social media groups. One woman wrote, "I am not going to ever be a survivor. Feels like we are the under belly. ... No 'you got this.' ... There is no stage 4 fanfare."

Many women with stage 4 breast cancer also feel like little is being done to showcase the less optimistic and more frightening aspects of metastatic disease.

Several organizations are starting to fill these gaps. Some are devoting themselves to funding research for breast cancer, while others are now paying more attention to stage 4 patients—or at least moving in that direction. [Metavivor is one organization](#) focused exclusively on serving the metastatic breast cancer community. The Susan G. Komen organization has also begun offering resources and [information about metastatic breast cancer](#).

I see hopeful signs that some of these efforts are making a difference. Just the other day, I stopped by my cancer center's gift shop to buy some mastectomy bras and saw that they were handing out pink-ribbon bracelets. So I asked the woman running the shop if they could get bracelets representing metastatic [breast cancer](#). I was encouraged that—without hesitation—she said it shouldn't be a problem.

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