

# Chapter 6: Public Education: Building Awareness of MBC

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## Abstract

Breast cancer campaigns have heightened public awareness yet have propagated unexpected misinformation. **Methods:** We informally explored various aspects of misinformation around MBC. **Results:** The most persistent myths relate to the breast cancer “survivor,” which masks the reality that a proportion of women who have had early breast cancer will eventually develop metastatic disease. Further, the promotion of the “survivor” can stigmatize patients whose breast cancer progresses. The majority of adults in a recent survey reported they know little to nothing about MBC, that breast cancer in the advanced stages is curable, and that breast cancer progresses because patients did not take the right medicines or preventative measures. **Conclusions:** There is an opportunity for the Alliance to help ensure the facts about MBC are brought into the public awareness; to do so, a broad communication strategy should be informed by MBC patient advocates and developed drawing on Alliance member’s collective experience, resources and spheres of influence.

## Discussion

The Alliance aims to build an understanding of MBC, and how it differs from early stage breast cancer, among those diagnosed, their families, HCPs, researchers, and health policy experts.

The past 30 years of breast cancer campaigns have been successful in shining the light on the disease, the importance of early detection, and the methods of screening. And yet with this heightened public awareness of “survivorship” has come unexpected misinformation. A 2014 Pfizer-sponsored study of more than 2000 adults in the general public found that 72% believed breast cancer in the advanced stages is curable if diagnosed early; 50% believe that breast cancer progresses because patients did not take the right medicine or preventative measures, and more than 60% said they knew little to nothing about MBC<sup>[111]</sup>.

The focus on fighting and beating breast cancer has led to the creation and dominance of the breast cancer “survivor”—an identity central to various public fundraising events, celebrity endorsements, and calls to action. This “survivor” identity masks the reality that 20-30% of women who have had early breast cancer will eventually develop metastatic disease<sup>[112]</sup>.

Campaigns with a focus on “the cure” distract from a research agenda to increase the quality and quantity of life for MBC patients. Drives based on “beating cancer” and survivorship also deny the fact that women who have early breast cancer can develop metastatic disease. Further, the promotion of the survivor stigmatizes patients whose breast cancer progresses; they are seen or may even see themselves at fault for the cancer’s progression, and ultimately failing to win the battle for survival.

“We did nothing wrong. Our medical team did nothing wrong. Metastatic breast cancer happens...at any time...regardless of your age, whether you did chemo[therapy], radiation, had a mastectomy, had a bilateral mastectomy, ate well, took vitamins, exercised regularly, prayed, had positive thoughts, had negative thoughts, got regular mammograms, did self exams religiously, had a tiny stage 1 primary tumor, or a stage 0 primary tumor, or a stage 3 primary tumor, or never even had primary breast cancer. It doesn’t matter.” — MBCN website [www.mbcn.org](http://www.mbcn.org)

Nearly half of surveyed MBC patients report a sense of stigma, of feeling like outcasts or feeling isolated, especially within the larger social context of the breast cancer community.

Effects of stigmas and myths cannot be overstated. A global survey on perspectives about cancer determined that myths and stigma present significant challenges to cancer control, have a silencing effect, and affect individuals' behavior in seeking out support and making treatment and quality of life decisions<sup>[113]</sup>. According to researchers, key aspects of stigma are secrecy, myths and misinformation, social rejection and isolation, and shame, self-blame and low self-esteem<sup>[114]</sup>. These key elements are hallmarks of the MBC experience, within the breast cancer community and in the community at large. "When misfortune strikes, it is a natural human tendency to search for a reason," wrote psycho-oncologist Jimmie Holland. "The ready explanation is often 'he must have brought it on himself.' By blaming the victim, we get a false sense of security that we can prevent events that are beyond our control"<sup>[115]</sup>.

How can we, as an alliance of individual members, begin to challenge the myths and stigmas that cause fear in the breast cancer community and the larger public, resulting in financial, social, and emotional distress for people living with MBC? How do we reduce the isolation that many people with MBC feel? How can the Alliance focus its resources on educating different groups about MBC and the importance of helping those with MBC to live longer and better?" To address the lack of understanding of MBC, the Alliance will draw on our collective experience, resources, and spheres of influence. The following principles will guide our future efforts to build understanding across all spheres of MBC, including scientific and quality of life research, epidemiology, and information and support services:

- Our actions must be led by advocates and informed by research and evaluation if we are to change the landscape for people living with MBC.
- The Alliance will not duplicate efforts of individual member organizations of the Alliance.
- We value learning from other cancers and other diseases, so we can apply best practices to our work.
- People living with MBC come from diverse backgrounds; differing cultural values and belief systems must inform the provision of information and support services, as well as public education about the disease, treatments, and quality of life.
- Collaboration is essential. Advocate organizations and industry members of the Alliance will work together to learn from each other's experience and research.
- As our work is resource intensive and time consuming, we will be thoughtful in how we commit our assets to future campaigns.
- Developing an evaluation framework that goes beyond counting pamphlets, banners, press releases, radio announcements, and Facebook posts is an exciting challenge for the Alliance and one that will be a major part of our planning for 2015–2016.

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Public awareness – The extent of common knowledge about disaster risks, the factors that lead to disasters and the actions that can be taken, individually and collectively, to reduce exposure and vulnerability to hazards. Resilience – The ability of a system, community or society exposed to hazards to resist, absorb, adapt to and recover from the effects of a hazard in a timely and efficient manner, including through the preservation and restoration of its essential basic structures and functions. Public awareness and education programmes can be started modestly, and tailored to meet the needs of specific populations, risks, and target groups. They can build on and support existing volunteer mobilization and peer-to-peer communications. Public awareness-raising activities carried out by the UN system and the UN Communications Group include: – UNite to combat climate change – a UN-wide campaign to promote an inclusive, comprehensive and ratifiable deal in Copenhagen. – Reinforced work to include climate change in education for sustainable development – Maintaining a central portal/Gateway connecting to all UN system entities active on climate change ([www.un.org/climatechange](http://www.un.org/climatechange)) and cooperating with the International Institute for Sustainable Development (IISD) for Climate-L.org ([www.climate-l.org](http://www.climate-l.org)). The Public Education & Awareness Committee oversees programs and initiatives to inform, educate, and engage the general public and students to advance knowledge and help people everywhere realize the benefits of human genetics and genomics research. Works to enhance ASHG members’ skills and motivation to engage in public communication and education activities. Helps develop Annual Meeting events and year-round programs that inform and engage ASHG members in public education, awareness and engagement. Provides input on media relations planning for Annual Meeting. Helps identify key concepts Improved public awareness of MBC as a distinct disease. There is a need for public education that living with MBC is very different from living with early-stage breast cancer, as it is a disease that can be controlled but currently cannot be cured – this will help prepare patients as well as educate family members, employers, policy makers and wider society as to the nature of the disease. More tailored support for the unique needs of people with MBC. There is a huge discrepancy between information and support currently delivered to women with early disease and those with MBC. Information needs to be streamlined and tailored to CONSUMER EDUCATION. GOAL: Increase public awareness of MBC’s mission, activities and services. Desired Outcome. Patients are able to make informed decisions about medical practitioners and unlicensed practitioners and know how to seek remedies through accessible information provided by the Medical Board. Performance Indicator. Align relationship-building activities with communication plan priorities. Completion Status Working with a variety of organizations on legislation. Working with a variety of organizations on legislation.