



**Changing the
Landscape for
People Living
with Metastatic
Breast Cancer**

Metastatic Breast Cancer

MBCalliance >

together we are stronger than the disease

**Metastatic Breast Cancer
Landscape Analysis:
Research Report**
October 2014

Second Edition

Executive Summary

Why present another report about breast cancer?

Few would dispute that breast cancer has a higher profile than other types of cancer. Since the establishment of National Breast Cancer Awareness Month in the mid 1980s, a tremendous effort has been invested in messaging aimed at screening for early stage breast cancer, while celebrating those who survive diagnosis and treatment.

40,000 women and men still die of breast cancer every year in the US.

The dominance of the “breast cancer survivor” identity masks the reality that patients treated for early stage breast cancer can experience metastatic recurrence. The focus on survivorship obscures the fact that, in spite of decades of breast cancer awareness and research funding, **40,000 women and men still die of breast cancer every year in the United States (US) [1] with metastasis the cause of virtually all deaths from breast cancer.**

Metastatic breast cancer originates in the breast and then spreads to other parts of the body, such as bones, liver, lungs, or brain.

Metastatic breast cancer (MBC), also referred to as stage IV breast cancer, is an incurable, albeit treatable, progressive cancer that originates in the breast and then spreads to other parts of the body, such as bones, liver, lungs, or brain.

While some progress with research and new treatments has been made in reducing mortality rates from breast cancer, median survival after an MBC diagnosis is 3 years—and this has not increased meaningfully in more than 20 years^[2]. Despite these statistics, research funding for MBC accounts for only 7% of the total breast cancer research investment.

While treatable, MBC remains incurable.

Currently, data are not collected on how many people experience a recurrence of early stage breast cancer as MBC or the number of people living with the disease. We have only estimates of how many women diagnosed with early stage breast cancer will experience a recurrence. For unknown reasons, their breast cancer returns after a few months or as long as up to 20 years or more after initial diagnosis. It is also *estimated* that at least 150,000 people of all ages and all racial and ethnic groups are living with MBC in the US^[3].

Public messaging about the “cure” and survivorship is so pervasive that people diagnosed at stage IV with MBC can be stigmatized by the perception that they’ve failed to take care of themselves or undergo annual screening. With breast cancer organizations’ main focus on detection and screening of early stage breast cancer, MBC patients and their caregivers face real challenges in finding MBC-specific support and information from these organizations. Further, many MBC patients persist in believing a cure is likely, and health care professionals do not always have the time and skill to discuss treatment options when the prognosis is poor.

A lack of awareness about MBC and how it differs from early stage breast cancer; little research funding to combat this unique and deadly disease; a lack of accurate statistics on incidence, prevalence, and survival; and difficulty in finding information and support services essential for people living with MBC—these are the issues that have defined the work of the Metastatic Breast Cancer Alliance (MBC Alliance) over the past year.

The MBC Alliance

Many patient advocate groups have been working to change the landscape of MBC. In 2012, representatives of breast cancer organizations joined with MBC patient advocates to discuss ways to change the persistent lack of understanding about MBC and how organizations could work together to provide better information and support services to people living with MBC. All agreed that more could be achieved through working together than could be achieved by working alone. Assistance for these early steps was provided by Celgene Corporation.

On October 13, 2013 (National Metastatic Breast Cancer Awareness Day), the MBC Alliance of 16 nonprofits and 5 pharmaceutical corporations was launched. Over the past year, the Alliance has experienced growth in its membership as new advocates and industry partners realized the Alliance's potential to create positive change and impact individual lives. Currently, there are 29 member organizations.

Recognizing the valuable current and future contributions of each member to the MBC field, the Alliance is committed in its approach not to duplicate efforts of its members. Collaboration and learning from others is vital if the Alliance is to have real impact in improving the lives of people living with MBC.

Landscape Analysis of MBC

As its first initiative, the Alliance undertook a landscape analysis to assess gaps, duplication, and opportunities in MBC research, patient information and support services, and public awareness to capitalize on identified opportunities, and identify the ways Alliance members could work together to meet the unique needs of those living with MBC.

Aspects of the MBC landscape examined by advocates and experts with knowledge and experience specific to the area of investigation were:

1. Scientific research, including clinical trials, focused on MBC
2. Quality of life of MBC patients and their families and caregivers
3. Information and support services provided by MBC Alliance members
4. Epidemiology of MBC: Challenges with population-based statistics
5. Public awareness of MBC.

5 Areas of MBC investigation:

Scientific Research
Quality of Life
Information and Support Services
Epidemiology
Challenges
Public Awareness.

Methods

The Alliance collected and reviewed multiple sources of data and information for the landscape analysis:

- Scientific research—a first time effort to analyze information on breast cancer treatment trials recruiting MBC patients in the US and information on breast cancer and MBC research grants awarded by most of the major cancer and biomedical research funding organizations. Interviews were conducted with 59 key opinion leaders with scientific expertise relevant to MBC research.
- Quality of life for MBC patients, and their families and caregivers—more than 150 published, peer reviewed articles relevant to the experience and needs of people living with the disease and 13 MBC surveys from 2006–2014 were analyzed.
- Information and support services specific to MBC—Alliance members were interviewed about their efforts in research, patient advocacy, patient education and support, and community awareness. Collateral materials, including surveys and research reports and information about services and support relevant to MBC, were collected from Alliance members. Member organizations' print and web-based materials were analyzed, and a short survey on telephone information/helplines was conducted.
- Epidemiology—the literature was reviewed to identify shortcomings in currently available population-based statistics relating to MBC.
- Public awareness of MBC—over the course of work of the landscape analysis, discussions among advocates, patients, and industry members at MBC Alliance meetings highlighted the need to educate the public about MBC. Members helped to compile information on common misconceptions around MBC and brainstormed actions for the Alliance to increase understanding.

Key Findings

MBC Scientific Research

More funds need to be directed to MBC research. MBC-focused research made up only 7% of the \$15-billion invested in breast cancer research from 2000 to 2013 by the major governmental and nonprofit funders from North America and the United Kingdom. Specific scientific areas are understudied. The field of MBC research is relatively small.

- MBC research grants are focused on the metastasis steps of invasion and metastatic colonization, with far fewer studying intravasation and circulation, arrest and extravasation, or metabolic deregulation. Why these gaps exist in funding and research focused on these areas of the biology of metastasis need further exploration.
- The distribution of funding across stages of MBC research (basic, translational, clinical, and cancer control) has not changed over the past decade, with most funding going to support basic research. There is a paucity of research in MBC cancer control, outcomes, and survivorship.
- Research on mechanisms of disease in cell lines and animal models is usually focused on tissue taken from early stage, primary breast cancer, and not metastatic tumors. In addition, clinical trial endpoints such as tumor shrinkage may not have relevance to tumor spread or metastasis.
- More research is needed to understand all the steps of metastasis to develop new treatments for the multiple types of MBC and to understand how best to improve the quality and duration of the lives of women and men in whom breast cancer becomes metastatic.
- Barriers to clinical trials include too many “me-too” trials in industry and the academic “reward” system for single investigators conducting single-institution phase II trials. To accelerate MBC clinical research, these barriers must be broken down by the conduct of multi-institution, multi-investigator trials.

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Quality of Life for MBC Patients and their Families

Patients with MBC have unique emotional, physical, and psychosocial needs, and these have not changed over the last decade of academic research and patient surveys. The needs of minority and poor populations living with MBC have not been fully addressed in research or patient surveys.

Some estimates are that as many as one third of MBC patients suffer from mood disorders such as major depression and anxiety, and one quarter experience mild depression.

Fatigue is by far the most common physical symptom reported by MBC patients, occurring in 80% or more of those undergoing treatment.

Better communication among patients, caregivers and providers and better access to supportive and palliative care are needed.

- Emotional distress, experienced by a majority of MBC patients, is associated with increasing physical symptoms. Depression and anxiety are common, yet patients receiving mental health services are a minority; many methods exist for addressing psychosocial distress, most of which are underutilized.
- Most patients initially report adequate emotional support from friends, family, and community, but many feel isolated by the experience of the disease; social stigma is felt by half of MBC patients, especially within the breast cancer community.
- Individualized information about MBC is a critical factor for informed participation in treatment decision making. Information also plays an important role in coping by reducing uncertainty, lack of control, and distress.
- Many MBC patients do not receive adequate information from health care providers (HCPs) to enable them to understand the disease and its treatments so they can make informed decisions. Patients' understanding of the nature of the disease and goals of treatment is often poor; many believe they will be cured. Limitations of time and resources in busy oncology practices may result in poor patient–doctor dialogue, including one-way “doctor-knows-best” communication. MBC patients also report confusion about reliable sources of information.
- Most MBC patients suffer multiple symptoms of disease and side effects of treatment that disrupt their lives—most common are fatigue, pain, and sleep problems. Despite this, half of patients say they are not routinely asked about their symptoms and express concern about “bothering” their doctors.
- Financial hardship is a common issue for families dealing with MBC, and many patients do not realize they will likely qualify for Social Security Disability benefits or Medicare. Even, if eligible, the 2-year waiting period for Medicare represents a financially vulnerable time; many file for bankruptcy and face lower standards of living. Other practical needs may include transportation to treatment, home, shopping and child care, disability and insurance applications, and work-related issues, among others.
- A significant number of MBC patients report they are not receiving the help they need to address their physical symptoms, side effects from treatment, and emotional distress. Better communication among patients, caregivers and providers and better access to supportive and palliative care are clearly needed.
- Action and initiatives based on the findings from surveys of patients' needs, and other research, are lacking.

MBC Patient Information and Support Services

Alliance members, and others, need to improve consistency of information about MBC across agencies; better quantify the numbers of people living with MBC they are serving; understand what services are most often accessed; and expand reach into all communities regardless of socioeconomic status, gender, race, culture or geography.

- Quantitative data on the demographics and numbers of MBC patients accessing programs and services are not consistently collected. As a result, it is not known how patients use the tools, how the programs and services can be optimized, and which patients are not being reached.
- The majority of organizations report that their programs and services are underutilized, surmising that patients don't know about them, do not consider the programs to be suited to their needs, or are seeking information and support in other places.
- Many Alliance members provide high-quality information and support services to MBC patients and their families. However, the information provided requires that patients have relatively high health literacy and be Internet savvy. Organizations must consider how to reach other subgroups of the MBC patient population. Because Alliance members offer so much general information, it is difficult for individual patients to find what they need.
- Persistent gaps in MBC information on members' sites and in print include detailed information on the latest treatments; monitoring of treatment, including for side effects and quality of life; palliation; and advanced directives and end-of-life care. Information on how MBC is diagnosed could be improved, and there is a dearth of information on new drugs in clinical research.
- Alliance member websites do not address MBC facts sufficiently to inform the MBC patient populations or even caregivers and early stage breast cancer patients. More content and community can be created by enhancing current information, using a modern design, and adding tools for social networking.

Information and support are not distinct from one another. MBC patients find information to be supportive and seek information from their support systems; thus, services for MBC patients should refer to both.

Nearly half of MBC patients surveyed say they find the information they need difficult to locate and confusing, and that what they do find doesn't fully address their needs.

Epidemiology of MBC

Better epidemiologic data are needed on the numbers of early stage breast cancer patients who experience a recurrence and metastasis and on outcomes and length of survival after a metastatic diagnosis. Only modest improvements in survival after a metastatic diagnosis have been observed, and not in all populations.

Data are not collected on how many people experience a recurrence of early stage breast cancer as MBC, or the number of people living with the disease.

Today, an estimated 3.1 million women living in the US have a history of breast cancer, but we have no way of knowing how many of these people are actually living with MBC.

- Over the past few decades, the duration of survival after metastatic diagnosis has increased modestly—by a matter of months, not years. Hospital-based studies generally report a larger survival benefit than population-based studies.
- The modest increase in survival has been observed mainly in ER+ (estrogen receptor positive/hormone sensitive) MBC and/or HER2+ (human epidermal growth factor receptor 2–positive) MBC and is attributable to the wide use of targeted therapies. No survival benefit has been found in triple-negative MBC.
- The disparity in survival between black women with MBC and non-Hispanic white women with MBC appears to be increasing. It is unclear how much of the observed disparity in outcome is related to access to care and socioeconomic concerns and how much is related to the greater incidence of triple-negative MBC among black women.
- The prevalence and incidence of patients with MBC is unknown. Also unknown is whether the number of recurrent MBC patients is increasing, decreasing, or staying the same. Without this information, we cannot accurately and effectively demonstrate the need for services or plan and fund the application of services.
- Disease trajectories, outcomes, and patient experiences for the different subtypes of MBC have not been well characterized.
- Many critical questions regarding the optimal treatment of MBC remain unresolved. It is imperative that the use, effectiveness, and impact of MBC treatments on the overall MBC population be understood.
- Despite existing research, we have no accurate estimate of how long MBC patients are likely to live. The factors underlying observed variability in median survival across studies are unknown. Among the potential factors are differences in access to newer drugs (especially targeted therapies) and multiple lines of treatment, access to careful follow-up and expert palliative care to preserve optimal quality of life, and the presence of co-morbidities.
- Despite research demonstrating poorer outcomes for disadvantaged, underinsured populations overall, the true impact is unknown of socioeconomic factors on what treatments and care are available for MBC patients and, in turn, how this may affect duration of survival and quality of life.

Public Awareness of MBC

A greater understanding of what MBC is and how it differs from early stage breast cancer is needed among patients, their families and HCPs, researchers, and the public.

- The focus on “fighting” and “beating” breast cancer has led to the creation and dominance of a breast cancer “survivor” identity, which masks the reality that women who have had early stage breast cancer can develop metastatic disease.
- The focus on screening and survivorship can stigmatize patients who experience a recurrence or are diagnosed at stage IV—they may be perceived to be at fault for the cancer’s progression.
- The effects of public and professional misconceptions or lack of understanding about MBC can negatively influence decisions made by patients and their doctors regarding treatment and quality of life.
- More can be done to build the understanding of HCPs about how to discuss treatments and quality of life, including palliation with their patients.

“The deaths of 108 people today from MBC will not make the nightly news. If they did, most of the public might be surprised, but then conclude that these women and men probably did not get a mammogram early enough, or fight the disease hard enough.”
Shirley Mertz,
SABCS 2013

Analysis to Action

This landscape analysis has provided the Alliance with a foundation of shared knowledge of the MBC landscape and pointed us to some critical gaps/needs to be addressed. Collectively, we are now better informed about the areas of scientific research for further exploration, the need to accelerate improvement in quality of life, the gaps in information and support services that require resources, and the current state and limitations of the epidemiology of MBC.

One of the forces that drove breast cancer and MBC advocate organizations to join in an Alliance was the need to build understanding about the different types of MBC and how it differs from early stage breast cancer, not just for people living with the disease and their HCPs, but also researchers, policy makers, and the general public.

In moving forward, MBC Alliance members agree that pivotal to resolving gaps/needs is an effort to build greater understanding in all our future endeavors.

The power of the Alliance lies in our collective experience, resources, and spheres of influence. Guiding our approach to future work is a commitment to not duplicate efforts of individual organizations in the Alliance, and to collaboration to ensure we learn from each other’s experience and research. As our work is resource intensive and time consuming, we will be thoughtful in committing our assets and will develop an evaluation framework as part of our planning for 2015–2016.

We have identified a series of actions for our next phase of work over 2015 and 2016. These actions require sustained commitment of multiple stakeholders and MBC Alliance members stand ready to contribute time and energy to this work.

We look forward to reporting on our progress in 2015.

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People living with metastatic breast cancer and patient advocates at the Metastatic Breast Cancer Network 2013 Annual Conference

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