

Chapter 4: MBC Information and Support Services—an Analysis of MBC Alliance Member Efforts

Katherine Crawford-Gray²

²*Metastatic Breast Cancer Alliance*

Abstract

Information and support services are essential in helping patients manage common aspects of living with MBC. **Methods:** Staff and volunteers of 16 nonprofits were interviewed to identify gaps and duplications in member services. The most recently available Form 990s, as well as research reports, surveys, scientific roundtables, posters, and services were also reviewed for MBC-specific content. Information and support services provided on the websites of the nonprofits, as well as 5 pharmaceutical members, were assessed for quality, breadth, and depth of MBC information. Member websites were also assessed for attractiveness to the user, 13 aspects of MBC information, evidence supporting the MBC information provided, recency of updates, ease of navigation, and use of social media tools. Thirteen organizations were sent an online survey about helpline/hotline services. Finally, 10 publicly available surveys and 4 proprietary reports provided by Alliance members were reviewed. **Results:** While the majority of the nonprofit members focus on meeting the information and support needs of the breast cancer community, not enough attention is paid to the MBC patient populations. Print and electronic material provided by the Alliance members requires that patients have relatively high health literacy and be Internet savvy. There are no dedicated helpline services for MBC patients; conferences and in-person networking events tend to be in large cities. Opportunities to create community through social media are very limited. Nonprofits report their services are underutilized and there is a lack of data collected on who is using the services. Gaps in information from members include lack of detailed information on the latest treatments, quality of life, palliation, and advanced directives and end-of-life care. **Conclusions:** Alliance members provide some level of high-quality information and support services to MBC patients and their families. However, because Alliance members offer so much general information, it is difficult for individual patients to find what they need. Organizations must consider how to reach other subgroups of the MBC patient population.

Introduction

Information and support services are essential in helping patients manage common aspects of living with MBC. MBC patients experience psychosocial distress, particularly depression and anxiety; require emotional support from family, friends, community, and other people with the disease; need information to help facilitate and empower decision making around treatment and end of life; deserve relief of physical symptoms, both during treatment and end of life; and must resolve practical issues with work, insurance, and finance. (These issues are addressed in detail in **Chapter 3**.)

The literature review in **Chapter 3** finds that, despite a greater knowledge and recognition of these quality of life issues over the past 2 decades, they persist—and addressing them remains a challenge for advocate organizations.

Another part of this landscape analysis was to better understand the breadth and depth of information and support services provided by MBC Alliance members, which are some of the most active advocate organizations in the US. The analysis will help the Alliance to identify gaps, duplications, and opportunities to most effectively leverage its collective resources, power, and influence to improve the quality of life of people living with MBC.

Scope of Alliance Membership

The MBC Alliance currently includes 23 nonprofit organizations working in cancer, breast cancer, and MBC. The 23 nonprofit members vary greatly in scope of mission but share a desire to improve quantity and quality of life of MBC patients and their families. Collectively, Alliance members raise \$750 million annually in philanthropic support for cancer. Each offers various educational and patient support services, including information and support services for MBC patients and their families.

The 6 industry members of the Alliance all develop and market drugs to treat MBC. Representatives from the patient advocacy departments have actively participated alongside the advocate organizations in the research and review process for the landscape analysis.

We know that MBC Alliance members are only 1 part, albeit a crucial part, of the landscape serving patients and caregivers living with MBC. Public and community hospitals, health care systems, university medical centers, grassroots organizations, and many others undertake very valuable work across the country. The services provided outside of the MBC Alliance are not covered in this analysis.

Methods

We interviewed executive, program, and/or volunteer leadership of 16 nonprofits and 5 pharmaceutical members of the Alliance to identify the major gaps and duplications in services across the Alliance in meeting the needs of MBC patients, recommend strategies for how the organizations can better work together to reduce gaps, and identify areas ripe for collaboration. A table of interviewees is provided in **Appendix 6**.

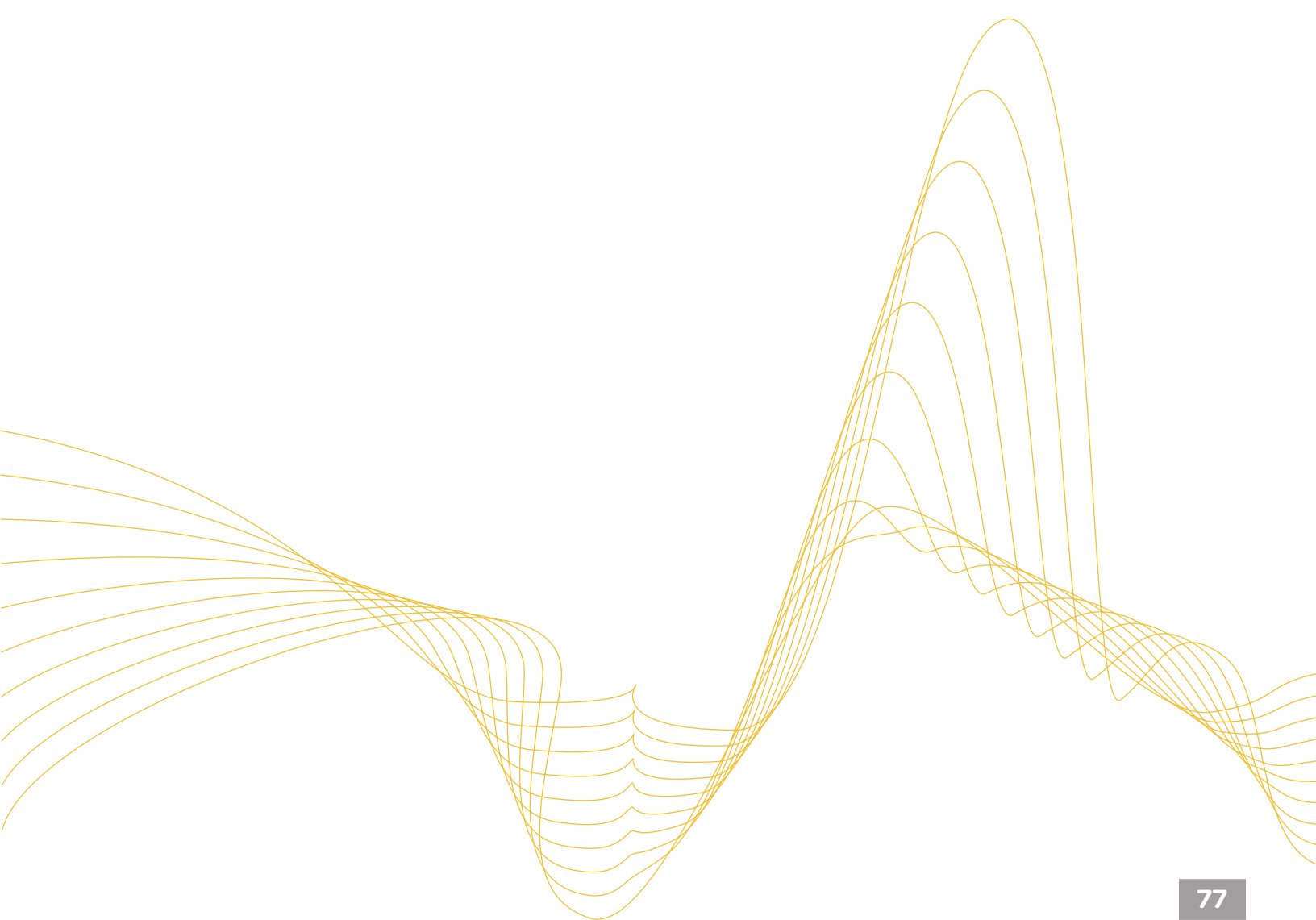
Information about each organization was collected from their respective websites and most recently available Form 990. Additionally, collateral specific to MBC was reviewed, including research reports, surveys, scientific roundtables, posters, and services such as conferences, networks, support lines, counseling, and peer-to-peer group support.

Websites of Alliance members, including pharmaceutical members, were assessed for attractiveness to the user, amount of MBC information, evidence supporting the MBC information provided, recency of updates, ease of navigation, and use of social media tools. The quality of MBC-specific content was assessed to identify to what extent, and at what

level, the websites offered information in 13 areas: diagnosis, current treatment options, latest research and new treatments, symptoms and side effects, monitoring treatment, clinical trials, complementary medicine, pain management, communication, psychological and social support, parenting issues, hospice and end of life care, and advance directives. Print materials (excluding those from pharmaceutical members) were appraised for the extent and quality of MBC content. Videos and webinars were not assessed. Thirteen organizations were sent an online survey to capture information about helpline/hotline services; 8 organizations completed the survey. The survey participants are provided in **Appendix 7**.

A top-line review of 10 publicly available surveys and 4 proprietary reports provided by Alliance members was undertaken to identify continuing themes, recent trends, and new gaps in information.

Preliminary findings were discussed with Alliance members in a meeting in New York City on March 3-4, 2014.



Results

Profile of MBC Alliance Members

The Alliance members are as diverse as the people they serve.

The majority of the nonprofit members focus on meeting the information and support needs of the breast cancer community. Within this group, several Alliance members specialize in supporting women with particular types of breast cancer (Inflammatory Breast Cancer Research Foundation, Triple Negative Breast Cancer Research Foundation, and Triple Step Toward the Cure). A small number of members support and/or advocate for people with any type of cancer (American Cancer Society Cancer Action Network, CancerCare, Cancer Support Community, Patient Advocate Foundation). Two Alliance members—AdvancedBC.org and the Metastatic Breast Cancer Network—focus exclusively on MBC (**Figure 9**).

Figure 9: MBC Alliance Members by Cancer Focus



* Breast and Ovarian cancer

^Δ These 16 organizations were interviewed as part of the landscape analysis.

Some members work for particular target populations, such as patients with hereditary risk (FORCE [Facing Our Risk of Cancer Empowered]), black patients (Sisters Network Inc.), Latina/o patients (Nueva Vida), Jewish patients (Sharsheret), and young patients (Young Survival Coalition).

Some members have an online presence only; others have a more extensive reach. Susan G. Komen, for example, works at both the national and local levels through its headquarters and national network of more than 100 local affiliates. (Note that, for the most part, Komen reported MBC-related information and activities of its headquarters rather than the local affiliates, for which the data are not complete.) Other participating Alliance members were Avon Foundation for Women and Breast Cancer Research Foundation; these 2, in addition to Komen, are among the largest private funders of breast cancer research in the US. In contrast, many Alliance members have relatively limited resources; those with the most revenue typically have the broadest focus on breast cancer. The 2 organizations focused solely on MBC are the least resourced.

There is considerable variability among members as to where they direct their resources. As noted, some nonprofits are active on a number of fronts, including research, patient support and education and policy advocacy, whereas others are more focused in the scope of their activities. Each member organization offers various educational and/or patient support services, with almost all including information and support services for MBC patients and their families. Of the advocate organizations providing information and support services to people living with MBC, education is the largest area of investment.

Tables 7a and 7b provide a snapshot of the breadth of information and support services provided by advocate members.

Table 7a: MBC Information and Support Activities of MBC Alliance Members

Organization	MBC Goals	Patient Advocacy	Research	Policy	Patient Education	Patient Support	Awareness	Clinical Trials / Registries	Scientific Contribution
AdvancedBC.org	✓	✓	✓	✓	✓	✓	✓	✓	
American Cancer Society Cancer Action Network		✓		✓					
Avon Foundation for Women	✓		✓						✓
Breastcancer.org		✓	✓		✓	✓	✓	✓	
BreastCancerTrials.org							✓	✓	✓
Breast Cancer Research Foundation	✓		✓				✓	✓	✓
Cancer Support Community					✓	✓	✓	✓	✓
CancerCare					✓	✓			
Dr. Susan Love Research Foundation		✓			✓	✓	✓	✓	
FORCE		✓	✓		✓	✓	✓	✓	
Inflammatory Breast Cancer Research Foundation			✓		✓			✓	✓
Living Beyond Breast Cancer					✓	✓	✓	✓	
Metastatic Breast Cancer Network	✓	✓	✓		✓	✓	✓	✓	
Nueva Vida					✓	✓			
Patient Advocate Foundation		✓			✓	✓	✓		
Research Advocacy Network			✓						
SHARE	✓	✓		✓	✓	✓	✓	✓	
Sharsheret		✓	✓	✓	✓	✓	✓		
Sisters Network, Inc.									
Susan G. Komen	✓		✓		✓	✓	✓	✓	✓
Triple Negative Breast Cancer Research Foundation		✓			✓	✓		✓	
Triple Step for the Cure		✓			✓	✓			
Young Survival Coalition	✓	✓	✓		✓	✓			

detail

Abbreviations:

FORCE= Facing Our Risk of Cancer Empowered

SHARE= Self-Help for women with Breast or Ovarian Cancer

Table 7b: MBC Patient Support Provided by MBC Alliance Members

Patient Support Organization	Print	Teleconference	Support Groups	Radio/ Podcasts	TV/ YouTube	Chat	Message Boards	Facebook	Twitter	Blog	Helpline	Social Media App	Financial Assistance	Conference / Networking
AdvancedBC.org	✓													
Breastcancer.org	✓			✓		✓	✓			✓				
Cancer Support Community	✓	✓	✓			✓					✓	✓	✓	
CancerCare	✓	✓	✓	✓							✓		✓	
Dr. Susan Love Research Foundation	✓			✓				✓	✓	✓				
FORCE		✓					✓				✓			
Living Beyond Breast Cancer	✓	✓	✓	✓	✓						✓			✓
Metastatic Breast Cancer Network	✓		✓		✓			✓	✓	✓				✓
Nueva Vida	✓	✓				✓								
Patient Advocate Foundation													✓	
SHARE	✓	✓	✓	✓	✓			✓	✓	✓	✓			✓
Sharsheret	✓	✓	✓		✓	✓					✓			
Susan G. Komen	✓						✓				✓			✓
Triple Negative Breast Cancer Research Foundation	✓						✓							
Triple Step Towards the Cure													✓	
Young Survival Coalition	✓		✓	✓		✓	✓	✓	✓	✓				✓

Definitions

Patient Advocacy - Use of health plans/mediation/arbitration; supporting patients to become advocates

Research - supporting MBC research; surveys; convened round tables

Policy - providing MBC policy forums

Patient Education - information to patients and their caregivers that will alter their health behaviours or improve their health status

Awareness - about MBC for the wider community; for families

Clinical Trials/Registries - providing information about clinical trials; maintaining registries

Scientific Contribution - MBC funded research

*current as of June, 2014

Information and Patient Support

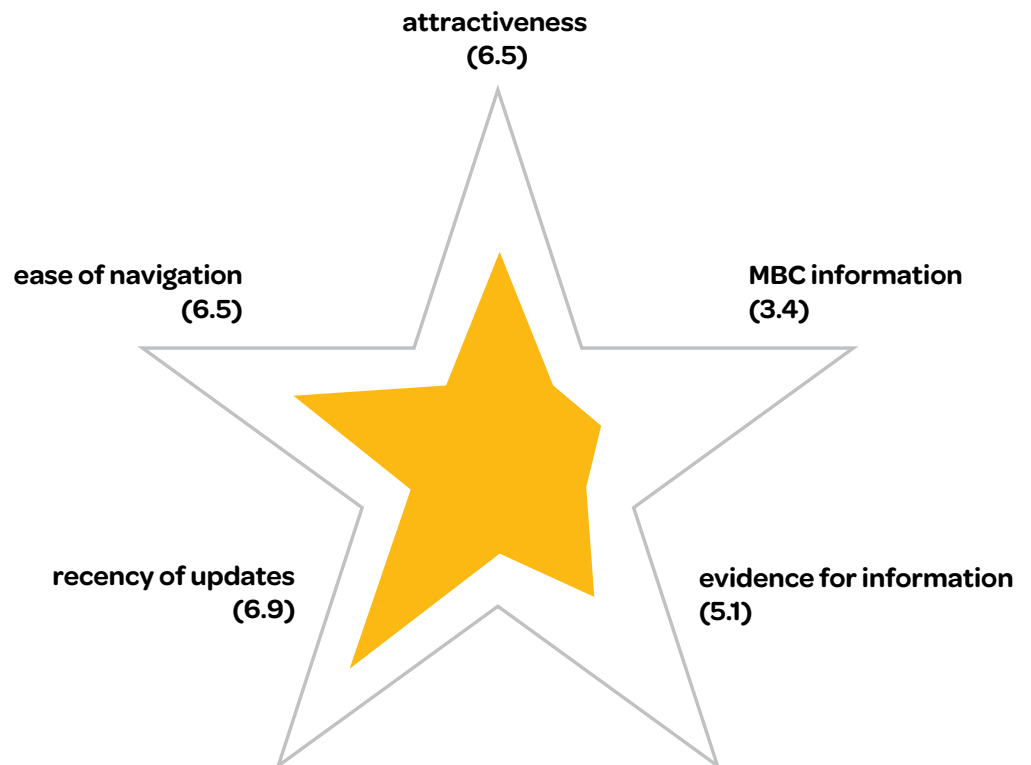
For MBC patients, information and support are often one and the same. The 2 main sources of information for MBC patients are electronic and print. Other “live” sources include conferences, telephone helplines, and webinars.

Between 2006 and 2013, the Alliance’s advocate members developed a variety of educational materials about MBC. This information is featured on 12 websites as well as in over 40 print documents, 8 posters, 8 telephone and 7 online support groups, nearly 40 blog posts, 17 videos/television clips, more than 20 first-person stories, 19 webinars, and 78 conferences and workshops. Industry members among them have 5 unbranded disease-based programs and 6 disease-state programs.

Websites

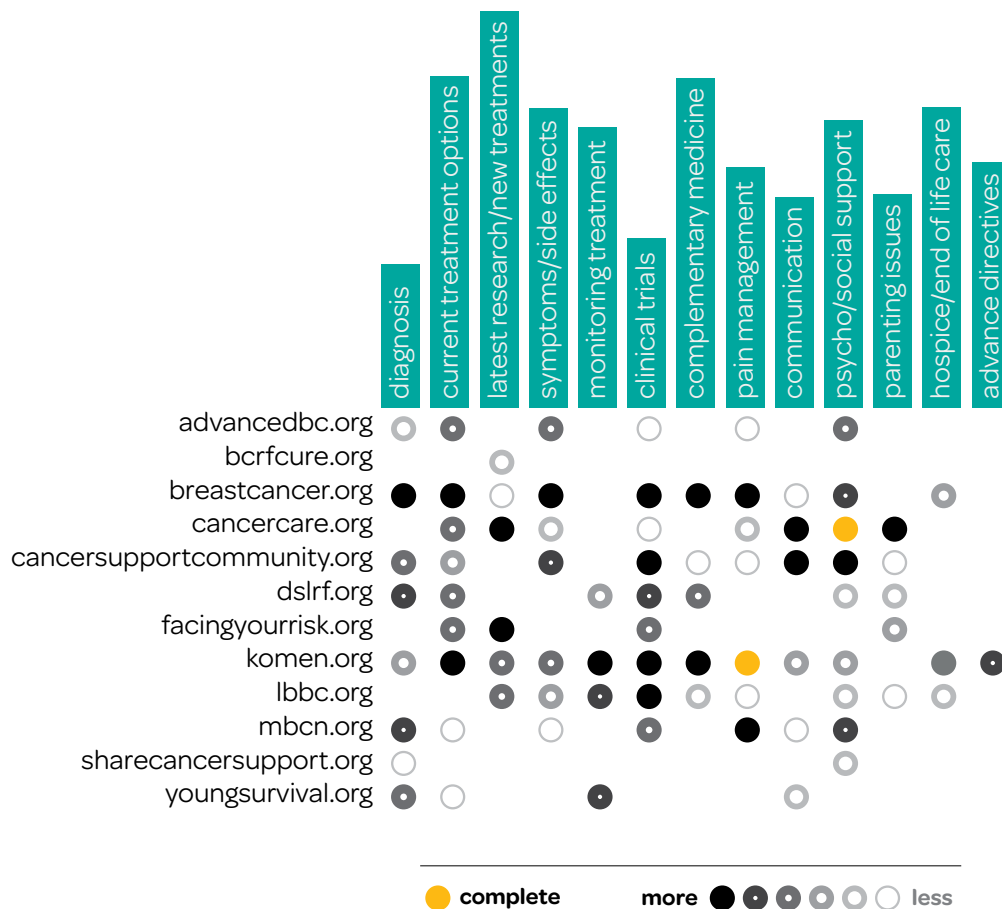
Websites are a main source of information. **Figure 10** shows findings on the usability of advocacy member websites. On the scale of 1 to 10, the overall mean across the 16 members was 5.7, with overall means for the individual score categories—attractiveness, ease of navigation, MBC information, evidence for the information given, and recency of updates—from 3.4 to 6.9. Some sites offer multiple languages and 1 allowed users to create customized pages. Most of the sites are not modern or designed with the end user in mind.

Figure 10: Usability of Advocacy Member Websites (on of a scale of 10, with 10 being the best and 0 being the worst)



On MBC advocate member websites, not enough attention is paid to the MBC patient populations or even to informing caregivers and early stage breast cancer patients about MBC facts. Opportunities exist to create more specific MBC content, social networking, and up-to-date information and to design more user-friendly websites. Regarding breadth of information, no single website among the Alliance members' sites provided MBC information and support, such as webinars and chat rooms, across all the desired topics, even when PDFs available on the sites were considered. Most topics are covered by fewer than 50% of the websites. Of the websites that do provide information on MBC, the depth and breadth of coverage varies (see **Figure 11a**).

Figure 11a: Breadth and Depth of MBC Information in Advocate Member Websites



Excludes Avon Foundation for Women, Research Advocacy Network, and Sisters Network Inc., which do not provide MBC information on their websites.

Most Alliance member websites provide information about clinical trials and encourage patients to discuss options with their health care team to enroll in trials. Some websites also provide services that match clinical trials to patients. For example, BreastCancerTrials.org (which joined the Alliance in March 2014) encourages patients to enroll in clinical trials as a routine care option. However, enrollment in clinical trials remains low owing to multiple factors, including lack of encouragement from physicians, the inconvenience of trial participation, fear of receiving a placebo, and difficulty meeting inclusion criteria^[97].

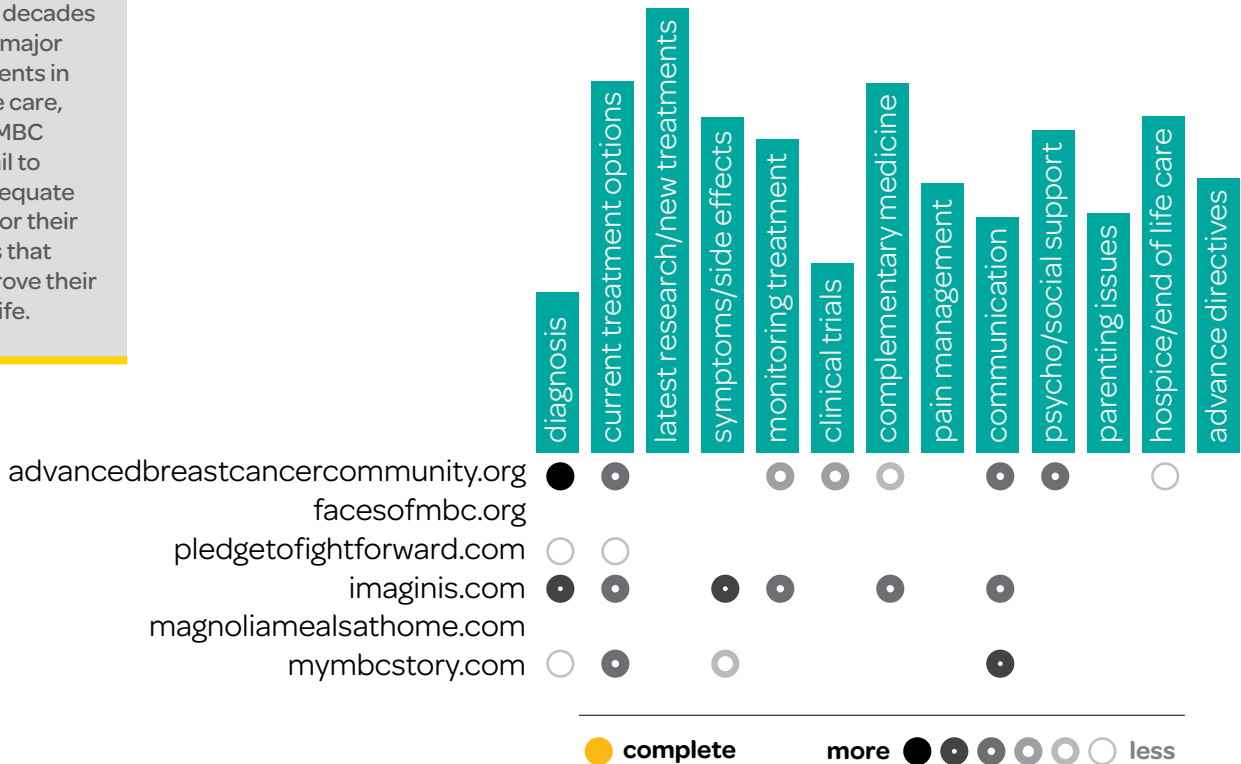
Unbranded disease based websites:

- advancedbreastcancercommunity.org
- facesofMBC.org
- pledgetofightforward.org
- imaginis.com
- myMBCstory.com

The 5 unbranded disease-based websites of our industry members are primarily designed as “sharing platforms” for patients, supporting social elements such as viewable comments and chat rooms. Those that do provide information, such as www.advancedbreastcancercommunity.org, tend to focus on diagnosis, current treatment options, and communication. Most sites provide links to patient MBC advocacy organizations and funder sites. In general, the websites lack overall cohesion, MBC content, and a well-organized links section. There appears to be no commitment to consistently update the sites. These issues leave the user wondering “Why am I here?” The breadth and depth of MBC information is shown in **Figure 11b**.

The past 2 decades have seen major improvements in supportive care, but many MBC patients fail to receive adequate palliation for their symptoms that could improve their quality of life.

Figure 11b: Breadth and Depth of MBC Information in Industry Member Unbranded Disease-Based Websites



A more complete source of MBC information and support for patients is housed in the disease-state websites (branded by drug name) of each pharmaceutical company. Here, content includes MBC disease information, treatment information specific to the marketed drug, support tools for patients such as treatment planners, questions for HCPs, links to community groups and discussion boards, as well as financial support for treatment.

Social Media

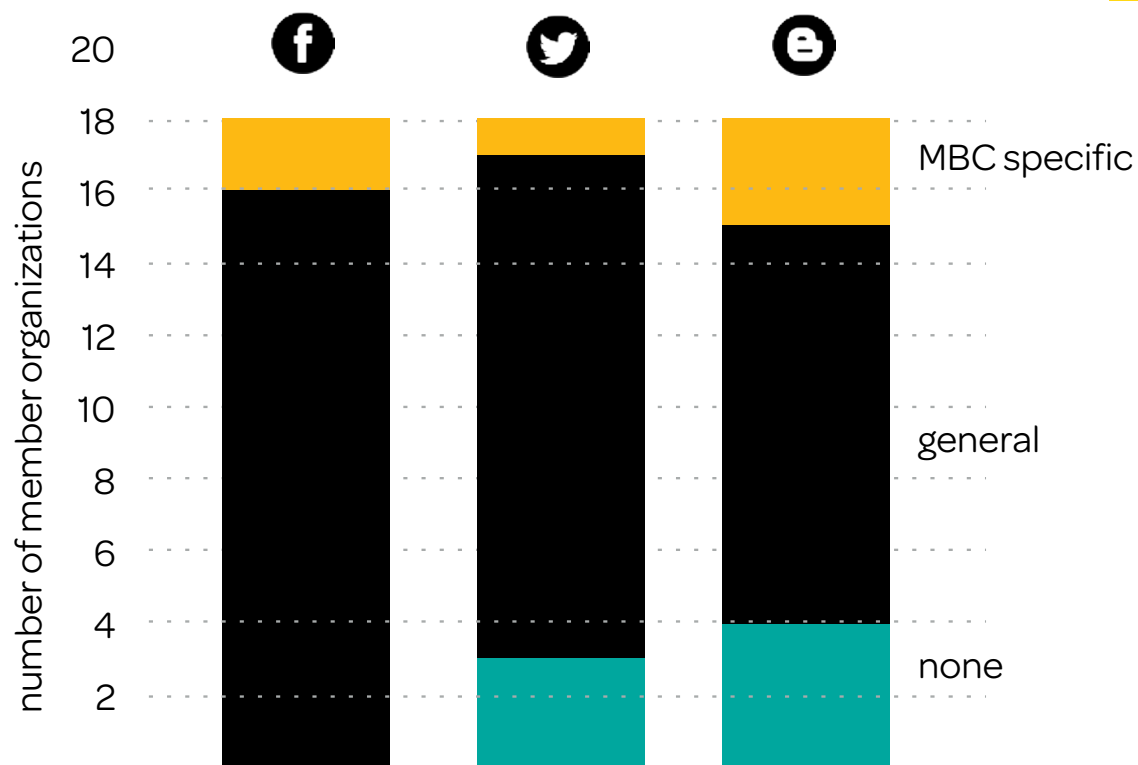
Beyond its potential for fundraising, social media provides powerful tools for educating a large population about the disease^[9]. It also reduces isolation by creating engagement. Most MBC Alliance members use social media, although few provide MBC-specific communications (see **Figure 12**). Unlike traditional online communities, social media support for cancer patients allows members to be seen by their own personal social network and by the public^[10]. This aids in increasing the visibility of MBC among the public. Six in 10 cell-phone owners access the Internet on their cell phones, with blacks and Hispanics more likely to do so than whites^[98]. However, MBC Alliance members provide few mobile websites or smartphone apps. These, along with forums, chat rooms, and social media tools catering to the smartphone portion of the MBC population, would provide another avenue of support to patients.

Notable Discussion Boards

- Breastcancer.org*
- BCMets.org
- Inspire
- TNBC Foundation

* just for Stage IV caregivers/family

Figure 12: Social Media Focus of Advocate Members



Notable MBC publications:

Guide for the Newly Diagnosed – Metastatic Breast Cancer, LBBC & MBCN, 2014

Frankly Speaking About Cancer: Metastatic

Breast Cancer Series, Cancer Support Community, 2013

Metastatic Navigator, YSC, 2010

Managing Practical Concerns Raised by MBC, CancerCare, 2013

Notable MBC Specific Conferences and networking events:

- LBBC - Annual
- MBCN – Annual
- SHARE - Regular networking events on MBC topics

Notable support groups:

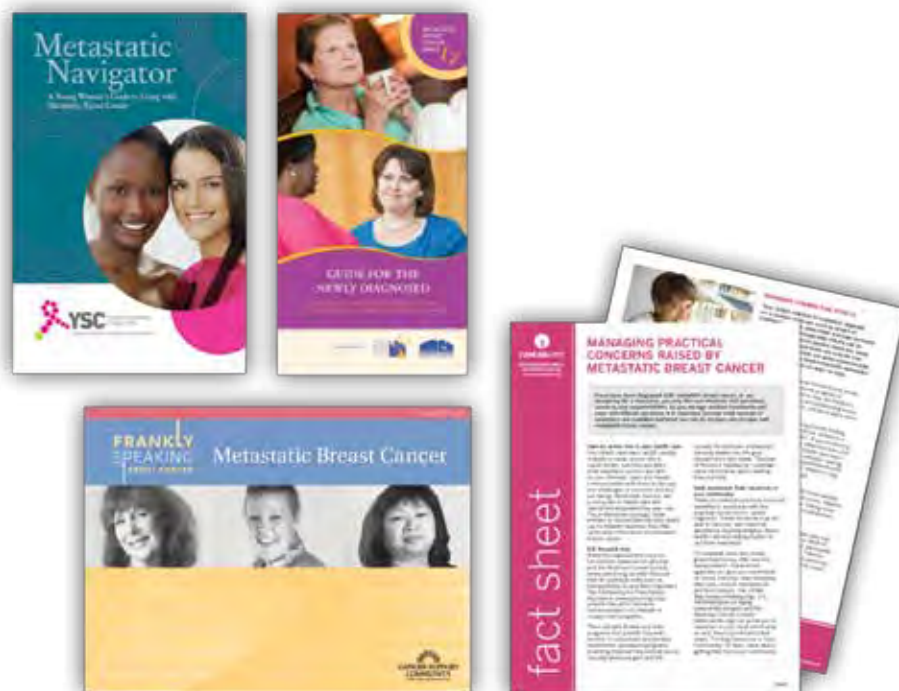
MBC Retreats: A Journey of Courage and Hope for Couples by Johns Hopkins Hospital is supported through Avon Foundation for Women

Metastatic Breast Cancer Network provides a list of known in person groups at <http://mbcn.org/support#in-person-groups-for-mbc>

Print Materials

As with web content, there is a scarcity of MBC information across print materials of individual Alliance members. The print materials tend to be of high quality, but few focus exclusively on the needs of people living with MBC (see **Figure 13**). Specific information provided by Alliance members in print and online tends to be complex, requiring a tenth-grade reading level for a basic understanding. Information about drug therapy is even more difficult to understand. This is a concern because of estimates that 1 in 5 patients have poor literacy and 89% of patients prefer visual materials to nonvisual material; wordy educational materials may not be read.

Figure 13: Print Publications of Alliance Members Specific to MBC



Conferences, Webinars, Support Groups, and Telephone Resources

In-person support is vital for some MBC patients to help reduce feelings of isolation and allow for identification with others. Conferences, retreats, in-person support groups and other networking opportunities specifically for MBC patients help participants feel part of a community. Many breast cancer conferences do include MBC programs, but they could have more content. Conferences tend to be located in large cities, and some MBC patients find it hard to travel during treatment periods. Living Beyond Breast Cancer and Metastatic Breast Cancer Network have annual conferences specifically for MBC patients and caregivers. Information about in-person support groups is hard to find.



Photo: Living Beyond Breast Cancer's 2014 Eighth Annual Conference for Women with Metastatic Breast Cancer

Webinars are another important source of information and often cover new research and treatments. Organizations such as Living Beyond Breast Cancer and SHARE (Self-Help for Women with Breast or Ovarian Cancer) have webinars on results of MBC studies from major symposia, such as the American Society of Clinical Oncology meeting and the San Antonio Breast Cancer Symposium. Programs on practical matters in living with MBC, such as financial issues, are also available in this format, which allows for replay.

Nearly half of Alliance member organizations provide telephone support services, all of which assist MBC patients in some capacity, even if just to refer them to other telephone helplines. Few telephone support services focus specifically on MBC patients; the ones that do include those by the Cancer Support Community, Living Beyond Breast Cancer, Susan G. Komen, and SHARE. Data collected on the use of helpline services by MBC patients is very limited. Most have live counselors during business hours and, at other times, callbacks within 24 hours.

Nearly half the services use professional counselors; the rest use breast cancer survivors as counselors. Some helplines provide follow-up calls and/or matched mentors. All the helplines have Spanish-speaking counselors; several have counselors and/or translators available in other languages. Challenges for helplines include how to broaden awareness and utilization of services, how to retain well-trained counselors (especially for MBC patients), and how to manage technological problems with the telephone system.

Information for HCPs

Alliance members provide information and support to educate patients about their cancer and treatment options, which helps to empower patients in their conversation with health care professionals. However, oncologists and general practitioners often face their own obstacles in their communication with MBC patients. Information developed by Alliance members could be very helpful to providers, so both parties have a shared basis on which to discuss diagnosis and treatment. Web and print materials of members are not currently geared toward assisting providers in these tasks.

Helplines to assist MBC patients:

CancerSupportCommunity
1-888-793-9355

Living Beyond Breast
Cancer
888-753-LBBC (5222)

Susan G. Komen
1-877 GO KOMEN

SHARE
866-891-2392

Discussion

“There is a lack of information on new drugs, current clinical research, advanced directives, end of life care, and monitoring treatment.”
MBCA Landscape Analysis - web content analysis, Pamela Miller 2014.

Providing accurate, up to date, comprehensive, and relevant (to the person seeking it) information and support services on MBC is challenging. Over time, patients move from diagnosis into a series of treatments until medicines and therapies no longer work. Over the course of their disease, information needs change, usually prompted by a change in treatment or life circumstances. Patients seek information about their disease subtype and their demographic. Caregivers have different information needs as well.

This analysis found that Alliance advocate members provide high quality information and support services to MBC patients and their families. However, information provided by the Alliance members requires that patients have relatively high health literacy and be Internet savvy. Organizations must consider how to reach these people and other subgroups of the MBC patient population. Unfortunately, quantitative data on the demographics and numbers of people who are accessing the programs and services is not consistently collected. As a result, the profiles and needs of the patients who are and who are not accessing the information and support are unknown.

While the disease-state websites of industry partners is comprehensive, the information is hard to find for patients not using the product/drug. There is a duplication of patient support tools across the websites such as treatment planners, discussion guides, accessing community groups. Similar to the advocate organizations, data are not collected on the patient using the websites. Without understanding who the user is and what types of information they seek and value, it is difficult to know how to make the sites more useful.

The majority of nonprofits report that their programs and services are underutilized. This may be because people are not aware of the advocacy organizations and where to find information or are finding support in other places. Because members offer so much general information, it is difficult for individual patients to find what they need.

Persistent gaps in information 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 people are diagnosed with MBC could be improved, and there is a dearth of information on new drugs in clinical research.

MBC Alliance members recognize that there are a number of opportunities to use our collective resources to extend the quality and reach of our information and patient support services. A next step is to understand more clearly who is and who is not using the support services and tools, how the services are being used, and how they can be improved to better meet the needs of people living with MBC. Through a collaborative effort, we will work to offer better support to address MBC patients' unique needs and empower them to be informed partners in their treatment decision making.

Notable end of life sources:

CancerCare.org:
Caregiving at the
End of Life (2011)

Susan G. Komen
on Advanced
Directives
ww5.komen.org/
uploadedFiles/
Content_Binaries/
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People living with metastatic breast cancer and patient advocates at the Metastatic Breast Cancer Network 2013 Annual Conference

Metastatic Breast Cancer Alliance

c/o Avon Foundation for Women

777 Third Avenue

New York, NY 10017

mbcalliancesocial@gmail.com

www.mbcalliance.org

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