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# LESSONS LEARNED FROM THE METASTATIC BREAST CANCER COMMUNITY

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**OBJECTIVE:** *To present findings from two large surveys that explored the needs for information, emotional support, provision of services, perceptions, and attitudes of women with metastatic breast cancer (MBC).*

**DATA SOURCES:** *Published articles and surveys.*

**CONCLUSION:** *Results from an online needs assessment of 618 women with MBC and a global survey of 1,342 women with MBC living in 13 countries interviewed following referral by their physicians revealed that the most urgent needs are for good, accurate, in-depth information about their disease, standard and emerging treatments, and ways of coping with side effects and symptoms.*

**IMPLICATIONS FOR NURSING PRACTICE:** *Much research has focused on coping with early breast cancer, but little has been studied about the needs and experiences of women living with MBC. Nurses can learn from what patients have told us about what they want, to better respond to these needs.*

**KEY WORDS:** *Metastatic breast cancer, needs assessment, patient survey.*

**T**HE BURDEN of metastatic breast cancer (MBC) is devastating. At well over half a million deaths each year, breast cancer is the leading cause of cancer deaths in women worldwide, occurring in about

one third of the 1.3 million women who will be diagnosed each year.<sup>1-3</sup> Even in developed countries like the United States (US), as many as 30% of women diagnosed with early breast cancer will develop distant metastatic disease, an incurable condition that progresses to death in all but a small percent of patients.<sup>4</sup> In developing countries, a majority of breast cancers are diagnosed at later stages. For 5% of American patients, the disease has already progressed to stage IV when it is first diagnosed – a rate that is higher among minority and poor women.<sup>5</sup>

Yet the picture is not completely bleak, as advances in the treatment and management of MBC have resulted in women living with the disease for increasing periods of time, often

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0749-2081/2603-832.00/0.

doi:10.1016/j.soncn.2010.05.004

several years, and with improved quality of life.<sup>6</sup> Population-based studies have demonstrated longer survival over the past decade and a half, as new treatments have been introduced.<sup>7</sup> While the number of annual deaths from breast cancer in the US has held constant at approximately 40,000,<sup>8</sup> no accurate statistics are kept on the prevalence of distant metastatic disease in the US; in other words, women *living* with metastatic disease.

The reality of lengthening survival means that women living with advanced disease experience increasing needs that are clearly quite different from those of women with early breast cancer. For these metastatic patients, breast cancer is no longer a clearly defined medical crisis that resolves as adjuvant treatment is completed, allowing them to go on with their lives. Longer life for women with MBC can only be obtained through continuous treatments, each of which is bound to fail sooner or later. Typically, as the disease progresses, new chemotherapy or hormonal or biological therapies introduced to combat the cancer's spread tend to work for increasingly shorter periods of time, and with lowered effectiveness. As a result of these treatments, women typically experience cumulative side effects and toxicities over time, for which they must receive additional therapies. In addition, they must cope with ongoing symptoms of the disease as it progresses, necessitating further supportive care for chronic pain, nausea, fatigue, and other debilitating symptoms. Thus, the medical, economic, and psychosocial burden of living with an incurable, progressive, and ultimately fatal disease on patients and their families cannot be overestimated.

The past two decades, during which most of the improvements have come in extending and enhancing life for patients with MBC, have also seen dramatic increases in support, information, and practical services for women with breast cancer in the US. Breast cancer appears in the news almost daily. Breast cancer "awareness" has become ubiquitous, and pink ribbons now appear on many branded products. National and local support and advocacy has led to the formation of hundreds of organizations with the dual focus of: 1) breast cancer awareness, screening, and early detection; and 2) helping women with breast cancer diagnoses, treatment, and survivorship. Yet within the "survivor" community of some 2.5 million women already diagnosed with breast

cancer,<sup>9</sup> few programs have been devoted to the unique concerns of women living with metastatic disease. In 1995, when I first set out to write a guide for these women and their families,<sup>10</sup> and began to do patient and family interviews, the most comprehensive information source offered only a few listings on hospice care and viatical settlements. Today, while the situation has improved somewhat, dedicated services for this population are still quite uncommon.

Many women living with MBC find the annual media and commercial saturation known as Breast Cancer Awareness Month each October to be emotionally difficult. "The pink ribbon is a ribbon of hope," one patient explained. "I think what is troubling is that we feel forgotten and like we represent the lack of hope. When we are remembered, we are recognized as 'losing the battle.' We are what the pink crowd wants to forget because we are the painful reminders of what can happen."<sup>11</sup>

#### LIVING BEYOND BREAST CANCER NEEDS ASSESSMENT SURVEY

A search of the literature reveals that while the needs of early breast cancer patients had been widely studied, the specific needs of women living with MBC had not been researched. In fact, little research has been done with regard to the needs of people living with advanced cancers in general, so we hoped that in studying metastatic breast cancer, it might be possible to understand the needs of other patients with advanced cancers as well.

In 2005, the organization Living Beyond Breast Cancer (LBBC)<sup>12</sup> and its consultants undertook to design, implement, and analyze a comprehensive online needs assessment survey that would help to guide this organization and others in the provision of services for this often neglected patient population. We believed it was important to ask the patients themselves about their experiences and preferences; we felt they were the 'experts.'

The LBBC Survey consisted of 65 questions, taking approximately 40 minutes to complete, and was conducted online during April–May 2005. A discussion of the results of that survey, including the survey instrument used, is available on the LBBC website as a white paper entitled "Silent Voices: Women with Advanced

**TABLE 1.**  
LBBC Survey Demographics (N = 618)

Demographics	Response (%)
Age 40–59	70
Caucasian	94
College degree +	66
Live with partner/husband	74
Have children at home	33
Still employed	47
On disability (SSD)	25
Had private insurance	73

(Metastatic) Breast Cancer Share Their Needs and Preferences for Information, Support and Practical Resources.”<sup>13</sup> The survey results have been presented at a number of conferences.<sup>14-16</sup>

In all, 618 women completed the survey. Demographic data are provided in Table 1. Respondents typically described themselves as having lived with MBC for less than 5 years, with multiple metastatic sites, being in continuous treatment, and reported a wide variety of symptoms and side effects. See Table 2 for the most commonly reported side effects and symptoms. Despite reported side effects and symptoms, 44% found maintaining daily routines and activities *very easy* or *easy*, and only 19% found it *difficult* or *very difficult*.

Detailed questions asked about multiple sources of information and the kinds of information respondents found most and least useful. Information about the disease and its treatments was highly important to these women. Nearly three quarters (73%) said they sought out information on a daily or weekly basis. Women were most likely to seek information when deciding on new treatments (65%), experiencing recurrence or

**TABLE 2.**  
Most Commonly Reported Side Effects and Symptoms (N = 618)

Side Effect	Response (%)
Fatigue or weakness	67
Cognitive problems	60
Sexual dysfunction	60
Disturbed sleep	56
Hot flashes	50
Pain	49
Depression	34
Anxiety	28

**TABLE 3.**  
Most Important Informational Needs (N = 618)

Informational need	Response (%)
Current treatment options	96
New treatments and emerging research	96
Coping with side effects and symptoms	95
Clinical trials information	84
Pain management	79
Communicating with health care team	79

disease progression (61%), or dealing with side effects of treatment or symptoms of disease (56%). Varied sources of information were used and desired, with a slight preference for printed and web-based materials, as well as high attendance in online programs and teleconferences. They reported that different members of their health care team provided information in different ways. Most had attended lectures by oncologists or other experts, and they rated these meetings highly. See Table 3 for the most important informational needs identified by the participants.

Despite high levels of motivation and information seeking, more than a third of these women reported being unaware of the availability of informational resources in their community or online. In terms of emotional support, respondents reported high levels of support and support-seeking, not only when they were feeling anxious or sad, but when they needed help in coping with medical aspects of the disease. Siblings, spouses/partners, children, and friends were the most frequent sources of support and, with the exception of children, were highly rated. They also reached out for support when they “felt alone with their cancer”; more than two thirds found support in hearing from others with MBC and in sharing their own experiences with others. Many had attended face-to-face groups, as well as participating in online groups, whether in the form of bulletin boards, chat rooms, or mailing lists. Online groups were preferred, perhaps because of convenience and availability. Many women also sought out support in one-on-one relationships and wanted groups to be professionally led by a nurse or mental health professional. Table 4 identifies the most important programs that provided emotional support. Table 5 identifies the value of the support received by the oncologist, nurse, and mental health professional.

**TABLE 4.**  
**Most Important Programs Offering Emotional Support**  
**(N = 618)**

Program	Response (%)
Support groups	78
Stress management programs	71
Individual counseling	55
Spiritual guidance	52
Peer network/buddy programs	51

The most valued practical resources were: referrals to doctors and/or cancer treatment centers (72%), information on health insurance (67%), information about Medicaid, Medicare, and disability (56%), and financial assistance for medical needs (49%). In our survey, there appeared to be a positive relationship between reported levels of information and emotional well-being. In other words, those women who reported the highest levels of knowledge and information-seeking about the disease less frequently reported the negative effects of anxiety, depression, pain, sexual difficulties, and appearance issues. There was a similar finding with regard to levels of emotional support.

**Limitations**

Cautions about generalizing data from this survey center primarily around the self-selective nature of those who volunteered to take this questionnaire online. As Internet users, respondents' socioeconomic status may not be representative

**TABLE 5.**  
**Value of Formal Sources of Support (N = 618)**

<b>Makes time to speak with me about my concerns.</b>	
74%	Medical oncologists
67%	Oncology nurses
52%	Mental health professionals
<b>Treats me in a caring and respectful way.</b>	
77%	Medical oncologists
76%	Oncology nurses
54%	Mental health professionals
<b>Suggests coping skills.</b>	
51%	Mental health professionals
48%	Oncology nurses
41%	Complementary and holistic practitioners
27%	Medical oncologists

of the patient population as a whole. Respondents are clearly younger, better educated, and better insured than average. Nevertheless, it is striking that a very sizable proportion of even this highly motivated, educated group of information-seekers was either unaware of or unable to locate needed resources.

**THE BRIDGE GLOBAL SURVEY OF METASTATIC BREAST CANCER**

In 2008, a steering committee comprised of three patient advocates, two oncologists, a psycho-oncologist, and an oncology nurse met to build on the foundation of the LBBC Survey and design a second survey that would capture a broader, more representative patient population, on a global basis. The BRIDGE Survey was supported by funding from Pfizer, Inc. and was conducted by Harris Interactive between September 2008 and November 2009. To offer a balance between low- and high-resource countries, approximately 100 women from each of 13 countries were recruited through physician referral, including Australia, Latin America (Argentina, Brazil, Mexico, Venezuela), Europe (Belgium, France, Spain, the United Kingdom), North Africa (Egypt), and North America (Canada, US). To enhance diversity, no doctor could refer more than five patients.

The survey's 34 questions were divided into five sections: 1) resources/information/knowledge; 2) emotional support; 3) attention from society; 4) impact on self/lifestyle; 5) and clinical trials. Topics included resources for MBC, support networks, relative attention given to MBC in contrast with early breast cancer, psychosocial impact of the disease, and enrollment in clinical trials as well as perceived barriers to participation. The interview process took approximately 25 minutes, and was conducted face-to-face by female native-language speakers in each of the low-resource countries. In high resource countries, survey methods included telephone, mail, and face-to-face interviews, depending on participant preference.

Overall, 1,342 women completed the survey (approximately 100 from each country). Median age of participants (55 years) was relatively young, except for a younger cohort from Egypt, where the median age was only 44, possibly reflecting earlier onset of the disease reported in Africa.

Most women (52%) felt that MBC was given too little consideration in their countries, and when asked to compare this with attention given to early breast cancer, women in all but three of the countries (Egypt, Mexico, Venezuela) felt that early breast cancer got far more attention. This perception was particularly pronounced among women from the US, where nearly two thirds (64%) believed MBC got too little attention.

On metastatic diagnosis, most women reported having felt scared, confused, depressed, angry, and alone. Their most common concerns centered on issues related to dying from the disease, maintaining quality of life and managing side effects, inability to care for their families, and end-of-life care. Table 6 identifies the reported emotions when first diagnosed, and major concerns with MBC. In general, those women who had first been diagnosed with early breast cancer and then suffered a recurrence of distant metastatic disease (52%) had a more positive outlook on life than those with an initial stage IV diagnosis (48%). Although most women (59%) recognized the negative impact of the disease on their lives, three quarters (74%) reported still being able to enjoy their lives, a testament to their resilience. While almost all these women reported receiving enough support from at least one person in their “inner circle” (family, friends, neighbors, health care professionals), over a third (38%) were fearful of talking openly about MBC, and nearly half (48%) said that their friends and family were uneasy talking about it.

Overall, three quarters of study participants (76%) reported that they took an active role in searching for information on MBC, and an even higher number (81%) said they played an active

**TABLE 6.**  
**Reported Emotions and Concerns with MBC (N = 1,342)**

Identified Emotions and Concerns	Response (%)
Scared	80
Confused	66
Depressed	66
Angry	57
Alone	55
Dying from MBC	69
Maintaining good quality of life	59
Possible side effects and symptoms	56
Ability to care for their families	54
End of life care	51

**TABLE 7.**  
**Most Valued Types of Medical Information (N = 1,342)**

Types of Information Most Valued	Response (%)
General information about MBC	79
Available treatment options for MBC patients	78
How to manage side effects and symptoms	76
Type of care available for MBC patients	74
Updates on clinical trials that assess new treatments	68
Possible changes in physical appearance	68
How long MBC patients are living	65
Alternative treatments like herbs, acupuncture	55
Possible problems having children	47
Decreased interest in sexual activity	47

role in treatment decision-making. Table 7 identifies the most valued types of medical information. Even though medical information was listed as most important, other issues were cited as well. Three quarters of women (75%) said they liked to hear stories from other patients. Advice on how to talk to others about metastatic disease was valued by two thirds (67%). Patients also wanted to learn about how to pay for medical care and treatment (70%) and said they had sought support from charitable and voluntary organizations (74%). Participants were questioned about the format of information they preferred.

About one quarter (26%) of survey participants had searched for information about clinical trials, and 18% had actually enrolled in a trial. While relatively few women had been invited to participate in a trial (23%), of those who were, two thirds (67%) had agreed to participate and had gone on to enroll in a trial. Overall, “information-seeking” women with MBC were most likely to participate in clinical trials.

The size of the individual country cohorts, as well as the possibility of selection bias because of patient recruitment, precludes robust country-to-country comparisons. Cultural differences are likely to be present in women’s attitudes about being diagnosed with MBC, as well as their willingness to discuss their disease. In some countries, the findings may indicate that significant stigma is associated with the diagnosis, a subject for further inquiry. Country-specific differences reported in the BRIDGE Survey suggest that

provided resources should be culturally relevant. To date, presentations of the BRIDGE Survey results have been made at three scientific meetings and are being prepared for publication.<sup>17-19</sup>

### DIFFERENCES AND SIMILARITIES BETWEEN THE SURVEYS

The LBBC Survey was a detailed examination of needs and preferences regarding resources offering information, support, and practical assistance to women with MBC. By contrast, the BRIDGE Survey assessed these needs in more general terms and focused also on societal attitudes and potential stigma experienced, psychosocial coping, and clinical trials participation.

Although the relatively young age for both groups was similar, other demographic factors were quite different. The LBCC Survey participants were clearly a more homogenous group, socioeconomically as well as geographically. In general, the self-referred women in the LBBC Survey displayed the demographics of Internet users. Only a small percentage lived outside the US, whereas over 90% of BRIDGE Survey participants resided in other countries. Because they relied on physician referral, the BRIDGE Survey methodology was able to capture a more heterogeneous population, particularly in developing countries.

Although these two surveys were focused in somewhat different areas, there were important areas of overlap. Perhaps the most striking similarity overall linking the results of the two surveys is that despite the diversity of culture and country of residence, women with MBC expressed a very strong need to seek out information about their disease. Clearly, these patients shared a common need that drove their information-seeking. They all were coping with a progressive illness with a poor prognosis. They all were struggling to make the best treatment decisions and get the best medical care. They all were managing their symptoms and side effects for the best quality of life.

In essence, they were struggling to maintain a sense of control over their lives, a challenge for all MBC patients. Maintaining a sense of control is particularly challenging in the face of the physical decline and loss of role function of progressive disease, with the accompanying persistent symptoms of pain, fatigue, and nausea. Seeking infor-

mation is one powerful and adaptive way in which patients accomplish this task. The importance of establishing a sense of control in coping with disease is not unique to breast cancer, of course. The importance of this task is demonstrated by extensive literature on this subject.<sup>20</sup>

Information-seekers in both surveys expressed a universal need for good information about their disease and its treatments. Of particular interest were both standard and new therapies under development. They wanted to know how to manage side effects and symptoms of the disease. They sought help in coping with many other aspects of life with MBC, specifically detailed in the "Silent Voices" white paper, accompanied by specific recommendations for strategies to offer relevant services.<sup>13</sup>

Also striking was the interest expressed by women in both surveys in hearing from and sharing with others in similar circumstances, perhaps as a way of combating the sense of isolation reported by more than half of all women surveyed. This has clear implications for establishing a variety of forms of peer and patient support, to augment existing mental health services.

### **Metastatic Breast Cancer Advocacy Working Group Consensus Document**

In 2008, when the BRIDGE Survey was initiated, a Metastatic Breast Cancer Advocacy Working Group of patient advocates was convened, also supported by Pfizer, drafted a consensus document drawing attention to the obstacles faced by women with metastatic breast cancer and to propose potential solutions to enable unmet needs to be addressed.<sup>21</sup> Members of this working group represented breast cancer organizations in seven countries, including Argentina, Brazil, Canada, Malaysia, Mexico, the UK, and the US. The three principle recommendations from the consensus document were as follows:

- 1) Heighten attention to the MBC community – create a unified voice and platform that speaks to their unique needs.
- 2) Improve access to tailored information, resources, and support for women with MBC.
- 3) Increase understanding of and access to clinical trials.

The results of the two surveys reported here not only confirm the relevance of these

recommendations, but they underscore the urgent need for access to tailored resources, and for breast cancer “awareness” to extend to the full range of the breast cancer experience, rather than dwelling exclusively on the more “pink” and positive messages of survivorship and screening.

Because there is currently no cure for metastatic disease and because it is progressive and nearly always fatal, it has been emotionally challenging for organizations, often staffed with survivors, to fully acknowledge these threatening realities. Yet as a result of these two surveys, and the advocacy work of groups like the Metastatic Breast Cancer Network, a new awareness and acceptance is beginning to spread. New services are being offered. It is our hope that this interest will foster more research into the specific needs of this neglected population.

### Lessons Learned From the MBC Community

Messages taken from the findings in these two surveys can inform services and programs designed for people living with other kinds of advanced cancers. The most urgent need expressed by patients and their families is for good, accurate, in-depth information about their disease, on standard and emerging treatments, and on ways of coping with side effects and symptoms. The proliferation of online communities and patient-directed websites, as well as the wide utilization of hospital and organizational cancer websites, clearly demonstrates the need for and the keen interest in accurate, up-to-date information on advanced cancers of all kinds. The finding that information-seeking patients were more likely to participate in clinical trials, and that a large majority were motivated to seek clinical trials information, may have implications for the broader dissemination of trials information in a format integrated with other kinds of information of interest to patients with advanced cancer.

Support is no less urgent a need because people with advanced cancers and their families often feel extremely isolated. For less common or even rare cancers, as well as for those that are most common (eg, lung, prostate, colorectal, and breast cancers), the Internet has afforded a unique opportunity for patients to find others similarly afflicted to exchange information and offer emotional support. As one example, ACOR (the Association of Cancer Online Resources)<sup>22</sup> offers free membership to 159 mailing lists that focus

on many different kinds of cancer and cancer-related issues. Together, these mailing lists deliver more than a million messages to cancer patients and their families each week.

Many, if not most, of the available online resources are initiated and maintained by patients and their families on a volunteer basis. Over the past 15 years, these innovative and often very high-quality resources have offered important lifelines to patients, overcoming isolation, and lack of information. Non-profit organizations and health care providers can learn from what patients have told us they want and need, and could and should be doing far more to better respond to these needs. Clearly, people seeking information desire to learn in multiple ways, from printed materials, websites, online communities, teleconferences, and in-person educational meetings. For patients who are not able to use the Internet or prefer printed materials, brochures and pamphlets can easily be developed by health care providers and posted online for printing and distribution to patients. Videos, live meetings, and teleconferences can make good information accessible to everyone. In our experience, oncologists, oncology nurses, and other providers have been more than willing to volunteer their time to help a population they too perceive as neglected.

Undoubtedly, there is stigma associated with the metastatic, progressive, incurable, and ultimately fatal form of the disease. Cancer strikes fear into the hearts of most people. But patients and families clearly need help in living with their cancer, having the best quality of life for as long as they can. Few resources are available for advanced cancers of any kind, a deficiency that only becomes more acute as more lives are being extended by newer forms of therapy. While the disparity between attention paid to early breast cancer and MBC is particularly striking, there is no reason to believe that the fundamental needs for information, support, and practical resources expressed by women with MBC are in any way unique to that form of advanced cancer. Patients and families want, need, and deserve better services.

### CONCLUSION

The women in these two surveys have spoken clearly and specifically about their need for services, and described how under-recognized

MBC has been within the otherwise well-developed and well-resourced breast cancer community. We hope that these results will help to empower other women with MBC to speak out and demand that their experiences and needs become an important part of the public dialogue on breast cancer.

These survey findings issue a clear call for action and a response on the part of all those

organizations and individuals whose work it is to meet the needs of *all* women with breast cancer, and men and women with other advanced cancers. This “forgotten population”—as a social worker at Memorial Sloan Kettering Cancer Center referred to her metastatic breast cancer patients<sup>23</sup>—must be remembered, not only after they die, but now, while they are still alive.

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