

# Living with metastatic breast cancer: a global patient survey

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Worldwide, one-third of patients who present with early-stage breast cancer will go on to develop metastatic disease. Despite a serious diagnosis with a grave prognosis, treatment advances have meant that women are living longer with metastatic breast cancer. Although the clinical aspects of metastatic breast cancer have been well studied, little is known about the personal, psychosocial, and emotional experiences of women living with the disease. Because early-stage breast cancer is highly visible in the media and is a focus for most patient advocacy groups, women with metastatic disease feel isolated and alone. This paper presents the results of an international survey that questioned 1,342 women with metastatic breast cancer from 13 countries. The survey was designed to understand the nonmedical attitudes of patients living with metastatic breast cancer, identify perceived gaps in resources available to these patients, and define barriers to clinical trial enrollment and participation.

“Sometimes I feel like I am hidden and forgotten.”\* These sentiments of Lynn, a woman with metastatic breast cancer (MBC), are echoed by countless others with the disease.

Those who work with such patients often encounter this seeming paradox: despite the high visibility of breast cancer as a media focus, a research priority, and a support and advocacy movement, women who are living with advanced disease often feel marginalized and alone.

In developed countries, approximately 30% of patients having an initial diagnosis of early-stage breast cancer (EBC) will go on to develop MBC,<sup>1</sup> while in developing countries, where breast cancer is often first diagnosed at later stages, MBC rates are much higher.<sup>2</sup> Worldwide, breast cancer is the leading cause of cancer death among women, accounting for an estimated 465,000 annual deaths, a figure that represents nearly 36% of 1.3 million diagnosed cases of breast cancer each year.<sup>3,4</sup> Metastatic disease therefore presents a major clinical problem in oncology. Despite recent advances in understanding the clinical and biological aspects of MBC, it is still not curable for the vast majority of patients.

The focus on clinical issues means that the true impact of MBC goes underestimated, under-

reported, and underresearched. While enduring the symptoms of MBC and the adverse effects of therapy, many women are able to live with the disease for a number of years. However, women with MBC and their families experience marked psychosocial challenges that profoundly affect quality of life. In addition to medical concerns, there are emotional, social, and spiritual demands.

Breast cancer is typically portrayed in the popular media with an upbeat message that emphasizes the positive effect of early detection and the high likelihood of a cure. The disease is described as having nearly been “beaten,” and the concept of long-term survival is stressed.

In the United States, one month in particular—October, designated as Breast Cancer Awareness month—is difficult for many women with MBC. In that month, all the attention seems to be on “screening, prevention, and curability,” said Sue, who had stage IV disease at initial diagnosis. “It

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\* All quotations in this article are taken from interviews with metastatic breast cancer patients in the United States, identified by their first names.

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implies that breast cancer which is detected 'early' can always be cured, which places an indirect form of responsibility on those whose cancer is not detected early. I can't wait till the 'pink' month passes by each year!"

In contrast, the reality of metastatic disease is rarely mentioned, even in the meeting rooms of breast cancer advocacy and support groups. "Is it because people are afraid?" asked Lynn. "Maybe they want to believe if you don't acknowledge it, it can't happen to you." Having metastatic disease can cause women to feel isolated from others within their support groups who have not had a recurrence. They may withdraw and censor what they say for fear of upsetting the other women.

Women with MBC report a broader sense of social stigma that may even create a sense of guilt about having developed advanced disease. "People tend to shy away from me when they find out about my disease," said May. "I like to be charitable and assume it's because the thought of it scares them, but sometimes I think they believe I must have done something wrong to 'deserve' it."

In addition, the prognosis for MBC is frequently misunderstood. "Most people believe that those with metastatic disease will die very quickly after diagnosis so there is no point in focusing on it," said Robin. "When I explain what 'metastatic' means, I see the look of pity or sadness and a complete lack of understanding that one can live quite normally with metastatic breast cancer for many years."

Taken together, these factors can create a climate of silence that prevents the real story of women living with MBC from being told. It is important that women with MBC emerge from the "pink ribbon's shadow" and are given a voice, particularly as the 5-year survival rate for MBC in developed countries is 27% and advances in treatment have meant that

some women are living longer, with 9% still alive at 10 years.<sup>5-9</sup>

### The BRIDGE (Bridging Gaps, Expanding Outreach) Survey

Given the seriousness and prevalence of MBC and its global burden, it is surprising that so few studies have focused on its impact on the lives of patients and their families. To better understand the experience of living with this incurable, progressive disease, in 2008 we developed an international survey—the BRIDGE (Bridging Gaps, Expanding Outreach) Survey—designed to reach women with MBC in a variety of different cultures. Its aims were threefold: to understand attitudes of those living with MBC; to determine perceived gaps in resources, information, and psychosocial support for women with MBC; and to identify perceived barriers to clinical trial enrollment and participation.<sup>10-13</sup>

We recruited to the survey pa-

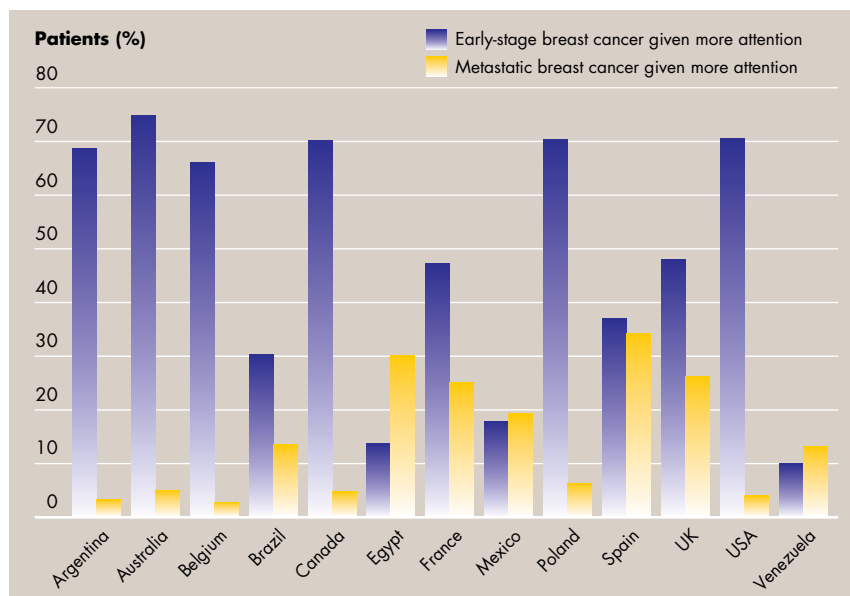
tients from 13 countries: Argentina, Australia, Belgium, Brazil, Canada, Egypt, France, Mexico, Poland, Spain, the United Kingdom, the United States, and Venezuela. Women at least 18 years of age with MBC were asked a total of 34 questions, a process that took approximately 25 minutes. Interviewers in developing countries were female local-language speakers. To minimize selection bias, patients in developing countries (and most developed countries) were referred by a minimum of 20 physicians practicing in several locations within each country. The survey methodology in each country (method of recruitment and survey technique used) is summarized in Table 1.

### Results

A total of 1,342 women with MBC participated in the BRIDGE Survey, suggesting that the survey itself may be offering a welcome platform for women with advanced dis-

**TABLE 1**  
Survey methodology by country

Country	Number of respondents	Method of recruitment	Survey technique
Argentina	100	Physician	Face to face
Australia	100	Physician; support group; newspaper advertisements	Telephone; face to face
Belgium	108	Physician; patient association	Telephone; mail
Brazil	100	Physician; support group; patient association	Face to face
Canada	92	Physician; support group/patient association; online focus group database; newspaper advertisements; patient list; recruitment at breast cancer race	Telephone; face to face
Egypt	105	Physician within a hospital	Face to face
France	100	Physician	Telephone
Mexico	100	Physician	Face to face
Poland	130	Physician; patient association	Telephone; face to face
Spain	100	Physician	Telephone
United Kingdom	100	Physician	Telephone
United States	107	Physician; patient list; patient association	Telephone; mail
Venezuela	100	Physician; support group; patient association	Face to face



**FIGURE 1** Attention given to metastatic breast cancer compared with early-stage breast cancer in different countries.

ease to express their thoughts and concerns.

At 55 years, the median age of respondents was relatively young, with the sample including a younger cohort from Egypt with a median age of 44 years, perhaps reflecting earlier onset or more aggressive disease reported in African countries.<sup>2,14</sup> Patients were about evenly divided between those with an initial diagnosis of MBC (48%) and those with an initial diagnosis of EBC who later developed recurrence (52%).

#### *Attention paid to MBC versus EBC*

A particularly sensitive issue for many women with MBC is the disproportionate amount of attention paid to the needs of women with EBC. “Early-stage disease still gets the bulk of the focus,” said Mara. “Most organizations focus on getting through treatment and attaining ‘survivor’ status.”

When questioned on the degree of attention MBC receives in their countries, most women (52%) in the BRIDGE Survey felt that MBC is given too little consideration. In 11 of the 13 countries, the majority of patients believed that MBC did not

receive enough attention. Mexico and Brazil were the exceptions. Patients were then asked to compare the attention that MBC receives with the attention that EBC receives. Approximately half (48%) felt that EBC is given more attention than MBC; however, 14% actually felt that MBC received more attention. This trend was also observed when we analyzed the data by country (Figure 1). In three countries—Egypt, Mexico, and Venezuela—women said MBC receives more attention than EBC. In these countries, diagnosis with locally advanced and stage IV breast cancer is more common, and it is possible that cultural norms and insufficient facilities for screening and early detection may account for a relatively greater perceived emphasis on MBC as compared with EBC.

Resources for women with breast cancer have become more widely available in the past 10 years, but how are these support services perceived with respect to the attention they give MBC? Only 24% of women felt that advocacy, voluntary, and/or charitable organizations paid “a lot of attention” to MBC. In comparison, 44% and 15% of surveyed patients felt that

healthcare professionals and the media, respectively, paid “a lot of attention” to MBC.

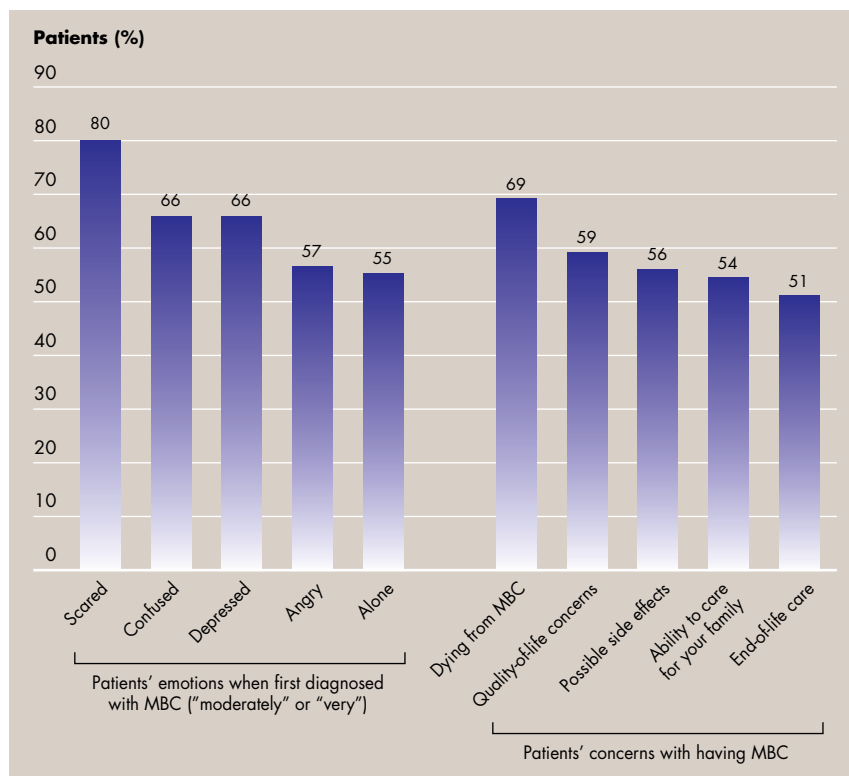
#### *Psychosocial issues and support*

Despite some commonalities in the treatments of EBC and MBC, some experiences and emotions are unique to women with advanced disease. “Today in the infusion room, another patient asked when I will be finished with treatment,” said Beth. “I felt uncomfortable saying that I would never be finished.”

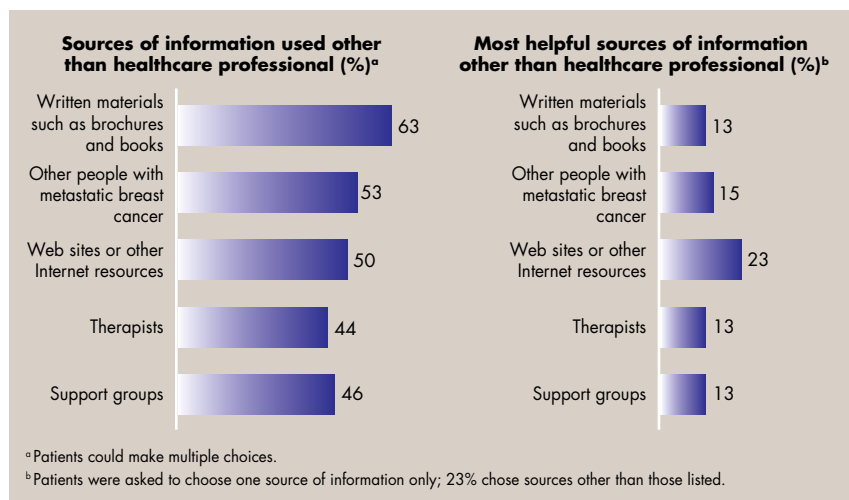
Negative emotional reactions are common when women are first faced with the knowledge that their cancer has metastasized. Responses to survey questions revealed that patients experienced an array of negative emotions when first told their diagnosis, with the majority, 55%–80%, reporting feeling scared, confused, depressed, angry, and alone at that time (Figure 2).

Understandably, the majority, 51%–69%, reported serious concerns related to MBC as well, including fear of dying and worry about end-of-life care, fear that their quality of life would deteriorate, and fear of possible treatment adverse effects (Figure 2). They also expressed concern about losing their ability to care for their families. In fact, 59% of women surveyed said that most aspects of their lives had changed in a negative way.

Despite the negative emotions and serious concerns they cope with on a daily basis, many women with MBC appear to possess an extraordinary ability to adapt to difficult circumstances. Three-quarters (74%) of the women in the BRIDGE Survey said they were still able to enjoy life despite having MBC, and two-thirds (67%) reported feeling generally optimistic. Although survivorship as a concept is rarely associated with women with MBC—many of whom object to being called survivors—it is striking that 61% of the women in our survey did consider themselves to be cancer survivors.



**FIGURE 2** Patients' emotions and concerns when given a diagnosis of metastatic breast cancer (MBC).



**FIGURE 3** Sources of information used by patients with metastatic breast cancer.

This level of coping would hardly be possible without considerable social and emotional support. Encouragingly, 98% of survey respondents felt they receive sufficient support from at least one person in their "inner circle" of family and friends. Equally encouraging, most women

said they received enough emotional support from their oncologists and nurses (83% and 81%, respectively).

Despite a high level of perceived support from the people closest to them, 48% reported that friends and family were uneasy talking about MBC, and 38% reported anxiety

about being open with their friends and family. Women in Egypt, Mexico, and Spain were most afraid of such openness, whereas women in Argentina, Australia, Belgium, Brazil, and the United States were least afraid. National differences around disclosure of diagnosis and experiences related to MBC may suggest that at least some of this fear may be culturally linked.

Women's experiences with others offer insight: "Most other people seem so petrified of early-stage cancer," said Mara. "I don't want to deal with whatever anxieties they have that seem to overflow when they learn about my metastatic disease."

*Available resources*

Information plays an important role in helping women cope with MBC. Overall, three-quarters (76%) of the women in the BRIDGE Survey reported taking an active role in searching for information on MBC, and a similar percentage (81%) said they were actively involved in making decisions about their treatment.

"Having metastatic cancer brings with it an intense feeling of having no control over my own life," said Pam. "While I cannot control the cancer cells themselves, I can control how actively I participate in treatment, learn about ongoing research, trials, and drugs that are under development."

In addition to consulting their healthcare professionals, women used a variety of other sources to search for information on their disease (Figure 3). Although the majority of patients (63%) used written materials, only 13% felt that written materials were the most helpful. Overall, the most helpful source of information was the Internet.

Medical information was in greatest demand, but women also asked for nonmedical information such as advice on how to talk to other people about MBC (67%) and how to

**TABLE 2**

Activities and materials that women with metastatic breast cancer (MBC) would value

Activities/materials that women with MBC would like to have available	Percent <sup>a</sup>
Written materials	68
Support groups for people with MBC	65
Educational public service announcements	64
Assignment of a patient navigator	61
Conferences held for people with MBC	61
Inclusion of people with MBC in the media	60
Research efforts to determine how long people with MBC are currently living	58
Recognition of public figures with MBC	55
Web sites	52
Free telephone workshops or teleconferences	48
Stories/events that women with MBC like to hear or read about	Percent <sup>a</sup>
Updates on new research or treatments	85
Stories of survivors or people who are in complete remission from breast cancer	75
Breast Cancer Awareness Month	72
Personal stories of people living with MBC	69
Personal stories of people living with early-stage breast cancer	66
Data on how long people with MBC are living	52

<sup>a</sup>Percentage of women endorsing the specific activities/materials/stories/events

pay for medical care and treatments (70%), and psychosocial and emotional support from advocacy, voluntary, or charitable organizations (74%). Women were also asked if they would like to see more of certain activities and materials. A summary of their responses is provided in Table 2.

Interestingly, information-seeking behavior appeared to correlate with participation in clinical trials. Overall, 34% of women who had searched for information on clinical trials had gone on to participate in one. In contrast, only 12% of women who did not search for information participated in clinical trials.

Despite their participation in this survey, it is worth noting that even in developed countries, only a minority of these “engaged” women participated in trials. Trial participation seemed to be largely influenced by access. Participation in countries with few ongoing clinical trials such as Egypt (13% of women had participated in a trial) was low compared with that in coun-

tries such as Belgium (27%), Canada (35%), and Mexico (35%). Unfortunately, although the number of clinical trials available for patients with MBC has increased in recent years, there has not yet been a comparable increase in the number of patients being enrolled.<sup>15</sup>

### Limitations and recommendations

The results of the BRIDGE Survey should be interpreted with caution, particularly with regard to comparisons between countries. As might be predicted in a global survey, cultural differences most certainly have influenced the findings. It is difficult to qualify and quantify these cultural differences in a preliminary survey such as this one. These differences may be related to the way physicians communicate with their patients or to women’s primary point of contact (physicians versus nurses). Furthermore, cultural mores may influence patients’ experience of social stigma or personal shame associated with a

disease that may be seen as “sexualized.” In addition, some of the developing countries may not have any established breast cancer support networks, which in turn may influence the responses of women in these countries.

On the basis of the survey’s findings, the BRIDGE Survey Steering Committee recommends the following:

- Increase the quality and quantity of MBC-related activities covered by the media and patient-interest groups in order to shift dialogue in the public domain toward MBC.

- Ensure that all existing and newly available medical and support materials on MBC are culturally relevant, up to date, and easily accessible. Consider prioritizing the Internet as a source of this literature.

- Provide patients having MBC with a broad range of information from medical to nonmedical, and ensure that information is translated into local languages.

- Encourage healthcare professionals to have more comprehensive conversations with women with MBC, ensuring that quality-of-life issues are emphasized in discussions.

- Help women with MBC to develop tools for communicating and sharing their experiences more effectively with family, friends, and their community.

- Develop more initiatives to educate the broader community (eg, community leaders and workplaces). Engage relevant advocacy organizations and healthcare professionals in activities that focus attention on women living with MBC.

### Conclusions

A diagnosis of MBC is devastating, yet many women in our survey showed an extraordinary ability to cope. “It made my life spiral out of control and left me broken and hopeless,” said Darlene. “This learning process and renewed sense of empowerment gives me the greatest gift

a cancer patient could ever receive—HOPE!”

A clear message from the BRIDGE Survey is that most women with MBC find both information and support important. Those who seek out information are more likely to be actively involved in their treatment decisions and to participate in clinical trials. A 2006 online survey of 618 women with MBC, most from the United States, undertaken by the organization Living Beyond Breast Cancer, reached a similar conclusion.<sup>16</sup> As more and more women live longer with metastatic disease, offering informational resources for this population takes on increasing importance. Our study also suggests that informed patients tend to be more collaborative with their physicians. The voluntary participation of these women in clinical trials facilitates the translation of novel therapeutics from the laboratory to the clinic. With the development of new treatments comes the possibility of transforming MBC into a true chronic disease, one that most affected patients will be able to live with for extended periods of time, as some do today. For an informed patient at this critical point in breast

cancer science, there is much to learn about novel therapies and approaches to treating and understanding the disease. Clearly, a majority of women with MBC do want to learn. In fact, women in our survey requested updates on new medical research and treatments more often than on any other topic.

Support services are equally critical. With an incurable disease that requires ongoing treatment, quality-of-life issues assume priority. The adverse effects of therapy as well as the symptoms of disease take a physical and emotional toll on women and their families. A focus on treating the whole patient, not just the cancer, becomes critical, as do the services of an integrated and multidisciplinary healthcare team.

The overarching concern reflected globally in the BRIDGE Survey has to do with the invisibility of this large patient population, especially striking in the countries with well-developed breast cancer communities. Until now, shame, silence, and isolation have been hallmarks of MBC. However, we know from what has happened with other life-threatening illnesses (such as AIDS/HIV) that this can change.

Before this change can occur, the medical community, ideally working with support and advocacy organizations, must make a commitment to offer new sources of information and support to women with MBC. The prevalence of the disease and the needs of patients must be measured and quantified in further research. Before change can occur, women with MBC must be encouraged to emerge from obscurity to tell their own stories, not only the sad tales of dying from the disease or of orphaned children and bereft husbands, but also the stories of quiet heroism, of women who are living with the disease day to day, who despite constant treatment are working, raising their families, and living their lives. It is time for

metastatic breast cancer to step out from the pink ribbon's shadow.

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## References

- O'Shaughnessy J. Extending survival with chemotherapy in metastatic breast cancer. *Oncologist* 2005;10:20–29.
- Anyanwu SN. Temporal trends in breast cancer presentation in the third world. *J Exp Clin Cancer Res* 2008;27:17.
- Parkin DM, Bray F, Ferlay J, Pisani P. Global Cancer Statistics, 2002. *CA Cancer J Clin* 2005;55:74–108.
- World Health Organization. Stewart BW, Kleihues P, eds. *World Cancer Report*. Lyon, France: IARC Press; 2003.
- Chia SK, Speers CH, D'yachkova Y, et al. The impact of new chemotherapeutic and hormone agents on survival in a population-based cohort of women with metastatic breast cancer. *Cancer* 2007;110:973–979.
- Surveillance Epidemiology and End Results (SEER) Stat Database, NCI. <http://www.seer.cancer.gov>. Accessed January 15, 2010.
- Ernst MF, van de Poll-Franse LV, Roukema JA, et al. Trends in the prognosis of patients with primary metastatic breast cancer diagnosed between 1975 and 2002. *Breast* 2007;16:344–351.
- Gennari A, Conte P, Rosso R, et al. Survival of metastatic breast carcinoma patients over a 20-year period: a retrospective analysis based on individual patient data from six consecutive studies. *Cancer* 2005;104:1742–1750.
- Giordano SH, Buzdar AU, Smith TL, et al. Is breast cancer survival improving? *Cancer* 2004;100:44–52.
- The BRIDGE (Bridging Gaps, Expanding Outreach) Survey Web site. <http://www.bridgembc.com>. Accessed January 15, 2010.
- Mayer M, Hunis A, Oratz R, et al. Evaluating the needs of women living with metastatic breast cancer: a global survey. Paper presented at: 11th Bi-Annual Conference on Primary Therapy of Early Breast Cancer; March 11–14, 2009; St Gallen, Switzerland. Abstract 235.
- Fallowfield L, Hunis A, Oratz R, et al. Identifying barriers preventing clinical trial enrollment: results of a global survey of patients with metastatic breast cancer. In: *Proceedings*

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of the 100th Annual Meeting of the American Association for Cancer Research; April 18–22, 2009; Denver, CO. Abstract 4836.

13. Mayer M, Hunis A, Oratz R, et al. Importance of providing tailored resources to patients with metastatic breast cancer: results of the Global BRIDGE Survey. Presented at the 32nd San Antonio Breast Cancer Symposium; December 9–13, 2009; San Antonio,

TX. Abstract 3085.

14. Huo D, Ikpat F, Khrantsov A, et al. Population differences in breast cancer: survey in indigenous African women reveals overrepresentation of triple-negative breast cancer. *J Clin Oncol* 2009;27:4515–4521.

15. Simon M, Du W, Flaherty L, et al. Factors associated with breast cancer clinical trials participation and enrollment at a

large academic medical center. *J Clin Oncol* 2004;22:2046–2052.

16. Mayer M, Grober S. Silent voices: women with metastatic breast cancer share their needs and preferences for information, support and practical services. *Living Beyond Breast Cancer*, 2006. <http://www.lbbc.org/data/news/LBBCsilentvoices.pdf>. Accessed January 15, 2010.