Abstract 3085

Importance of Providing Tailored Resources to Patients with Metastatic Breast Cancer: Results of the Global BRIDGE* Survey

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*BRIDGE Survey (Bridging Gaps, Expanding Outreach – Metastatic Breast Cancer Patient Survey)

Introduction

- Worldwide, breast cancer is the leading cause of cancer death among women, with 410–560K annual deaths, representing 31–43% of 1.3 million diagnosed cases of breast cancer each year.[1–3]
- In developed countries, approximately 30% of patients who present with early breast cancer (EBC) will go on to develop metastatic breast cancer (MBC),[4] while in developing countries where breast cancer is often first diagnosed at later stages, MBC rates are much higher.[5]
- Advances in the treatment and management of MBC suggest that more women with MBC are living with the disease. While the 5-year survival rate for women with newly diagnosed MBC in developed regions is approximately 27%, some patients will live longer.[6]
- Undergoing continuous treatment, women with MBC often endure symptoms of disease and side effects of treatment for many months or years. In addition to these medical concerns, there are also emotional and psychosocial challenges to be faced on a daily basis. Therefore, the global burden of MBC should be measured not only by the number of women *dying* of breast cancer but also by the experiences of women *living* with breast cancer.
- To determine patients' own perceptions of the unmet needs associated with living with MBC, an international survey (the BRIDGE survey[7]) was developed by the authors of this poster and was sponsored by Pfizer Inc. Women from Australia, Latin America, the USA, Canada, Europe, and North Africa were invited to participate.
- A parallel initiative, also sponsored by Pfizer Inc., was a consensus report of the first meeting of the MBC Advocacy Working Group, a group of patient advocates who discussed obstacles faced by women with MBC and potential solutions to enable their unmet needs to be addressed.[8–11]
- Here, we present updated results from the BRIDGE survey[12,13] that demonstrate how the recommendations made in the consensus report (shown in the pink boxes in this poster) are supported by the responses of patients who took part in the survey.

Objective

- To evaluate unmet needs of women living with MBC in Australia, Latin America, USA, Canada, Europe, and North Africa.

Methods

- The BRIDGE survey content was developed by the authors of this poster (three thought leaders and four patient advocates) with the support of Pfizer Inc. and was conducted by Harris Interactive™ from September 16th 2008 to November 4th 2009.
- To provide a balance between low- and high-resource countries, approximately 100 women from each of 13 countries (Argentina, Australia, Belgium, Brazil, Canada, Egypt, France, Poland, Mexico, Spain, UK, USA, and Venezuela) aged ≥18 years with stage IV/MBC were recruited and interviewed.
- The survey comprised 34 questions split into five sections: resources/information/knowledge; support; attention from society; impact on self/lifestyle; and clinical trials.
  - The survey was designed to take ~25 minutes to complete.
- Topics included MBC resources, support networks, attention given to MBC relative to EBC, and the personal impact of the disease. Patients were also asked if they had ever participated in, or searched for information about, clinical trials. Survey methods included telephone, mail, and face-to-face interviews, dependent on country and patient preference. Interviewers were female and spoke the language of the country. Survey participants with MBC were referred by at least 20 physicians in each of the 13 countries.

Results

Demographic Information

- 1,342 women completed the survey. Overall, the median age was 55 years, with patients from Egypt younger at 44 years.
- The countries involved, patients' ages, and the methods employed in the survey are summarized in Table 1.

Attention Paid to MBC versus EBC

Consensus Report Recommendation:

'Heighten attention to the MBC community – create a unified voice and platform that speaks to their unique needs'

BRIDGE Survey Results that Support the Recommendation

- Overall, most women (52%) felt that MBC is given too little consideration. When asked to compare the level of attention that MBC receives with that of EBC, 48% felt that EBC received more attention than MBC and 14% felt that MBC was given more attention. This trend was observed when the data were analyzed by country (Figure 1), the exceptions being Egypt, Mexico, and Venezuela where more patients felt that MBC was given more attention than EBC.

Table 1. Patients' age and survey methodology by country.

Country	Respondents (n)	Median age (years)	Method of recruitment	Survey method
Argentina	100	57	Physician	Face-to-face
Australia	100	56	Physician; support group; newspaper ads	Telephone; face-to-face
Belgium	108	53	Physician; patient association	Telephone; mail
Brazil	100	50	Physician; support group/ patient association	Face-to-face
Canada	92	58	Physician; support group/ patient association; online focus group database; newspaper ads; patient list; recruitment at breast cancer race	Telephone; face-to-face
Egypt	105	44	Physician within a hospital	Face-to-face
France	100	58	Physician	Telephone
Mexico	100	52	Physician	Face-to-face
Poland	130	57	Physician; patient association	Face-to-face; telephone
Spain	100	58	Physician	Telephone
UK	100	57	Physician	Telephone
USA	107	58	Physician; patient list; patient association	Telephone; mail
Venezuela	100	53	Physician; support group/ patient association	Face-to-face

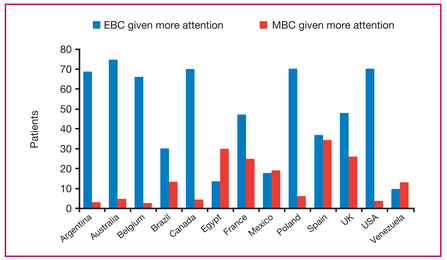

Figure 1. Attention given to MBC compared with EBC.

Q. Do you feel that the same amount of attention is given to metastatic breast cancer and early breast cancer, or do you feel that more attention is given to metastatic breast cancer or more attention is given to early breast cancer?

Impact of MBC on Patients' Lives and Psychosocial Support

- Following a diagnosis of MBC, most surveyed women understandably experienced a complex array of emotions and had predictable concerns regarding living with the disease (Figure 2). While most women (59%) recognized the negative impact that MBC had on their lives, a majority (74%) also said they were able to enjoy their lives and some (61%) considered themselves to be cancer survivors.
- The proportion of women whose first diagnosis was MBC (48%) was similar to the proportion whose first diagnosis was EBC (52%). In general, women whose first diagnosis was EBC had a more positive outlook on life (data not shown).
- While almost all women (98%) felt they received enough support from at least one person in their inner circle (family, friends/neighbors, healthcare professionals [HCPs]), 38% were still fearful of talking about MBC openly and 48% said their friends and family were uneasy talking about MBC. Notably, 3% said they did not have any friends/family to turn to for support.

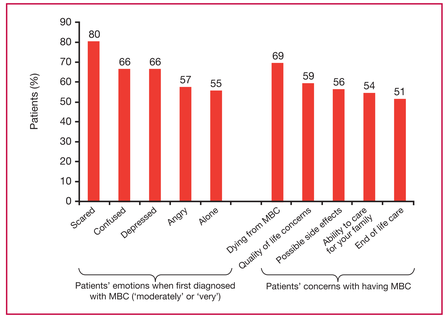

Figure 2. Patients' emotions and concerns when diagnosed with MBC.

Q. When you were first diagnosed with metastatic breast cancer, to what extent did you experience each of the following emotions?

MBC Resources

Consensus Report Recommendation:

'Improve access to tailored information, resources and support for women with MBC'

BRIDGE Survey Results that Support the Recommendation

- Overall, most women (76%) took an active role in searching for information on MBC, and 81% said they were actively involved in making decisions about their treatments.
  - In addition to consulting their HCP, women used a variety of information sources to search for information on their disease (Figure 3). Of the listed sources, most patients (63%) used written materials, but only 12% felt that written material was the most helpful. Overall, the most helpful source of information was the internet (21%).
  - In terms of the quantity, quality, and access to information on MBC, 42% of patients found it either 'somewhat difficult' or 'very difficult' to find information on MBC, while 53% found it either 'somewhat easy' or 'very easy'. In total, 50% thought that the available information on MBC did not address their needs.

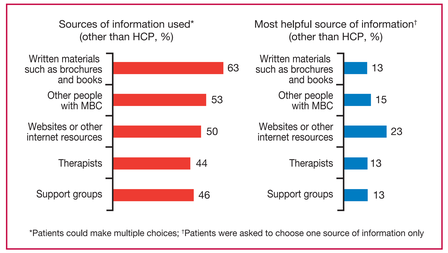

Figure 3. Information utilization by patients with MBC.

Q. Apart from the healthcare professionals who treat your cancer, which of the following sources of information, if any, do you regularly use to learn more about metastatic breast cancer?

Q. Of the sources of information you regularly use, which is the most helpful overall?

- When questioned on the information that they 'liked' or 'disliked' hearing or reading about, 85% of patients liked updates on new research or new treatments, and 75% liked to hear survivor stories, while 26% disliked information on how long women with MBC are living and 22% disliked reading stories of women with EBC.
- While medical information was in greatest demand, patients also asked for non-medical information such as advice on how to talk to other people about MBC (67%), how to pay for medical care and treatments (70%), and information about support from advocacy, voluntary or charitable organizations (74%).

Clinical Trial Participation

Consensus Report Recommendation:

'Increase understanding of and access to clinical trials'

BRIDGE Survey Results that Support the Recommendation

- In total, 345 respondents (26%) had searched for information on clinical trials. Women in the USA, Australia, and Canada were most likely to have searched for trials information (Figure 4a). In total, 239 respondents (18%) had participated in clinical trials. There was some variation in participation across the surveyed countries (Figure 4b).
- Although few women had ever been asked if they wanted to participate in a clinical trial (23%), approximately two-thirds (67%) of those who were invited went on to participate.
- Among those who had not participated in a clinical trial, patients from Argentina, the USA, and Egypt were more likely to cite lack of awareness of clinical trials as a barrier to participation than patients from other countries. Similarly, patients from Argentina, the USA, Canada and Poland were less likely to have been recommended for a clinical trial by their HCP.
- Among women who had participated in a clinical trial, more than half (56%) reported that knowledge of the benefits and risks of participation was helpful during the course of the trial (Table 2). Importantly, most women who had participated in a clinical trial (74%) stated that their HCP was a helpful source of support whilst they were participating in the clinical trial. Overall, 'information-seeking' women with MBC were most likely to participate in a clinical trial.

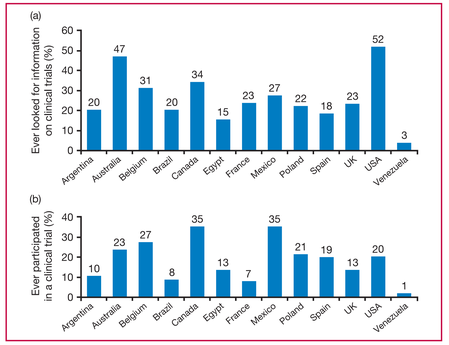

Figure 4(a) and (b). Patients who search for information on, or participate in, clinical trials.

Q. Have you ever looked for information about a clinical trial or research study on your own? (All respondents, n=1,342)

Q. Which of the following best describes your experience with clinical trials or research? (You have never participated in a clinical trial; you are currently participating in/have participated in a clinical trial; all respondents, n=1,342)

Limitations of the Survey Data

- It is possible that there may be selection bias due to inter- and intra-country differences in patient recruitment (e.g. recruitment from clinics versus hospitals).
- Whether or not a patient had previously received a diagnosis of EBC before developing MBC may have influenced patients' responses to specific questions.
- Relatively small numbers (base sizes <100) and multiple variables do not lend themselves to robust comparisons between countries.
  - Some countries may not have established breast cancer support networks.
  - Cultural differences may present themselves in women's attitudes to being diagnosed with MBC and whether or not they are willing to divulge information about their disease. In some countries, having MBC may carry a stigma.
  - Clinical trials may be more widely available to patients in certain countries.
  - Differences in reimbursement for the costs of clinical trials may drive enrollment in certain countries.

Table 2. Services or resources that patients valued when taking part in a clinical trial.

Q. What services or resources, if any, did you find useful in helping you through the clinical trial or research study throughout the enrollment or trial process? (Respondents who have ever participated in a clinical trial or research study, n=239)

Services or resources that patients valued when taking part in a clinical trial: top six responses	Patients (%)
Support from treating HCP	74
A guide to help participants understand the risks and benefits of taking part in a clinical trial	56
Follow-up calls from a staff member involved in the clinical trial or research study	57
Information that explained the frequency and severity of potential side effects	58
Information material written for people who are not medical experts	48
Assistance with enrollment forms or informed consent forms	46

Conclusions

- The results of the BRIDGE survey suggest that women with MBC have needs that differ from those of women with EBC and that these needs are not always being met.
- It is clear that most women with MBC actively search for information and resources to help them live with their disease. The country-specific differences reported here suggest that materials provided must be culturally relevant.
- Recommendations made by the MBC Advocacy Working Group and published as a consensus report (shown in the pink boxes in this poster) correlate with the results of the BRIDGE survey. This suggests that these advocacy groups are accurate in their assessment of patient concerns.
- It is encouraging that other MBC initiatives are also being developed:
  - An on-line survey of patients with MBC was conducted in 2006 by Living Beyond Breast Cancer (lbbc.org).[14]
  - In 2005, the European School of Oncology assembled a task force (ESO–MBC Task Force) and developed international guidelines for the management of MBC.[15]
  - Some countries, including Canada and the USA, have now designated October 13 as Metastatic Breast Cancer Awareness Day.
- Women who participated in the BRIDGE survey have informed us that the impact of MBC is under-reported and they are calling for the provision of new information and resources. It is hoped that the momentum provided by this and other MBC initiatives will encourage collaboration between healthcare and support organizations, and ultimately meet the needs of this under-served patient population.
- For more information, please visit www.BRIDGEMBC.com.

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