Breast Cancer Center Survey: Cancer center management, support, and perception of mBC patient needs across 582 healthcare professionals

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INTRODUCTION

Although we have seen some advances for patients with mBC over the past decade, globally there is still much we don’t know. Recognition of this gap in knowledge spurred Pfizer’s efforts to better understand the needs of patients with mBC and provide new information that would help mBC communities worldwide. Pfizer Inc., working collaboratively with the European School of Oncology (ESO) and within the scope of the Advanced Breast Cancer Third International Conference (ABC3), commissioned the Global Status of Advanced/Metastatic Breast Cancer 2005-2015 Decade Report (Global Status of mBC Decade Report, Pfizer, 2016) with the support, guidance, and direction of the Global Status of mBC 2015 Decade Report Steering Committee. Research to inform the report was undertaken to obtain a detailed, holistic assessment of current provision of care and first-hand experiences of people with mBC. Both primary and secondary research outputs were combined, using a “wide net” approach to capture a panoptic overview of the mBC healthcare environment. The full report can be found at http://www.breastcancervision.com/.

The aim of this paper is to provide detailed results and key insights for the Breast Cancer Center Survey. This survey was completed by 582 physicians, nurses, and administrators across breast cancer centers in 8 countries. In this research, specialists involved in providing or managing care services for patients with breast cancer were surveyed to understand how breast cancer centers in different countries around the world manage and
INTRODUCTION (cont)

support patients with mBC (compared with breast cancer any stage or specifically patients with eBC, defined as breast cancer that is not stage 4).

KEY FINDINGS:

• Breast cancer centers across the world feel that they are addressing the care needs of patients with mBC
• Proactive communication between healthcare professionals and patients with mBC and their caregivers was highlighted as a gap in care
  – Action needs to be taken to ensure that communication skills are embedded into the core curriculum for oncology training, such as how patients can be further involved in therapy decisions and how physicians can bring bad news to patients and families

TABLE 1. Primary Surveys Research Design

<table>
<thead>
<tr>
<th>Survey</th>
<th>Breast Cancer Center Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample size</td>
<td>582</td>
</tr>
<tr>
<td>Respondents</td>
<td>Physicians, nurses, and cancer center directors from oncology programs</td>
</tr>
<tr>
<td>Countries sampled</td>
<td>United States, Australia, Germany, United Kingdom, Italy, Portugal, Brazil, Mexico, and Sweden</td>
</tr>
<tr>
<td>Objective</td>
<td>Understand the role of breast cancer centers in the management and support of mBC patients, describe healthcare providers’ (HCPs) perceptions of mBC patients’ needs, fears, misconceptions, and desire/opportunity to participate in treatment decisions, and identify channels of communication and resources used to educate and inform mBC patients and HCPs</td>
</tr>
<tr>
<td>Survey approach</td>
<td>A standardized, 30-minute questionnaire</td>
</tr>
<tr>
<td>Data collection</td>
<td>Self-administered via the internet</td>
</tr>
<tr>
<td>Interpretation</td>
<td>Because the total sample size in Sweden was small, results were analyzed separately and included in open-ended reporting only. Therefore, the total sample in the quantitative analysis was 568 respondents. Results were based on respondent perceptions and recall. All findings from this research were unweighted, and any significant differences across countries and respondents were reported at a 95% CI (P&lt;0.05).</td>
</tr>
</tbody>
</table>
Global Breast Cancer Center Survey

In total, 582 physicians, nurses, and cancer center leaders across 8 countries were surveyed online. The majority of respondents per country were physicians (51%–71%), with the exception of Portugal where the proportion of physicians was lower (44%). Across all countries, the proportion of hospital leaders was lowest (0%–8%) (Table 2). The results of the survey highlighted a number of key themes relating to the support of mBC patients by breast cancer centers.

**TABLE 2. Breast Cancer Center Survey Respondent Characteristics**

<table>
<thead>
<tr>
<th>Country</th>
<th>EU</th>
<th>LA</th>
<th>Australia</th>
<th>Germany</th>
<th>UK</th>
<th>Italy</th>
<th>Portugal</th>
<th>Brazil</th>
<th>Mexico</th>
<th>Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician (n=327)</td>
<td>103</td>
<td>159</td>
<td>47</td>
<td>18</td>
<td>29</td>
<td>41</td>
<td>67</td>
<td>22</td>
<td>23</td>
<td>24</td>
</tr>
<tr>
<td>Nurse (n=203)</td>
<td>50</td>
<td>98</td>
<td>41</td>
<td>14</td>
<td>25</td>
<td>24</td>
<td>24</td>
<td>25</td>
<td>21</td>
<td>20</td>
</tr>
<tr>
<td>Leader (n=38)</td>
<td>19</td>
<td>16</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>6</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Total (n=568)</td>
<td>172</td>
<td>273</td>
<td>91</td>
<td>32</td>
<td>57</td>
<td>71</td>
<td>95</td>
<td>50</td>
<td>45</td>
<td>46</td>
</tr>
</tbody>
</table>

*Total Sample (n=568) throughout. Because of the small sample in Sweden (n=14), results were analyzed separately and included in open-end reporting only. †Leader identified as an oncology department chief, head, director, or chair, a cancer center administrator or director, an oncology program administrator, a cancer service line manager or leader, or a CEO or CFO.

Breast cancer center specialists clearly identify the perceived needs of patients with mBC

Overall, respondents most frequently identified improvements in emotional support and quality of life as the most important needs of patients with mBC, beyond basic medical care (Table 3). Regional variations were observed for financial support, with respondents in the US, the UK, and Australia more frequently listing this element as an important need for patients with mBC compared with respondents from Latin America, Italy, Germany, Portugal, and Sweden.
### TABLE 3. Perceived mBC Patient Needs According to Breast Cancer Center Healthcare Professionals

<table>
<thead>
<tr>
<th>Support</th>
<th>Regions</th>
<th>EU</th>
<th>LA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional/Psychosocial Support</td>
<td>79%</td>
<td>84%&lt;sup&gt;a&lt;/sup&gt;</td>
<td>72%</td>
</tr>
<tr>
<td>Family Support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Availability of caregivers / physician</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Life</td>
<td>72%</td>
<td>71%</td>
<td>77%&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Pain Control/Management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Life</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutrition/Diet/Weight</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom Control/Management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Management of Disease</td>
<td>32%</td>
<td>27%</td>
<td>38%&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
<tr>
<td>Survival/Overall Survival/PFS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Effective/more effective treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alternative/new treatment options</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial Support/Cost/Insurance</td>
<td>31%</td>
<td>51%&lt;sup&gt;b&lt;/sup&gt;</td>
<td>19%</td>
</tr>
</tbody>
</table>

*Significant differences across countries are reported at the 95% CI (P<0.05). Significant differences are represented as a superscript letter next to a number (eg, 75%A). In this example, (75%A) means that the 75% achieved for that country is significantly higher than the percentage for the countries presented as (A). Abbreviations: Aus=Australia; Bra=Brazil; EU=Europe; Ger=Germany; Ita=Italy; LA=Latin America; Por=Portugal; Swe=Sweden; UK=United Kingdom; US=United States.*

**Variance exists in breast cancer centers current ability to support the specific needs of patients with mBC from both an infrastructure and staffing perspective**

Across regions, the surveyed centers had similarly constituted breast cancer teams (Figure 1). All centers interviewed, for example, had a medical oncologist on staff, and most had cancer-specific or breast-cancer–specific nurses on staff as well. One difference that stands out is which specialists compose counseling personnel, who provide patients with emotional and psychosocial support. Centers in Latin America, Europe, and Australia were more likely to have a mental health counselor, psychologist, and psychiatrist involved than those in the US (78%, 86%, 81%, and 45%, respectively). Centers in the US (79%), Latin America (69%), and Australia (81%), were more likely to have a social worker/social assistant involved in breast cancer care versus those in the EU (45%). Another difference is that centers in the US and the UK were significantly (P<0.05) more likely to have financial counselors for patients with breast cancer than those in other countries of the EU, Latin America, and Australia (52%/42%, 16%, 12%, and 3%, respectively).

However, the survey revealed lower levels of multispecialty support services specifically for patients with mBC. In all regions, centers were more likely to offer their services for patients with breast cancer versus specific services for patients with mBC (Figure 1). Seventy-three percent of the centers offered emotional/psychosocial support to both eBC and mBC patients specifically, a top need identified for patients with mBC; 66% offered supportive care to both groups; 61% offered nutritional advice; and 63% offered practical and educational advice. In Europe, Latin America, and Australia, more than 66% of centers had a dedicated psychologist or mental health counselor for mBC patients. More than 59% of centers in the US, Latin America, and Australia had a social worker/assistant for mBC patients. Only 36% of centers had this for European patients. Approximately 59% percent of centers offered end-of-life care to mBC patients only. Medical oncologists were equally likely to be involved in breast cancer care of any stage as in mBC care overall (100% versus 97%), but there were also significant (P<0.05) differences between these disease areas for nurses, surgeons, oncologists, and radiologists. In the US, nurse practitioners and physician assistants were involved in mBC care in fewer centers (67% and 40%, respectively) than in general breast cancer care (80% and 53%, respectively). Almost all the centers (more than 79%) reported offering a cancer or breast cancer nurse for mBC patients specifically.
Effective communication and a positive relationship with their healthcare team are both important in influencing the experiences of patients living with mBC

Survey respondents believed that only approximately half (47%) of their mBC patients feel comfortable bringing up concerns/requests. Differences were observed according to specialty type. Generally, physicians more frequently reported believing that patients with breast cancer are comfortable raising concerns, whereas nurses believed a lower percentage of breast cancer patients are comfortable raising concerns (52% and 42%, respectively).

Although individual opinions ranged, overall, the perceived levels of comfort between patients with eBC or mBC are comparable regarding raising concerns or requesting information. While 28% of respondents felt patients with mBC are more comfortable than those with eBC in raising concerns and requests for information, the same percentage felt the opposite (that mBC patients were less comfortable). The remaining 44% believed that the levels of comfort were the same among patients with eBC and mBC. Perceived levels of comfort were noticeably lower for Germany in eBC patients (30%) and Italy in mBC patients (35%).

Respondents, who were all healthcare practitioners (HCPs), perceived that the key constraints contributing to a lack of patient comfort in raising questions and concerns arose from fears about receiving bad news or anxiety (83%). Approximately one-third (34%) felt that any reluctance of patients in raising questions or concerns may be related to less positive previous experiences with their physician or healthcare staff or because they had not yet formed a relationship with their HCPs. Survey respondents emphasized their belief that having a positive relationship with mBC patients was the most important factor in enabling those patients to raise questions. In fact, 80% believed that HCP relationships and effective and open communication make mBC patients feel more...
comfortable raising concerns and questions about their disease, prognosis, symptoms, and treatment (Figure 2). A sound relationship is necessary to facilitate joint decision-making between HCPs and patients, ensuring such discussions are in line with the patient’s actual desire for participation. (Filleron, 2015; Grunfeld, 2006)

**FIGURE 2. Making mBC Patients Feel More Comfortable Raising Concerns and Questions About Their Disease, Prognosis, Symptoms and Treatment**

<table>
<thead>
<tr>
<th>HCP Relationship</th>
<th>Support</th>
<th>Information</th>
<th>Comfort</th>
</tr>
</thead>
<tbody>
<tr>
<td>80%</td>
<td>46%</td>
<td>40%</td>
<td>19%</td>
</tr>
</tbody>
</table>

- Good/open communication
- Close/strong relationship with HCP
- Asking patient for feedback/updates
- Trust in physician/staff/nurses
- Emotional/psychological support
- Family support/family present
- Education/understanding of diagnosis
- Eg. pain and/or symptom control/management, friendly environment, etc.

According to respondents, the most common misconceptions that mBC patients hold about their condition are that pain is inevitable and uncontrollable, that no effective treatments are available, and that a cure for mBC remains possible. Regional variations in frequency of agreement appeared. In Latin America, 31% of HCPs said their patients believe that a cure is possible (vs 13%–17% in other countries surveyed). In Australia, 38% of respondents said their patients believe treatment is not effective (vs 15%–26% in other countries).

Respondents believed that patients should be informed that there may be multiple treatment options remaining, that support is available, that the disease is treatable even though incurable, that treatment can maintain quality of life, and that they will continue to receive the best care. Access to a number of mBC-specific, patient-directed resources was considered helpful by more than 62% of respondents (Figure 3). Access to such resources is very limited, however, with as few as 19% of respondents actually having some of these resources available (Figure 3).
This survey found that on average, three discussions with the oncologist are needed before patients with mBC have a clear understanding of the goals of their therapy. According to respondents, only about half (56%) of patients are likely to voice their own therapy goals, whether unprompted or in response to a direct question from a doctor.

In Australia, 66% of respondents believed patients should be made aware of their prognosis and the indefinite nature of the disease (Table 4). This compared with much lower rates in the US (38%) and lower rates in Europe (47%) and Latin America (59%). Results of the survey showed that physicians believe that they first raise end-of-life discussions only after multiple changes to treatment. Support and training for healthcare teams about bringing bad news to patients and families was identified as a key need by 83% of respondents, but only 43% reported received this level of training.
**TABLE 4. Topics to Convey to mBC Patients when Discussing Prognosis**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Total (n=568)</th>
<th>US (n=172)</th>
<th>EU (n=273)</th>
<th>LA (n=91)</th>
<th>Australia (n=32)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care/Treatment (NET)</td>
<td>77%</td>
<td>70%</td>
<td>77%</td>
<td>85%</td>
<td>84%</td>
</tr>
<tr>
<td>All Treatment Options Are Available</td>
<td>16%</td>
<td>13%</td>
<td>17%</td>
<td>20%</td>
<td>9%</td>
</tr>
<tr>
<td>Treatment Can Help/Disease Is Treatable</td>
<td>13%</td>
<td>11%</td>
<td>12%</td>
<td>21%</td>
<td>19%</td>
</tr>
<tr>
<td>Physicians/Staff Will Provide Best Care Possible</td>
<td>11%</td>
<td>9%</td>
<td>12%</td>
<td>6%</td>
<td>19%</td>
</tr>
<tr>
<td>Prognosis (NET)</td>
<td>48%</td>
<td>38%</td>
<td>47%</td>
<td>59%</td>
<td>66%</td>
</tr>
<tr>
<td>Disease Is Incurable</td>
<td>12%</td>
<td>13%</td>
<td>10%</td>
<td>13%</td>
<td>16%</td>
</tr>
<tr>
<td>Patient Can Maintain Quality of Life</td>
<td>9%</td>
<td>6%</td>
<td>9%</td>
<td>15%</td>
<td>6%</td>
</tr>
<tr>
<td>Support (NET) (eg, emotional/psychosocial support available, ensure family support, assurance that family will be supported, etc.)</td>
<td>25%</td>
<td>27%</td>
<td>25%</td>
<td>19%</td>
<td>38%</td>
</tr>
</tbody>
</table>

Eu=Europe, LA=Latin America, US=United States.

“Women living with metastatic breast cancer need access to a broad range of heath professionals who can provide emotional and practical support to help them to live well. But we know that breast cancer does not just happen to an individual woman, it has a ripple effect on partners, children and other family members. There needs to be a much greater emphasis within the clinical setting on the needs of families and caregivers, recognising the distress that they can also experience.”  

-Danielle Spence, Breast Cancer Network Australia, 2016
DISCUSSION

As patients with mBC progress through their treatment, support needs from HCPs continue to evolve in intensity and type. Beyond basic medical needs, respondents from the Breast Cancer Center Survey reported that they perceive that mBC patients want access to emotional support and better quality of life, including pain control/management and nutritional advice, treatments that improve survival outcomes, and/or financial support. It is also important that mBC patients become more fully aware of the resources available to them; other research suggests that this may not always occur. (Mayer, Lessons Learned, 2010) For example, despite the impact that an mBC diagnosis can have on psychosocial health, and despite the availability of psychology, psychiatry, counseling, and/or social work service, other research has shown that the majority of patients with mBC fail to seek mental health support. (Mosher, 2013) Developing additional interventions beyond breast cancer center grounds, such as telephone and internet-based counseling, has potential to assist patients who face obstacles in accessing mental health services. (Mosher, 2013)

Following improvements in breast cancer care over the past decades, patients with mBC now face an increasingly complex array of options to choose from, depending upon their individual treatment goals and preferences. Decisions are often time-sensitive and must balance the reality of uncertain outcomes with treatment toxicity and quality of life. To play an active role in the decision-making process, patients need ready access to specific and relevant information. The data collected, however, suggest that healthcare providers experience difficulties in providing appropriate mBC-focused materials to patients. Examples of materials considered useful included identification of currently available resources for mBC patients and guiding patients to these resources; goal-setting tools and potential questions for mBC patients and families/caregivers to ask their physician; referral to peer support and/or specific consumer organizations to support mBC patients; a patient/caregiver empowering guide outlining expectations for their own mBC experiences; a conversation guide that patients can share with physicians to discuss some of the benefits and risks associated with recommended treatments to determine the appropriate treatment options for them; a visual breast cancer backgrounder specifically for mBC patients that details the various stages of breast cancer and the unique characteristics of each; and an mBC dictionary including some terms commonly used in treatment discussions, defined in patient-friendly language.

Physicians, nurses, and cancer center directors all perceived that many patients are not comfortable asking questions or raising concerns when diagnosed or treated for mBC. Any limitation in effective communication between HCPs and mBC patients can foster misconceptions about the true meaning of the diagnosis, with the result of patients not fully understanding their treatment options, goals, and decisions. There is an acute need for greater emphasis on creating opportunities for patients to vocalize their own treatment goals with their healthcare providers and for clinicians to ask more probing questions. Discussions must be sensitive, tailored to the individual, transparent, and cognizant of the realities of an mBC diagnosis. Distressing misconceptions that pain is inevitable or that treatment is ineffective should be addressed head-on, with this understanding reinforced at subsequent visits. At present, such clinical messaging is not always present; prior research showed that oncologists tended to minimize the severity of metastatic disease. One result was that misleading or false prognostic information was given, which could ultimately reduce the total time available for patients to make appropriate plans. (Global Status of mBC Decade Report, Pfizer, 2016)

Approximately one-third of respondents (34%) agreed that some aspect of the interaction between patients and their healthcare team works to constrain the possibility of open communication. This finding was supported by research carried out in 2013, in which half of patients/caregivers surveyed reported feeling
that care could be enhanced if HCPs listened more to patients and ensured continuity of care with the same doctors, nurses, and specialists. (Harding, 2013) It has already been noted that access to physician training and information on how to conduct discussions and respond to questions about prognosis and end-of-life matters may be beneficial, (Danesh, 2014) but respondents in the Breast Cancer Center Survey reported often that this training is not available to them.

CONCLUSION

Patients need multidisciplinary, holistic and individualized approaches to their mBC care. Beyond the basic medical needs, cancer services care should be expanded to ensure that the emotional, quality-of-life, supportive care and financial needs of mBC patients are addressed. At present the majority of, but not all, breast cancer centers provide access to some of these services. It remains important, however, that those affected by mBC including patients and their caregivers are aware that they can ask for such support. Open and effective communication between patients with mBC and their health care teams is crucial. Currently, high communication standards are not universally achieved, an unfortunate phenomenon that has several apparent causes. Among them are a common reluctance to give/receive bad news and constraints in the relationship between patients and their health care teams that inhibit an open line of communication. Further training for physicians on how to improve their discussions about patient prognosis or end-of-life care is both recognized as necessary and desirable. A range of patient directed, mBC-focused educational materials would be helpful for transmitting information that supports physicians in ensuring patient understanding to aid them to voice their treatment goals and participate in joint decision-making.
Global Breast Cancer Center Survey

References


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