

# Silent Voices: Executive Summary

## **1. Background and Statement of Problem**

This year, 212,920 American women join the 2.3 million already living with a diagnosis of invasive breast cancer. While most are diagnosed with early stage breast cancer, significant numbers already have, or will later develop, advanced (metastatic) breast cancer (ABC), the form of the disease responsible for 40,970 deaths in 2006.

With a median survival of two to three and a half years, at least 150,000 women are thought to be currently living with metastatic breast cancer in the United States. Variability in the course of disease, as well as significant advances in treatment and supportive care, enable some women with ABC to live for extended periods of time, often with good quality of life. Yet their lives are inevitably colored by the realities of disease progression and ongoing treatments, and punctuated by periods of well-being and relapse, and by anxiety, sadness, and uncertainty. They live with a pervasive sense of limited time and what that may mean for themselves and their families.

The public face of breast cancer is turned toward early detection and mammography screening, and the hopeful prognosis of early disease. While extensive support and information networks are in place for women with primary breast cancer, established breast cancer organizations have been slow to identify and address the needs of women with metastatic disease. Clearly, women with ABC face different issues and challenges than newly diagnosed early breast cancer patients, and the same resources are not appropriate. Little research has been done to examine their specific needs.

While some resources for women with ABC do exist, they remain widely scattered, disorganized, and difficult for women to locate, and access. There is currently no comprehensive dedicated website that serves as an information clearinghouse for this population.

## 2. LBBC Advanced Breast Cancer (ABC) Needs Assessment Survey

To address this problem, Living Beyond Breast Cancer (LBBC) and its consultants developed a 64 question online survey to assess the needs of women with ABC. The survey focused in great detail on their use of and preferences for services in three domains: information, support, and practical resources. Respondents were asked about the type of support services they found helpful, their satisfaction with those providers and organizations where they received services, and their preference for future services, including mode of service delivery.

Following revisions based on pilot results and input from a professional advisory committee, the finalized survey was posted with a link from the Advanced Breast Cancer webpage at the Living Beyond Breast Cancer website, [www.lbbc.org](http://www.lbbc.org), from April 13, 2005, to May 13, 2005. The data obtained from the 618 online respondents were analyzed with SPSS, using descriptive statistics, Chi-square tests, and ANOVA to examine associations among service usage and preferences, and demographic and medical variables.

## 3. Demographic and Medical Data on Survey Respondents

Respondents reflect the demographics of Internet users, with 70% between the ages of 40 and 59. The majority were white (94%), well-educated (66% completed college or more), partnered (74% live with spouses/partners), mothers (76%), and privately insured (73%). Almost half were working full or part-time (47%) and 25% were receiving disability benefits.

Respondents typically had lived with ABC for less than five years (89%), with metastases to bones (71%); lymph nodes (63%); liver (44%); and lungs (39%). Seventy-nine percent were in treatment when surveyed, with an additional 10% between treatments. Reported treatments include: chemotherapy (85%), hormonal therapy (78%), surgery (75%), radiation (72%), and biologic therapies (41%). Twenty-two percent had participated in clinical trials. A majority had used complementary therapies.

Respondents suffered from a variety of symptoms and side effects related to the disease and its treatments. Most commonly reported were fatigue (92%), insomnia (84%), pain (79%), hot flashes (79%), cognitive problems (78%), hair loss (77%), sexual problems (73%), depression (66%), anxiety (59%), neuropathy (65%), loss of appetite (60%) and nausea (55%). Despite this, most found daily routines fairly to very easy, suggesting good supportive care from healthcare professionals, and effective personal coping or adaptive abilities.

## 4. The Role of Information in the Lives of Women Living with Advanced Breast Cancer

Studies have found that about half of breast cancer patients seek information online. Our survey participants reinforced these findings. Data from this survey indicate that women with ABC:

- Highly value information about their diagnosis and are quite knowledgeable about it.
- Seek information frequently: almost three-fourths access information about advanced breast cancer on a daily or weekly basis.
- Find support in the use of information, and information in support programs.
- Find that different members of the healthcare team provide information in different ways.
- Consider programs focused on current and new treatments, and on their side effects and cancer symptoms very important, and many attend these programs. Over two-thirds rate these offerings most favorably, by comparison with other types of information.
- Rate programs focused on end-of-life issues such as advance directives and hospice as important, but do not access them.
- Despite high levels of education and information-seeking, indicate, in substantial numbers, a clear lack of knowledge about the availability of the most common educational programs in their community or on the Internet.
- Use varied sources of printed patient information; government websites and articles targeted to medical professionals were most often accessed.
- Infrequently attend patient conferences and scientific conferences despite high ratings by those who have participated. In contrast, two-thirds had attended lectures by experts.

## 5. The Role of Support in the Lives of Women Living with Advanced Breast Cancer

The research literature on the psychosocial impact of ABC indicates high levels of psychological distress, with an estimated 22% to 50% of patients meeting the criteria for a psychiatric diagnosis of depression, and 33% meeting the criteria for having an acute stress disorder.

Because of this, as well as the toll ABC takes on family members, this study took an extensive look at psychosocial supports available to and needed by women with ABC, including professional services, support groups, and less formal sources of support.

Data from this survey indicate that women with ABC:

- Report high levels of support and support-seeking.
- Seek support not only when they are feeling anxious or sad, but also when they need help coping with the medical aspects of their disease.
- Also reach out for support when they “feel alone with their cancer.” More than two-thirds of women find it quite helpful to read about or listen to the experiences of others with ABC.
- Find that different members of the healthcare team provide support in different ways.
- Attend face-to-face and online support groups in large numbers.
- Are eager to learn about the experiences of other women living with metastatic disease. A high percentage of women in support groups say that they sought groups out to learn about the experiences of others with ABC.
- Believe that stress management skills and individual counseling are important, but most did not make use of these services. When used, however, these services were rated more positively than support groups.
- Do not often use or highly rate hotline volunteer contacts, family/couples counseling, and counseling for children.
- Find that prayer and pets are highly effective in providing support.
- Indicate that siblings, spouses/partners, children, and friends (in that order) are the most frequent sources of support, and with the exception of children, are highly valued for support.
- Would like a group to be professionally led by a nurse or mental health professional.
- Rate the informational and support value of both groups and one-on-one modalities positively with equal frequency.

## 6. The Role of Practical Resources in the Lives of Women Living with Advanced Breast Cancer

In terms of financial, medical, and home/family concerns, the lives of women with ABC include practical demands that far surpass those of healthy individuals and tax their limited time and energy.

Data from this survey indicate that women with ABC:

- Use practical services less than educational and support services.
- Most often use and value treatment-related practical resources: including help with public/private insurance; assistance with disability insurance/benefits; and referrals to physicians/treatment centers. This preference for treatment related programs and services is consistent with women’s preferences for educational topics.
- Are unaware of the availability of these services in significant numbers, and this may account for their low usage rate.

## 7. Preferred Service Delivery Methods, Barriers to Accessing Services and Psychosocial Aspects of Service Use

For the purposes of program development, this study investigated how women with ABC would like to receive services and how they perceive barriers to accessing desired services.

- Half of women prefer online presentation of information.
- More than half of women want in-person support. However, more experienced support-seekers have a slight preference for online groups.
- A clear majority of women prefer online access to practical resources and services. Written materials on these areas are a strong second choice. For these highly motivated and knowledgeable patients, the most frequent obstacles to accessing services of all types were:
  - Lack of awareness of the types of services available (45%).
  - Not even knowing where to look for specific services (34%).
  - Known lack of availability in their community (31%).
  - All other reasons combined, including transportation difficulties, childcare problems, poor health and no computer/Internet access, are only seen as barriers by 29% of women.

This survey included questions designed to gather preliminary data on psychosocial aspects of service use, including what motivates women to seek out specific services. Analyses looked at any relationships between services used and reported symptoms. The trends below are important areas that merit future research. Respondents report:

- That accessing information about their disease provides support, and conversely, participating in support services provides them with information about ABC.
- Less difficulty with anxiety, depression, and fatigue when they report the highest levels of knowledge about ABC.
- Anxiety, depression, pain, sexual difficulties, and issues with appearance less frequently when they report the highest levels of support.

## 8. Implications for Program Development and Service Delivery

Detailed suggestions for program development can be found in the full survey report, and focus on the following areas:

- General trends and preferences in service usage;
- Preferred modalities for service delivery;
- The appeal of one-on-one support;
- Specific strategies for website programming;
- Telephone and in-person educational offerings;
- Written materials;
- Ways to familiarize women with services offered;
- Professional education, collaboration, and dissemination of findings.

Certain topics rated as “most important” by survey respondents formed the basis for program development and service delivery recommendations for women with ABC contained in this section of the survey report. Those topics include the following:

- **Information:** Current treatment options (96%); New treatment options (96%); Symptom and side effect management (95%); and Clinical trials (89%).
- **Support:** Support groups (77%); Stress management (71%); Individual counseling (55%); Spiritual guidance (52%); and Peer network/buddy program (51%).
- **Practical Resources:** Referrals to doctors and/or cancer treatment centers (72%); Information on health insurance (67%); Information about Medicaid, Medicare, and disability (56%); and Assistance with employment issues related to cancer (42%).

Because nearly half of respondents reported lack of awareness about available services, service providers should devote adequate planning and resources to disseminating information about services.

## 9. Study Limitations and Directions for Future Research

While this online survey is an important first step in systematically understanding the needs, experiences, and preferences of women living with ABC, lack of random sampling methods may have resulted in respondent selection bias. Although a growing majority of breast cancer patients and the public access the Internet, our sample does not equally represent all populations, and significantly under-represents minority, older, and less well-educated women, as well as non-English speakers and women from lower socio-economic groups.

The trends found as a result of analyses of the study data should not be broadly generalized. Because of the multiplicity of demographic, medical, behavioral, and attitudinal variables examined, future studies should seek to obtain a stratified random sample in order to make useful comparisons and related recommendations. A small pilot study of this survey administered on paper rather than online indicated demographic differences, especially in lower levels of education and older age. Replication of this study using paper survey administration with a more extensive outreach effort might be considered.

Given the opportunity, we found that women with ABC are strongly motivated to express what they want and need, which is critical because their interests have sadly not yet been well represented in the large, highly organized breast cancer support community. Surrounded by throngs of survivors each October, many women with ABC feel this marginalized status acutely. "When we are remembered," one woman said, "We are recognized as losing the battle, we are what the pink crowd want to forget because we are the painful reminders of what can happen."

When Living Beyond Breast Cancer staff and consultants posted this survey online in April, 2005, the project team hoped for perhaps 200 responses to what was an extremely complex and demanding set of questions. The simple magnitude of the response to this survey, more than three times what we had hoped for, poignantly illustrates the need of these women to be heard and to be served.

The voices of women with advanced breast cancer are silent no more.