Silent

Women with Advanced (Metastatic) Breast Cancer Share Their Needs and Preferences For Information, Support, and Practical Resources

Voices

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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, 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.

I. Background and Statement of the Problem

Little is known in specific terms concerning the needs of women with advanced (metastatic) breast cancer for information, support, and practical services. Existing research has largely focused on psychosocial interventions and coping mechanisms, most often in the context of studying all advanced cancer patients or in women with primary breast cancer.

Within the larger community of those living with a breast cancer diagnosis, this important subgroup has remained largely silent, with the result that relatively few services have been targeted specifically to this population.

Initially, this gap in services might seem unexpected, given the strong emphasis on breast cancer awareness in the United States, and the number of organizations and advocates whose work is focused on helping people with the disease. Breast cancer is often in the media, but to the careful observer, media coverage typically emphasizes potential research breakthroughs, early detection and upbeat stories of survival. After a decade and a half of effective breast cancer advocacy, many organizations dedicated to this cause are making significant contributions to research, support and public awareness. Yet, surrounded by throngs of survivors in pink ribbons, women with advanced breast cancer often feel invisible, and this feeling is frequently intensified during the annual media saturation each October, where the emphasis remains on mammograms, early detection, and uncomplicated survivorship.

Given the opportunity, some women with advanced breast cancer feel this marginalized status acutely, and eloquently express it to others living with the same diagnosis. "Why isn't the truth ever told about breast cancer during 'Awareness Month'?" one woman wrote to BCMETS, a mailing list for women and their families who are dealing with advanced breast cancer.[1] "Why do we hear this same old worn out message? Why are we with metastatic disease not mentioned or ignored and viewed as breast cancer's dirty little secret?" Another woman explained that she and other women with metastatic disease often don't identify with breast cancer survivor groups and their symbols: "The pink ribbon is a ribbon of hope and I think what is troubling is [that] we feel forgotten and feel 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."

Even within the health care community, patients have similar experiences. Social worker Roz Kleban, who leads the metastatic breast cancer support group at Memorial Sloan-Kettering Cancer Center in New York, refers to these women as "forgotten patients, shunted aside because they have 'failed.'…Women with metastatic breast cancer connote a failure of medical knowledge and science, which clearly the system doesn't feel good about."[2]

While the underlying causes for this silence and neglect are complex and beyond the scope of this report, the needs assessment survey discussed in this paper was developed to give these women a voice with which to speak out and let the health care and support community know what services they need. By participating in this project, these women provide invaluable information about what they and their families need in the way of assistance during the course of their disease in the three critical dimensions of information, support and practical assistance.

Breast Cancer Incidence, Recurrence and Mortality

More women in the United States have breast cancer than any other form of cancer (excluding skin cancer). The National Breast Cancer Coalition estimates the prevalence of this disease to be more than 3 million, with 2.3 million having been diagnosed and one million unaware they have the disease.[3]

In the year 2006, the American Cancer Society projects that 274,900 new cases of breast cancer will be diagnosed in American women, of which 212,920 will be invasive cancers, and 61,980 will be *in situ*, a non-invasive form of the disease that carries a potential for becoming invasive.[4] Although overall mortality rates from breast cancer per 100,000 women have decreased somewhat in recent years, breast cancer is still the second leading cause of cancer death in U.S. women after lung cancer.

The American Cancer Society estimates that 40,970 American women will die from the disease in 2006. For younger U.S. women, between the ages of 20 and 59, breast cancer remains the leading cause of cancer death. Breast cancer is also the leading cause of cancer death for women of all ages worldwide, representing more than 410,000 deaths among the 1.1 million women diagnosed each year.[5] This year, approximately 1,720 new cases of invasive breast cancer will be diagnosed among American men, and approximately 460 men in the U.S. will die from the disease.

Stage at initial diagnosis is a strong predictor of distant metastatic recurrence, with women diagnosed with cancer that is locally advanced, spread regionally beyond the breast, much more likely to recur than breast cancer diagnosed as localized, although as many as 30% of localized cancers ultimately do recur, and many of these will go on to develop distant metastases.

The stage of disease at diagnosis is higher in African American women. Despite a lower overall incidence, the most recent 2003 figures, published by the National Cancer Institute's Statistics, Epidemiology and End Results (SEER) database show that the five-year survival rate for black women diagnosed with invasive breast cancer is only 77%, while the five-year survival rate for white women now stands at 90%.[6]

Despite decades of effort aimed at early detection, SEER reports estimate that in nearly two-fifths (37%) of newly diagnosed patients with invasive breast cancer, the disease had already spread either regionally (31%), or to distant metastatic sites (6%).[7,8]

Almost all deaths from breast cancer are the result of the progressive spread of cancer from the breast to other parts of the body, where the tumor can cause symptoms, disability and eventually disturbs some vital function. While most cases of metastatic breast cancer represent the recurrence of primary invasive breast cancer, in 6% of new invasive breast cancer cases (representing approximately 12,775 American women a year), the cancer will have already spread to distant metastatic sites when first diagnosed.

Once breast cancer metastasizes to distant sites, it is generally considered incurable, and is almost always progressive. This progression may be rapid in treatment-resistant patients with aggressive, fast-growing disease or it may follow a relatively indolent course over a number of years in patients with tumors that are responsive to treatment, especially hormonal therapies. According to the National Breast Cancer Coalition, "Approximately 12% of women diagnosed with invasive breast cancer die from the disease within five years. At ten years, 20% will have died. The 2003 statistics show that 40% of all women diagnosed with invasive breast cancer died from the disease within 20 years."[9] Of course, since these figures reach back to look at the outcomes of patients diagnosed 20-25 years ago, it is not possible for them to reflect potential recent gains in survival due to new medical treatment developments or diagnosis at earlier stages.

Estimating the Size of the Affected Population

Despite these dismal statistics, advanced breast cancer is usually treatable and may allow many women with metastatic disease to live a number of years. Median survival after diagnosis with metastatic disease is generally estimated to be from two- to three-and-a-half years. However, the disease course is extremely variable, and 22% of patients with distant metastases will live at least five years, and about 10% will live 10 years or more. Only two-three percent are considered cured.[10] On a more encouraging note, more recent research suggests that newer treatments that have become available over the last 15 years may have somewhat enhanced length of survival.[11, 12]

An undetermined number of women initially diagnosed at Stages I-III will go on to have distant recurrences of their original breast cancer at some point after their first diagnoses, and almost all of these will eventually die of their disease. About half of distant recurrences occur within five years of diagnosis, and the remainder in subsequent years. While the vast majority of metastatic recurrences will happen in the first 15 years, a few occur as late as 25 to 30 years after initial diagnosis. Between one-half and two-thirds of women diagnosed at Stage II and III (regional disease) will ultimately develop metastatic disease. In combination with the women who initially present at Stage IV (distant disease), this would mean that every year between 73,000 and 86,000 American women discover they have metastatic breast cancer.[13]

We can therefore estimate that at any given time, a low estimate of 150,000 and a more reasonable estimate of 250,000 American women are facing the ongoing challenges of living with metastatic disease. Many more at high risk of recurrence are living in fear that may significantly impact daily life and are also in need of support and information on advanced breast cancer.

Public Perceptions and Available Resources

What these data may obscure is that among the millions of breast cancer survivors there is another sizable, largely silent and invisible population of women living with advanced (metastatic) disease. Incidence and mortality statistics concern themselves with diagnosis and death, and tell us nothing about the lived experience of advanced breast cancer.

Although research and medical advances are helping patients with metastatic breast cancer to live longer, with better quality of life, often these women describe themselves as isolated, even from other breast cancer survivors.

Their experiences and needs are not well understood. A 1995 study sponsored by the National Alliance of Breast Cancer Organizations surveyed 200 women with metastatic breast cancer and their caregivers. Most of those surveyed "believe the public sees these women as being near death—with little or no time to live."[14]

Often, life for them can seem quite normal in the early months and even years after diagnosis. Yet periodically at first, and then with greater frequency as their disease progresses, their lives do become dominated by the reality of their illness, by the treatments they must receive, and by having to deal with symptoms, side effects and tests to assess disease progression. As each treatment fails, the search for further life-extending treatment comes to the foreground. Their lives and those of their families and loved ones are often thrown into turmoil by the stresses involved.

At the same time, some women with advanced breast cancer find that few social and informational supports exist for them in their own communities. In fact, while breast cancer resources in general grew during the last decade and a half as a result of advocacy and public health efforts, patient education, information, and psychosocial supports for women with advanced breast cancer and their families appear to have lagged far behind the significant advances in research and treatment.

In general, established breast cancer organizations have been slow to identify and address the needs of women with metastatic disease on an ongoing or regular basis. The vast majority of patient education materials and media coverage on breast cancer still focus on the experience of primary breast cancer survivors who benefit from early diagnosis and treatment and will never face a recurrence of their cancer.

Women with advanced breast cancer face very different issues and challenges than do newly diagnosed primary breast cancer patients, and the same resources are often not appropriate for them. Yet there are few resources specifically dedicated to their needs.

For example, the 82-page 2000/2001 edition of the *NABCO Breast Cancer Resource List* had one page on P*lanning for the End of Life* and a half page on myths and facts about managing cancer pain. Its listed resources on *Recurrence and Metastatic Breast Cancer* consisted only of five booklets, one video, and what still remains, five years later, the only book-length patient guide to the disease.[15] In 2006, NABCO, as well as the website on recurrent breast cancer it developed to address this deficiency, no longer are in existence.

Relatively few in-person support groups have been set up specifically for women with advanced breast cancer. In fact, there were fewer than 20 nationwide in 2001, according to a NABCO estimate, from among the many hundreds offered for women with primary breast cancer.[16] Increasingly broad usage of the Internet has to an extent ameliorated the isolation some of these women feel. A number of women living with metastatic breast cancer appear to have found companionship and support in online mailing lists, bulletin boards and chat rooms, while others have been able to find hospital-based in-person support groups for patients with a variety of advanced cancers.

Information sources have increased over time, especially online, with some websites offering frequent research updates timed to the major cancer conferences by experts and thought leaders in the medical community, and easy-to-understand write-ups of emerging research. Increasingly, government-sponsored websites offer access to information about clinical trials and treatment options. While it is clear that some resources for women with advanced breast cancer do exist, they remain widely scattered, disorganized, and difficult for women to locate, evaluate and understand. There is currently no comprehensive dedicated website that serves as an information clearinghouse for this population.

2. LBBC Advanced Breast Cancer Needs Assessment Survey

Description of Survey

Living Beyond Breast Cancer (LBBC) staff, consultants and a Professional Advisory Committee (see Appendix) developed a 64-question survey administered online to people with advanced (metastatic) breast cancer. This survey, designed to provide cancer support and treatment organizations with the information they need to develop programs for this underserved population, focused in great detail on the use of and the preferences for services in three domains: information, support, and practical resources. In each of these areas, respondents were queried about the role of healthcare professionals, support groups/one-on-one peer support, cancer support organizations, and treatment centers in providing services. In addition, participants rated their satisfaction with the services they utilized to provide data on the perceived quality of these experiences. Preferences for and experiences with different methods of service delivery, including online, in-person, print media, and telephone presentations, were queried as well to understand how to best meet the needs of this underserved population.

To further achieve the goal of developing quality programs the following areas were also assessed:

- Patterns of use within the information and support domains;
- Frequency of use and motivation for using available support and educational services;
- Availability of services in the community;
- Knowledge of service availability;
- Barriers to service access;
- Sources of information and support in addition to healthcare professionals and programs offered by cancer support and/or cancer treatment organizations;
- The websites considered most helpful for information and support;
- Perceived levels of support and knowledge;
- Current level of knowledge and support;
- Use of and perceived role of complementary therapies.

Method

Before dissemination, following feedback from the staff of Living Beyond Breast Cancer and a Professional Advisory Committee, the survey was piloted on a small sample of seven women to identify any difficulties with comprehension, completeness, or length. After pilot data were examined and necessary suggestions were incorporated, the survey was posted with a link from the Advanced Breast Cancer webpage at the Living Beyond Breast Cancer (LBBC) website, www.lbbc.org, and was widely publicized to a variety of sources within the breast cancer community. The survey was posted online on April 13, 2005, and was removed on May 13, 2005. During this month, nearly 800 women started the online survey, and a total of 618 women completed the online survey. We mailed 150 surveys to women identified as not having access to the Internet. Seventy-nine completed the mailed survey. However, because this sample was not large enough to be adequately powered for meaningful statistical analysis, this paper focuses on the results from online data.

Survey questions were composed by LBBC staff and consultants, based upon extensive research by consultants. Upon survey completion, the data were analyzed to understand how to best meet the needs of women living with advanced breast cancer by developing targeted programs providing support, information, and practical resources.

All descriptive statistics were first calculated for the entire sample of 618 respondents. Frequencies are based on this sample for questions on demographics, medical variables, and the provision of support and information by healthcare professionals. Where only a portion of the sample were expected to respond, (e.g. preferences and ratings for support group types among those who have actually used support groups) percentages were based upon the number of women who responded to the given question. All descriptive statistics for these questions are therefore based upon the sample size of respondents as opposed to the overall sample of 618. This base size varies in accordance with the number of women eligible to respond to each question. In all analyses, we did not control for demographic variables due to the homogeneity of the sample.

Limitations of the Survey

This project did not use random sampling methods. Rather, a purposive sample was selected from the sources previously discussed for the express purpose of preliminarily understanding the behaviors and unmet needs of women with advanced breast cancer. Trends found as a result of analyses cannot be generalized beyond this sample of women, all of whom are distinguished by their use of the Internet for online support and educational resources, and by their self-selection as respondents. In addition, respondents are overwhelmingly white and well-educated. The trends identified among these participants should be verified in a random, stratified sample. Because of the multiplicity of demographic, medical, behavioral, and attitudinal variables examined, a stratified random sample would be helpful in order to make useful comparisons and related recommendations.

However, the data from this study represent an interesting and important starting point in outlining the experiences and needs of one segment of this underserved population, and in conceptualizing new programs for them. Any new programs designed based on findings in this report should be piloted on target groups, and if implemented on a larger scale, thoroughly evaluated.

Since the survey respondents took the survey online, it is reasonable to conclude that this population's demographics may reflect that portion of the public who use the Internet to seek health resources. A 2005 report by the Pew Internet and American Life Project concluded that eight out of ten Internet users look for health information online: "That translates to about 95 million American adults (18+) who use the Internet to find health information." Sixty-six percent of these looked for information on a specific disease or medical problem.[17]

The Pew report also determined that "certain groups of Internet users are the most likely to have sought health information online: women, Internet users younger than 65, college graduates, those with more online experience, and those with broadband access….39% of health seekers have at least a college education and 60% have six or more years of online experience."

While we did not seek the same information about Internet use, the demographics in our report generally reflect these observations. Regarding age, more than half (54%) of our online respondents were over 50, and 17% were 60 or over, while less than a third (31%) of the "Health Seekers," as defined in the Pew report, were over 50, and only 6% were 65 or older. The older age of the advanced breast cancer survey respondents is likely to reflect the age of disease onset, which is far less common in women under 40 than many other diseases and health conditions for which people seek online information. A survey of nearly 6,000 adults assessing community-wide informational intervention involving multiple sources, including online,[18] showed that "older adults were no less likely (and were sometimes more likely) to use health information as a result of the intervention than younger adults." This finding held up even for computer usage.

Level of education is another demographic associated with online searches for health information. The overall U.S. population's educational status shows nearly half (47%) have a high school diploma or less, 23% have some college education, and 25% possess a college degree or more. The group defined as "Health Seekers" in the Pew report have the following educational background: 27% have a high school diploma or less, 31%

have some college, and 39% possess a college degree or more. Our online survey respondents tended to be even more highly educated than this "Health Seeker" group, with only 11% having a high school diploma or less, 23% having some college, and a full two-thirds (66%) possessing a college degree or more.

Education	U.S. Population Pew Report	"Health Seekers" Pew Report	ABC Survey Online Respondents
Less than High School	14%	5%	3%
High School diploma	33%	22%	8%
Some college	23%	31%	23%
College degree or more	25%	39%	66%

The term "digital divide" has often been used to describe racial, generational, and socioeconomic disparities, as well as other demographic differences, that exist between populations that have the access, skills, and motivation to use computers and the Internet, and those who do not. A 2000 survey, focusing on the different demographics for Internet users, found African Americans significantly less likely to have access to a computer and the Internet than whites. However, this survey found that "once people have access to the Internet, the health information digital divide tends to disappear."[19]

The 2005 Pew Internet and American Life Project report, entitled "Digital Divisions,"[20] found that as of summer 2005, 68% of American adults, or about 137 million people, now use the Internet, but that some groups lag behind, notably those aged over 65, African Americans and those who are less well educated. A new digital divide has sprung up between those with high-speed connections and those with dial-up connections. Rural areas are also less well represented, perhaps related to issues of access.

Interestingly, one aspect of demographics in our survey mirrored those in American society.[21] Almost half (48%) of Americans live in suburban settings, while an equal number (26%) live in both urban and rural settings. In our survey, 56% lived in suburban or small town settings, while 33% lived in urban settings, and 11% in rural settings.

Use of the Internet from a home computer is particularly well-suited to people who may be home-bound with chronic and/or debilitating illnesses, and to those who may be geographically isolated. For many, the Internet represents not only a window into the world, but offers many possibilities for interactive support and advice.

In the face of a serious, life-threatening illness like metastatic breast cancer, some women will seek out information, support and practical services, and some will not. Research suggests that help-seeking behaviors vary considerably among cancer patients, and may at times even delay diagnosis.[22] For some people, the perception that they may be exposed to emotionally threatening situations—for example, meeting other patients with advanced breast cancer in a support group or finding out information about the disease—may be painful and/or may act as a deterrent to use of needed services.

The question must be asked: in surveying women who are willing to invest the time to fill out a complex questionnaire to share their preferences and needs, are we "preaching to the choir?" In other words, do the help- and information-seeking skills of the women we surveyed ensure that these women are already well-served? Or are there ways in which program development and delivery can be improved even for this resourceful group? And can the experiences and preferences, and still unfulfilled needs of these women also be used to plan and implement services for others who may be more difficult to reach? These interesting questions are raised by this initiative and serve as a foundation for replication of this research with other groups of women living with advanced breast cancer.

However, results from the Health Information National Trends Survey (HINTS) suggest that 60% of all American women do seek information about cancer, which indicates that help-seeking is an extremely common behavior. While efforts to provide information, support, and practical resources online may not reach all women with advanced breast cancer, certainly they have the potential of reaching a majority of them.

3. Demographic and Medical Data on the 618 Women Participating in the Survey

Demographics:

- **AGE**: Seventy percent of respondents are between the ages of 40 and 59. Younger women, 30-39, comprise 14% of the sample, as do women in their sixties. The youngest (29 and under) and the oldest (80 and above) participants each represent 1% of participants.
- **RESIDENCE**: The majority of women live in suburban areas or small towns (56%), with one-third living in urban areas, and only 11% residing in rural locations.
- **RACE**: Virtually all participants completing surveys (94%) are Caucasian.
- **EDUCATION**: Respondents are highly educated: almost one-third (32%) earned a graduate degree; slightly over one-third (34%) have a college degree; and almost one-fourth (24%) have some college education. Only 8% stopped schooling after high school, and only 3% have less than a high school education.
- **LIVE WITH**: Almost three-quarters (74%) live with spouses/partners. Comprising this group, 41% live only with their spouses/partners, and 33% also have children living at home. Fifteen percent live alone and 7% live with children only.
- **CHILDREN**: Over three-fourths (76%) have children while almost one-fourth (24%) have no children.
- **INSURANCE**: Almost three-quarters (73%) of respondents have private health insurance, 12% have Medicare and private insurance, and 6% have Medicaid or Medicare without private insurance. Only 3% are uninsured.
- **EMPLOYMENT**: A considerable number of women are working full or part-time (47%). In contrast, 25% are receiving disability and another 5% are on medical leave. Eight percent describe themselves as mothers/homemakers and 6% are currently unemployed.

Medical Status

- **YEARS WITH ABC**: Twenty-four percent have been living with metastatic breast cancer for less than a year; 37% for one to two years; and 29% for three to five years. In contrast, fewer respondents have lived with advanced breast cancer for 6-10 years (9%) or over 10 years (2%).
- **AREAS OF METASTASIS**: The four most frequent areas of metastases are: bones (71%), lymph nodes (63%), liver (44%), and lungs (39%). Twelve percent had brain metastases.
- **CURRENT TREATMENT STATUS**: Four out of five women are currently in treatment (79%), and 10% are between treatments. Two percent have chosen to stop treatment or elected comfort care. One percent has just been diagnosed.
- **EASE OF ACTIVITIES:** Forty-two percent report that maintaining their usual daily routines/activities is easy (21%) or very easy (21%). Thirty-nine percent rate this quality of life measure, "somewhat easy." Difficulty with daily routines was reported by 20% of women, however only 4% of those women found these activities "very difficult." The surprisingly good quality of life and ease of activities these women reported may reflect several factors: (1) that most are relatively early in the course of their metastatic disease; (2) selection bias indicating that patients who are not very ill may be more motivated or able to fill out the survey; and (3) good access to treatments and excellent quality of medical and supportive care enables these pro-active patients to help keep their symptoms and side-effects under good control.
- **TREATMENTS USED**: Currently, or in the past, 85% of respondents have had chemotherapy; 72% have had radiation; 75% have had surgery; 78% have had hormonal therapy; 41% have had biological therapies; and 22% have had investigational treatments, administered in clinical trials.
- **SIDE EFFECTS**: More women than not suffered from a wide variety of symptoms. The two symptoms reported most frequently were fatigue (92%) and trouble sleeping (84%). More than three-quarters of respondents, at some time, experienced: pain (79%); hot flashes (79%); trouble with memory, concentration and/or organization (78%); and hair loss (77%). More than two-thirds indicated difficulty with vaginal dryness (73%) and/or discomfort with sex (68%). Two-thirds (66%) said depression was a problem and more than half (59%) reported anxiety. Neuropathy was also common (65%). Problems with appetite (60%) and nausea (55%) affected the majority of women. In addition to hair loss, women experienced other problematic changes in appearance (63%). Mouth sores occurred in almost half (48%) of survey participants but hand-foot syndrome was less frequent (36%). The frequency and number of reported side effects and symptoms is surprising, considering the largely positive ease of daily activities reported by four out of five patients. This suggests both good supportive care from healthcare professionals and effective coping or adaptive abilities on the part of patients.
- **COMPLEMENTARY THERAPIES**: More women than not used various complementary therapies: 70% took vitamins, supplements, or herbs; 59% used psychological and spiritual approaches like relaxation, meditation, or visualization; 58% exercised in some form whether aerobically, with strengthening routines, and/or stretching; and 53% reported use of dietary approaches and changes. Only physical modalities like massage, acupuncture, or chiropractic methods were used by less than half (40%) of respondents. Complementary therapies were used by more than half of respondents to reduce stress (56%). They were used less often but with almost equal frequency to both cope with side effects (41%) and as "treatments in their own right" (42%).

In summary, surveyed women with advanced breast cancer: were predominantly white, well-educated, partnered, mothers, employed or on disability, and privately insured. They typically described themselves as living with advanced breast cancer for less than five years with metastases to bones, lymph nodes, liver and/or lungs and were in treatment, with chemotherapy and/or hormonal therapies, and reported a wide variety of side effects. Nevertheless, they found daily routines very to fairly easy, and they used complementary therapies to reduce stress or cope with side effects.

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

Background

Most women diagnosed with advanced (metastatic) breast cancer have experienced a recurrence, so they have already lived through an initial diagnosis with primary disease. Often, they've sought information about breast cancer before metastases are discovered and already have a healthcare treatment team in place. Other women, however, do not seek information until they learn their cancer has spread, and still others are diagnosed at Stage IV, when their breast cancer has already spread to a distant site. Although the timing, amount, complexity, and frequency of information-seeking may vary, people living with advanced breast cancer want to know about treatments; clinical trials; resources for second opinions; where to find the best and/or most convenient cancer-treatment facility; symptoms, side effects, and remedies for them; and where to find local resources and insurance coverage for standard and experimental treatments.[23]

The use of the Internet for health information has expanded enormously since its inception, enabling consumers to learn about diagnosis, treatment, and services for both common and rare health challenges. Usage rates of the web for information by cancer patients are cited as ranging from 39-58% and similar moderately high rates (42-49%) are cited for breast cancer patients.[24] One small study confirmed that among educated older women with a high internal locus of control, those with computer access and a degree of comfort with the technology were more willing than men to use the Internet to find medical information to manage a chronic health problem.[25]

Perspectives on our needs assessment survey for advanced breast cancer are enhanced by the findings of a large random-sample survey of information-seeking behaviors on cancer. The National Cancer Institute's Health Information National Trends Survey (HINTS 2003)[26] surveyed over 6,000 Americans through random digit-dialing about their information-seeking behavior with regard to cancer. They found that 45% of all Americans sought out information on cancer, and that most of these (51%) were looking for cancer-specific information. Considering women only, the percent of information-seekers was even higher at 60%.

While healthcare providers were cited as the "most trusted information source," there were striking differences between where people *say* they would prefer to go for information, and where they actually *do* go: "For example, while nearly 50% of Americans report that they would go to their health care provider for health information, only 11% actually sought information from a health care provider during their last search." Older people preferred information from healthcare providers, as opposed to younger people, who preferred the Internet. However, the survey concluded, "Increasingly, Americans are looking to the Internet" for health information.

Surveys representative of the cancer patient population as a whole have looked at how patients find and use information. An outpatient clinic-based survey done at Memorial Sloan-Kettering Cancer Center on the use of information resources by patients with cancer and their partners found that two-thirds of patients were computer owners, and nearly as many had Internet access. More partners (60%) than patients (44%) reported use of the Internet to obtain cancer-related information, reflecting the important role played by loved ones in helping their significant others through a serious health crisis. As in our survey, those patients who themselves searched the Internet, tended to be well-educated. In this study, cancer patients using the Internet were also younger.[27]

Rates of information-seeking for women with advanced breast cancer are likely to exceed those of women with primary breast cancer because of the more complex and continuous medical decisions they face and the increased likelihood of more troublesome symptoms and side effects. The treatment of metastatic breast cancer is far more individualized than treatment of primary breast cancer, entailing many treatment decisions and continuous management of treatments, symptoms and side effects, typically over a period of years.

Of course, the Internet is only one source of information for women with advanced breast cancer. Printed materials and educational programs, delivered in-person or over the phone, are also available. Information also is provided in many other ways, and by many different people, ranging from physicians to other patients. These varied options were presented to the 618 women who participated in this survey initiative, and they not only indicated which educational resources they had accessed but also which topics and formats they preferred.

As noted earlier, however, there is significantly less available information, in all forms, about metastatic breast cancer and so the women surveyed are truly self-identified information seekers. Because of this, the development of targeted and comprehensive informational and educational resources and services would greatly benefit this population. A later section of this paper identifies trends that will help healthcare professionals, cancer support organizations, and treatment centers create programs that will be enormously valuable to these women.

The Importance of Information

The educated, web-conversant women with advanced breast cancer who responded to our survey highly value information. Virtually all (98%) believed that information about treatment, side effects, and symptom management is important (11%) or very important (87%) in helping them cope with cancer. Moreover, 91% are the primary person who gathers needed information.

Not surprisingly, the clear majority of women (64%) rate their current level of knowledge about advanced breast cancer and its treatments as excellent or very good; and an additional 25% consider their fund of information good. While only 10% report a fair level of knowledge, even fewer women (2%) believe their current knowledge is poor.

The frequency of information-seeking is also an indicator of the importance of knowledge. The vast majority of these women (73%) seek information on either a daily (32%) or weekly (41%) basis. Less frequent users include those looking for information on a monthly basis (17%) and those who seek it less than once a month (10%). In fact, only 2% of participants reported that they never sought information.

How to cope with a progressive illness whose prognosis is poor, how to make the best treatment decisions, manage symptoms and side-effects, and yet still maintain a sense of control over one's life is a challenge for all advanced breast cancer patients. The importance of establishing a sense of control in coping with disease can't be overstressed, as is demonstrated by an extensive literature on this subject.[28] 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 information is one powerful and adaptive way in which patients accomplish this task.

The Timing of Information-Seeking

It is important not only to understand how often women look for information on advanced breast cancer, and how informed they perceive themselves to be, but also to discover the circumstances that motivate information-gathering. Identifying these situations will further increase the utility of this survey in developing salient services. Results indicate that almost two-thirds of women rely on information when they are making decisions about starting a new treatment (65%) or when there is a recurrence or progression of their breast cancer (61%). More than half seek information when they experience treatment side effects or discomfort from cancer (56%). Although fewer respondents turn to information when they experience non-specific psychological discomfort (i.e. worries or sadness), a considerable number of women (44%) do further educate themselves, which likely reflects a coping style among this sample.

Healthcare Professionals and Information

Healthcare professionals can help women with advanced breast cancer in many ways other than administering and monitoring treatment. They can also provide needed information about the disease and its treatment. Because of this, women were asked whether their healthcare team provided information in three key areas: treatment options; possible treatment side effects; and symptom/side-effect management (See Table 1).

Results indicate that a variety of healthcare professionals are helpful in educating women in areas critical to their care. The top three in each area are highlighted below:

- Medical oncologists were most frequently endorsed as providing needed information on treatment options (82%), followed by physicians seen for a second opinion (63%), with surgeons (60%) and radiation oncologists (59%) coming in third in this area. These findings make sense since patients generally consult with medical oncologists to develop a treatment plan, and second opinions may be considered helpful less often because they frequently confirm the treatment plan of the treating medical oncologist. Surgeons and radiation oncologists typically deliver the treatments discussed by women with their medical oncologist, and may therefore be endorsed by fewer respondents as helpful in this regard.
- Medical oncologists and oncology nurses are both viewed by equal numbers of respondents (72% for each profession) as having provided useful information on possible side effects of treatment. Because these two healthcare professionals usually function as the primary healthcare team members for cancer patients, this result is not surprising. Radiation oncologists, however, are not always healthcare team members, and often just deliver treatments rather than advise or follow patients. It is likely that they were perceived as helpful in this way by the majority of women (59%) who consulted them because they imparted their knowledge about the very specific side effects of radiation treatments as a routine part of their service delivery.
- Oncology nurses (73%) are seen as helpful in managing side effects of treatment and cancer symptoms by more women than any other healthcare professional. Patient education and support are important functions of oncology nurses in oncology practices and cancer centers, and this finding reflects their typical role on the healthcare team. Medical oncologists are each endorsed by well over half (60%) of those surveyed as also having provided this information. These two professionals are typically part of the "core" caregivers for cancer patients, and in this capacity have the responsibility and opportunity to inform women about how to cope with symptoms and side effects. Radiation oncologists, paralleling their communication of possible side effects, are seen by almost half of respondents (49%) as providing information in this area. This information is probably focused on dealing with the symptoms that arise from treatments they deliver. Finally, nurse practitioners, though not as often as oncology nurses, were seen as helpful by 51% of women, even though they do not work in all practices.

Cancer Support Organizations and Treatment Centers as Sources of Information

Cancer support organizations and treatment centers serve many functions, and women with advanced breast cancer contact them for many types of services. This survey investigated the use of educational programs on a variety of salient topics, and user ratings of program quality. Respondents also indicated if these topics were important to them, and if they were available in their community.

The data (see Table 2) on educational programs is quite interesting, indicating a discrepancy in perceived importance (attitudes) and use (behavior), a discrepancy also noted by researchers involved with the Health Information National Trends Survey mentioned above.[29] Across topics, more women rated programs "important to me" than actually attended them. Also, there were a surprising number of respondents who did not know if these services were available in their communities. This lack of knowledge regarding service offerings is particularly striking given the high level of educational attainment achieved by these women and the value they place on information about advanced breast cancer. Specific results are described below:

Top Three Programs in Attendance and Importance

- Ninety-six percent of women considered programs on "current treatment options" and programs on "new treatments and the latest research" as "important to me." An almost identical percentage (95%) felt similarly about presentations on "symptoms and side effects." These three programs were also accessed by the most respondents: current treatment options (62%); new treatments and the latest research (60%); and symptoms and side effects (57%). Nonetheless, there are large discrepancies between perceived value and actual attendance.
- Over a quarter of women did not know whether programs on current (29%) and new treatments (32%) were available, and almost one-quarter (23%) did not know whether programs on symptoms/side effects were available. This important gap in knowledge about accessing valued educational content, may account for the importance/use discrepancies. However, it is likely that these numbers also reflect a not uncommon trend for behaviors and attitudes to vary, and there are many factors that intervene between a belief and an action.
- Ratings of program quality were high, with 72% judging presentations on current and 71% rating programs on new treatment options "excellent" or "very good." Almost two-thirds (64%) felt the same way about the offerings on symptoms and side effects.

Table 1: Areas in which Healthcare Professionals Provided Information

Type of Information

Healthcare Professional	Treatment Options	Information on Possible Treatment Side Effects	Managing Symptoms and Side Effects	Percent Not Seeing This Professional
Medical Oncologist	**82%**	**72%**	**60%**	1%
Radiation Oncologist	**59%**	**59%**	45%	27%
Surgeon	**60%**	39%	30%	21%
Primary Care Doctor or Internist	21%	19%	29%	34%
Physician Seen for Second Opinion	**63%**	29%	19%	39%
Oncology Nurse	28%	**72%**	**73%**	7%
Nurse Practitioner	27%	46%	**51%**	49%
Physician's Assistant	22%	33%	33%	50%
Mental Health Professional	12%	16%	42%	46%
Complementary and Holistic Practitioners	25%	22%	45%	55%
Home Health Aide or Hospice Worker	1%	12%	15%	75%

(N=618; with percents in each category based on those who saw that professional)

Table 2: Education Topics: Usage, Importance, Ratings, and Availability

Topic	Used	Considered Important Program	Excellent/ Very Good	Good	Fair/Poor	Available	Don't Know if Available
Current Treatment Options	**62%**	**96%**	**72%**	22%	6%	**62%**	29%
New Treatments/Latest Research	**60%**	**96%**	**71%**	21%	9%	54%	32%
Symptoms and Side Effects	**57%**	**95%**	64%	28%	8%	**70%**	23%
Clinical Trials Information	39%	84%	61%	25%	15%	54%	33%
Pain Management	29%	79%	51%	33%	16%	56%	36%
Communicating with Healthcare Team	38%	79%	**71%**	21%	8%	**58%**	32%
Parenting Issues	9%	34%	34%	26%	35%	29%	**61%**
Complementary Medicine	34%	61%	63%	20%	17%	47%	**41%**
Hospice/ End of Life Care	6%	60%	50%	33%	17%	53%	**43%**
Advance Directives	16%	66%	63%	31%	6%	57%	37%

(N =618; program ratings are based only on users)

Other Programs Considered Important

- Well over three-fourths of women with advanced breast cancer also considered clinical trials information (84%), pain management (79%), and communicating with the healthcare team (79%) important.
- These three topics, like the "top three" cited above, were also accessed by fewer women than judged them important, and in this case, the discrepancies were of a larger magnitude. Specifically, the percentages of women accessing program topics were as follows: clinical trials (39%); communicating with the healthcare team (38%); and pain management (29%).
- The high frequency with which women indicated that clinical trials information is important is not surprising since two of the top three programs previously discussed also focus on treatment, and the third on treatment side effects. However, there is an even larger discrepancy with this program element between the number of respondents considering this topic important (84%) and the number who attended a presentation in this area (39%). This finding cannot be accounted for by lack of information about availability or availability alone, since these numbers are not dissimilar to those of the "top three topics." Possible explanations for the lower attendance include: (1) women may believe they will have difficulty understanding this information so they don't participate; (2) women don't feel this information is important for others, not for themselves, (i.e. "I won't need a clinical trial"); (3) women rely on their healthcare team in this area; or (4) clinical trials are viewed negatively. Research on this discrepancy would be important, since it seemingly echoes the low 5% adult cancer clinical trials enrollment.[30]
- Complementary and Alternative Medicine (CAM) was seen as an important educational offering by well over half of respondents (61%). However, only one-third (34%) actually took advantage of these programs. This low usage could be attributable in part to the high number of women (41%) who did not know about the availability in their community or online of presentations on this topic.

The Three Educational Topics with the Lowest Rates of Use

- Advance directives (16%), Parenting Issues (9%), and Hospice/end of life care (6%) were the least accessed programs.
- Parenting issues (34%) was also the topic considered important by the fewest women.
- Presentations/Information on advance directives, although only used by 16% of respondents, was considered important by a full two-thirds (66%) of participants. Similarly, hospice/end-of-life care education was valued by well over half (60%) of women, yet had the lowest attendance rate of all offerings (6%).
- Given the educational level of these women and the high value they place on learning about their illness, these findings are striking. The data suggest a number of hypotheses that merit attention. Among this sample of women with advanced breast cancer, information on preparing for death and dying was very infrequently sought out, but is clearly relevant and important. It seems likely that their reluctance to educate themselves in these areas reflects their strong focus on living with the disease, not dying from it, and learning about the best treatments, as well as coping with side effects and symptoms.
- This finding coincides with observations that there may be discrete stages of coping with incurable, progressive illness, and suggests that preparation for death may be part of a process that for most belongs to a later stage than that of living with advanced breast cancer, which can occur over many years with reasonable quality of life. The underutilization of hospice services in the United States until the last week or two of life indicates that preparation for dying is something about which women with advanced breast cancer, as well as others in our society, feel profoundly ambivalent.[31]

A later section of this report links information-seeking with reduction of anxiety. However, some research in health care decision-making suggests that with outcomes over which one has little or no control, avoidance behaviors may take over, even among patients whose normal coping strategy is that of information-seeking.[32]

- It is also unclear why education and information on parenting issues is avoided and devalued. Possibly, respondents were not relating this topic to the impact of their health status on their children, or, this too, is an emotionally difficult area for women to consider. Another explanation may be that children with mothers with advanced breast cancer are often adults and therefore a less pressing concern than younger children would be for these women. Clearly, this area deserves further exploration.

Other Sources of Information on Advanced Breast Cancer

In addition to educational programs offered by cancer support organizations and cancer centers, women use other sources to increase their knowledge. Their responses indicate:

- The most frequently used sources are: patient books, brochures, and handouts (95%); government websites (e.g. cancer.gov) (78%); and medical journals/articles/books for healthcare professionals (77%). Of these, medical publications were rated highest, with two-thirds (67%) considering them very good or excellent, compared to government websites (55%) and patient publications (51%), which were not judged as favorably.
- Pharmaceutical websites were the next most used resource (66%); however, they were viewed considerably less favorably than the top three frequently used informational sources. Only one-third of users (33%) considered them very good or excellent, and more than one-fourth (28%) considered them fair or poor. In fact, they received the lowest favorability rating of any resource listed in this category. This finding may indicate a fairly sophisticated critical appraisal of potentially biased marketing information.
- In-person talks or lectures by professionals and experts in the field were widely attended (60%) and also were well received (very good or excellent ratings) by two-thirds (66%) of women living with advanced breast cancer. Some organizations offer opportunities for patients to gather together to listen to a noted authority discuss emerging research, treatments, or other issues, thus offering an opportunity for interaction and support, as well as a source for information.
- Lectures are often shorter than day-long and weekend conferences and this may be a factor in the different attendance frequency at live informational events. This trend should be examined to determine what factors and barriers contribute to low utilization of the conference resources that were seen as very worthwhile by those utilizing them.
- The only other resource category used by many women (57%) was "university and/or organizational websites" (e.g. Oncolink.org, breastcancer.org). They garnered "very good or excellent" ratings from 55% of users.
- Patient conferences received the highest favorability rating (68% viewed them as excellent or very good), but they were only attended by 29% of women. By contrast, medical articles were accessed by far more respondents (77%) than viewed them favorably (67%).
- Live web-casts were used by over one-third (35%) of women, and were seen in a positive light by more than half of users (57%), who gave then a very good or excellent rating. These live web-casts are typically transcribed or archived, offering another way for women to access or review them, if the live event has occurred at a time they could not participate.
- Telephone education sessions by experts (23%); telephone information services such as the National Cancer Institute's Cancer Information Service (CIS) (21%); and scientific conferences for medical professionals (19%) were *accessed* by the fewest respondents.
- However scientific conferences (62%) and telephone education sessions (61%) elicited the highest favorability ratings (i.e. very good or excellent) from well over half of participants. This may indicate that while women recognize the value of these materials, they may not be able to relate this to their own situation or may not feel able to critically absorb the information in this format. Further exploration of this and other discrepancies would be important.

These preferences are crucial to consider when developing educational materials and programs for women living with advanced breast cancer. This very educated, information-seeking segment of the larger population of metastatic breast cancer patients values highly respected sources such as professional publications and websites with sophisticated and extensive content. They often use written materials specifically developed for patients. Combining some characteristics of professional literature (i.e. sophistication and detail) and of government websites (i.e. comprehensiveness and reliability) with consumer friendly and relevant patient publications would likely be a good mix to maximize the utility and value of information.

In summary, the responses of surveyed women with advanced breast cancer indicate that they:

- 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 rated 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 information with printed materials for patients; government websites and articles targeted to medical professionals most often accessed.
- Infrequently attend patient conferences and scientific conferences, despite high ratings by those who 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

Background

"For the advanced breast cancer patient, facing the prospect of a foreshortened future, in addition to the steady decline of health, ongoing medical treatment, and the effect of the medical condition on loved ones is certain to bring forth an array of painful and difficult emotions."[33] This concise overview of the emotional challenges faced by women living with the disease comes from psychiatrist David Spiegel and his Stanford University colleagues, known for their group work and research with women living with metastatic breast cancer.

The limited literature on the psychosocial impact of advanced breast cancer does indeed show 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.[34] These figures are echoed in our survey results, where symptoms of depression were reported by 34% of women, and anxiety by 28%.

One study followed 269 women diagnosed with early breast cancer for three years, then interviewed 38 of the 61 patients who developed recurrences during that time.[35] Fifty percent of the women were found to be suffering from clinical depression, anxiety or both conditions. Of particular concern was the fact that four out of five of these women didn't receive any services or referrals to help them with their emotional distress. Clearly, this kind of experience can lead to further isolation, and does not constitute optimal care, which can be said to involve not only the management of the disease and its symptoms, but also meeting the needs of patients for psychosocial support and information.

Emotional distress is closely tied to the physical manifestation of symptoms and side-effects, and is likely to be particularly acute at several critical junctures in the course of the disease: at the time immediately after initial diagnosis with advanced breast cancer;[36] repeatedly, whenever successive treatments fail and disease progression occurs; and during the terminal phase of the illness as the woman and her family make the difficult transition from fighting the cancer to preparing for the end of life. Persistent and debilitating symptoms and side effects like fatigue, pain, nausea, and dyspnea take an emotional as well as physical toll, as does the unpredictability of whether a given treatment will work, for how long it will work, and at what cost in toxicity. The uncertainty of treatment response, and disease progression or stability may be profoundly disruptive in the lives of families, especially those with children at home. Some studies have suggested that the impact on partners and caregivers may be even more devastating than on the patients themselves.[37]

Quality of life has been described as a variable measure of both functional status and patient appraisal of how a health condition affects enjoyment of life. As assessed and defined by standard instruments, quality of life has been found to be an independent predictor of response to treatment and survival time in women with advanced breast cancer. "Quite apart from potential survival benefits, enhancing quality of life by minimizing the physical and psychological impact of the disease and treatment side effects is an important endpoint in itself and should be the focus of health care for people with metastatic disease."[38]

One useful quality of life model proposes that "person factors" (demographics, self-efficacy, current concerns), "social factors" (family hardiness, social support), and "illness factors" (symptom distress, stage of disease, disease-free interval) are mediated by "appraisal factors" (appraisal of illness, uncertainty, hopelessness) to yield a sense of quality of life for both patient and family members.[39] According to this model, "Self-efficacy is defined as the amount of confidence that cancer patients have in their ability to manage the demands associated with their illness."

Originated by Lazarus and Folkman over 20 years ago,[40] this model suggests that "adjustment to a stressful situation is influenced by the characteristics of the stressful situation along with attributes of the individual, the individual's situation-specific cognitive appraisals, and the coping strategies the individual uses to manage the situation."[41]

Many theories have been set forth about what kinds of coping strategies enable women to successfully adapt to a diagnosis of advanced cancer. We will briefly touch on four of these here without going into the supporting research.

First, self-efficacy, as defined above. Second, a fighting spirit, defined as an optimistic but realistic appraisal of the illness, has been associated with lessened levels of anxiety and depression, but a sense of helplessness, anxious preoccupation, and fatalism were associated with increases in anxiety and depression.[42]

Third, a great deal of psychological research demonstrates that emotional suppression in the face of life-threatening illness, especially feelings of anger, sadness, and fear, is not a good way to cope, and doesn't represent good psychological adjustment. Many forms of psychosocial treatment, from individual counseling and support groups, to dance and music therapy, are founded on the belief that self-expression is fundamentally a healthy and life-affirming method of coping, even though at times it may mean experiencing painful or scary feelings. Expressiveness also can also enhance intimacy in relationships.

Fourth, research also strongly supports the adaptive benefit of the development and maintenance of strong social supports from all sources, from partners and other family members, from friends and community groups, and especially from other women with advanced breast cancer. Finding ways to overcome the isolation of illness and avoiding withdrawal into illness can make an important difference in how women feel.

Psychosocial Interventions

A substantial literature assesses the efficacy of psychosocial interventions in women with early-stage breast cancer. Women with advanced breast cancer, however, are facing very different prognoses, and this impacts their psychosocial distress as well as their overall qualities of life. Fortunately, some fairly rigorous studies have been done with these women to determine the impact of a variety of support programs and groups. Many forms of support ranging from relaxation training to structured cognitive-behavioral group therapy have been evaluated, some using randomized trials. This intensive interest was spurred by early provocative findings about extension of survival in women randomized to a year-long supportive-expressive therapy group.[43] While these survival results have not been confirmed in later trials, the other benefits of these approaches will be discussed.

The initial controlled trial, first published in 1981 by David Spiegel of Stanford, randomized 86 women to receive at least one year of weekly supportive-expressive group therapy or no treatment. By comparison with a control group that received no group therapy, the treatment group had improved mood and decreased maladaptive coping responses and phobias.[44] A pilot study of 24 women reporting pain with advanced breast cancer randomized to an intervention involving single sessions of individual training in relaxation and visualization plus cognitive-behavioral therapy vs. no intervention failed to show a difference between groups in pain or mood, although the treatment group showed an ability to decrease pain.[45]

Eight weekly sessions of cognitive-behavioral therapy, followed by three monthly sessions and a family meeting, were evaluated in a randomized trial of 121 women with metastatic breast cancer, showing improved mood and enhanced self-esteem at the end of therapy, but no benefits after 3 and 6 months, indicating that positive psychological effects of such treatments may be temporary.[46] In another study, 66 women were randomized to receive either a cognitive-behavior group with a coping skills weekend, and relaxation training, or a home cognitive-behavioral therapy package including a coping skills workbook, relaxation, and supportive phone calls five times over the course of a year. Despite some observed shortterm changes, investigators reported that systematic measurement of improved mood and increased coping was difficult.[47]

In a study, done with the intention of replicating Spiegel's initial findings, that showed a survival benefit, 125 women with advanced breast cancer were randomized to receive either weekly supportive-expressive group therapy for the rest of their lives or educational materials. While no survival data have yet been reported, the intervention significantly reduced traumatic stress symptoms, and if measurements from the final months of life were excluded, showed an improvement in mood. At least one other study has shown that, not surprisingly, psychological distress increases significantly prior to death.[48]

Finally, another larger randomized trial done to replicate Spiegel's initial findings, examined weekly supportive-expressive group therapy in 235 metastatic breast cancer patients, following a treatment manual prepared by Spiegel, which fosters support and encourages emotional expressiveness and confrontation of the effects of illness and change in self-image. This study did not find a survival benefit, despite being adequately powered to do so. However, the intervention did replicate the psychological benefits reported earlier, in that it enhanced mood, and reduced anger, anxiety, depression, confusion, and pain.[49]

The report, *Meeting Psychosocial Needs of Women with Breast Cancer*,[50] published in 2004 by the National Cancer Policy Board, the National Research Council, and the Institute of Medicine, found that these trials, along with observations in multiple non-randomized studies, "provide evidence of beneficial effects of a range of psychosocial interventions in both early and metastatic breast cancer. Notably, there is evidence for the benefit of relation/hypnosis/ imagery interventions in early-stage breast cancer, for group interventions in both early and metastatic breast cancer, and for individual interventions, primarily in the early setting. Although it needs strengthening, this evidence supports the conclusion that psychosocial interventions can be expected to reduce psychiatric symptoms and improve quality of life in routine clinical care of breast cancer."

Taking a broad look at psychosocial supports, our survey examines the use of, preferences for, and perceived value of a variety of support modalities including groups, one-on-one approaches such as "buddy programs" and hotline volunteers, individual counseling, and stress management techniques. Also, respondents' ratings of a variety of interpersonal relationships and common activities/interests which can be considered "informal" support are identified to determine whether they may contribute to psychosocial well-being.

Level of Support and General Use of Support Services

The women surveyed report high levels of support in their lives. Three-fourths (75%) of respondents consider their support "very good or excellent," 16% rate it "good," and only 9% categorized it as fair or poor. Closely paralleling the findings on information-seeking, a decided majority of women seek support frequently, with over two-thirds (68%) doing so on a daily (33%) or weekly (35%) basis. An additional 13% accessed support on a monthly basis.

However, more women report rare (16%) or no use (4%) of support services than of informational services (rare use: 10%; no use: <1%). The somewhat lower frequency of reported use of "formal" support services, by comparison with frequency of use of information resources, may be attributable to the ability of existing "informal" support (e.g. friends, family, religious or community groups) to provide some of the same benefits. Information about advanced breast cancer, however, cannot be easily or accurately provided by existing resources in women's lives.

Women seek support from a variety of sources for a variety of reasons, and at critical times in the course of illness. More than half of respondents access support for the following reasons: making a decision about or starting a new treatment (62%); having problems with treatment side effects (60%); experiencing a recurrence or a progression of their disease (59%); and feeling worried or sad (58%). Exactly half of these women also want help with coping when they feel alone with their cancer (50%). Fewer respondents seek emotional support, practical support, and coping tips when they're not well enough to do the things they find meaningful (38%); and less commonly when they're having problems with families, partners, and/or friends (26%).

It is important to note that information and support are both sought when women are dealing with treatment decisions, recurrences and progressions, and side effects. However, the majority of surveyed women access some form of support modalities, not information, to cope with general anxiety and dysphoria. Nonetheless, it is likely that information does provide women with "support" in a very specific way when they are faced with difficult medical decisions and situations. By providing answers to women's questions about advanced breast cancer treatment, side effects, and symptoms, knowledge itself may act as an intervening variable, moderating levels of distress, and restoring some sense of control.

However, the literature on coping mechanisms and information-seeking styles is complex and seemingly contradictory. The emotional component of threatening medical information can lead both to intensive information-seeking, known to theorists in this field as "monitoring," and to avoidance behaviors, known as "blunting."[51,52] Or, as humanistic psychologist Abraham Maslow once wrote: "We can seek knowledge in order to reduce anxiety and we can also avoid knowing in order to reduce anxiety."[53] The role of information in the adjustment to advanced breast cancer is a fruitful field for investigation, and the findings would be important in program planning and development.

Learning about the Experiences of Others

All women were asked if they found it helpful to listen to or read about other people's experiences with breast cancer. This opportunity presents itself in many situations, both through formal support modalities or through informal interactions with other women. A clear majority of women (69%) found this experience quite helpful, and 22% found it somewhat helpful. In fact, only 4% of all women in the sample did not find it helpful. Women also reported that they sought out support when they were "feeling alone with their cancer." Clearly, learning about others faced with similar challenges has a positive effect.

Healthcare Professionals and Support

All the professionals on the healthcare teams who treat women with advanced breast cancer have multiple opportunities to provide support and coping tips along with medical care and advice. If health care professionals routinely attended to mental health as well as to physical health, they could optimize psychosocial adjustment in a patient population that is likely to experience significant distress at certain key points after diagnosis.

Various tools are currently being evaluated for use in assessing psychosocial problems in medical settings, and the NCCN Distress Thermometer is one such tool. The Distress Thermometer is specifically designed for use in physicians' offices and clinics. It is easy to administer, with patients rating global distress on a ten-point scale. Brief questions in the areas of practical, family, spiritual, emotional, and physical issues identify the source(s) of distress. The development and suggested use of the Distress Thermometer supports the importance of medical staff attending to the total well-being of their patients. Administration of this quick measure brings the "whole person" into the office and encourages communication about often ignored issues. If difficulties are identified, referrals to appropriate resources and helpful coping tips can be provided during office visits, saving time and effort for patients and providers alike.[54]

Healthcare professionals can also provide support to women by honing their communication skills. Patients value practitioners who listen well, and with respect. Many medical schools are including courses on how to speak with patients because it is good medicine as well as good business. Listening to patients can contribute to better diagnosis, treatment, side-effect management and well-being, all of which are critical in the care of women with advanced breast cancer.

This survey assessed the frequency with which different types of medical professionals provided support, either as a byproduct of an empathic, involved communication style and a caring, respectful manner, or by suggesting helpful resources and strategies (see Table 3). Specific findings, by topic, include:

Supportive Communication and Professional Style

Medical oncologists and oncology nurses were viewed as engaging in behaviors that are considered supportive more frequently than other healthcare professionals. More women surveyed indicated that these particular categories of physicians and nurses took the time to address their concerns (medical oncologists, 75%; oncology nurses, 67%) and treated them with care and respect (medical oncologists 77%; oncology nurses 76%).

Mental health professionals (52%), surgeons (50%), and radiation oncologists (50%) were perceived as addressing concerns by the next largest numbers of women, but an equal number of respondents did not feel this way. Similarly about half of respondents felt that radiation oncologists (56%), surgeons (55%), and mental health professionals (54%) were caring and respectful in their patient interactions.

Surprisingly, mental health professionals were not viewed as caring, respectful, or taking time to address concerns much more frequently than surgeons and radiation oncologists. In fact, they were seen as engaging in those two supportive behaviors by almost one-fourth fewer women than medical oncologists and oncology nurses.

Active Interventions to Provide Support

- Again, medical oncologists and oncology nurses take the lead, with 27% in each profession, in reported referrals to support resources. However primary care doctors (27%) and mental health professionals (27%) also made these referrals with the same reported frequency.
- Surgeons (16%) and radiation oncologists (12%), although seen as supportive in their "bedside manner," did not often refer patients to needed resources for support. This finding can be better understood by considering the nature of the care they provide to patients. These specialists, unlike medical oncologists, oncology nurses, and primary care physicians, do not

Table 3: Areas in which Healthcare Professionals Provided Support

	SUPPORTIVE STYLE		ACTIVE SUPPORT		
Healthcare Professional	**Makes time to speak with me about my concerns**	**Treats me in a caring, respectful way**	**Referral to support resources**	**Suggests coping skills**	**Percent not seeing this professional**
Medical Oncologist	**74%**	**77%**	**27%**	27%	<1%
Radiation Oncologist	50%	56%	12%	15%	29%
Surgeon	50%	55%	16%	15%	23%
Primary Care Doctor or Internist	46%	53%	**27%**	17%	30%
Physician Seen for Second Opinion	4%	7%	13%	0%	44%
Oncology Nurse	**67%**	**76%**	**27%**	**48%**	6%
Nurse Practitioner	48%	52%	22%	30%	48%
Physician's Assistant	30%	33%	12%	17%	61%
Mental Health Professional	52%	54%	7%	51%	46%
Complementary and Holistic Practitioners	45%	51%	20%	41%	55%
Home Health Aide or Hospice Worker	16%	18%	8%	15%	4%

(Percents based only on those who saw that professional)

Table 4: Support Services: Usage, Importance, Ratings, and Availability

Support Modality	**Used**	**Considered Important Program**	**Excellent/Very Good**	**Good**	**Fair/Poor**	**Available**	**Don't Know if Available**
Stress Management Skills	**44%**	**71%**	**72%**	20%	8%	69%	23%
Support Group	**68%**	**78%**	66%	17%	17%	78%	12%
"Buddy Program" or Peer Network	22%	51%	69%	14%	18%	46%	41%
Hotline Volunteer Contact	15%	28%	64%	14%	23%	51%	43%
Individual Counseling	**36%**	**55%**	**72%**	19%	9%	71%	26%
Family or Couples Counseling	7%	26%	59%	25%	16%	57%	39%
Counseling for Children	9%	31%	71%	20%	10%	50%	45%
Guidance with Spiritual Issues	24%	52%	**78%**	17%	5%	68%	29%

(Program ratings are based only on service users) usually develop on-going relationships with patients that are focused on multiple medical issues. Instead, their relationships are more often time-limited and present fewer opportunities to get to know and treat the 'whole' patient.

- All oncologists and other physicians fare poorly in the area of suggesting coping skills to patients. In fact, none of these medical professionals provided this important support to more than one-fourth of women who had contact with them. However, almost half of respondents reported that oncology nurses provided strategies to help them cope.
- Slightly more than half of women with advanced breast cancer (51%) indicated that mental health professionals suggested coping skills, and complementary medicine practitioners provided this active support to 41% of the sample.

Cancer Support Organizations and Treatment Centers as Sources of Support Services

Cancer support organizations and treatment centers not only provide educational services and information, but also offer a variety of support services. Women with advanced breast cancer are likely to experience distress at some point after diagnosis. In fact, two-thirds of these respondents indicated that they were currently or had been depressed, and over half (52%) reported symptoms of anxiety and/or panic.

Table 3 summarizes survey data on use, perceived importance, knowledge of, and ratings for a variety of programs. These results share the trend first seen in the discussion of educational offerings, Again, more women perceive programs to be important than actually use them. Unfortunately, considerable numbers of these educated respondents are also unaware of the availability of support services in their communities or online. It was beyond the scope of this survey to analyze discrepancies in use and importance or to attribute this finding to their lack of availability or knowledge. As mentioned earlier, the difference between attitude and behavior may also account for these results. However, this area should be investigated to maximize the use of services by women who need them and to optimize the development of truly needed programs. The main findings in this data are described below.

Top Three Programs in Attendance and Importance

- Women most frequently indicated that support groups (78%), stress management skills (71%), and individual counseling (55%) were important in their coping. These programs were also attended most frequently, although support groups (68%) far surpassed stress management (44%) and individual counseling (36%) in this category.
- However, of these three programs, individual counseling and stress management received the highest ratings from more respondents (72% each), while support groups, considered important by most, received somewhat fewer highly positive evaluations (66%). Perhaps this is related to the individualized, tailored nature of counseling and stress management compared with the collective setting of a support setting where all needs must be accommodated.
- These three programs were available to the majority of women, yet about one-fourth did not know how to access either individual counseling (26%) or stress management programs (23%). This is an information gap that can have serious consequences for adjustment and quality of life, given reports of dysphoric symptoms.

Other Programs Considered Important

- Slightly over half of respondents indicated that "buddy programs/peer networks" (51%) and guidance with spiritual issues (52%) were important, and they were rated highly by many women (69% and 78%, respectively).
- Although considered important by the majority of women, these services, like the "top three" were accessed by considerably fewer women. Only one-fourth (25%) sought spiritual guidance and less than one-fourth (22%) made use of peer support.
- It is important to note that 41% of survey participants do not know if peer support services are available and therefore a considerable number of women cannot access a service they consider important.

Programs with the Lowest Rate of Use

- Family or couples counseling (7%), counseling for children (9%), and hotline volunteer contact (15%) were the least frequently used support options, and also were considered important by the fewest women.
- These three low use/low importance programs were rated positively by the majority of people who used them, although one-fourth of women only had a fair or even poor experience with hotline contacts.
- It should be noted that women frequently don't know where to access these "low use" services and there are women who did find them important (over one-fourth for hotlines and family/couples counseling; almost one-third for children's counseling). These numbers indicate a need for more information about these support resources as well as the others previously discussed.

Perceived Effectiveness of People and Activities as Sources of Support

Women living with advanced breast cancer often report that they are able to cope with the psychological and physical sequelae of their illness with the help of friends and family members who comprise their support networks. Also, people with life threatening diagnoses sometimes find that participating in certain kinds of activities can provide them with additional emotional support by enhancing spirituality; encouraging self-expression; or by offering the opportunity to be connected and of service to others. To assess the experiences of metastatic breast cancer patients and to understand the variety of ways these women use to cope, the survey specifically asked about these areas. The data are discussed below for both potentially supportive relationships and activities.

People

- Frequency of Use:
  - Siblings (85%), spouses/partners (82%), children (75%), and friends (74%) were the categories of people used by more women than any others.
  - Other relatives (69%) and parents (67%) provided support for more than two-thirds of women.
  - Support group members (65%), and other women with breast cancer (62%) also were accessed often by respondents. Surprisingly, a similar number of advanced breast cancer patients (64%) considered co-workers as a potential source of support.
  - The fewest respondents indicated that clergy (43%) and assigned "buddies" (39%) from breast cancer organizations were approached for support.
- Quality of Support:
  - Respondents were most satisfied with the support they received from spouses/partners (76%), "buddies" from breast cancer organizations (71%), and from siblings, friends, and support group members (71% each for these last three categories), rating the support they provided as "excellent/very good."
  - Contacts with other women with breast cancer (not including support group members) was also very well received, with 70% viewing them as excellent or very good.
  - Although not many women reported using a "buddy" for support, 72% of those who did, highly rated this interaction.
  - Support from children (61%) and parents (51%), though considered "excellent/very good" more often than not, did not receive this rating as often as the support provided by other family members, specifically spouses/partners and siblings. However, "other relatives" were seen as optimally satisfying support contacts by the fewest (39%) respondents of any category surveyed, family or non-family members. Only neighbors fared that poorly, with 40% of women giving their support the highest ratings.
  - Interactions with co-workers (60%) and clergy (54%) were highly positive sources of support for more than half of respondents who had contact with them.

Activities

- Frequency of Use:
  - More women by far turned to prayer (77%), pets (60%), and religious services (56%) for support than any other activities listed, including counseling, volunteering or advocacy work, and art/music/dance therapy. The latter activities were only engaged in by one-fourth of respondents.
  - Half of women did try books or printed materials, and over one-third (38%) sought individual counseling specifically focused on coping with cancer.
- Quality of Support
  - The top four most frequently used activities also received the highest ratings from more women. Prayer was judged an excellent/very good source of support by 73% of respondents; pets by 71%; and both religious services and individual counseling focused on coping with cancer by 68% of those surveyed.
  - Other activities mentioned in the frequency of use section were also very favorably viewed by approximately two-thirds of users. However, books and printed materials satisfied the fewest respondents, with slightly over half (55%) categorizing them as excellent or very good sources of support.

Support Group and One-on-One Experiences: Use, Preferences, and Value

There are numerous sources of support for people living with cancer. Because more programs have been developed for the newly diagnosed, for cancer patients in general, or for people with varied metastatic cancers, men and women who want support focused on a specific advanced cancer have even fewer options for direct support.

To guide cancer organizations and centers in the development of these greatly needed support services, this survey investigates the use, preferences, and experiences of women who have participated in either support groups or one-on-one support services, or in both.

Please note that in this report "support group" refers to any group for cancer patients, regardless of whether it is offered for advanced or primary breast cancer, online or in-person, or led by professionals or peers. Data are reviewed below with separate sections discussing women who have and have not participated in support groups. Both support group and one-on-one experiences are discussed.

Women who Have Been in Support Groups: Who Participated?

- More than three-fourths of women (79%) have participated in support groups. Analyses indicate no significant difference in participation by age, race, type of place living (rural/urban/suburban), or treatment status.
- Significant differences in participation were found in three variables: years living with advanced breast cancer; depression status; and ease of engaging in usual activities and routines. (See Table 5)
- Women who had been living with advanced breast cancer for the shortest period of time, were significantly less likely than other women to participate in support groups. This difference disappears after the one year mark.
- Women who had the most difficulty with daily activities and routines had much lower rates of support group membership, yet 50% still participated.
- Somewhat more women who had been depressed in the past reported support group experience than did women who had never been depressed or had experienced depression in the past.
- These differences merit investigation. While the reasons for less support group participation during the first year after a metastatic diagnosis are not clear, it may be very important for women to have the opportunity to be connected with support when they first find out their breast cancer has metastasized. Also, women whose daily routines are most impacted by their diagnosis may have a strong need for support and coping tips. If they are unable to access support and want it, programs to reach this sub-group should be developed.
- However, it should be noted that with the exception of women who had great difficulty in their daily lives, more women than not had been part of a support group, and these differences do not account for a good deal of the variability in who does and who does not participate.

Table 5: Medical Variables and Differences in Support Group

VARIABLE	IN SUPPORT GROUP	NOT IN SUPPORT GROUP	CHI SQUARE VALUE	SIGNIFICANCE
YEARS WITH ABC			**17.52**	**.001**
Under 1	**66%**	**34%**		
1-2	80	20%		
3-5	86%	14%		
6 and over	83%	18%		
DEPRESSION STATUS			**7.21**	**.03**
Never	77%	23%		
In the Past	**86%**	**14%**		
Currently	74%	26%		
EASE OF ACTIVITY			**10.96**	**.03**
Very Difficult	**50%**	**50%**		
Difficult	81%	19%		
Somewhat Easy	80%	20%		
Easy	76%	24%		
Very Easy	81%	21%		

(N=540)

Type of Group and Preferences for Group

Data on the 427 women who participated in support groups are summarized below:

- **Support Group Type**: Sixty-three percent were in in-person groups; 11% were in telephone groups; 50% participated in online listserv/mailing list support groups; 44% experienced bulletin/message board groups; 13% were in chat groups, and 6% could not specify the particular type of online support group they had joined. These women are comfortable with using computers and the Internet, and their broad use of the Internet for support as well as for information is reflected in their preferences.
- **Reasons for Seeking Out Support Groups**: The most popular reason for participation was to learn about the experiences of others with metastatic disease (87%). In addition, over three-fourths (79%) of women wanted information on advanced breast cancer and its treatments; general emotional support (77%); and to feel less alone (76%). Learning about how to manage treatment side effects (73%) and finding resources (72%) were also motivations for many support group users. It is very interesting to note that "feelings of anxiety and sadness", although a reason for over half of support group participants (53%), was the least frequently endorsed choice.
  - It is possible that women experiencing distressing emotions only endorsed "general emotional support" or other reasons listed on the survey for seeking out a group because those choices subsumed the category of anxious and depressed feelings.
  - It should be noted that there were practical and informational factors influencing women's decisions to be in a support group. Respondents with advanced breast cancer also sought treatment, side effect and symptom management information and practical resources.
  - The possibility that the informational component of support groups, in addition to the emotional support, strongly contributes to their popularity and their success in helping women cope with advanced disease is an important topic for future research.
- **Type of Group and Type of Leader Preferred**: Among "experienced" support group users, online formats (44%) were most preferred, with in-person groups a close second (38%). Telephone groups were not popular (2%), and 15% had no preference. Choices for type of group leader were clear, with the most frequent preference for a group with a nurse or mental health professional as a leader (36%). Less than one-fourth of women selected groups led by a breast cancer survivor (20%) and leaderless groups (21%). Twenty-three percent had no preference. The preference for a professional group leader may apply only to in-person groups. Online support groups may or may not be moderated, but many, if not most, do not have health care professionals as moderators.

Ratings of Support Groups by Participants:

- **Informational Value:** Two-thirds of women rated the value of their support group in providing them with information about advanced beast cancer, treatments, side effects, and practical resources as "excellent or very good". Another 17% felt that the groups were "good" in this respect. Only 17% were dissatisfied (fair or poor ratings).
- **Support Value**: Similarly, almost two-thirds of women (65%) felt that groups provided an "excellent or very good" experience in terms of providing emotional support and coping tips. Also paralleling informational ratings, another 19% felt support was "good" and only 16% felt it was "fair or poor".

One-on-One Peer Support Experiences of Women who Have also Been in Support Groups

- **Use**: Among the 427 women who were in support groups, only 19% also used one-on-one modalities such as volunteer telephone hotlines, helplines or other types of peer support. However, when the women who accessed both types of support were asked which they preferred, two-thirds (67%) indicated that their preference was dependent on the situation. In contrast, only 20% preferred support groups across the board and 13% peer support.
- **Ratings**: Among users, ratings of the efficacy of one-on-one peer support in providing information about advanced breast cancer treatment, side effects, and symptoms were positive with 60% judging it "excellent or very good", and an additional 22% describing it as "good." Similarly, almost two-thirds (65%) of women were very pleased with these services ("excellent and very good" ratings), and an additional 22% rated them "good." Participation was considerably lower, however.

Although women with advanced breast cancer used one-one-one peer support much less frequently than support groups, among those who accessed this type of support, ratings of its informational and support value were very similar to those received by groups. It is important to keep in mind as well that these ratings were made by women who had experienced both types of support.

- **When Women Prefer One-on-One Support**
  - Those women who have experienced both group and one-on-one support choose to use one-on-one services when they have immediate needs for support or information. More specifically, women use one-on-one support when they are either anxious and/or have a problem and want help now.
  - Other women stated that they used one-on-one services when they wanted to be in contact with someone with a diagnosis of advanced breast cancer because they didn't have this opportunity elsewhere.
  - Some respondents reported that the anonymity of the phone was desirable and facilitated discussion of personal issues.

One-on-one phone support does provide a human touch for shy or private women in a less threatening environment than in-person groups. It should be noted here that the common practice of "lurking" in online mailing lists or bulletin boards may also help shy people feel in contact with others.

- Two additional reasons for choosing to use one-on-one support were: (1) the ability of newly diagnosed women who were anxious and worried to connect fairly quickly with another woman with advanced breast cancer; and (2) to get support before they were in a support group. Often, these women were given referrals to groups during their phone contacts.

Women who Have Not Been in Support Groups

Less than one-fourth (22%) of respondents had not participated in any form of support group. As mentioned earlier, accessing groups was seen in fewer of the women living with advanced breast cancer for less than one year, and fewer of the women with the most difficulty maintaining regular activities access groups. However, it is worth repeating that, despite these differences, more women than not participate even during the first year of diagnosis and only half of women reporting high levels of difficulty maintaining routines/activities also join some sort of support group. The experiences and preferences of these women are summarized below:

- **Reasons for Non-Participation**
  - The most frequent reasons given for not joining a support group could be categorized as "psychological". More than one-fourth (29%) of women felt they were too private for this modality and an additional one-fourth (25%) believed that participation would "be too upsetting for me."
  - Women (21%) wanted groups composed of only advanced breast cancer patients and "there are no support groups like this."
  - Lack of knowledge about where to find a support group (13%) or about what support groups are like (8%) was a deterrent as well.
  - Ten percent (10%) reported that they didn't feel well enough to participate.
  - A variety of practical barriers (childcare issues; transportation, no computer) were only endorsed by 5% as a reason for non-attendance.
- **Preferences:** Of those who had not been in a support group, more women said that they would prefer an in-person group (46%) than any other type of group. Twenty percent selected an online group, while only 5% chose telephone groups. It is interesting, but understandable, that almost one-third of non-participants in support groups (30%) didn't know which type they would want.
- **Experiences with One-on-One Peer Support:**
  - More than three-fourths (79%) of women who did not take part in support group also did not make use of one-on-one peer support. Twenty-one percent did access this service, paralleling the findings in this area for women who have been in support groups. Further study would be required to see if these choices characterize a group of women who are avoidant about seeking both information and support, for whom other kinds of services might be helpful.
  - Because so few women (N=23) used this type of support, percents will not be reported for ratings, however more women than not were satisfied with these interactions as sources of information and support.

In summary, surveyed women with advanced breast cancer:

- 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 metastatic 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 advanced breast cancer.
- Find that different members of the healthcare team provide support in different ways.
- Attend face-to-face and online support groups in large numbers. Support groups are used less often by women who have been living with advanced breast cancer for the shortest time, or who have difficulty maintaining their regular routines.
- 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 were 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.
- Revealed that the frequency of use of a support modality does not necessarily correspond to quality of support. "Buddies" from breast cancer organizations were used by the fewest women but received the highest rating. Fellow support group members also were highly valued but used less often than other contacts.
- If choosing not to participate in a support group, do so most frequently for "psychological" reasons.
- Prefer online groups, with in-person groups a close second. However, women who had never been in a support group prefer in-person groups, perhaps because of their anxieties about this activity.
- 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.
- Rate the informational and support value of one-on-one modalities similarly.

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

For women with advanced breast cancer and their families, practical concerns often take an inordinate amount of time and energy. Navigating the complex tangle of medical bills, insurance claims, Medicare and Medicaid eligibility, public and private disability programs, and other financial issues can become an overwhelming task, consuming precious time and energies when both are scarce. Applying for patient assistance programs and for help with co-payment for newer treatments that can cost many thousands of dollars per month can cause additional stress for patients and families. Seeking the best sources for medical second opinions and referrals when needed is an additional practical issue, including help with the process of securing patient records, scans, and test results, etc. that such second opinions require. Information about job security and disability retirement, and the legalities governing these issues, represents another important area. Finally, in the later stages of disease, there is often an increased need for household help and assistance with maintaining functions and roles normally performed by the patient and also the partner/spouse who may be working full time, while maintaining a semblance of normal family life, as well as caring for the ill wife or partner, offering transportation to appointments, helping to deal with the medical team, and doing childcare, housecleaning and shopping, and the like. Clearly, practical concerns play a large role in the day-to-day challenges of living with advanced breast cancer.

Services addressing these types of more practical concerns are offered less frequently than educational and support services. Hospital social workers offer help to patients in some of these areas, while other services, like referrals for second opinion consultations, may be much more difficult to find. Housekeeping and childcare services generally must be provided by the patient's own family, at least until hospice home services may offer some help and respite care. In general, our survey shows that women with advanced breast cancer are not aware of the availability of services. Given the important caretaking and household roles that women typically play, it would not be surprising to learn that some would feel ambivalence about asking for help.

We assessed the role that practical resources play using a format similar to the one we used for information and support issues.

Cancer Support Organizations and Treatment Centers (see Table 6)

Importance

- The top three services in terms of importance focused on getting health care and paying for health care. Disability options, eligibility, and benefits available were also considered most important. More than one-half of respondents shared these priorities. The percentage of women considering these services important are all as follows:
  - Referrals to physicians and cancer treatment centers: 72%
  - Information on health insurance: 67%
  - Information about Medicaid, Medicare, and disability: 56%
- Services to deal with concerns about finances and employment were the second highest area of program importance, but they were endorsed by considerably fewer women than the top three:
  - Financial assistance with medical needs: 49%
  - Assistance with employment issues related to cancer diagnosis: 42%
- Areas related to receiving help with practical tasks were least valued by these women, and viewed as important by approximately one-third of them.

Use of Practical Services

- Consistent with informational and support programs, practical services were used by fewer women than the number judging them to be important.
- However, the three most important programs were the three used by the most respondents:
  - Referrals to doctors and cancer treatment centers: 46%
  - Information on health insurance: 32%
  - Information on Medicaid/Medicare/disability: 30%
- Few women used the other services.
- Of special note, the fewest women (3%) received help with childcare, and this service is not included on Table 6 because there were too few responses. This finding is consistent with the information and support data previously reviewed. Educational programs on parenting issues and counseling for children were also the least used services, and were not considered important by the majority of women either.

Knowledge of Availability of Practical Services

- It is likely not a coincidence that the services that most women know are available in their community or online are the most used services, and the services women do not know about are the least used.
- This apparent relationship between availability, knowledge of availability, and use may also reflect importance. That is, breast cancer organizations and treatment centers focus on providing the services that women consider most critical.
- Still, as with education and support services, but to an even greater extent, it is striking that so many of these educated information seeking women do not know if many of these services are available.

In summary, surveyed women with advanced breast cancer:

- Use practical services less than educational and support services.
- Most often use and value treatment-related practical resources, including help with public/private insurance to pay for care, 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. However, some of these services were not considered important by many women either. Future research to determine if this trend holds true across relevant medical (e.g. level of physical impairment and/or pain) and demographic variables (e.g. living with others or alone) would be important.

Table 6: Practical Resources: Usage, Importance, Ratings, and Availability

Services	Used	Considered Important Program	Excellent/ Very Good	Good	Fair/Poor	Available	Don't Know
Information about Medicaid/ Medicare/ Disability	30	56%	44%	21%	25%	54%	38%
Information on Health Insurance	32%	67%	43%	29%	24%	57%	35%
Assistance with Employment Issues re: Cancer Diagnosis	22%	42%	51%	24%	25%	37%	52%
Referrals: Doctors & Cancer Treatment Centers	46%	72%	72%	19%	10%	61%	33%
Financial Assistance: Medical Needs	14%	49%	38%	17%	47%	33%	56%
Financial Assistance: Other Needs (ex. Child Care)	5%	20%	40%	8%	52%	23%	68%
Home Healthcare from Aide	6%	30%	46%	21%	33%	40%	55%
Help Driving to and from Appointments	16%	34%	53%	24%	24%	30%	58%
Help with Laundry/ House-Cleaning	10%	34%	69%	17%	13%	30%	58%
Help Shopping, Errands, Meals	11%	30%	76%	17%	7%	32%	57%

(N=618; program ratings are based only on users)

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

All women were asked how they would like to receive services, and about perceived barriers to accessing desired services. These data are important for program development, and should be considered along with other variables affecting attendance including knowledge of program availability, program content, and the interaction between support and education in providing an optimal experience for women coping with advanced breast cancer.

Preferred Delivery Methods

- **Education/Information:** Half of women (50%) preferred online presentation in this area. In open-ended responses, they indicated that they liked the constant availability of information, and also appreciated the fact that they could print it out and re-read it as needed. The desire to "hold on" to information may account, in part, for the second choice (31%) of informational presentation style: written materials. In-person came in a poor third (15%), and this rating may account in part for the poor attendance rate at conferences relative to the high quality ratings they receive.
- **Support Services**: More than half of women (55%) wanted in-person support. This finding is consistent with the preferences of women who have not been in support groups, and is reflected in the 63% of support group users who had attended in-person groups. However, experienced consumers of both one-on-one and group support formats, as a segment of the sample, had a slight preference for online rather than in-person groups (44% and 38% respectively). Further research is needed to understand these somewhat inconsistent findings because many variables determine support preferences. In this case, one critical dimension is the lack of availability of in-person support groups composed only of women with advanced breast cancer whereas dedicated online support for metastatic breast cancer patients is available.

A growing literature points to benefit for online support groups.[55, 56, 57, 58, 59] Perhaps, in addition to the other elements of psychosocial support discussed elsewhere in this report, another mechanism may be suggested by evidence from the work of James Pennebaker, University of Texas, Austin, who has extensively studied the mental and physical health benefits of the formation of narrative through expressive writing.[60] Although he has not specifically researched online support groups, Pennebaker's findings may well apply to women telling their stories through written messages online. Further research should help to clarify whether those who participate in various forms of online support derive as much as or perhaps even more benefit from their participation as do women who participate in in-person groups.

An important issue here that lies beyond the scope of this report concerns the relative effectiveness of peer self-help in the form of online groups, many of which are unmoderated (at least by mental health professionals), and in-person support groups, which are usually led by trained facilitators like oncology nurses, social workers, psychiatrists, psychologists, and counselors. While we surveyed women with advanced breast cancer about their preferences for group leadership, we did not inquire into this issue in any depth. Yet in the lives of many women with advanced breast cancer, the parallel paths of professional support services and self-help groups clearly interact in ways deserving of further study.

- **Practical Services:** A clear majority of women (53%) prefer online access to practical resources and services. Written materials on these areas (e.g. insurance issues, referrals to physicians) are a strong (33%) second choice.

Barriers to Accessing Programs and Services

- Consistent with findings described throughout this paper, the most frequent obstacles to accessing services of all types are women's lack of awareness of the types of services available (45%); not even knowing where to look for specific services (34%); and known lack of availability in their community (31%). All other reasons combined are only seen as barriers by 29% of women, and include transportation difficulties, childcare problems; poor health; and no computer/Internet access.
- These findings have serious implications for cancer treatment centers and non-profit organizations that offer services to women with advanced breast cancer. In addition to developing and offering targeted programs for this population, adequate planning and resources must be devoted to disseminating information about existing services and other marketing efforts. Resource guides would be very valuable in this regard.
- It is worth noting that these women are highly educated, knowledgeable consumers of services and still do not know enough about available services and how to find them. This barrier will likely be much more significant in other groups of women with advanced disease.
- Existing barriers for older, non-English speaking, poor and/or less educated women from culturally diverse backgrounds cannot be overstated, and it is hoped that this effort to survey women with advanced breast cancer will be a stimulus for further efforts to understand the needs of these different populations.

Psychosocial Aspects of Service Use

This survey included questions designed to gather preliminary data on the situations which motivate women to seek information, support, and support groups specifically (see Table 7).

Based on the entire sample, women most frequently seek information (65%) when they are making decisions about starting a new treatment, although an almost equal number (61%), and the largest percent in this category of service, rely on emotional and practical support for this as well. Importantly, among women who have participated in support groups, more than three-quarters (79%) of them describe using support groups when they want information about treatments. Participants also use support groups to learn about resources (72%), another informational need. This trend suggests the inseparability of information and support, and the 44% of women who seek information when they are "worried or sad" lends additional credence to the usefulness of services across domains.

Respondents report:

- That a high percentage (87%) of women in support groups sought them out to learn about the experiences of others with advanced breast cancer;
- That fewer women sought out support groups for anxious and/or sad feelings (53%);
- That the highest percentage of women sought out varied assistance (emotional and practical support as well as coping tips) when they were worried or sad. However, the exact nature or combination of the services they sought could not be determined from the data;
- That over three-quarters of support group members also participated in them for general emotional support (77%) and to feel less alone with their cancer (76%);
- That getting side-effect and symptom information was also a frequent use of support groups by women who had participated in them (73%); however, over half (56%) of all women met this need through directly seeking information.

Additional analyses were conducted to determine the impact of the use of information and support on anxiety, depression, pain, nausea, fatigue, sexuality, and changes in appearance, symptoms often positively affected by educational and psychosocial interventions. The results indicated significant positive effects, with the women who were most highly informed and highly supported experiencing these difficulties with less frequency. These results are detailed below.

Table 7: When Women Seek Information, Support, and Membership in Support Groups

Situations in which women are most likely to seek information		Situations in which women are most likely to seek emotional support, practical support, and coping tips		Reasons women seek out support groups	N=427
When there is a recurrence or progression of their breast cancer	61%	When there is a recurrence or progression of their breast cancer	59%	To learn about the experiences of others with advanced breast cancer	87%
When making decision about starting a new treatment	65%	When making decision about starting a new treatment	61%	For information about advanced breast cancer and treatments	79%
				For general emotional support	77%
		When feeling alone with their cancer	50%	To feel less alone with my cancer	76%
When having a problem with treatment side effects or discomfort from the cancer	56%	When having a problem with treatment side effects or discomfort from the cancer	60%	To learn about managing treatment side effects and cancer symptoms	73%
		When having problems with family, partner, or friends	26%	To learn about resources for people with advanced breast cancer	72%
When feeling worried or sad	44%	When feeling worried or sad	58%	For help with feelings of anxiety or sadness	53%
		When not well enough to do the things that are meaningful to them	38%		

(Support group percentages are based only on respondents who participated in them; other percents are based on all respondents surveyed)

Relationship between Perceived Levels of Knowledge and Reports of Symptoms

Anxiety

- Among women who have the highest level of knowledge of advanced breast cancer, 81% are not anxious, and 44% report never experiencing anxiety since their diagnosis.
- Strikingly, only 19% of women with the greatest knowledge of their disease report feeling anxiety at this time.
- In contrast, more than half of women reporting the lowest level of knowledge of advanced breast cancer are currently experiencing anxiety (57%) and one-third of women with the second poorest level of knowledge report anxiety at present.

These findings demonstrated statistical significance: (X2=30.08; *p*<.001)

Clearly, information about advanced breast cancer serves to "inoculate" these women against anxiety. For some women, knowing what to expect may be a good antidote to fear.

One leading theory about this suggests that seeking knowledge is strongly driven by an imperative for what is termed "uncertainty reduction." In the face of threat, people have a drive to reduce uncertainty to make the world more predictable by learning facts about a threatening situation.[61,62] The implications of this finding for program development are crucial. Educational conferences and workshops are vital for reducing anxiety. Education of healthcare professionals regarding the protective effect of knowledge against anxiety is also very important.

However, not all women with advanced breast cancer will respond to offers of information positively. Some research suggests that up to one-third of patients avoid or choose to distract themselves from threats they perceive as uncontrollable.[63]

Depression

- Among women with the highest level of knowledge, almost three-fourths (73%) are not currently depressed and more than one-third of those have never been depressed since diagnosis. Only 27% are living with depression at this time.
- In sharp contrast, more than two-thirds of women (64%) with the least knowledge of advanced breast cancer are currently depressed; an additional 13% were depressed (for a total of 75%); and only one-fourth have not experienced depression since diagnosis

These findings demonstrated statistical significance: (X2=26; *p*<.001)

Knowledge also appears to be related to depression. Whether knowledge protects against dysphoria, or whether less depressed women have the energy to seek out more education cannot be determined. However, the percentage of women suffering with this problem decreases as self-reported knowledge of advanced breast cancer goes up.

Fatigue

- Half of women reporting the highest level of knowledge about advanced breast cancer report fatigue (53%), while almost one-half (47%) either never experienced fatigue (11%) or had this symptom in the past (36%).
- Among women with the least knowledge of advanced breast cancer, 82% report having fatigue now, while only 18% are fatigue-free.
- Women with moderate information fall in the middle of these two groups, with 70% currently fatigued, and approximately 29% not fatigued.

These findings demonstrated statistical significance: (X2=16.89; *p*=.01)

The explanation for the finding is not clear from this analysis. Fatigue may be related to depression; alternately, women who do not experience fatigue may spend more time educating themselves about their diagnosis.

In summary, there are differences in reports of anxiety, depression, and fatigue among groups of women living with metastatic breast cancer based on their perceived levels of knowledge of their disease. Women with the most knowledge are less likely to have ever experienced or be currently living with these symptoms and side effects of cancer and its treatment.

Relationship between Perceived Levels of Current Support and Reports of Symptoms

Anxiety

- Women living with advanced breast cancer who report the highest level of current support are less anxious than their peers with less support:
  - A considerable number of these women have not experienced anxiety at any point (42%).
  - Of the 58% of women who have experienced anxiety, only 21% are currently anxious, while 37% no longer have this problem.
- Among women with metastatic breast cancer who report the lowest levels of current support, a greater number (44%) are currently living with anxiety.

These findings demonstrate statistical significance: (X2=16.18; *p*=.01)

Depression

- Only 28% of women with the highest level of support are currently depressed, compared to almost two-thirds (65% of women) with the lowest level of support.
- In fact, over one-third of the women who had the highest (34%) and second-highest levels (39%) of support never experienced depression since diagnosis with ABC.

These findings demonstrate statistical significance: (X2=28.81; *p*<.001)

Pain

- There is a significant difference, too, in the number of women with different levels of support having pain at present.
- Thirty-nine percent (39%) of women with the most perceived support report current pain; however, 71% of women with the least support are currently reporting pain as a symptom.
- High-support women also are more likely never to have had pain since diagnosis (28%), while only 7% of low-support women did not.

These findings demonstrate statistical significance: (X2=21.04; *p*<.01)

Sexuality

- Sexual problems after diagnosis also vary by level of support.
- Although almost half (48%) of high-support women report current difficulties, a slightly higher percentage (51%) have either never had sexual symptoms after diagnosis (34%) or these problems have resolved (18%).
- In contrast, 69% of women with the lowest level of support currently have these issues, and slightly less than one-third of these women (31%) have either never had sexual side effects (21%) or have had them in the past but are no longer experiencing them (11%).

These findings demonstrate statistical significance: (X2=14.31; *p*=.03)

Issues/Problems with Appearance (Other than Hair Loss)

- While 62% of high-support women do not report difficulties in this area (having either resolved or never experienced them), less than half (43%) of low-support women have not experienced (27%) or are no longer (16%) living with this challenge.

These findings demonstrate statistical significance: (X2=18.76; *p*=.01)

In summary, surveyed women with advanced breast cancer:

- Use information and varied support modalities to learn about treatments and side effects.
- Find support in the use of information, and information in support programs.
- Are very interested in learning about the experiences of other women living with metastatic disease.
- When studied by use of information and support services, have less difficulty with anxiety, depression, and fatigue. When they report the highest levels of knowledge about advanced breast cancer, less frequently report anxiety, depression, pain, sexual difficulties, and issues with appearance when they report the highest levels of support.
- Reveal a trend toward an as yet unspecified relationship between the benefits of information and support on particular areas of need that merits well-designed study.
- Experience fewer negative effects in the areas of distress, pain, fatigue, sexuality, and concerns about their appearance if they report high levels of knowledge and/or support. Again, this important relationship needs to be understood and investigated in future research projects.

8. Developing Services for Women Living with Advanced Breast Cancer

This section suggests ideas and trends that should be considered when planning and developing new services for women living with advanced breast cancer. Suggestions for program development will focus on:

- General trends and preferences that are applicable to services across the board;
- Preferred modalities for service delivery;
- The appeal of one-on-one support among women who have also used support groups;
- Specific strategies for website programming;
- Telephone and in-person educational offerings;
- Written materials;
- Professional education and dissemination of findings;
- Valued services: educational, support, and practical resources.

General Trends and Preferences

These findings and implications are reported to inform the development of all service types, and are not specific to any particular program or initiative.

Support services need an informational component and conversely, educational/informational services require a support component.

In-depth analysis of surveys suggests that valued educational services provide information in a supportive environment and style to enhance the ability of women to process and cope with complex and sometimes anxiety-provoking communications. Similarly, effective support programs also inform and educate women about their diagnosis and its treatment to facilitate coping, feelings of competence, and better quality of life.

In fact, 79% of women attend support groups for the informational value, comparable to the 77% who attend for the emotional support. More specifically, 73% want information on managing side effects and symptoms, and 72% want to learn about resources.

Suggested ways to use this information in program development and service delivery:

- Keep in mind that educational products (i.e. teleconferences, conferences, booklets, and networking events) are opportunities to provide women with the emotional support they need. This support can be conveyed through language, specific formats, or through connecting women with each other and/or healthcare professionals.
- Offer networking events using recordings of past teleconferences and have an oncology nurse and oncology social worker "listen" with small groups of women. Before the event, the nurse can introduce the topic and identify herself as a resource for the program. After the talk is over, the nurse can lead a question-and-answer period. Following this, women can interact informally and exchange contact information.
- Booklets with educational content should have a support chapter or support content interspersed throughout the publication.
- For organizations with telephone hotline programs, volunteers can provide women who call for emotional support with resource information for metastatic breast cancer. Similarly, when women call for resources, they can be given the name of a local or national support group (online, etc.) to take care of emotional needs.

Supporting the previous finding, the reasons why women seek information and support are similar.

Women living with advanced breast cancer seek information when making treatment decisions (65%); when they have a recurrence (61%); and when they are having difficulties with treatment side effects or cancer symptoms (56%). Similarly, 61% of women seek support when making treatment decisions; 59% when diagnosed with a recurrence; and 60% when having problems with treatment side effects and cancer symptoms. However, more than half of women (58%) seek support when they are worried or sad, while fewer (44%), though not a small group of respondents, turn to information when they experience those feelings. Feelings of loneliness (50%) also motivate women to seek support. Clearly, support and information/education have overlapping functions, but support services add another dimension that assists women in coping with the complex and difficult emotions associated with a serious illness.

Suggested ways to use this information for program development and service delivery:

- Although the need for overlap between education and support functions is strong, support services provide benefits that education/information do not. For this reason, it is important that all planned services address the anxiety and isolation that women with advanced breast cancer experience.
- Opportunities to do this could take the form of:
  - Developing booklets focused on emotional issues and coping;
  - Developing educational networking events focused on teaching coping and stress management techniques for these women, perhaps co-led by health professionals and peer volunteers who are living with advanced breast cancer;
  - Developing a separate and demographically diverse volunteer helpline devoted specifically to the needs of women with advanced disease.

Women do not know if crucial services are available to them, despite their interest in using educational, support, and practical resources.

Survey respondents reported on their knowledge of the availability of educational, support, and practical services in their community and online. It was striking to discover that these well-educated, Internet-savvy women, who tend to be more well-informed than their less educated peers, reported large gaps in their awareness of the types of services that were available to them in their communities or online. Women knew the least about access to practical information and resources, with more than half of patients responding "don't know about availability" to many areas in this domain. In the area of educational programs one-third or more of women did not know where to find eight out of ten important informational offerings. There were also many women who were not knowledgeable about the availability of support services, with percentages ranging from 23% to 43%. Support group availability was the exception; only 12% of women living with advanced breast cancer did not know if these were available in their community or online.

Suggested ways to use this information in program development and service delivery:

- Posting resources on the web, and widely disseminating the URL, enhancing access by making it prominent to Google and other Internet search engines;
- Sharing resources and materials developed for women with advanced breast cancer with other cancer organizations and cancer centers. Look into forming cooperative alliances and seeking funding to create models that can be individually "branded" without being re-developed by each center, as primary breast cancer resources have been;
- Making sure that websites and printed materials list organizations that can refer people to "practical services," especially financial assistance programs and means of financing needed care, help with domestic tasks including childcare, and employment issues;
- When scheduling breast cancer teleconferences, conferences, and networking events, devoting some part to a focus on specific issues faced by women living with metastatic breast cancer, especially diagnosis-specific information; clinical trials information; updates on new treatments and research; and current treatment options;

- Use the stated preferences for topic areas from this survey as a guide for program planning;
- The above services, as well as any other informational and support services developed for women with advanced breast cancer, should be presented on websites separately from other services/programs and clearly labeled: "For women living with advanced or metastatic breast cancer." We cannot stress enough the importance of letting these women know that their distinct needs are recognized, and identifying any programs/services for them as dedicated only to women with advanced breast cancer;
- Organizations and cancer treatment centers should consider strengthening their identity as organizations that are committed to, knowledgeable about, and innovative in the development of programs for women with advanced breast cancer. This will increase the utilization of existing programs and services for this population, as well as attracting funding to develop additional initiatives.

Women living with advanced breast cancer want services targeted to them, not to all women diagnosed with breast cancer. Similarly, young women with advanced breast cancer and newly diagnosed women with advanced breast cancer want to participate in or be educated about programs designed for women who are "like them."

Throughout the survey, in responses to open-ended questions, women reported needing the support of women with advanced breast cancer, and unsuccessfully seeking specific information about the complexities of living with this metastatic illness. Clearly, the emotional and medical challenges faced by these women are very different from women whose breast cancer is not advanced. As previously noted, support for these women also involves the sharing of information, and this need cannot be met by people with other cancer diagnoses or women with diagnoses of early-stage breast cancer.

In fact, although women prefer in-person support, even when groups are available in their community and there are no structural barriers to attending them, women go online for support, their second choice modality, because in-person groups are generally composed of mixed breast cancer diagnoses or all cancer diagnoses. Although women give up the benefit of being in the company of others, in online support situations they feel understood and are able to get the support, information, and resources they need because the other participants "have been there, done that."

Similarly, younger women (under 40) with advanced breast cancer have different developmental concerns than their older counterparts. Areas of concern include dating, fertility, career issues, childcare, and facing a life-threatening illness at an early age. There is a strong need for the development of services for this cohort of metastatic breast cancer patients, and for them to receive support from peers.

Newly diagnosed women with metastatic breast cancer, regardless of age, express strong feelings of anxiety and an urgent need to connect with someone who has been living with advanced breast cancer for a longer period of time. They want reassurance, information, and a look at what lies ahead. In fact, when these women are able to connect with someone who shares their diagnosis, they choose to reach out quite rapidly. This contact is critical, and seems to serve as an important first step in enabling women to move forward with gathering information and making decisions about their illness.

Suggested ways to integrate this information into program development and service delivery:

- Services applicable to advanced breast cancer, including education, peer support, written materials, and websites, should be clearly labeled as such and clustered together in a separate web section;
- Separate educational materials, conferences, and networking events should be developed for young women with advanced breast cancer;
- A similar approach should be used for newly diagnosed women, with materials targeted to this anxious and information-hungry group. Material for this group, as for all advanced breast cancer patients, should be both educational and supportive. Importantly, organizations and cancer centers should consider offering the services of one-on-one peer volunteers who can speak with newly diagnosed women, or at least contact them to set up another time to connect, within 24 hours after the hotline call. Only helpline volunteers with advanced breast cancer should work with this population;
- Women with advanced breast cancer who use an organization's services could be offered the opportunity to volunteer by providing contact information on either the website or on a form at an educational event or in a publication. Date of diagnosis and age information could be requested in order to develop a coterie of volunteers who themselves are "young women" and/or are "newly diagnosed";
- Organizations should strengthen their collaborations with other organizations that may already be providing specialized services for targeted populations, like young breast cancer patients, Latina and African-American patients and others, so as to expand services available to all women living with advanced breast cancer. Organizations could pursue the possibility of seeking joint funding to further develop advanced breast cancer sections on their sites, with specific focus on content as appropriate for each organization.

Preferred Modalities for Service Delivery

Women surveyed prefer in-person support (55%), although one-third prefer online support. Online educational services are the service delivery method of choice for half of respondents, and written materials, their second choice, were preferred by almost one-third of women. Practical information and resources perfectly paralleled the educational preferences with 53% selecting online access and close to one-third preferring written resources.

- Women prefer in-person support services, but tend to use online support services for a variety of reasons including the lack of support groups specifically for metastatic breast cancer patients, the distance to an appropriate group, and schedule conflicts. Online support groups such as mailing lists (listservs) and bulletin boards offer asynchronous communication that may actually increase involvement for women who have to cope with side effects and symptoms of their disease. Being able to choose the time of involvement and come and go without leaving the group or losing the support of its members is an important feature of online support. In large online groups, members can often post their messages at any hour of the day or night and find someone who will respond within minutes.
- Online groups are also selected for the breadth of information and the broad experiences that come from a large, diverse group of women. When hundreds of women participate in such a group, any given side effect, symptom, or manifestation of disease is likely to have been shared by others, and archived messages can be searched for personal accounts. For the many women who prefer to "lurk" (not sharing directly with the whole group), corresponding privately with a few others, or simply reading the experiences of others can be comforting and informative. For others, the comfort of anonymity which some women find facilitates opening up "strangers"; and the combination of online group participation with one-on-one emails or phone calls to other online group members "personalizes" online support.
- Women prefer educational services online because they are available at any time, day or night, and are (ideally) kept up to date. However, women print out the information they want, so online information functions as a form of customized "written materials" as well. Although in-person education was selected least often, women saw definite advantages in this modality; namely, that in-person education offers them the opportunity to ask questions, and get immediate answers.
- Practical resources online were preferred by half of participants.

Suggested ways to integrate this information into program development and service delivery:

- One-on-one telephone support through a volunteer network may be important. Use of a helpline or hotline for support provides women with the opportunity to ask questions, and have them answered quickly, another valued program attribute. For many, phone is more personal than the Internet, and the matching aspect of a helpline or hotline ensures that women will speak with someone with a similar diagnosis and age. Of course, volunteers must be trained to answer the most common questions and issues presented by newly diagnosed patients. But their most important function may simply be to serve as a role model of someone coping well with a diagnosis of advanced breast cancer;
- Because having questions answered is so important to the emotional well-being and educational needs of these women, a well-developed series of FAQs (frequently asked questions) across all services including websites, educational programs, written materials, and other products and services should be created. In addition:
- Having a teleconference devoted to frequently asked questions, and responded to by a panel of multi-disciplinary experts, would be welcomed. Programs could focus on popular topics such symptom management, pain management, stress management, and new treatment options;
- Having a place on the website for visitors to ask questions, and responding to a select number of representative questions each month, is another way to meet this need. This section could be a "monthly feature" on the advanced breast cancer section of the website;
- Networking events and conferences can feature question and answer periods, and at conferences, where there are break-out sessions, one such session could be devoted to "Ask the Experts";
- Booklets targeted to specific populations such as newly diagnosed, or young women with advanced breast cancer, or focused on one topic such as clinical trials or pain management, can be written in a question and answer format;
- Professional education about the importance of offering population-specific support groups for women with metastatic disease should be a priority. If more groups for women with advanced breast cancer were offered across the country, women would gladly attend. Separate groups should be created for newly diagnosed and young women whenever possible;
- Because women prefer online educational materials, but prefer reading this information offline, user-friendly printing formats like PDFs and handout sheets should be used so that the information prints quickly and without unnecessary illustrations;
- Transcripts of networking events and conferences can be posted online for download by women who prefer not to attend events and to get their information online. In fact, summaries of these that are less time-consuming and less expensive to download would also be welcomed.

The Appeal of One-on-One Peer Telephone Support Among Women who Have Also Used Support Groups

Those women who have experienced both group and one-on-one support choose to use one-on-one services when they have immediate needs for support or information. More specifically, women use one-on-one support when they are either anxious and/or have a problem and want help now. Other women stated that they used one-on-one services when they wanted to be in contact with someone with a diagnosis of advanced breast cancer because they did not have this opportunity elsewhere. Some respondents reported that the anonymity of the phone was desirable and facilitated discussion of personal issues. One-on-one phone support provides a human touch for shy or private women in a less threatening environment than in-person groups. Two additional reasons for choosing to use one-on-one support were: (1) the ability of newly diagnosed women who were anxious and worried to connect fairly quickly with another woman with advanced breast cancer; and (2) to get support before they were able to join a support group. Often, these women were given referrals to groups during their phone contact.

Suggested ways to integrate this information into program development and service delivery:

- Offer a volunteer hotline or helpline to meet the needs of newly diagnosed women, women with pressing questions, and women who needed immediate emotional support;
- Develop marketing materials, including brochures, newsletters, and the website, that list the situations in which women find one-on-one support helpful, and also list the needs it cannot meet, with appropriate options for the latter;
- Educate hotline or helpline volunteers about the needs of one-on-one support users and have training focused on these needs. Volunteers should have lists of support groups for women in their own communities who want in-person groups and also lists of online groups. As mentioned earlier, volunteers should be able to make needed referrals from a resource guide developed for this purpose;
- A hotline dedicated to women with metastatic breast cancer would be most welcome. Some young women living with advanced breast cancer, as well as women with fairly recent diagnoses, should be sought to match with callers. Of course, these resources should also be developed for all women with advanced breast cancer, including Latina and African-American women;
- Callers to the hotline or helpline with advanced breast cancer could be asked if they are interested in the opportunity to contact other women of similar age, diagnosis, and time living with metastatic breast cancer. With consent, a list of women could be used to develop an email or phone contact network where women could be each other's support on an as-needed rather than ongoing basis;
- Hotline or helpline volunteers could be trained to make follow-up calls to check on callers who want immediate information or immediate help with distressful emotional states. Further referrals for support or education could be made as needed.

Specific Strategies for Website Programming

Websites can provide information, education, and support to this underserved group of women in the breast cancer community. It is clear from this survey, and from other literature, that women living with advanced breast cancer accurately perceive themselves as a group apart from women with early-stage breast cancer. Their needs for support, education, and resources are different and the information they are seeking from appropriate clinical trials to the latest treatment is different. Because of this, it is recommended that organizations dedicate a separate section of their website to women living with metastatic breast cancer. Specifically, please note these suggested ways to integrate this information into program development and service delivery:

- Separate "Learn More," "Stay Informed," and "Participate" sections can be developed for these women. "Learn More" could focus on basic information. This would facilitate women finding the information they need without sorting through posted articles, programs, and services that are not relevant to their diagnosis. Also, a separate section would not only better meet their educational and support needs, but it would serve to legitimize their concerns, providing women with advanced breast cancer with a welcome sense of being understood and heard;
- Almost three-fourths (71%) of survey participants report that they find it very helpful (42%) or helpful (29%) to read about the experiences of other women with advanced breast cancer. In addition, 87% of women who participated in support groups sought them out to learn about other women's experiences. Websites could feature a new monthly story of a woman living with metastatic disease, and vary the age, race, and medical issues of the "face" of advanced disease every month. Helpline and hotline volunteers with advanced breast cancer could also be featured;

- Message or bulletin boards, chat rooms, and mailing lists could be started, with or without moderators. These may be topically focused and threaded, or could be free-flowing. Both models have their advantages and disadvantages, and will appeal to different women;
- Focused, moderated message boards or mailing lists with volunteer health professionals (oncologists, oncology nurses) to answer patients' questions would be welcomed;
- A web-based, up-to-date resource guide should be a part of the site, with links to resources provided to facilitate access to other organizations and service providers;
- FAQ sections could be posted on a monthly basis, with different topics of interest addressed. Making the site participatory could help give these underserved women a voice. For example, under the FAQ section, women could email their suggested questions and/or topic areas;
- Information and programs of particular interest to young women with advanced breast cancer should be clustered together. Separate message boards or mailings for women under 40 would encourage communication about relevant issues;
- Frequent updates on treatments and side effect/symptom management, and clinical trials are particularly important for these women. New information could be highlighted in some way so frequent visitors will not have to search for it;
- Make this section more personal, using pictures, stories, message boards, and integrating this supportive approach with educational and informational content.

Teleconferences, Educational Conferences and Networking Events

As discussed in this paper, women value education and information on treatment and other topics relating to managing their diagnosis. However, women living with advanced breast cancer also find travel difficult at times, not only because of incapacity, but also because of commitments to family and work. Perhaps for these reasons, the majority of women prefer to access information online and their secondary preference is for written materials. However, even those women who prefer online searching frequently print out the materials they have found because they find them easier to read off-screen. Also, some women want to keep these pages for reference. It is worth emphasizing yet again that information and education are best delivered with a dose of support.

Suggested ways to integrate this information into program development and service delivery:

- Make downloadable transcripts and audio replays of educational programming relevant to women with advanced breast cancer. Summaries of key research or other content presented at conferences should also be posted. This would meet both the need for ease of online access and for providing vehicles to enable women to refer back to information;
- Educational content on topics that are less likely to be outdated (e.g. coping/pain management/communicating with your healthcare team) can be posted on the website and/or distributed in printed form;
- If introductions that show how to visit web versions of these educational and informational efforts, either in text or audio as appropriate, could be done by a woman with metastatic breast cancer and/or a professional, it would serve to personalize the content, highlight the importance of the information, and add a support element;
- One strong advantage associated with in-person education is the ability to have questions answered immediately. Women who are just diagnosed are particularly grateful for this opportunity. Because of this, consider focusing smaller, more frequent in-person education/information programs on women newly diagnosed with advanced breast cancer.

Written Materials

Written material is defined here as fact sheets, booklets, pamphlets, and other "stand-alone" publications, and does not include downloads from the Internet. Preferences for written material took second place as the preferred delivery method in the service categories of information/education and resource/practical advice. Women with advanced breast cancer like written materials for a wide variety of reasons: they can share them with others; refer back to them; absorb them at their own pace (as opposed to in-person education). They reported that when they were first diagnosed, anxiety interfered with their ability to process spoken information. Written information was viewed by some as "more in-depth," and, on an emotional level, some women found them "comforting." The comforting quality of written material is most likely a function of its other positive attributes—i.e. the ability to share it; the ability to literally "hold onto it"; its availability at all times; and, like a favorite book, it has the capacity to become an "old and familiar friend."

There are limited comprehensive, intelligently written materials available for women living with metastatic breast cancer, so there is a great deal of opportunity for organizations to provide targeted, informative, and supportive publications to this population.

Suggested ways to integrate this information into program development and service delivery:

- Publications on niche topics and topics that will not quickly become obsolete are recommended. As mentioned, a booklet for women newly diagnosed with advanced breast cancer, and one for young women with advanced breast cancer are suggested. A third possible topic, also discussed in other sections of this paper, is "frequently asked questions about…" (any number of areas such as pain, symptom management, etc.);
- Personalize these booklets, like the website, with the stories and faces of women living with advanced breast cancer. Women like to learn about the experiences of others;
- Breast cancer organizations might think of designing publications for healthcare professionals about the needs of women living with advanced breast cancer;
- Hard copies of continually updated resource guides could be provided to oncology treatment teams and to other cancer organizations and treatment centers;
- Women have distinct preferences for educational, practical, and support services, and when analyzed by level of education, women with less education endorsed the importance of more topics than women with higher education. This finding indicates a greater need in this subgroup for information. Because it is likely that lower levels of education are associated with lower levels of literacy in general, and health literacy in particular, a series of basic booklets written simply, illustrated, and containing glossaries is recommended for less well-educated women.

Educating Health Professionals and Other Cancer Organizations

No single organization working alone can meet all these needs of women with advanced breast cancer. For this reason, outreach is important—to health professionals, cancer organizations, and cancer centers by developing programs to educate these groups on how best to meet the educational, support, and practical needs of women with metastatic disease. By reaching professionals and organizations, productive collaborations to further meet the needs of this population will expand. Finally, a focus on professional education will increase the ability of healthcare teams to work productively and knowledgeably with this growing population.

Suggested ways to integrate this information into program development and service delivery:

- Present posters and workshops at professional conferences focusing on the support, educational, and practical needs and preferences of women with advanced breast cancer;
- Add these findings in a separate section to the professional section on relevant websites;
- Feature the newly developed professional web section and publications during a designated "advanced breast cancer" month. If that's not feasible, launch many of these new initiatives during Breast Cancer Awareness Month;
- Disseminate this report to professional organizations working with women with breast cancer;
- Provide professionals with information about service preferences in terms of content, style, and delivery method to assist them in their efforts to support women living with advanced breast cancer;
- In providing information about service preferences, emphasize the need for in-person support groups composed only of women with metastatic breast cancer. The preference of women under 40 for separate groups should be shared as well, and implemented when feasible. A group for newly diagnosed women would also be desirable;
- Gather the names of support groups and mental health professionals who specialize in working with this population to include in the resource guide because in-person support groups are highly valued and difficult to locate. Identifying therapists is also critical because of the levels of anxiety and depression experienced by women at various points in the course of their illness;
- Distribute the resource guide to healthcare professionals, cancer organizations, and cancer centers;
- Offer a teleconference for professionals on serving women with metastatic disease.

Most Valued Services: Information, Support, Practical Needs/Resources

To summarize, within their categories, these topics were rated important by the most women:

INFORMATION: Current treatment options (96%); New treatment options (96%); Symptom and side-effect management (95%); and Clinical trials (84%).

SUPPORT: Support groups (78%); 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 financial assistance for medical needs.

9. Conclusions and Directions for Future Research

Introduction

Women with advanced breast cancer generally receive educational, support, and practical services that have not been designed with their very special needs in mind. This survey of highly educated, Internet-savvy, information-seeking women is a crucial first step in understanding their specific needs in educational, support, and practical services. Although this sample is clearly not representative of the diverse group of women living with metastatic disease, identifying the needs, preferences, and usage patterns of these experienced, active consumers of programs and services provides the breast cancer community with a detailed description of the needs of an important, articulate segment of women, and serves as a starting point for additional research with other groups of women coping with advanced breast cancer.

A pilot study of this survey in paper rather than online form was designed for women who were on the other side of the "digital divide" (without access to online resources), and the demographic differences were striking, with twice as many online respondents having college degrees or graduate school education. Also, there were considerably more women over age 70 in the pilot group. For this reason, their data were not included in the analyses. As an important next step, this survey, in paper and pencil form, should be disseminated to a random sample of women in order to develop a representative and comprehensive framework for strategic planning of service delivery across target groups. However, the trends discussed in this section provide important insights into a large segment of the advanced breast cancer population that is composed of informed women whose opinions most likely reflect many of the views held by others living with this difficult diagnosis.

Levels of Information and Support

Women with advanced breast cancer find both information and support critically important, and act on this conviction, seeking both kinds of services very frequently. In fact, survey respondents also indicate that they have high levels of knowledge and support. These variables should be studied in less educated, more ethnically mixed, and older samples, and the relationship between information and support to each other and to adjustment and other psychosocial variables should be examined. Importantly, the benefits derived from education and support should be identified, and programs should be designed to maximize these benefits. In addition, studies with more diverse groups can examine how best to provide needed information and support in terms of health literacy and cultural appropriateness.

Information and Support: Use, Preferences, Ratings

These resourceful women have been able to find information and support in many places. Healthcare professionals provide information on medical aspects of care and some measure of support by suggesting coping techniques and resources, although less frequently. Medical oncologists and oncology nurses have generally been most helpful in both these areas, although mental health professionals succeed most often in imparting techniques to cope.

In addition, many women participate in educational programs on advanced breast cancer, finding treatment-focused programs most important, and attending these most often. However, programs on clinical trials, although a treatment option for metastatic disease, are not considered as important and are not as well attended. This issue merits further investigation. Clearly participation in clinical trials is an option for many in this population, and if this well-educated group of women do not seek or value education in this area, other women most likely share this view.

End-of-life issues offer another area requiring study. Our survey showed that while women believe that advance directives and hospice care are important to learn about, very few do so. It has been well documented that making a transition from active treatment to overtly palliative care and preparation for the final stages of life is a difficult one for many if not most critically ill patients and their families, regardless of their illness.[64] Daniel Callahan, medical ethicist and president of the Hastings Institute, framed a crucial question: "Is death to be accepted as a part of life, or fought to the end? Most doctors, and most Americans, are just not certain what the answer to that question is—and it shows in the way patients are treated at the end of their lives, and sometimes in the way they (or their families) are treated."[65] For the women we surveyed, a focus on survival and coping, as well as some aspect of denial of disease progression, may fuel their responses. Research could determine what factors are at play and help organizations develop and disseminate programs on these topics in the most effective, relevant manner.

In addition to programs at cancer treatment centers and non-profits, women become more informed about advanced breast cancer from multiple sources, including government websites and medical journals and books. In fact, a large percentage of patients who used medical publications rated them "excellent or very good," and almost two-thirds of those who attended medical conferences rated them highly. However, many women were not able to attend either medical conferences or patient conferences, which received the highest ratings from the largest number of respondents. A more thorough investigation of the appeal of information geared to medical professionals should be undertaken. When reasons for this preference are identified, a study examining the reactions and needs of less educated, more ethnically diverse women for this level of information could be undertaken, with areas of inquiry including how to present this information at an appropriate literacy level in an appropriate cultural context. Also, if access is part of the favorability/use discrepancy for conferences of any kind, transcripts and webcasts should be considered for presenting highlights of these events. Increasingly, breast cancer organizations have been offering these web-based services following the major scientific conferences at which research on emerging therapies is presented.

Educational programs on parenting issues and counseling for children are among the least accessed but also least important services among women surveyed. This is noteworthy in a sample in which slightly over three-fourths of respondents (76%) have children, many of them still school-aged. Similarly, couples and family therapy is not used or valued by many. Using in-depth interviews or focus groups to explore this finding would be an important step in understanding this counter-intuitive pattern, given the well-documented impact of serious illness on children and partners. In families where advanced cancer is not an issue, mothers typically do the "emotional" caregiving and monitoring of children and, often, of spouses or partners as well. Perhaps women coping with advanced breast cancer are understandably focused on maintaining their own physical and emotional well-being and are not able to provide their usual level of support to loved ones. Understanding the low utilization of services focused on children and families is crucial for both developing programs and for deciding to whom they should be marketed. For example, perhaps spouses/partners should be educated not only about the effect on them in their role as companions and caregivers, but also about the need to consider how advanced breast cancer is affecting their children.

Not surprisingly, the majority of women seek support from various types of online and in-person support groups, and less frequently, seek it in one-on-one support modalities, which are seen as best to get information quickly and to discuss things privately with someone who shares their medical diagnosis. Stress management skills and individual counseling are also viewed as important by many respondents, but they were accessed far less than support groups. It would be worthwhile to more specifically investigate the benefits women hope to find from support group membership, and to explore reactions to incorporating stress management techniques into them to increase the number of women learning these skills. In addition, the specific appeal of one-on-one support and the circumstances in and population for which it is most suitable merits rigorous attention.

Across most demographic variables, there were no significant differences in support group participation. However, women who have been living with advanced breast cancer for less than a year, and women who have the most difficulty maintaining their daily routines were significantly less likely to participate in support groups. Perhaps women who have just been diagnosed are still caught up in gathering information and undergoing treatment, or may not have grasped the full impact of their changed prognosis and have not yet begun to search for support.

Women who are least able to function in their day-to-day lives may be too physically uncomfortable to be involved with in-person support groups, as symptoms of illness increasingly take over their lives. Approaching the final stages of their disease, they may withdraw from support groups so as not to dishearten others, just as newly recurrent women often withdraw from early breast cancer support groups. Very ill people often withdraw into their "inner circles," sociologist Kathy Charmaz points out. "Immersion in illness shrinks social worlds…Pulling in permits ill people and their caregivers to tighten the boundaries of their lives, to reorder their priorities, and to struggle with the exigencies of illness."[66] Necessary though this may be, Charmaz points out, this pulling in "sets an empty stage for future social isolation." These women might benefit greatly from this support modality, feeling emotional support from others who share their diagnosis, and learning not only more about treatment options and how others are living with metastatic disease, but also acquiring coping techniques and side-effect/symptom management information. If this finding is confirmed by well-designed studies, ways to involve more of these women in groups should be developed.

Women who did not participate in support groups most often reported "psychological" reasons for non-participation. More specifically, some women considered themselves "too private" for groups, and others felt that participation could be upsetting to them. These women may well be among those patients who are at risk for distress at some point after diagnosis. Qualitative research, followed by quantitative research based on interviews, would be very important to understand the emotional status of these women, and how best to provide them with the support they need.

Motivations for Seeking Information and Support

Women seek information and support to make decisions about treatment, to learn about side-effect and symptom management, and to cope with a variety of psychosocial issues. Importantly, both categories of service provide a measure of assistance with overlapping needs. For example, many women seek information when they are experiencing distress, and likely find this additional knowledge positively impacts their anxiety and feelings of helplessness/sadness. Also, women use support modalities and the concomitant interactions with others living with advanced disease to gather information from other "experienced" consumers. It appears, from this study, that it would be an oversimplification to separate the functions of support and information in understanding and developing services for women with metastatic disease. This area emerges from the data as one of the most important for further research initiatives.

The Importance of the Experiences of Others

Both women in support groups and all women queried about the value of learning, reading, or hearing about the experiences of others living with advanced disease frequently saw this activity as important. There is a vast literature on the benefit of women writing about their own lives, feelings, and thoughts, but there is a need to investigate and clearly delineate the underlying factors in the process of "learning about others' experiences" in order to understand how this process can most benefit advanced breast cancer patients.

Importance and Use Discrepancies

Across all service categories, more women rated services "important" than actually use them. This pattern may reflect a discrepancy between attitude (perceived importance) and behavior (participation in a program or service), which is not uncommon. However, other explanations must be considered as well. For example, while almost three-fourths (71%) of women consider stress management important, less than half of women (44%) use it, though more than two-thirds (69%) know where it is available. Qualitative research on preferences and use of programs should be designed to understand this inconsistency and to assure optimal service delivery of truly valued support and information services.

The Impact of Support and Knowledge on Symptoms and Side Effects

This survey provided a glimpse into the positive effect of self-reported high levels of knowledge and support on both psychological and physical effects of advanced breast cancer and its treatment. This finding, if replicated in studies using representative samples and multiple measures of these variables, would not only be of enormous benefit in program design and delivery, but also could have important significance in the allocation of funding for these services.

Concluding Comments

This extensive survey of a particular sample of women living with advanced breast cancer represents a very important first step in systematically understanding the needs, experiences, and preferences of a group of breast cancer patients whose needs have been underserved. Programs and services for metastatic patients are becoming increasingly important as more and more women live with advanced disease for longer periods of time. Both information and support services are critical, and understanding how women currently view these programs will enable professionals to strategically address the development and positioning of future initiatives. In addition, the data suggest important areas of inquiry for psycho-oncology researchers. Many studies are needed to understand the striking trends discovered in this first attempt to listen to the voices of this growing population.

When Living Beyond Breast Cancer staff and consultants put this survey online in April, 2005, the project team hoped for perhaps 200 responses to what was clearly an extremely complex and demanding set of questions about the needs of this underserved population. More than any other aspect of this project, 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.

10. Appendices

- References
- Top Websites
- Survey
- Resource Guide
- Professional Advisory Committee

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Top Ten Websites

(In order of frequency of mention)

1. **BCMets Mailing List**
   http://www.bcmets.org
2. **Association of Cancer Resources (ACOR) Metastatic Breast Cancer Online Support Group**
   http://listserv.acor.org/archives/club-mets-bc.html
3. **Her2 Online Support Group**
   http://www.her2support.org/
4. **BreastLink.org**
   http://www.breastcancercare.org
5. **Living Beyond Breast Cancer**
   http://www.lbbc.org
6. **Breastcancer.org**
   http://www.breastcancer.org
7. **AdvancedBC.org**
   http://www.advancedbc.org
8. **Breast Cancer Action Nova Scotia**
   http://www.bcans.org
9. **The Breast Cancer Mailing List**
   http://www.bclist.org
10. **Breast Cancer Network Australia**
    http://www.bcna.org.au

Survey
Living Beyond Breast Cancer Needs Assessment for Advanced Breast Cancer

Living Beyond Breast Cancer is committed to serving all people affected by breast cancer. This survey has been designed to assess the needs of those living with advanced (metastatic) breast cancer. By completing the survey, you will help design and shape programs LBBC will develop. Your responses will also be used to educate healthcare professionals and organizations about your needs.

We want to learn your opinions about the information, support and practical help you have already received, as well as the types of services you would like to have available.

Every question is very important in helping us to understand what people living with advanced breast cancer value in terms of information, support and practical help.

This survey will take approximately 30 minutes to complete. If you must stop taking the survey before finishing, you can save what you've answered, and come back at a later time to finish it. When you click on the link to the survey again, you will return to the first page. Just page forward to the place where you stopped before, and resume taking the survey.

On the last page, you will be asked if you would like to be contacted for an in-depth telephone interview that will help us learn even more about your experiences and needs. Participation in the phone interview and this survey is completely voluntary, and will not affect your ability to access services from Living Beyond Breast Cancer.

All information on this survey will be anonymous, and any report based on this will contain only collective information. A summary of our findings will be on our website after the project is completed.

If you have any questions about this survey or project, or if you want to ask about LBBC's services, please contact Living Beyond Breast Cancer at 610-645-4567 or mail@lbbc.org.

Thank you for your important help with this project.

DEMOGRAPHIC INFORMATION

1. **Where do you live?**

☐ United States
☐ Canada
☐ United Kingdom
☐ Australia
☐ Europe
☐ Asia
☐ Other

2. **How would you describe the place where you live?**

☐ Rural
☐ Suburban or small town
☐ Urban (city)

3. **How old are you now?**

☐ 29 or younger
☐ 30-39 ☐ 40-49
☐ 50-59 ☐ 60-69
☐ 70-79 ☐ 80+

4. **With what racial/ethnic group do you most identify?**

☐ White (Caucasian)
☐ Hispanic
☐ Black (African-American)
☐ Asian-Pacific Islander
☐ Native American
☐ Other

5. **What is your gender?**

☐ Female
☐ Male

6. **Who lives with you?**
[Check the one that best describes your household.]

☐ I live alone
☐ Spouse/partner
☐ Spouse/partner and children
☐ Children only
☐ Spouse/partner, children and other family
☐ Other family members only
☐ Friend
☐ Other

7. **How many children do you have?**

☐ None
☐ One
☐ Two
☐ Three
☐ Four or more

8. **Do you have children in the following age groups?** [Check all that apply.]

YES	**NO**	
☐	☐	Under the age of 5
☐	☐	6-9 years old
☐	☐	10-12 years old
☐	☐	13-18 years old
☐	☐	Aged 19 and over

9. **What education have you received?**
[Choose one.]

☐ Attended grade school
☐ Attended high school
☐ High school degree
☐ Some college
☐ College degree
☐ Graduate degree

10. **What kind(s) of health insurance do you have?**

☐ Medicare/Medicaid
☐ Private Insurance
☐ Medicare and Private Insurance
☐ Medicaid and Private Insurance
☐ No insurance
☐ Don't know

11. What is your current employment status?

☐ Working full or part time
☐ On medical leave
☐ Full-time mother/homemaker
☐ Unemployed
☐ Receiving disability income and not working
☐ Other

BREAST CANCER INFORMATION

12. In what year were you FIRST diagnosed with breast cancer? [Example: 1998.]

____

13. How many years have you been living with ADVANCED (metastatic) breast cancer now?

☐ Less than one year
☐ 1-2 years
☐ 3-5 years
☐ 6-10 years
☐ More than 10 years

14. Has your breast cancer spread to any of these areas in your body? [Check all that apply.]

	YES	**NO**	**NOT SURE**
Bones	☐	☐	☐
Lungs or pleura (lining of lungs)	☐	☐	☐
Liver	☐	☐	☐
Brain	☐	☐	☐
Skin, scar or chest wall muscles	☐	☐	☐
Lymph nodes	☐	☐	☐
Abdomen	☐	☐	☐
Other	☐	☐	☐

15. Please choose ONE statement that BEST describes your current treatment status.

☐ Newly diagnosed with metastatic breast cancer, and haven't started treatment yet.
☐ In treatment
☐ Between treatments or on a break from treatment
☐ I have chosen not to take treatment or to stop treatment
☐ I am now mainly focused on comfort care (palliative or hospice care)
☐ Other

16. Currently, how easy is it for you to maintain your usual daily routines and activities?

☐ Very easy
☐ Easy
☐ Somewhat easy
☐ Difficult
☐ Very difficult

17. **Which of these treatments have you had since your diagnosis with ADVANCED breast cancer?**
[Check one per category.]

TREATMENT	CURRENT TREATMENT	HAVE HAD, BUT IS NOT CURRENT TREATMENT	NEVER HAD
Chemotherapy	☐	☐	☐
Radiation	☐	☐	☐
Surgery/Recovering from surgery	☐	☐	☐
Hormonal Therapy (such as Arimidex, Femara, or Faslodex)	☐	☐	☐
Biological Therapy (such as Herceptin)	☐	☐	☐
Experimental treatment in clinical trials	☐	☐	☐

18. **Since your diagnosis with advanced (metastatic) breast cancer, have any of the following been a problem for you–either from your cancer or from treatment side effects?**
[Check only ONCE for each symptom.]

	NOW	IN THE PAST	NOT A PROBLEM
Pain	☐	☐	☐
Anxiety or panic attacks	☐	☐	☐
Depression	☐	☐	☐
Fatigue or weakness	☐	☐	☐
Trouble sleeping	☐	☐	☐
Nausea or vomiting	☐	☐	☐
Neuropathy (numbness, tingling or pain in hands or feet)	☐	☐	☐
Hand-foot syndrome (red, sore hands or feet)	☐	☐	☐
Mouth sores	☐	☐	☐
Hot flashes	☐	☐	☐
Hair loss	☐	☐	☐
Other changes in appearance	☐	☐	☐
Trouble with memory, concentration and/or organization	☐	☐	☐
Problems with appetite	☐	☐	☐
Problems with sexuality	☐	☐	☐
Vaginal dryness or discomfort with sex	☐	☐	☐

19. **What kind of complementary therapies do you use, if any?**
[Check all that apply.]

	USE	**DON'T USE**
Psychological/spiritual approaches, like relaxation, meditation, or visualization	☐	☐
Physical approaches, like massage, acupuncture, and chiropractic	☐	☐
Exercise: aerobic, strengthening and/or stretching	☐	☐
Vitamins, supplements and/or herbal remedies	☐	☐
Dietary changes and approaches	☐	☐

20. **What role do complementary therapies play in helping you deal with your cancer?**
[Check all that apply.]

☐ They help me to cope with side effects
☐ They help me to cope with stress
☐ I see them as treatments in their own right
☐ I don't use complementary therapies

HEALTHCARE PROFESSIONALS

Healthcare professionals can help people with advanced breast cancer in many ways other than administering and monitoring treatment. They can also provide needed information about the disease and its treatments, emotional support and help with coping skills.

21. **What kinds of INFORMATION offered by healthcare professionals have been helpful to you?** [Check as many as apply for each healthcare professional.]

HEALTHCARE PROFESSIONALS	TREATMENT OPTIONS	INFORMATION ON POSSIBLE TREATMENT SIDE EFFECTS	HOW TO MANAGE MY SYMPTOMS AND SIDE EFFECTS	NOT HELPFUL IN ANY OF THESE AREAS	DIDN'T SEE OR CONSULT
Medical oncologist	☐	☐	☐	☐	☐
Radiation oncologist	☐	☐	☐	☐	☐
Surgeon	☐	☐	☐	☐	☐
Primary Care Provider or Internist	☐	☐	☐	☐	☐
Physician you saw for a second opinion consultation	☐	☐	☐	☐	☐
Oncology or chemotherapy nurse	☐	☐	☐	☐	☐
Nurse practitioner	☐	☐	☐	☐	☐
Physician's assistant	☐	☐	☐	☐	☐
Social worker, counselor or other mental health professional	☐	☐	☐	☐	☐
Complementary and holistic practitioners	☐	☐	☐	☐	☐
Home health aide or hospice worker	☐	☐	☐	☐	☐

22. **List two kinds of healthcare professionals who have been most helpful to you in providing you with the INFORMATION you needed.** [Just list their occupations, not their names.]

____

____

23. **What kinds of SUPPORT offered by healthcare professionals have been helpful to you?**
[Check as many as apply for each healthcare professional.]

HEALTH CARE PROFESSIONALS	REFERRAL TO SUPPORT RESOURCES	MAKES TIME TO SPEAK WITH ME ABOUT MY CONCERNS	TREATS ME IN A CARING, RESPECTFUL WAY	SUGGESTS COPING SKILLS	NOT HELPFUL IN ANY OF THESE AREAS	DIDN'T SEE OR CONSULT
Medical oncologist	☐	☐	☐	☐	☐	☐
Radiation oncologist	☐	☐	☐	☐	☐	☐
Surgeon	☐	☐	☐	☐	☐	☐
Primary Care Provider, family doctor or internist	☐	☐	☐	☐	☐	☐
Physician you saw for a second opinion consultation	☐	☐	☐	☐	☐	☐
Oncology or chemotherapy nurse	☐	☐	☐	☐	☐	☐
Nurse practitioner	☐	☐	☐	☐	☐	☐
Physician's assistant	☐	☐	☐	☐	☐	☐
Social worker, counselor or other mental health professional	☐	☐	☐	☐	☐	☐
Complementary and holistic practitioners	☐	☐	☐	☐	☐	☐
Home health aide or hospice worker	☐	☐	☐	☐	☐	☐

24. **List the two kinds of healthcare professionals who have been most helpful to you in providing you with the emotional support and coping skills you needed.**
[Just list their occupations, not their names.]

____

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SUPPORT GROUPS AND ONE-ON-ONE PEER SUPPORT

Support groups and one-on-one peer support can be important in the lives of people with advanced breast cancer. Please help us understand if and how you have used these types of support, and what works for you, by answering the following questions. If you have not been in a support group or used one-on-one support, we are still interested in learning about your opinions, so please answer all the questions that apply to you.

25. **Since your diagnosis with advanced breast cancer, have you been in any type of support group?**
[Please consider online group support and telephone groups in your reply.]

☐ Yes
☐ No [Please skip to question #35.]

26. **Since your diagnosis with advanced breast cancer, which type of support group(s) have you participated in?**
[If you have participated in more than one, check all that apply.]

☐ In-person support group
☐ Telephone support group
☐ Online Listserv or Mailing List
☐ Online Bulletin Board or Message Board
☐ Online Chatroom
☐ Online but not sure what kind

27. **Since your diagnosis with advanced breast cancer, why did you seek out a support group?**
[Check all that apply.]

☐ For information about advanced breast cancer and treatments
☐ For general emotional support
☐ For help with feelings of anxiety or sadness
☐ To learn about the experiences of others with advanced breast cancer
☐ To learn about managing treatment side effects and cancer symptoms
☐ To feel less alone with my cancer
☐ To learn about resources for people with advanced breast cancer
☐ Other

28. **What type of support group do you most prefer?**

☐ In-person support group
☐ Online support group
☐ Telephone support group
☐ No preference

29. **What type of leader/moderator do you most prefer?**

☐ Professionally led by a nurse, social worker, psychologist or counselor
☐ Led by a breast cancer survivor
☐ No leader: we run the group ourselves
☐ No preference

30. **Since your diagnosis with advanced breast cancer, have you used one-on-one peer support, such as a telephone helpline or hotline?**

☐ Yes
☐ No [Please skip to question #33.]
☐ Neither, or not sure

31. **Which type of support do you prefer?**

☐ Support Group
☐ One-on-one peer support
☐ Prefer different types for different situations

32. **When and for what reasons did you seek one-on-one peer support (such as a hotline or helpline) rather than a support group?** [Please tell us briefly in your own words.]

____

____

____

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33. **How good was your support group and/or your one-on-one support peer experience in providing you with INFORMATION about advanced breast cancer, treatments, side effects, and needed resources?** [Rate one or both for the type of support you received.]

SUPPORT GROUP

☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ Never in a support group

ONE-ON-ONE PEER SUPPORT

☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ Never used one-on-one support

34. **How good was your support group and/or your one-one one peer support experience as a source of EMOTIONAL SUPPORT and COPING TIPS?** [Rate one or both for the type of support you received.]

SUPPORT GROUP

☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ Never in a support group

ONE-ON-ONE PEER SUPPORT

☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ Never used one-on-one support

Please answer questions # 35-39 only if you have NOT participated in a support group since your diagnosis with advanced breast cancer. If you have been in a support group, and have already answered questions #26-34, please skip to question # 40.

35. **We would like to know why you have decided NOT to join a support group since your diagnosis with advanced breast cancer.** [Please check all that apply.]

- ☐ I have no need for support
- ☐ I wanted an in-person group, and there aren't any in my community
- ☐ I don't know where to find a support group
- ☐ I don't know enough about support groups and what they are
- ☐ I didn't/don't feel well enough to participate
- ☐ I thought a support group might be too upsetting for me
- ☐ I'm a private person and don't like groups
- ☐ There are no support groups just for people with advanced breast cancer, and I didn't want any other kinds of patients in the group
- ☐ I don't have computer access for an online group
- ☐ Transportation problems
- ☐ Childcare issues
- ☐ Other

36. **If you were to join a support group, which type of support group would you prefer?**

- ☐ In-person support group
- ☐ Online support group
- ☐ Telephone support group
- ☐ Don't know

37. **Have you used one-on-one peer support, such as a telephone helpline or hotline?**

- ☐ Yes
- ☐ No [Please skip to question #40.]
- ☐ Not Sure [Please skip to question #40.]

38. **How good was your one-on-one support experience in providing you with INFORMATION about advanced breast cancer, treatments, side effects, and needed resources?**

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Never used one-on-one support

39. **How good was your one-on-one support experience as a source of EMOTIONAL SUPPORT AND COPING TIPS?**

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Never used one-on-one support

CANCER SUPPORT ORGANIZATIONS AND TREATMENT CENTERS

Cancer support organizations and cancer treatment centers serve many functions, and people with advanced breast cancer contact them for many different types of services. We would like to learn about your experience with them, so that LBBC can develop new programs and services for you.

40. **Please read the list of programs and services below offered by cancer support organizations and/or cancer treatment centers. Let us know if you used an EDUCATIONAL PROGRAM focused on each of the following topics, and how you would rate it.**
[Please check a response for each topic.]

	USED		RATING				
	YES	NO	EXCELLENT	VERY GOOD	GOOD	FAIR	POOR
Current treatment options	☐	☐	☐	☐	☐	☐	☐
New treatments and the latest research	☐	☐	☐	☐	☐	☐	☐
Clinical trials information	☐	☐	☐	☐	☐	☐	☐
Symptoms and side effects	☐	☐	☐	☐	☐	☐	☐
Pain management	☐	☐	☐	☐	☐	☐	☐
Communicating with your doctor and healthcare team	☐	☐	☐	☐	☐	☐	☐
Parenting issues	☐	☐	☐	☐	☐	☐	☐
Complementary and holistic medicine	☐	☐	☐	☐	☐	☐	☐
Hospice and end-of-life care	☐	☐	☐	☐	☐	☐	☐
Advance directives (choices about medical care at end-of-life)	☐	☐	☐	☐	☐	☐	☐

Let us know if you used each of the following SUPPORT SERVICES, and how you would rate it.
[Please check a response for each topic.]

	USED		RATING				
	YES	NO	EXCELLENT	VERY GOOD	GOOD	FAIR	POOR
Stress management skills (relaxation, meditation, yoga)	☐	☐	☐	☐	☐	☐	☐
Support group	☐	☐	☐	☐	☐	☐	☐
"Buddy program" or peer network	☐	☐	☐	☐	☐	☐	☐
Contact with hotline volunteer	☐	☐	☐	☐	☐	☐	☐
Individual counseling	☐	☐	☐	☐	☐	☐	☐
Family or couples counseling	☐	☐	☐	☐	☐	☐	☐
Counseling for children	☐	☐	☐	☐	☐	☐	☐
Guidance and help with spiritual issues	☐	☐	☐	☐	☐	☐	☐

Let us know if you used each of the following PRACTICAL INFORMATION and SERVICES, and how you would rate it. [Please check a response for each service.]

	USED		RATING				
	YES	NO	EXCELLENT	VERY GOOD	GOOD	FAIR	POOR
Information about Medicaid/ Medicare/disability	☐	☐	☐	☐	☐	☐	☐
Information on health insurance	☐	☐	☐	☐	☐	☐	☐
Assistance with employment issues related to your cancer	☐	☐	☐	☐	☐	☐	☐
Referrals to doctors and/or cancer treatment center	☐	☐	☐	☐	☐	☐	☐
Financial assistance for medical needs	☐	☐	☐	☐	☐	☐	☐
Financial assistance for non-medical needs (such as childcare)	☐	☐	☐	☐	☐	☐	☐
Home healthcare from aide	☐	☐	☐	☐	☐	☐	☐
Help driving or getting to appointments	☐	☐	☐	☐	☐	☐	☐
Help with laundry and house-cleaning	☐	☐	☐	☐	☐	☐	☐
Help with shopping, errands and preparing meals	☐	☐	☐	☐	☐	☐	☐
Help with childcare	☐	☐	☐	☐	☐	☐	☐

41. **How would you most prefer to receive the following type of services?**

[Please make only one choice for each service type.]

TYPE OF SERVICE	IN-PERSON	ONLINE	BY TELEPHONE	WRITTEN MATERIALS	AUDIO AND/OR VIDEO MATERIALS NOT ONLINE
Educational	☐	☐	☐	☐	☐
Support	☐	☐	☐	☐	☐
Practical Information and Resources	☐	☐	☐	☐	☐

Please help us understand the service types you selected by briefly explaining your preferences here, in your own words.

____

____

____

____

42. **Overall, please rate your experience with cancer organizations/cancer treatment centers as a source of INFORMATION.**

☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ I've had no experience with this

43. **Overall, please rate your experience with cancer organizations/cancer treatment centers as a source of SUPPORT.**

☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ I've had no experience with this

44. **List the one or two cancer organizations/cancer treatment centers that have been most helpful to you, and, in your own words, describe how they've been helpful.**

____

____

____

____

45. ☐ **Check here if you have had no experience with a cancer organization/cancer treatment center.**

OTHER SOURCES OF INFORMATION ON ADVANCED BREAST CANCER

There are many ways and places to get information about advanced breast cancer.
The sources listed below are used by some people to learn more about their illness.

46. Please rate the OTHER INFORMATION SOURCES you have used on the scale below.

	EXCELLENT	VERY GOOD	GOOD	FAIR	POOR	DIDN'T USE
Books, brochures, and handouts developed for patients	☐	☐	☐	☐	☐	☐
Medical journals, articles, and books for healthcare professionals	☐	☐	☐	☐	☐	☐
In-person talk or lecture by professionals or experts	☐	☐	☐	☐	☐	☐
Telephone educational session by professionals or experts	☐	☐	☐	☐	☐	☐
Day long conferences for patients by professionals or experts	☐	☐	☐	☐	☐	☐
Live webcasts by professionals or experts	☐	☐	☐	☐	☐	☐
Scientific conferences for medical professionals	☐	☐	☐	☐	☐	☐
Government websites (such as NCI at Cancer.gov; Medline at Pubmed.gov; FDA.gov)	☐	☐	☐	☐	☐	☐
University and organization websites (such as Oncolink)	☐	☐	☐	☐	☐	☐
Pharmaceutical (drug company) websites	☐	☐	☐	☐	☐	☐
Telephone services (such as Cancer Information Service [CIS] at 1-800-4CANCER)	☐	☐	☐	☐	☐	☐

47. List the one or two websites that you have found most informative.

____

____

48. How important is information about treatment, side effects, and symptom management in helping you cope with your cancer?

☐ Very important
☐ Important
☐ Neither important nor unimportant
☐ Not very important
☐ Not at all important

49. Who is the primary person who gathers information for you about advanced breast cancer?

☐ Myself
☐ My spouse or partner
☐ Other family member
☐ Friend
☐ Other
☐ None of the above

50. How would you rate your current level of knowledge about advanced breast cancer and its treatments?

☐ Poor
☐ Fair
☐ Good
☐ Very Good
☐ Excellent

51. How frequently, on average, do you seek information on advanced breast cancer from any source?

☐ Daily
☐ Weekly
☐ Monthly
☐ Less than once a month
☐ Never

52. In what situations are you most likely to seek out information about advanced breast cancer?
[Check all that apply.]

☐ When I'm making a decision about or starting a new treatment
☐ When there is a recurrence or progression of my breast cancer
☐ When I'm feeling worried or sad
☐ When I'm having a problem with treatment side effects or discomfort/ problems from the cancer itself
☐ None of the above

PEOPLE AND ACTIVITIES AS SOURCES OF SUPPORT

People living with advanced breast cancer often express the need for support in coping with their illness. That support can be emotional, social and practical—and is often all three. Support can come from other people and from valued activities.

53. Please rate the following people and activities as sources of SUPPORTaccording to this scale.

PEOPLE	EXCELLENT	VERY GOOD	GOOD	FAIR	POOR	DIDN'T USE
Spouse or Partner	☐	☐	☐	☐	☐	☐
Children	☐	☐	☐	☐	☐	☐
Brothers and sisters	☐	☐	☐	☐	☐	☐
Parents	☐	☐	☐	☐	☐	☐
Other relatives	☐	☐	☐	☐	☐	☐
Friends	☐	☐	☐	☐	☐	☐
Co-workers	☐	☐	☐	☐	☐	☐
Minister, priest, rabbi, pastoral counselor	☐	☐	☐	☐	☐	☐
Neighbor	☐	☐	☐	☐	☐	☐
A "buddy" from a breast cancer organization	☐	☐	☐	☐	☐	☐
Fellow support group members	☐	☐	☐	☐	☐	☐
Other women or men with breast cancer (not from support group)	☐	☐	☐	☐	☐	☐

ACTIVITIES	EXCELLENT	VERY GOOD	GOOD	FAIR	POOR	DIDN'T USE
Prayer	☐	☐	☐	☐	☐	☐
Attending spiritual or religious services	☐	☐	☐	☐	☐	☐
Individual counseling focused on coping with cancer	☐	☐	☐	☐	☐	☐
Couples counseling	☐	☐	☐	☐	☐	☐
Family counseling	☐	☐	☐	☐	☐	☐
Art, music or dance therapy	☐	☐	☐	☐	☐	☐
Working as a volunteer for a cancer organization	☐	☐	☐	☐	☐	☐
Cancer advocacy work	☐	☐	☐	☐	☐	☐
Reading books or printed materials	☐	☐	☐	☐	☐	☐
Writing, keeping a journal or diary	☐	☐	☐	☐	☐	☐
Spending time with my pet(s)	☐	☐	☐	☐	☐	☐

54. **Do you find it helpful or not helpful to listen to or read about other peoples' experiences with advanced breast cancer?**

☐ Very helpful
☐ Helpful
☐ Sometimes helpful
☐ Not very helpful
☐ Not at all helpful
☐ I don't listen to or read about these experiences

55. **How would you rate your current level of support?**

☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor

56. **List the one or two people who have been the best sources of support for you.** [Just list their relationship to you, not their names.]

____

____

57. **List two ONLINE resources that gave you the most support, including websites, mailing lists, listservs, chatrooms, message or bulletin boards.**

____

____

58. **How frequently, on average, do you seek out emotional support, practical support, and coping tips:**

☐ Daily
☐ Weekly
☐ Monthly
☐ Less than once a month
☐ Never

59. **In what situations are you most likely to seek emotional support, practical support, and coping tips?** [Check all that apply.]

☐ When I'm making a decision about or starting a new treatment
☐ When I'm feeling worried or sad
☐ When I'm having a problem with treatment side effects, or discomfort/ problems from the cancer itself
☐ When there is a recurrence or progression of my breast cancer
☐ When I feel alone with my cancer
☐ When I'm having problems with my family, partner or friends
☐ When I'm not well enough to do the things that are meaningful to me
☐ None of the above; I don't seek out support

PREFERENCES FOR SERVICES AND ACCESS TO SERVICES

60. Below are services that people with advanced breast cancer have asked for. If an EDUCATIONAL PROGRAM was focused on each of the following topics, would it be IMPORTANT to you?

Is a program on this topic already AVAILABLE to you in your community or online?

	IMPORTANCE		AVAILABILITY		
	IMPORTANT TO ME	NOT IMPORTANT TO ME	AVAILABLE	NOT AVAILABLE	DON'T KNOW
Current treatment options	☐	☐	☐	☐	☐
New treatments and the latest research	☐	☐	☐	☐	☐
Clinical trials information	☐	☐	☐	☐	☐
Symptoms and side effects	☐	☐	☐	☐	☐
Pain management	☐	☐	☐	☐	☐
Communicating with your doctor/healthcare team	☐	☐	☐	☐	☐
Parenting issues	☐	☐	☐	☐	☐
Complementary and holistic medicine	☐	☐	☐	☐	☐
Hospice and end-of-life care	☐	☐	☐	☐	☐
Advance directives (choices about medical care at end-of-life)	☐	☐	☐	☐	☐

Would this type of SUPPORT PROGRAM be IMPORTANT to you? Is a program like this already AVAILABLE to you in your community or online?

	IMPORTANCE		AVAILABILITY		
	IMPORTANT TO ME	NOT IMPORTANT TO ME	AVAILABLE	NOT AVAILABLE	DON'T KNOW
Stress management skills (relaxation, meditation, yoga)	☐	☐	☐	☐	☐
Support group	☐	☐	☐	☐	☐
"Buddy program" or peer network	☐	☐	☐	☐	☐
Contact with hotline volunteer	☐	☐	☐	☐	☐
Individual counseling	☐	☐	☐	☐	☐
Family or couples counseling	☐	☐	☐	☐	☐
Counseling for children	☐	☐	☐	☐	☐
Guidance and help with spiritual issues	☐	☐	☐	☐	☐

Would this type of PRACTICAL INFORMATION AND SERVICES be IMPORTANT to you? Is a program like this already AVAILABLE to you in your community or online?

	IMPORTANCE		AVAILABILITY		
	IMPORTANT TO ME	NOT IMPORTANT TO ME	AVAILABLE	NOT AVAILABLE	DON'T KNOW
Information about Medicaid/Medicare/disability	☐	☐	☐	☐	☐
Information on health insurance	☐	☐	☐	☐	☐
Assistance with employment issues related to cancer	☐	☐	☐	☐	☐
Referrals to doctors and/or cancer treatment center	☐	☐	☐	☐	☐
Financial assistance for medical needs	☐	☐	☐	☐	☐
Financial assistance for non-medical needs (childcare)	☐	☐	☐	☐	☐
Home healthcare from aide	☐	☐	☐	☐	☐
Help driving or getting to appointments	☐	☐	☐	☐	☐
Help with laundry and house-cleaning	☐	☐	☐	☐	☐
Help with shopping, errands and preparing meals	☐	☐	☐	☐	☐
Help with childcare	☐	☐	☐	☐	☐

61. Are any of the following barriers to your getting kinds of services listed in the previous question? [Answer Yes or No for each one.]

	YES	NO
Lack of availability where I live	☐	☐
Transportation problems	☐	☐
No childcare	☐	☐
Too ill to access	☐	☐
No computer or Internet access	☐	☐
Don't know where to look for services	☐	☐
Not aware of the types of services available	☐	☐

62. How did you first hear about Living Beyond Breast Cancer's survey for people living with advanced breast cancer?

☐ Online
☐ Newsletter
☐ Mailing or announcement from LBBC
☐ Saw on LBBC website
☐ Word of mouth
☐ I don't remember

63. If you heard about LBBC online, can you tell us where–which mailing list/listserv, online bulletin board or message board?

____

____

____

____

64. Have you ever used these Living Beyond Breast Cancer services?

	YES	NO
LBBC Survivors' Helpline	☐	☐
LBBC Newsletter	☐	☐
LBBC Teleconferences	☐	☐
LBBC Website at www.lbbc.org	☐	☐
LBBC In-person conferences	☐	☐
LBBC Library and Resource Center	☐	☐
Not familiar with LBBC programs	☐	☐

65. How helpful were the LBBC services that you used?

	VERY HELPFUL	HELPFUL	SOMETIMES HELPFUL	NOT VERY HELPFUL	NOT AT ALL HELPFUL	DIDN'T USE
LBBC Survivors' Helpline	☐	☐	☐	☐	☐	☐
LBBC Newsletter	☐	☐	☐	☐	☐	☐
LBBC Teleconferences	☐	☐	☐	☐	☐	☐
LBBC Website at www.lbbc.org	☐	☐	☐	☐	☐	☐
LBBC In-person conferences	☐	☐	☐	☐	☐	☐
LBBC Library and Resource Center	☐	☐	☐	☐	☐	☐

Thank You

Thank you for taking the time to fill out this survey! The information you provide will help Living Beyond Breast Cancer develop needed services for women and men living with advanced breast cancer.

The results of this survey are completely anonymous. When it is completed, a summary of this project will be posted on LBBC's website, www.lbbc.org.

If you would be interested in sharing more of your knowledge and experiences with us, we invite you to participate in a one-on-one hour-long telephone interview. These interviews will also be used to assist LBBC in offering you the services you most need.

To participate in a phone interview or to learn more about this opportunity, please send your contact information to Living Beyond Breast Cancer at 610-645-4567 or mail@lbbc.org.

Resource Guide: Information, Services, and Support for Advanced (Metastatic) Breast Cancer

Prepared by Musa Mayer, 10/10/06

National Organizations

American Cancer Society
(800) ACS-2345
http://www.cancer.org

Living Beyond Breast Cancer
(610) 645-4567
http://www.lbbc.org

The Susan G. Komen for the Cure
(800) I'M AWARE or (800) 462-9273
http://www.komen.org

The National Breast Cancer Coalition
(800) 622-2838
http://www.stopbreastcancer.org

National Coalition for Cancer Survivorship
(301) 650-9127
http://www.canceradvocacy.org

The Wellness Community
(888) 793-WELL
http://www.thewellnesscommunity.org

Y-Me National Breast Cancer Organization
Hotline: (800) 221-2141
Spanish Hotline: (800) 986-9505
http://www.y-me.org

Young Survival Coalition
(877) YSC-1011
http://youngsurvival.org

Inflammatory Breast Cancer Research Foundation
(877) 786-7422
http://www.ibcresearch.org

Sisters Network
(713) 781-0255
http://www.sistersnetworkinc.org
For African-American women living with breast cancer.

The Mautner Project for Lesbians with Cancer
(202) 332-5536
http://www.mautnerproject.org

Asian American Cancer Support Network
(650) 967-2305
http://www.aacsn.org

Native American Cancer Research
(303) 838-9359
http://www.natamcancer.org

Nueva Vida
(202) 223-9100
http://www.nueva-vida.org
A support network for Latinas with cancer.

MaleCare
http://www.malecare.org
Men's Health and Cancer: Prostate Cancer, Testicular Cancer and Male Breast Cancer Treatment and Support.

Information

BreastCancer.Net
http://www.breastcancer.net
Subscription e-mail service offering daily medical/scientific resource and media citations on breast cancer.

National Cancer Institute Breast Cancer
http://www.cancer.gov/cancertopics/types/breast
The National Cancer Institute breast cancer website with information on treatment, clinical trials and other issues.

How Cancers Grow
http://www.cancerhelp.org.uk/help/default.asp?page=88
Easy to understand information on cancer and the process of metastases from the UK's CancerHelp.

NCI-Designated Cancer Centers List by State
http://www3.cancer.gov/cancercenters/centerslist.html

The National Cancer Institute
NCI Fact Sheets
http://www.cancer.gov/cancertopics/factsheet

BreastCancer.org: Recurrent and Metastatic Disease
http://www.breastcancer.org/rcr_intro.html

AdvancedBC.org
http://www.advancedbc.org
A new resource for advanced breast cancer

Financial and Legal Information and Assistance

Needymeds
http://www.needymeds.com
Information on patient assistance programs that provide no-cost prescription medications to eligible participants.

Partnership for Prescription Assistance
https://www.pparx.org
The new Partnership for Prescription Assistance brings together U.S. pharmaceutical companies, doctors, other healthcare providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them.

Co-Pay Relief Patient Assistance Program
http://www.copays.org
Patient Advocate Foundation's Co-Pay Relief (PAF CPR) provides co-payment assistance for pharmaceutical products to insured Americans who financially and medically qualify.

U.S. Social Security Administration
(800) 772-1213
http://ssa.gov
Metastatic breast cancer is generally considered a qualifying disability. Pamphlets are available online at:
http://www.ssa.gov/pubs/englist.html

Social Security has a good website for Disability Retirement:
http://www.ssa.gov/disability

Benefits Eligibility Screening Tool (BEST):
http://best.ssa.gov

CancerAndCareers.org
http://www.cancerandcareers.org
A resource for working women with cancer.

Airlifeline
(877) 247-5433
http://www.nffr.org/Airlifeline.htm

Corporate Angel Network
866-328-1313
http://www.corpangelnetwork.org
These two organizations fly qualified patients to treatment sites, free, using empty seats on corporate flights.

In-Person Support

Note: In-person support groups specifically for women with advanced breast cancer may be hard to find outside of urban areas. Advanced breast cancer patients are likely to have more in common with other metastatic cancer patients than with women newly diagnosed with early breast cancer. Groups for patients with advanced cancers are offered in many hospitals and cancer centers, usually led by nurses or social workers. Local breast cancer support organizations may also have metastatic groups.

The Wellness Community
(888) 793-WELL or (888) 793-9355
http://www.thewellnesscommunity.org
A free program of emotional support, education, and hope for people with cancer and their families.

Commonweal
(415) 868-0970
http://www.commonweal.org/programs/cancer-help.html
The Commonweal Cancer Help Program conducts weeklong support and learning programs for people with cancer.

Gilda's Club
(888) GILDA-4-U
http://www.gildasclub.org
Free services in a clubhouse format offering emotional and social support for cancer patients, their families and friends.

Cancer*Care*, Inc.
http://www.cancercare.org/
Offers support services, education and information, referrals, and financial assistance.

Online Support

Free from the limitations of time, money and location, women with advanced breast cancer and their families can give and receive support and share information via the mailing lists and bulletin boards listed below. Mailing lists operate via an exchange of email, while bulletin boards take the form of messages posted on websites. Some offer both ways to make contact.

BCMETS Mailing List and Webpage
http://bcmets.org
Large, open mailing list for advanced breast cancer patients, family members and friends. Website has a browseable and searchable public archive of all messages over its six year history. Lurkers (people who don't want to post public messages) are welcome.

CLUB-METS-BC Mailing List
http://listserv.acor.org/archives/club-mets-bc.html
Mailing list for metastatic breast cancer patients and caregivers only. Archives only searchable by list members.

IBC Support Mailing List and Webpage
http://www.ibcsupport.org
Mailing list for inflammatory breast cancer support and information.

Breast Cancer Action Nova Scotia (BCANS) Support Forum
http://bca.ns.ca/forum
Active bulletin board with many advanced breast cancer patients.

Living Beyond Breast Cancer "Our Corner" Message Board
http://lbbc.org/message-boards.asp
A forum for women living with metastatic disease.

HER2 Support
www.her2support.org
Bulletin board for women with HER2+ breast cancer.

The Her2/Recurrence Board for Survivors
http://members3.boardhost.com/recurrence
Suppport for women with HER2+ breast cancer.

BreastCancer.org
http://www.breastcancer.org
Recurrence and Metastatic Disease Discussion Board;
See under "Support and Community."

Young Survival Coalition Bulletin Board
http://www.youngsurvival.org/?fuse=discussion.board.home
Support for young women with metastatic disease .

CaringBridge
http://www.caringbridge.org
CaringBridge offers free, easy-to-create web sites that help connect friends and family when they need it most.

Making Memories
http://www.makingmemories.org
This organization provides an opportunity for advanced breast cancer patients to fulfill a dream or wish.

Information Seeking

National Comprehensive Cancer Network (NCCN)
http://www.nccn.org/professionals/physician_gls/PDF/breast.pdf
The National Comprehensive Cancer Network has released new guidelines for the treatment of breast cancer, in decision-tree format.

CancerGuide: How to Research the Medical Literature
http://cancerguide.org/research.html
Steve Dunn has written the best online, step-by-step, thorough introduction to researching cancer and its treatments.

PubMed
http://pubmed.gov
Search the Medline database of medical/scientific citations and abstracts. Includes overview and tutorial on search methods, plus links to full text articles.

PDQ Health Professional Statement on Breast Cancer
http://www.cancer.gov/cancertopics/pdq/treatment/breast/HealthProfessional
PDQ is a cancer database maintained by the National Cancer Institute (NCI) and contains statements, updated monthly, of the most recent treatments, standard and investigational treatment protocols, clinical trials, and major cancer treatment centers and physicians. This peer-reviewed summary on breast cancer treatment for health professionals is reviewed monthly and is available in Spanish, and in a version for patients.

Levels of Evidence for Adult Cancer Treatment Studies (PDQ)
http://www.cancer.gov/cancertopics/pdq/levels-evidence-adult-treatment
An easy-to-follow description of how scientific evidence is evaluated for the PDQ documents and for cancer research in general.

Medscape
http://www.medscape.com
Continuing medical education, conference and research reports for physicians and consumers.

Treatment Information

How To Find a Doctor or Treatment Facility If You Have Cancer
http://www.cancer.gov/cancertopics/factsheet/Therapy/doctor-facility
From the NCI Cancer Facts, what you need to know about finding quality medical care.

RxList.org
http://www.rxlist.com
FDA-approved labeling information on prescription drugs.

Drugs@FDA
http://www.accessdata.fda.gov/scripts/cder/drugsatfda
A new, easy-to-use website to help consumers and health professionals find information about FDA-approved drug products.

Mayo Clinic Drugs and Supplements Index
http://www.mayoclinic.com/findinformation/druginformation/index.cfm
Drug information in consumer-friendly language.

MedlinePlus
http://medlineplus.gov
A service of the National Library of Medicine and the National Institutes of Health, consumer-friendly information on drugs, medical encyclopedia and dictionary.

Chemocare.com
http://chemocare.com
Information about drugs used in cancer treatment,
in patient-friendly format.

Harvard Medical School Family Health Guide to Diagnostic Tests
http://www.health.harvard.edu/fhg/diagnostics.shtml

LabTestsOnline.org
http://www.labtestsonline.org
Lab Tests Online has been designed to help patients and caregivers better understand the many clinical lab tests that are part of routine care as well as diagnosis and treatment of a broad range of conditions and diseases.

NCI Dictionary of Cancer Terms
http://www.cancer.gov/dictionary

Clinical Trials

Learning about Clinical Trials
http://wwwicic.nci.nih.gov/clinicaltrials/learning
The National Cancer Institute's introduction to clinical trials.

NCI Clinical Trials Search Page
http://wwwicic.nci.nih.gov/clinicaltrials

ClinicalTrials.gov
http://clinicaltrials.gov
User-friendly search site developed by the National Library of Medicine and the National Institutes of Health. Companies developing drugs are required to list Phase II and III trials for their drugs in development here. Also see "Understand Clinical Trials."

Cancer Cooperative Research Groups
Cooperative Groups design and conduct many of the studies done in advanced breast cancer .

Cancer and Leukemia Group B (CALGB)
http://www.calgb.org

Eastern Cooperative Oncology Group (ECOG)
http://ecog.dfci.harvard.edu

National Cancer Institute of Canada
Clinical Trials Group (NCIC CTG)
http://www.ctg.queensu.ca

The National Surgical Adjuvant
Breast and Bowel Project (NSABP)
http://www.nsabp.pitt.edu

North Central Cancer Treatment Group (NCCTG)
http://ncctg.mayo.edu

Southwest Oncology Group (SWOG)
http://www.swog.org

The Pharmaceutical Research and Manufacturers of America (PhRMA)
http://www.phrma.org
Professional association of drug manufacturers and biotech companies; see the ***2006 Report: New Medicines in Development in Cancer.***

Glossary of Clinical Trials Terms
http://clinicaltrials.gov/ct/info/glossary

Complementary and Alternative Therapy

National Center for Complementary and Alternative Medicine
http://nccam.nih.gov
Information from the CAM section of the
National Institutes of Health.

Thinking about Complementary and Alternative Medicine (CAM)
http://www.cancer.gov/cancertopics/thinking-about-CAM
National Cancer Institute brochure for patients.

MSKCC: Information Resource: About Herbs, Botanicals & Other Products
http://www.mskcc.org/mskcc/html/11570.cfm
Memorial Sloan-Kettering Cancer Center integrative medicine resource.

The Annie Appleseed Project
http://www.annieappleseedproject.org
Provides information, education, advocacy, and awareness for people with cancer and family and friends interested in complementary, alternative medicine (CAM) and natural therapies from the patient perspective.

Choices In Healing: Integrating The Best of Conventional and Complementary Approaches to Cancer
http://www.commonweal.org/pubs/choices-healing.html
Michael Lerner's classic book on CAM, free online in its entirety.

Supportive Care

Coping with Cancer
http://www.cancer.gov/cancertopics/coping
National Cancer Institute, with links for NCI materials on coping with fatigue, pain, and other side effects/treatment complications, as well as emotional and nutritional concerns and end-of-life issues.

Cancer Supportive Care
http://www.cancersupportivecare.com/breast.html
A broad series of articles on supportive care for cancer patients and health professionals.

Chemotherapy and You: A Guide To Self-Help During Treatment
http://cancernet.nci.nih.gov/chemotherapy/chemoint.html
Basic principles for handling side effects of treatment.

Pain PDQ
http://www.cancer.gov/cancertopics/pdq/supportivecare/pain
National Cancer Insitute PDQ guides for pain management for health professionals and patients (also in Spanish).

Pain Control: A Guide for People with Cancer and Their Families
http://www.cancer.gov/cancertopics/paincontrol
National Cancer Institute.

Radiation Therapy and You: A Guide To Self-Help During Treatment.
http://www.cancer.gov/cancerinfo/radiation-therapy-and-you
A basic introduction to the topic of radiation treatment, how and why it is done, and coping with the side effects.

American Cancer Society Tender Loving Care Catalog
http://www.tlccatalog.org
Hats, scarves, mastectomy products and more.

Recommended Reading

Patient Active Guide to Living with Advanced Breast Cancer
http://www.thewellnesscommunity.org/programs/active/advbreast_cancer
A helpful new resource from The Wellness Community and Living Beyond Breast Cancer.

When Cancer Recurs: Meeting The Challenge Again
http://www.cancer.gov/cancertopics/When-Cancer-Returns
NCI publication, touches on many of the major issues metastatic breast cancer patients will face.

I Still Buy Green Bananas: Living with Advanced Breast Cancer
http://www.y-me.org/publications/generalpubs/greenbananas.pdf
Helpful brochure published by Y-Me.

The Median Isn't the Message
http://www.cancerguide.org/median_not_msg.html
Ways to make sense of statistics by evolutionary biologist Stephen Jay Gould. "The wisest, most humane thing ever written about cancer and statistics."
–Steve Dunn, editor, CancerGuide.org

The Shock of Recurrence
http://www.patientcenters.com/breastcancer/news/ShockOfRecurrence.html
From Musa Mayer's *Advanced Breast Cancer: A Guide to Living with Metastatic Disease* (O'Reilly & Assoc, 1998, the only book dedicated to advanced breast cancer).

Within Measured Boundaries
http://www.cbhp.org/PersonalStories/Jenilu.html
Personal essay on living with advanced breast cancer.

Conversations From The Heart
http://www.thelifeinstitute.org/downloads/ConversationsFromTheHeart.pdf
Resources for talking with children about a parent's serious illness.

CancerLynx Metastatic Cancer Index
http://www.cancerlynx.com/metastatic_index.html
Links and articles.

Willow.org
http://www.willow.org/info/prs1.asp
Living, archived newsletters for metastatic breast cancer.

Living with Metastatic Disease
http://www.willow.org/pdfs/Metastatic%20English.pdf
http://www.willow.org/pdfs/Metastatic%20French.pdf
An information brochure for women with breast cancer, in French and in English

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