



Silent Voices: Information, support & practical services needs for metastatic breast cancer patients

Elyse S. Caplan, Jane Reese-Coulbourne, Kathleen Swiger, Musa Mayer and Susan E. Grober • Living Beyond Breast Cancer, Haverford, PA

BACKGROUND

It is estimated that more than 150,000 American women are currently living with metastatic or advanced breast cancer (ABC). Metastatic disease is defined as the progressive spread of cancer from the breast to other distant parts of the body.

Significant advances in treatment and supportive care have enabled many women with ABC to live for extended periods of time, often with good quality of life. The issues and challenges that women with ABC face are very different than those diagnosed with an earlier stage of the disease. Thus, the need exists for information and support services that are targeted for this group.

METHODS

To address this information barrier, Living Beyond Breast Cancer (LBBC) developed a survey in 2005 to assess the needs of women with ABC. This survey, focused in great detail on women with ABC and their use of and preferences for services in three domains: information, support and practical resources.

During the 30 days that the survey was posted in 2005, 618 people completed the 22-page survey online and a pilot sample of 79 completed a paper version of the same survey. The results of the online survey data only were analyzed and summarized in a report, *Silent Voices*, completed in December 2006. Although notable differences in the preferences between those completing the survey online and those completing the survey in the paper format could be observed, due to the small sample size, only online responses were used in the *Silent Voices* report. Therefore, in 2007, LBBC decided to put the identical survey in the field again in paper copy format only.

In May 2007, the paper survey was mailed to a set of LBBC constituents with ABC and sent via email to cancer-serving organizations. All organizations were sent both electronic and printed copies of the complete survey. Four hundred printed copies of the survey were mailed during the period May 1 – June 30, 2007. Seventy-three completed surveys were returned. Upon completion of the survey the data were compiled, analyzed and compared to the 2005 data.

DEMOGRAPHICS

	2005 (online) N=618	2005 (paper) N=79	2008 (paper) N=73
Gender	98% female	100% female	98% female
Residence	56% suburban/small towns	64% suburban/small towns	64% suburban/small towns
	33% urban	27% urban	26% urban
	11% rural	9% rural	10% rural
Race	94% Caucasian	91% Caucasian	90% Caucasian
			9% African-American
			1% Asian/Pacific Islander
Age	16% were 60 yrs or older	48% were 60 yrs or older	48% were 60 yrs or older
Educational Level	3% < high school	7% < high school	8% < high school
	8% high school degree	21% high school degree	23% high school degree
	23% some college	26% some college	26% some college
	34% college degree	26% college degree	26% college degree
	32% graduate degree	19% graduate degree	19% graduate degree
Live with	74% spouses/partners and children	66% spouses/partners and children	55% spouses/partners and children
	15% live alone	29% live alone	26% live alone
Health insurance	73% private insurance	65% private insurance	47% private insurance
	12% Medicare and private insurance	25% Medicare and private insurance	33% Medicare and private insurance
	3% no insurance	1% no insurance	4% no insurance
	6% Medicare/Medicaid only	13% Medicaid/Medicare only	23% Medicare/Medicaid only

MEDICAL STATUS

	2005 (online) N=618	2005 (paper) N=79	2008 (paper) N=73
Years with ABC	9% has been living with ABC for 6-10 yrs	17% has been living with ABC for 6-10 yrs	24% has been living with ABC for 6-10 yrs
	2% more than 10 yrs	21% more than 10 yrs	16% more than 10 yrs
Areas of Metastases	63% lymph nodes	70% lymph nodes	59% lymph nodes
	71% bones	45% bones	57% bones
	40% lungs	16% lungs	34% lungs
	44% liver	28% liver	31% liver
	11% brain	4% brain	12% brain
Current Treatment Status	79% currently in treatment	55% currently in treatment	66% currently in treatment
	10% between treatments	9% between treatments	9% between treatments
	1% chose no treatment or stopped	0% chose no treatment or stopped	1% chose no treatment or stopped
	1% comfort care	0% comfort care	3% comfort care

THE ROLE OF INFORMATION

Healthcare Professionals:

- 49% of the online group reported that their medical oncologist provided helpful information on possible treatment side effects, compared to 76% of the 2005 paper group and 82% of the 2008 paper group.

The Importance of Information:

- 80% of all respondents said that information about treatment and side effects and symptom management were a very important part of helping them cope with their cancer.
- Topics most important: current treatment options; new treatments and the latest research; clinical trials information; symptoms and side effects; pain management; and communicating with your healthcare team.

Access to Information:

- 80% of the online respondents said they had access to information on the identified topics listed above either in their community or online but only 45 – 50 % of those who took the paper survey said these topics were currently available to them.
- 82% of the paper groups vs. 56% of the online group said they received information about treatment options from their medical oncologist.

Barriers to Getting Information and Services:

- Even though the online group had more access to information and sought it out more often, both the paper and online groups reported the greatest barrier to accessing information was lack of awareness.

The Frequency of Information Seeking:

- 73% of the online group vs. 26% of the paper groups said they gathered information either daily or weekly basis.

In what situations are you most likely to seek out information about ABC?

	2005 Online	2005 Paper	2008 Paper
When I'm making a decision about or starting a new treatment	80%	58%	59%
When there is a recurrence or progression of my breast cancer	75%	62%	62%
When I'm feeling worried or sad	54%	25%	27%
When I'm having a problem with treatment side effects or discomfort/problems from the cancer itself	69%	46%	51%
None of the above	4%	13%	11%

THE ROLE OF SUPPORT

Sources of Support:

- The number one source of support in all groups was friends (75% in 2008 paper, 78% in 2005 paper, 68% in 2005 online).
- About 70% of both paper groups listed prayer as the most preferred activity vs. 56% of the online group.
- Second to prayer, 57% of the 2008 paper, 60% of the 2005 paper and 64% of the 2005 online groups said printed materials were very good to excellent sources of support.
- 74% of the 2008 paper, 82% of the 2005 paper and 75% of the online groups said that their current support was excellent or very good.

Frequency of Seeking Support:

- 30% of both the 2008 and 2005 paper groups sought support daily or weekly; 67% of the 2005 online group.
- 57% of the 2008 paper and 46% of the 2005 paper groups sought support less than once a month or never; 20% of the 2005 online group.

Type and Availability of Support Programs:

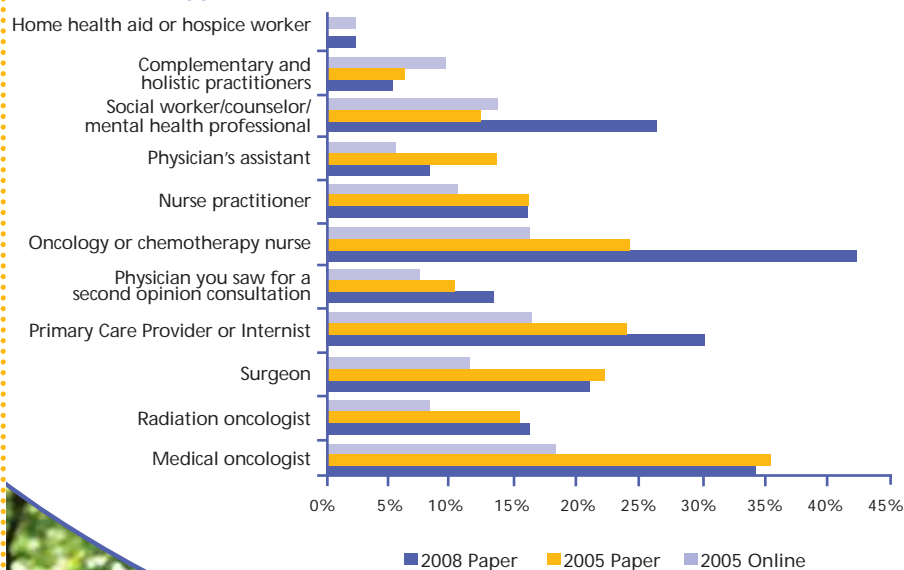
- 95% of all respondents thought that support programs that focused on current treatment options, new treatments and the latest research, clinical trial information and symptoms and side effects were available. 30% of all respondents did not know where to look for these services.

Healthcare Professionals and Support:

- 50% of the online group reported their medical oncologist made time to speak about concerns, compared to 84% of both paper groups.
- 40% of the online group felt their oncology nurses made time to speak about concerns, compared to 67% of the 2005 paper group and 75% of the 2008 paper group.

What kinds of SUPPORT offered by healthcare providers have been helpful to you?

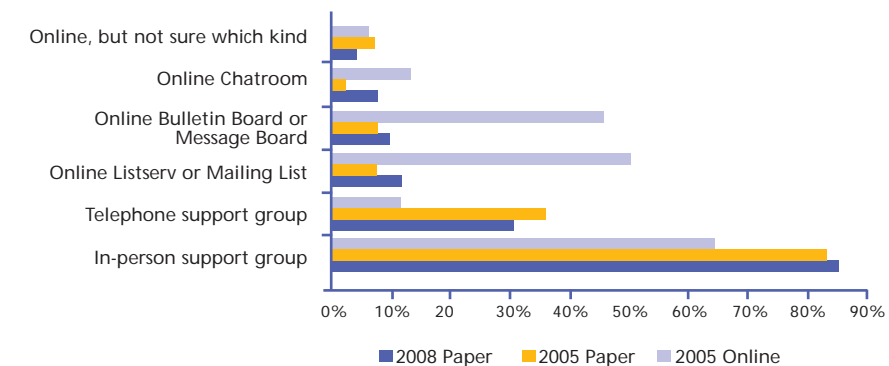
Referral to Support Services



Support Groups:

More than three-quarters of the online group reported that they have been in some type of support group, compared to 60% of the 2008 group and just over half (52%) of the 2005 paper group.

Of those who have participated in support groups, what type of support group(s) have you participated in?



Support Group Summary

	2005 (online) N=618	2005 (paper) N=79	2008 (paper) N=73
Participated in a Support Group	78%	52%	60%
Reasons for seeking a support group	88% learning about others' experiences	76% learning about others' experiences	84% learning about others' experiences
	77% feel less alone	57% feel less alone	75% feel less alone
	78% general emotional support	71% general emotional support	71% general emotional support
	81% find more information on ABC	57% find more information on ABC	59% find more information on ABC
	54% help with anxiety and sadness	48% help with anxiety and sadness	55% help with anxiety and sadness

Reason for Not Joining a Support Group:

Among those who did not participate in support groups...

- 32% of the both paper groups vs. 17% of the online group said they had no need for support.
- 33% did not join support groups because they thought a support group might be too upsetting.
- 21% of the online group said that they did not want to participate in groups with women without ABC; they reported that there were no support groups just for women with ABC in their area. Compared to 8% of the 2005 paper group and 10% of the 2008 group.

ROLE OF PRACTICAL RESOURCES

- Majority of respondents from all groups said information about non-medical issues such as health insurance and financial assistance are important.
- About 30% of all respondents said they had current access to this information.

LIMITATIONS

- Lack of random sampling methods may have resulted in respondent selection bias.
- Results are limited by the smaller sample size for both paper groups compared to online group.
- All three groups significantly under-represents minority, older and less well-educated women, as well as non-English speakers and women from lower socio-economic groups.
- The results of this study should not be generalized. Future studies should use a stratified random sample.

CONCLUSIONS

- Electronic educational materials, support and services help streamline the process of keeping information current; there is a segment of the population that prefers printed materials.
- Respondents across all groups felt they did not have adequate information or access to information about non-medical issues. Financial concerns and other non-medical issues were deemed important but little information was available to the population.
- While the majority prefer one-on-one, in person support, most said their friends, spouses/partner and other family were the best sources of support. When asked why they chose not to join a support group, one-third of the paper group said they had no need for support; a third said they found listening to other's experiences too upsetting.
- The 2008 survey reiterates the finding that a gap continues to exist in outreach to women living with ABC. The 2005 and 2008 paper groups answered survey questions in much the same way.

It is important to make breast cancer information, education and support efforts tailored to those living with ABC a priority in order to fill in a gap that continues to exist for these underserved women.

