Women with Metastatic Breast Cancer Want Better Information

By Kristina Fiore, Staff Writer, MedPage Today
Published: March 13, 2009
Reviewed by Robert Jasmer, MD; Associate Clinical Professor of Medicine, University of California, San Francisco .

Earn CME/CE credit for reading medical news



Copy the code below to embed audio on your website or blog:
<iframe src="http

ST. GALLEN, Switzerland, March 13 -- Women living with metastatic breast cancer are dissatisfied with the amount and quality of information available to them about their disease, according to a Harris Interactive survey released here.

Although three out of four respondents said they had attempted to research their condition, 51% said the available information was insufficient or ineffective, said Musa Mayer, M.S., founder of the advocacy group AdvancedBC.org and a member of the steering committee for the survey.

"Women with metastatic breast cancer are a neglected community," Mayer said at the International Conference on Primary Therapy of Early Breast Cancer. "By that I don't mean they receive inferior medical care, but their psychosocial and informational needs are often not very well met."

The survey, which polled 950 women in nine countries -- Argentina, Belgium, Egypt, France, Mexico, Poland, Spain, the U.K., and the U.S. -- found the following medical information needs:

- Metastatic breast cancer in general, cited by 77% of respondents
- Side effects and symptoms and how to manage them, 77%
- Treatment options used by the medical community, 73%
- Type of care available, 71%

Respondents also noted a lack of information on support services available in the community (68%), how to pay for care (66%), hospice and end-of-life concerns (64%), medical coverage (64%), and how to talk to people about their disease (63%).

Action Points

- Explain to interested patients that a survey of women with metastatic breast cancer found that most feel they need more and better information to help them cope with their disease.
- Note that the survey was funded by Pfizer.

Overall, however, survey respondents were pleased with their relationships with their healthcare providers -- 83% gave oncologists good marks for the emotional support they provide. And 78% said nurses were supportive.

Mayer said information "really helps women cope with their disease." She noted that the survey found that the use of the Internet for research is more widespread than had been thought, even in developing countries.

"If quality information is available in native languages, the Internet would be one inexpensive way of delivering that around the world to these patients and their families," she said.

The study also found that about 44% of women said they were afraid to talk openly about their disease -- a sign that a diagnosis of metastatic breast cancer may be stigmatizing, Mayer said.

Just over half of the respondents felt their disease receives too little public attention.

"Most media attention focuses on women newly diagnosed who have early stage breast cancer," said Ruth Oratz, M.D., of New York University, who was also involved in the survey. "Of course, that's the largest population, but we don't want to forget about the subset of women who are living with metastatic disease."

Worldwide, there are about 1.3 million new cases of breast cancer annually. In developing countries, the majority of women are diagnosed with advanced stage or metastatic disease.

In the U.S., there are about 180,000 new cases of breast cancer each year, with about 6% (11,000 cases) being metastatic disease.

Mayer noted that women with slow-growing, hormone sensitive tumors can survive for five to 10 years, although the average survival time is two to three years. The survey found that 66% of women are still able to enjoy their life with the disease.

"To many, a diagnosis of metastatic breast cancer is equated with death," Musa said. "People don't understand that patients live with disease often for many years, so the quality of their lives is a really critical thing."

Members of the survey's steering committee hope that the survey results will improve collaboration among metastatic breast cancer stakeholders, which includes more than 600 advocacy organizations.

They would like to see more easily accessible, quality information on the disease, as well as education programs that promote public awareness.

The survey was funded by Pfizer.

Primary source: International Conference on Primary Therapy of Early Breast Cancer
Source reference:
"BRIDGE Survey: Bridging gaps, expanding outreach -- Metastatic breast cancer patient survey" *Intl Conf Primary Therapy Early Breast Cancer* 2009.

Additional Breast Cancer Coverage »

MedPage Today provides daily, peer-reviewed medical news articles, written specifically for the clinician.

Why register?

1. While we cover most medical specialties, you can personalize the site to focus on your medical interests.
2. Know before your patients ask. Have quick access to evidence-based data, when patients print out what they found online and may be from questionable sources.
3. Optional breaking Medical News alerts. *We NEVER sell, rent or otherwise share your personal data.*
4. See article recommendations based on your specialty and declared interests.
5. Earn quick CME or CE credit for reading the news. *Available on most articles.*
6. It's Free

Register Today *Already registered? Sign In*

My News

- Antioxidants Widely Used Among Breast Cancer Patients
- ASCO: InFocus Reporters Focus on Meeting Highlights
- ASCO: Off-Label Therapy Common in Breast Cancer
- ASCO: No Survival Loss with Partial-Breast Irradiation
- ASCO: Action Needed in Early Breast CA with Isolated Cells in Lymph Nodes