

Perceptions of marginalization in those affected by advanced breast cancer

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Abstract

Those living with metastatic breast cancer have distinct and often unmet supportive and informational needs, even compared to others with breast cancer. To help address these needs, the Cancer Support Community has provided, for the past five years, *Frankly Speaking About Cancer: Advanced Breast Cancer*, a comprehensive educational program developed for those with metastatic breast cancer and their loved ones. These analyses investigate the psychosocial and educational needs of those affected by metastatic breast cancer and their perceptions about feeling marginalized. 1,827 workshop attendees nationwide (68% response rate; 64.9% diagnosed with breast cancer) responded to survey questions about experiences with advanced breast cancer since the program's inception. Of all respondents, the majority (58.3%) endorsed that people with metastatic breast cancer have unique emotional, physical, and informational needs that are often unmet. Taken together, the data strongly support the continued need for educational and support programs to address the needs of those affected by advanced breast cancer.

Background

Frankly Speaking About Cancer: Advanced Breast Cancer, launched in 2006, which is part of the *Frankly Speaking About Cancer* (FSAC) series developed by the Cancer Support Community (CSC). FSAC programs provide in-depth coverage of topics relevant to those affected by cancer, that are often not otherwise available in a comprehensive format.



This program's clinically facilitated evidence-based education workshops have reached 2,690 attendees, attending 150 workshops in over 25 states to date. The workshop provides valuable information about current treatments, side-effect management, and social and emotional challenges of an advanced breast cancer diagnosis. FSAC Advanced Breast Cancer program attendees were invited to complete a post-workshop evaluation onsite. 1,827 workshop attendees since the program's beginning have completed evaluations (68% response rate). Results from the attendee evaluation highlighting perceptions of those affected by advanced breast cancer are presented.

Objective

To investigate perceptions of the unique needs and perceived marginalization of those affected by advanced breast cancer.

Methods

- Participants: 1,827 U.S. people affected by advanced breast cancer (68% response rate) who attended one of CSC's *Frankly Speaking About Cancer: Advanced Breast Cancer* workshops held nationwide from 2006-2011.
- Measures: Post-workshop survey assessing demographics, cancer history and treatment. Additionally respondents provided information about:
 - Perceptions of needs of those with advanced breast cancer
 - Feelings of marginalization
 - Experiences seeking information and support and living with advanced breast cancer
- Analyses: In the present analysis, data across years were merged to investigate the psychosocial and educational needs of those affected by metastatic breast cancer and their perceptions about feeling marginalized.

Respondent Characteristics (n= 1,827)

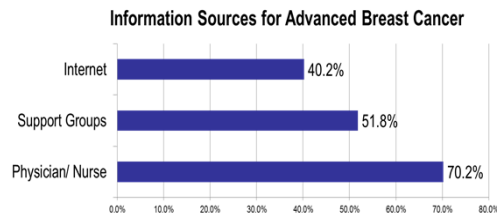
- 78.5% were Caucasian
- 4.1% were African-American; 8.2% were Hispanic
- Average age was 56.0 years (s.d.=12.6 years)
- Respondent composition:
 - Individuals with advanced breast cancer (64.9%)
 - Family members (6.7%)
 - Spouse/ partner (11.7%)
 - Health care professionals (9.9%)
 - Other (6.5%)
- Among those with Advanced Breast Cancer:
 - Average age was 57.6 years (s.d.= 10.8 years)
 - 19.3% received this diagnosis within the past year
 - 66.9% received the diagnosis at least two years ago
 - 75.1% rated themselves in "very good" or "good" health

Needs of Respondents

- Of all respondents, the majority (58.3%) believe that people with metastatic breast cancer have **unique emotional, physical, and informational needs** that are often unmet
- 30.4% of all respondents **believe that people with metastatic breast cancer are sometimes stigmatized** by others with non-metastatic breast cancer (31.7% of those with advanced breast cancer)
- Caregivers were equally as likely as patients to endorse that those with advanced breast cancer have unique, unmet needs. These trends were consistent across all years

Information & Support

- Patients report obtaining information about advanced breast cancer from:



- 59.6% of respondents with advanced breast cancer currently participate in support groups
- Among advanced breast cancer patients, who believed that those with advanced breast cancer are sometimes **stigmatized** were significantly **more likely to be in a support group** ($\chi^2 = 13.2, p < .01$).
- No difference in current support group participation in terms of:
 - Time since diagnosis;
 - Belief that those with advanced breast cancer have unique needs

Summary

- Over half of all respondents believe that those with advanced breast cancer have unique psychosocial and informational needs that are often unmet
- Similarly, nearly one-third reported that those with advanced breast cancer are often stigmatized
- Most with advanced breast cancer are currently connected with a support group, and most obtain information about their disease from their support group
- Those who are currently attending a patient support group were more likely to endorse feeling stigmatized

Discussion

- This finding supports existing literature that these unmet needs exist. Much research shows that women with advanced breast cancer are significantly more likely to suffer from depression and anxiety, even compared to other women with breast cancer.
- The data suggest an association between feeling stigmatized and support group participation. One goal for service delivery would be to implement supportive services which address these unmet needs and perceived biases.
- The data also suggest significant concerns of those caring for advanced breast cancer patients about the unique needs of this population.
- The data strongly support the continued relevance of programs developed specifically to meet the psychosocial and informational needs of those affected by advanced breast cancer.

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For More Information

Contact CSC at 1-888-793-9355 or
www.cancersupportcommunity.org



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Those living with metastatic breast cancer have distinct and often unmet needs, even compared to others with breast cancer. To help address these needs, the Cancer Support Community has provided for the past five years, *Frankly Speaking About Cancer: Advanced Breast Cancer*, a comprehensive educational program developed for those with metastatic breast cancer and their loved ones. The program's clinically facilitated evidence-based education workshops have reached 2,690 attendees since the program began in 2006. The workshop provides valuable information about current treatments, clinical trials, side-effect management, and social and emotional challenges of an advanced breast cancer diagnosis. In the present analysis, data across years were merged to investigate the psychosocial and educational needs of those affected by metastatic breast cancer and their perceptions about feeling marginalized.

1,827 workshop attendees nationwide (68% response rate) have responded to survey questions about experiences with advanced breast cancer since the program's inception. In addition to evaluating the workshop and reporting their cancer history, attendees have provided their perceptions of the needs of those with advanced breast cancer, feelings of marginalization, and their own experiences seeking information and support. 64.9% of respondents had been diagnosed with breast cancer; the remainder (35.1%) served in a caregiving capacity. Most respondents (78.5%) were Caucasian, and the mean age was 56 years. Among those with advanced breast cancer, most (66.9%) received the diagnosis at least two years ago. In addition, 75.1% rated themselves in "very good" or "good" health, and 59.6% currently participated in support groups. There was no difference in current support group participation by time since diagnosis.

Of all respondents, the majority (61.2%) endorsed that people with metastatic breast cancer have unique emotional, physical, and informational needs that are often unmet. This percentage remained unchanged across the five years of the program. Furthermore, 31.7% of all respondents endorsed that people with metastatic breast cancer are sometimes stigmatized by others with non-metastatic breast cancer. Among advanced breast cancer patients, those who believed that people with advanced breast cancer are sometimes stigmatized were significantly more likely to currently be in a support group ($\chi^2 = 13.2$, $p < .01$). Caregivers of advanced breast cancer patients were equally as likely as patients to endorse that those with advanced breast cancer have unique, unmet needs. As the data suggest an association between feeling stigmatized and support group participation, one goal for service delivery would be to implement supportive services which address these unmet needs and perceived biases. The data also suggest that addressing concerns of those caring for advanced breast cancer patients would be beneficial. Taken together, the data strongly support the continued need for educational and support programs to address the needs of those affected by advanced breast cancer.