

# A FIVE YEAR REVIEW OF AN EDUCATIONAL PROGRAM FOCUSED ON MEETING THE NEEDS OF ADVANCED BREAST CANCER PATIENTS

Ivy Ahmed, MPH, MCHES, Allison Harvey, MPH, CHES, Marni Amsellem, Ph.D. **Cancer Support Community**

## Program Rationale

Women living with advanced breast cancer (ABC) have distinct and often unmet needs, even compared to other women with breast cancer. For the past five years, the Cancer Support Community (CSC) has been committed to delivering *Frankly Speaking About Cancer: Advanced Breast Cancer*, a comprehensive psychosocial education program created for women with metastatic breast cancer and their families. The workshop provides valuable information about current treatments, clinical trials, side-effect management, and social and emotional challenges of an advanced breast cancer diagnosis. Workshop outcomes are analyzed annually, informing program content and ensuring the program is meeting the needs of those served. As the program enters its sixth year, data were consolidated across the past five years to investigate how the program has been meeting the needs of these women and their loved ones.

## Program Context & Content

*Frankly Speaking About Cancer: Advanced Breast Cancer*, launched in 2006, is part of the Frankly Speaking About Cancer (FSAC) series of programs developed by the CSC.



FSAC programs provides in-depth coverage of topics of relevance to those affected by cancer, guided by the Patient Empowerment concept, that are often not otherwise available in a comprehensive format.

FSAC program materials, representing the most up-to-date content, include:

- Web-based materials
- Booklets
- Online radio series and podcasts
- Professionally-led workshops held across the country

This program's clinically facilitated evidence-based education workshops have reached 2,690 attendees attending 150 workshops in over 25 states since its inception in 2006.

FSAC Advanced Breast Cancer program attendees were invited to complete an onsite post-workshop evaluation. 1,827 workshop attendees since the program's beginning have completed evaluations (68% response rate). Results from the attendee evaluation are presented.

## Workshop Evaluation

*Evaluations addressed:*

- Demographics and cancer history
- Satisfaction with workshop
- Pre/post-workshop knowledge about ABC
- Concerns and experiences of workshop participants related to advanced breast cancer
- Empowerment and patient/provider communication: Workshop participants rated on a 5-point scale (strongly disagree to strongly agree) whether, as a result of attending the workshop, they plan to:
  - Increase communication with healthcare team
  - Discuss side-effects/ ask questions to healthcare team
  - Ask about clinical trials

## 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)
- Respondents included:
  - Individuals with advanced breast cancer (64.9%)
  - Family members (6.7%)
  - Spouse/ partner (11.7%)
  - Health care professionals (9.9%)
  - Other (6.5%)
- 19.3% received ABC diagnosis within the past year

## Workshop Satisfaction

Overall, attendees reported that they were very satisfied with the workshop. Nearly all participants (98.3%) reported they would recommend the workshop to others affected by advanced breast cancer. Examples of feedback include:

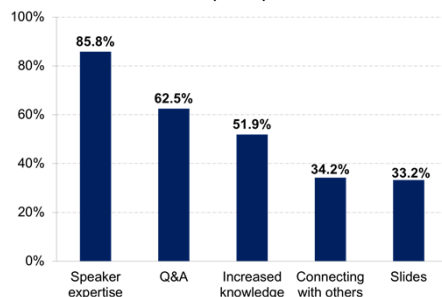
*"Very helpful, I am so grateful"*  
—2011 Participant, TWC Arizona

*"This was an excellent workshop; the speaker was extremely clear and used plain language (or explained the jargon)"*  
—2009 Participant, CSC Philadelphia

*"I was very impressed. The physician and speaker were excellent."*

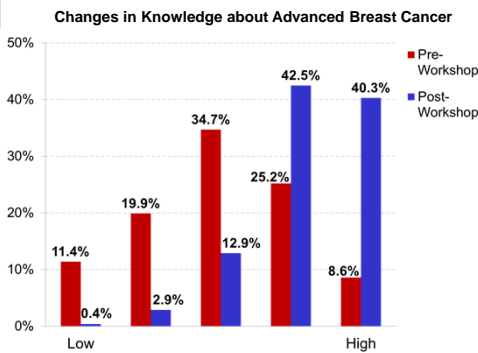
—2009 Participant, CSC Delmarva

## What was the most valuable aspect of the workshop for you? (n=372)



## Change in Knowledge

Respondents rated their level of knowledge of advanced breast cancer on a 5-point scale. Workshop participants reported a significant gain in knowledge about the workshop topic, post-workshop compared to pre-workshop levels (F= 76.7, p <.01). Most workshop respondents (83.8%) reported gaining a high or very high level of knowledge about advanced breast cancer, with significant increases compared with pre-workshop levels (p <.01).

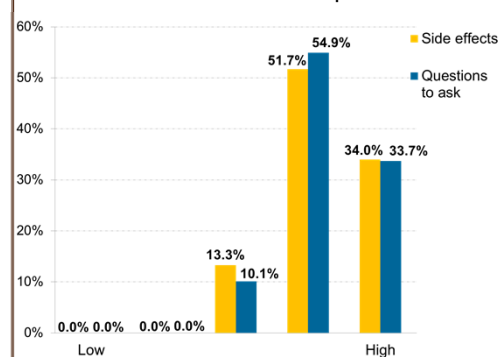


## Communication

Participants were asked, "As a result of this workshop, do you... a) "feel comfortable speaking with your healthcare team about treatment side-effects?"; b) "have a better idea of what questions to ask your healthcare team?" Most workshop attendees reported increased self-efficacy in:

- Asking questions to their healthcare team (88.6%)
- Discussing side effects of their cancer treatment with their doctors (85.7%), a key issue in regards to quality of life

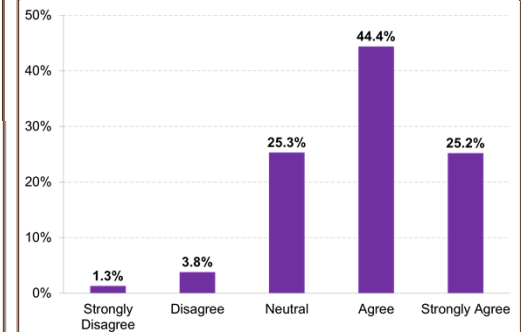
## Communication-Related Workshop Outcomes



## Clinical Trial Participation

Most participants (69.6%) reported planning to discuss possible clinical trial options with their healthcare team.

### Intention to Discuss Clinical Trial Options



## Summary

- Most attendees reported gaining knowledge from attending the workshop and recommend that others affected by advanced breast cancer attend the workshop.
- Large gains were seen in the critical role of being an active participant with one's healthcare team.
- Most attendees intend to increase and more effectively utilize communication with their clinical team following the workshop.
- Data indicate the continued relevance of this program for those affected by advanced breast cancer.

**For More Information** Contact CSC: 1-888-793-9355 or visit [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

## Future Directions

- Continue to meet the informational and support needs of advanced breast cancer patients and their loved ones
- Continue to review program data and to use evaluation results to inform future iterations of program

## Acknowledgement of Funding

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# Breast Cancer Symposium 2012

SEPTEMBER 13-15, 2012 | SAN FRANCISCO MARRIOTT MARQUIS | SAN FRANCISCO, CALIFORNIA

## A 5-year review of an educational program focused on meeting the needs of patients with advanced breast cancer

**Background:** Women living with advanced breast cancer have distinct often unmet needs, even compared to other women with breast cancer. For the past five years, the Cancer Support Community has been committed to delivering *Frankly Speaking About Cancer: Advanced Breast Cancer*, a comprehensive psychosocial education program created for women with metastatic breast cancer and their families. The program's clinically facilitated evidence-based education workshops have reached 2,690 attendees since its inception 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. Workshop outcomes are analyzed annually, informing program content and ensuring the program is meeting the needs of those served. As the program enters its sixth year, data were consolidated across years to investigate how the program has been meeting the needs of these women and their loved ones.

**Methods:** 1,827 workshop attendees since the program's beginning have completed evaluations (68% response rate) which included assessing levels of pre- and post-workshop knowledge about advanced breast cancer, patient-provider communication, and general workshop feedback.

**Results:** 64.9% of respondents were survivors, 78.5% were Caucasian, and the average age was 56. Most workshop respondents (89.6%) reported gaining a high or very high level of knowledge about advanced breast cancer, with significant increases compared with pre-workshop levels ( $p < .01$ ). Most reported intent to increase communication with their clinical team following the workshop. A majority reported feeling better equipped to ask questions to their health care team (92.1%), and discuss the possibility of clinical trials with their healthcare team (77.7%). Furthermore, 90% of attendees felt confident that after the workshop they could speak knowledgably about side effects of cancer treatment with their doctor, a key issue in regards to quality of life.

**Conclusions:** Taken together, the data indicate the continued relevance of this program for those affected by advanced breast cancer.