

EMPOWERING WOMEN WITH BREAST CANCER DURING THE DECISION-MAKING PROCESS ABOUT BREAST RECONSTRUCTION OPTIONS: RESULTS FROM NATIONWIDE PATIENT EDUCATION WORKSHOPS

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

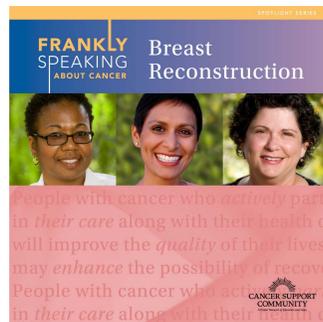
Background

For many women with breast cancer, making decisions about treatment is further complicated by decisions about breast reconstruction post-treatment. Guided by Social Cognitive Theory and results of a national survey conducted by Cancer Support Community to assess informational and psychosocial needs surrounding breast reconstruction in women with breast cancer, CSC developed and launched an educational program in 2011.

Frankly Speaking About Cancer: Spotlight on Breast Reconstruction, combines an educational booklet and professionally-led workshops designed to educate and empower those affected by breast cancer to become active partners with their health care team when making decisions about breast reconstruction. The present analyses examine how the program has met its goals.

Program Description

Frankly Speaking About Cancer: Spotlight on Breast Reconstruction is a national education program that streamlines information about breast reconstruction, emphasizing up-front education and tools for decision-making. The program encourages women to speak openly with their physicians about whether reconstruction is right for them.



The program launched in January 2011, which included a booklet, workshop, and online content. 34 clinically facilitated, evidence-based education workshops were delivered in 2011 across the U.S. to women who faced decisions about breast reconstruction following mastectomy.

This program is part of the *Frankly Speaking About Cancer* (FSAC) series. FSAC programs provide in-depth coverage on topics of relevance to those affected by cancer that are often not otherwise available in a comprehensive format. Program materials, representing the most up-to-date information, include:

- Web-based materials
- Comprehensive patient education booklets
- Online radio series and podcasts
- Professionally-led, community-based workshops

Evaluation of Program

All program attendees were invited to complete a post-workshop evaluation onsite, and 397 workshop attendees completed post-workshop evaluations (55% response rate).

Evaluations addressed

- Demographics
- Cancer history
- Satisfaction with workshop
- Breast reconstruction information-seeking
- Pre- and post-workshop knowledge about breast reconstruction
- Unmet informational needs
- Empowerment

Respondent Characteristics

(n= 397)

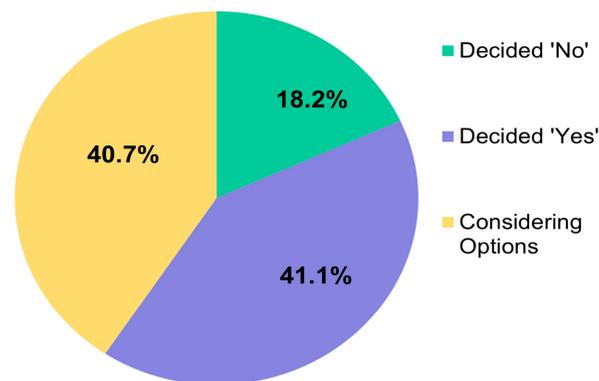
- 76.1% of respondents were women diagnosed with breast cancer; the remainder were spouses/partners; family members; and health care professionals
- 74.8% Caucasian
- 11.4% African-American
- 10.1% Hispanic
- 2.4% Asian
- Average age was 53.4 years

Of the 76.1% respondents diagnosed with breast cancer:

- 39.5% received their diagnosis in the past year
- 41.5% were in treatment
- 27.4% have had a recurrence

Decision Regarding Breast Reconstruction

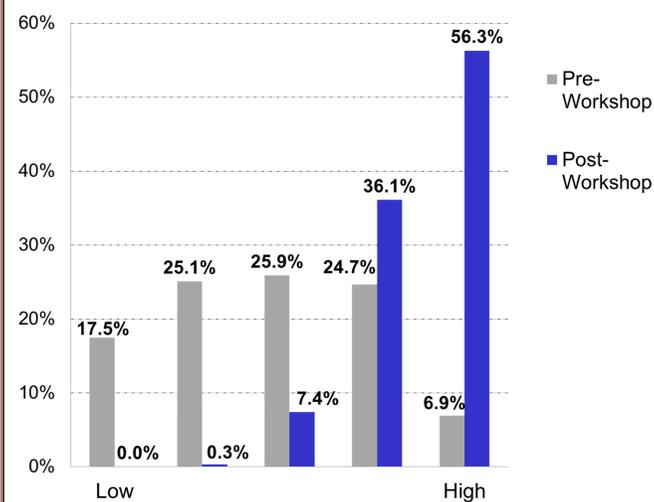
Of those eligible for breast reconstruction, 18.2% reported they had decided against reconstruction, 40.7% were considering their options, and 41.1% planned to undergo or had undergone reconstructive procedures.



Gains in Knowledge

Participants rated their level of knowledge of breast reconstruction on a 5-point scale. Participants reported a significant gain in knowledge about reconstruction, post-workshop compared to pre-workshop (F= 18.9, p <.01). Most respondents (83.8%) reported gaining a high or very high level of knowledge about breast reconstruction post-mastectomy.

Changes in Knowledge about Breast Reconstruction

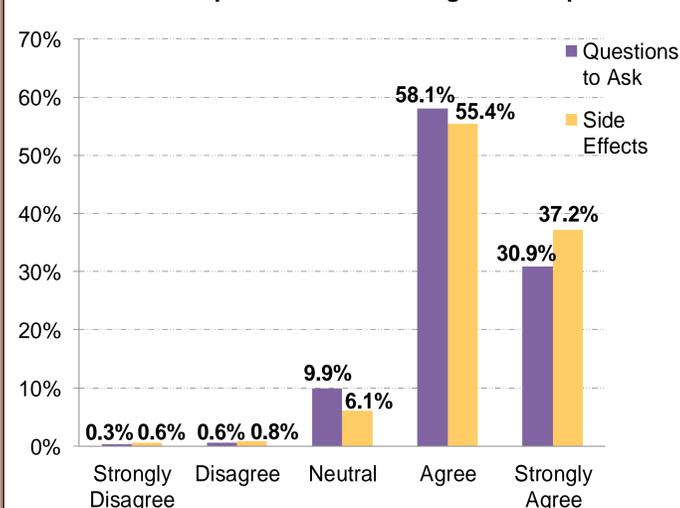


Communication with Health Care Team

After attending the program, nearly all respondents reported:

- A better understanding of what questions to ask the health care team to make decisions (92.6%)
- Improved confidence in speaking knowledgeably with health care team about side effects and realistic expectations (89.0%)

Gains Reported from Attending Workshop



Workshop and Booklet Satisfaction

Overall, respondents reported that they were very satisfied with the workshop and educational booklet. **97.6%** reported that they would **recommend the workshop** and **95.4%** would **recommend the booklet** to others seeking to learn more about breast reconstruction.

"I really appreciate that they show non reconstruction as an acceptable option."

–Workshop Participant, CSC Greater Cincinnati

"I wish I had had this booklet before my surgery."

–Workshop Participant, CSC Valley/Ventura/Santa Barbara

"Awesome workshop. Need to get the word out so we have an idea beforehand what to expect."

–Workshop Participant, GC Madison

Summary

- Most attendees reported gaining knowledge from workshop
- Nearly all recommend that others attend the workshop and read the educational booklet
- Workshop outcomes included large gains in the critical role of communicating openly and proactively with medical professionals
- Workshop results suggest the program is successful in improving access to comprehensive information about all reconstruction options, including not having reconstruction, and in filling unmet needs for those facing or considering breast reconstruction

Future Directions

- Continue to meet the informational and support needs of breast cancer patients facing decisions about breast reconstruction and their loved ones
- Continue to review program data and to use evaluation results to inform future iterations of educational materials

For More Information Contact CSC: 1-888-793-9355 or www.cancersupportcommunity.org

Acknowledgement of Funding

This program was made possible by a charitable contribution from Mentor Worldwide.



Empowering women with breast cancer during the decision-making process about breast reconstruction options: Results from nationwide patient education workshops

As breast cancer treatments have improved so have the number of women with breast cancer opting for breast reconstruction. According to the American Cancer Society (2012), 229,000 women will be diagnosed with breast cancer, which means a large cohort will face challenging decisions around reconstructive surgery. In 2010 the Cancer Support Community (CSC) took steps to improve access to honest and comprehensive information about reconstruction options women have after cancer. Guided by a national survey of 840 women, and Social Cognitive Theory an evidence-based educational program was developed. *Frankly Speaking About Cancer: Spotlight on Breast Reconstruction*, combines professionally-led workshops with a booklet to empower those affected by breast cancer to actively partner with their healthcare team when making treatment decisions.

Launched in 2011, the present analyses examine success in meeting program goals. 397 workshop attendees completed post-workshop evaluations (55% response rate). Most respondents (76.1%) were cancer patients/survivors, 74.8% were Caucasian, average age 53.4. Nearly all recommend the workshop (97.6%) and booklet (95.4%) to others facing similar concerns. Respondents reported a significant gain in knowledge about reconstruction options post-workshop ($F=18.9, p < .01$). Nearly all attendees reported increased self-efficacy in asking informed questions to healthcare providers (92.6%), in discussing side effects (89.0%), and in making decisions (89.8%). Workshop outcomes included large gains in the critical role of communicating openly and proactively with medical professionals. Workshop results suggest the program is successful in improving access to comprehensive information about all reconstruction options, including not having reconstruction.