

PATIENT INFORMATIONAL NEEDS ABOUT BREAST RECONSTRUCTION POST-MASTECTOMY

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

Background

For many women, receiving a breast cancer diagnosis is further complicated by decisions they will face about breast reconstruction post-mastectomy. While women are typically provided with some information about reconstruction options, little is known about the perceived value of this information and how it might ultimately affect their decision about reconstruction.

The Cancer Support Community investigated these questions in a national sample of women with breast cancer to better understand their information-seeking experiences, knowledge, and decision-making about reconstruction.

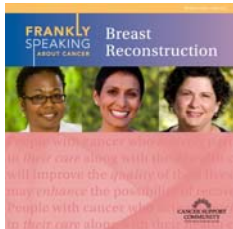
Program Background

In 2011, the Cancer Support Community launched *Frankly Speaking about Cancer: Spotlight on Breast Reconstruction*, a national education workshop 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. This program is part of the Frankly Speaking About Cancer (FSAC) series.

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
- Comprehensive patient education guide
- Online radio series and podcasts
- Professionally-led community-based workshops held nationwide



In 2011, this program's clinically facilitated evidence-based education workshops served numerous individuals across the U.S. who have faced decisions about breast reconstruction following mastectomy. All program attendees were invited to complete a post-workshop evaluation onsite, and 439 (56.4%) completed the evaluation.

Attendees reported their decisions about reconstruction as well as their experience receiving information about reconstruction. Results from the attendee evaluation are presented.

Workshop Evaluation

Evaluations addressed:

- Demographics and cancer history
- Satisfaction with workshop
- Breast reconstruction information-seeking
- Pre- and post-workshop knowledge about breast reconstruction
- Unmet informational needs
- Patient empowerment

Respondent Characteristics (n= 439)

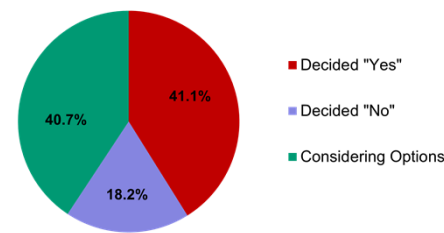
- 76.2% of respondents were women diagnosed with breast cancer; the remainder were spouses/ partners, family members, and health care professionals
- 74.8% were Caucasian
- 11.4% African-American; 10.1% Hispanic; 2.4% Asian
- Average age was 48.9 years

Of respondents diagnosed with breast cancer:

- 39.5% received their diagnosis in the past year
- 41.5% are currently undergoing cancer 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.



Workshop and Booklet Satisfaction

Overall, attendees reported that they were very satisfied with the workshop and educational booklet. **98.7%** reported that they would **recommend the workshop and booklet** to others seeking to learn more about breast reconstruction.

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

—Workshop Participant, TWC Greater Cincinnati

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

—Workshop Participant, CSC Valley Ventura

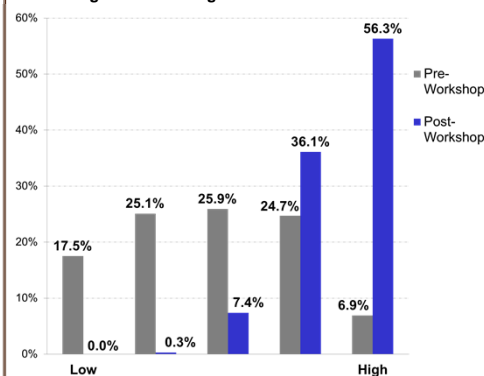
"Awesome workshop. Need to get the word out so we have an idea beforehand what to expect."

—Workshop Participant, CSC Madison

Gains in Knowledge

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

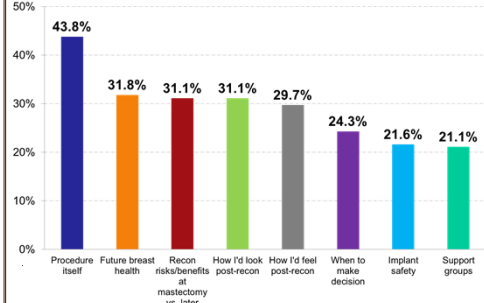
Changes in Knowledge about Breast Reconstruction



Informational Needs

Women reported they would have liked to have had more information prior to reconstruction about a variety of topics, including the procedure itself (43.8%), how they would look (31.1%) and feel (29.7%) after reconstruction, and information about their future breast health (31.8%).

Desired Information Not Received Prior to Breast Reconstruction

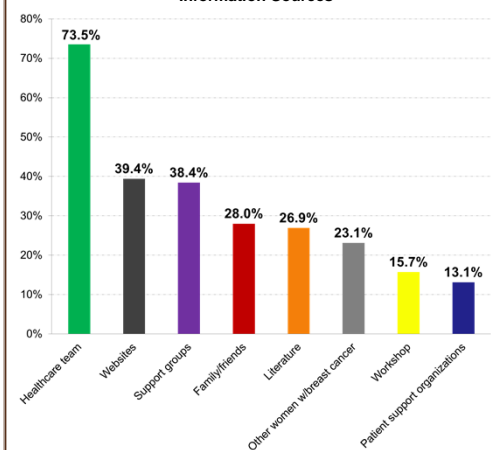


No differences were found in unmet informational needs based on their reconstruction decisional status with one exception: those who decided against reconstruction were more likely to report that they would have wanted more information about when to make their decision about reconstruction than the other two groups ($\chi^2 = 24.6, p < .01$).

Information-Seeking Decision Making

In addition to relying on their healthcare team for information about breast reconstruction, women with breast cancer reported also seeking information on the Internet (39.4%), in-person or online support groups (38.4%) as sources of information.

Information Sources



Summary

- Findings suggest women facing breast reconstruction often are not equipped with comprehensive information about procedures, options, outcomes, and recovery and most have a variety of unmet informational needs prior to the procedure
- Most attendees reported gaining knowledge from attending the workshop and recommend that others attend the workshop and read the educational booklet
- Results indicate this program's ability to provide valuable information and fill unmet needs for those facing or considering breast reconstruction

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

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

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Patient informational needs about breast reconstruction post-mastectomy

Background: For many women, receiving a breast cancer diagnosis is further complicated by decisions they will face about breast reconstruction post-mastectomy. While women are typically provided with some information about reconstruction options, little is known about the perceived value of this information and how it might ultimately affect their decision about reconstruction. The Cancer Support Community investigated these questions in a national sample of women with breast cancer to better understand their information-seeking experiences, knowledge, and decision-making about reconstruction.

Methods: In 2011, 439 participants attending *Frankly Speaking about Cancer: Spotlight on Breast Reconstruction*, a national educational workshop, completed a post-workshop survey (56.4% response rate). 76.2% of respondents were women diagnosed with breast cancer, who reported their decisions about reconstruction as well as their experience receiving information about reconstruction.

Results: Respondents were Caucasian (74.8%), Black (11.4%), and Hispanic (10.1%), and the mean age was 48.9. Nearly half (42%) of respondents reported low levels of knowledge about breast reconstruction prior to the workshop. 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. Women reported they would have liked to have had more information prior to reconstruction about a variety of topics, including more information about the procedure (43.6%), how they would look (31.1%) and feel (29.7%) after reconstruction, and information about their future breast health (31.8%). No differences were found in unmet informational needs based on their reconstruction decisional status with one exception: those who decided against reconstruction were more likely to endorse that they would have wanted more information about when to make their decision about reconstruction than the other two groups (chi square=24.6, $p < .01$).

Conclusions: Findings suggest women facing breast reconstruction often are not equipped with comprehensive information about procedures, options, outcomes, and recovery.