




Closing the gap: Results from a national survey of breast cancer survivors regarding breast reconstruction options and health education resources

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Each year, women with breast cancer (active or post-treatment) are faced with decisions about breast reconstruction. A review of available resources indicates a limited amount of thorough and comprehensive information available on this topic. Guided by Social-Cognitive Theory, the Cancer Support Community (CSC) conducted a national survey of breast cancer survivors to better understand women's information-seeking experiences and knowledge about breast reconstruction options. 840 U.S. female breast cancer survivors (762 eligible for breast reconstruction) participated in the survey online or by paper-and-pencil in 2010.

The survey queried participants about their diagnosis, treatment, and experience with reconstruction. In addition, women rated experiences in searching for and receiving information about options and realistic expectations for breast reconstruction. Over 40% reported their healthcare team did not speak with them about reconstruction at diagnosis. Women who received this information reported it to be somewhat (35.1%) or extremely (55.5%) useful. Aside from their healthcare team, 60% of women sought information about reconstruction from other women with breast cancer and 50% from the Internet. Other responses suggest gaps in information with regard to establishing realistic expectations about the procedures and outcomes, providing comprehensive information at various points throughout the process, and across various treatment options.

Findings offer a unique insight into the often challenging health information seeking process. Survey results informed the development of a new national education program, *Frankly Speaking About Cancer: Spotlight on Breast Reconstruction*, which seeks to increase self efficacy through education about and building communications skills in the decision making process.




Presenter Disclosures

Ivy Ahmed, MPH, MCHES

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose



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Cancer Support Community Mission

To ensure that all people impacted by cancer are:

- Empowered by Knowledge
- Strengthened by Action
- Sustained by Community



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Breast Reconstruction: Survey Justification

- Guided by Social-Cognitive Theory, the Cancer Support Community (CSC) conducted a national survey of breast cancer survivors to better understand women's experiences about breast reconstruction options.
- Little known about:
 - the patient experience of breast reconstruction
 - factors influential in making decisions about breast reconstruction
 - about how information is communicated with breast cancer patients
 - where patients seek information

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Survey Methods

- Survey
 - Online and Pencil & Paper
- Recruitment
 - CSC affiliates
 - Cancer survivor registry
 - Advocacy partners
 - Social media
 - E-mail and flyers
- Eligibility
 - Woman diagnosed with breast cancer
- Timeframe
 - July 14- August 20, 2010





Survey Items

Women provided information about:

- Demographics
- Cancer history, staging, Treatment
- Decision about reconstruction, decisional factors, decisional satisfaction
- Experiences, expectations, and satisfaction with reconstruction
- Communication with healthcare team about reconstruction
- Information-seeking about reconstruction

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Survey Sample Characteristics

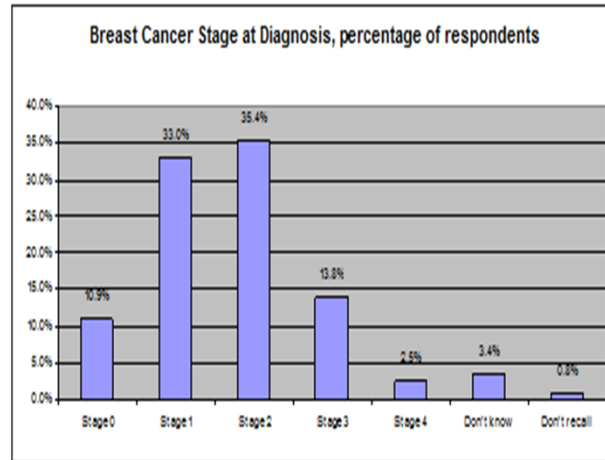
• **n= 840**

- Race/Ethnicity
 - **85.2%** Caucasian
 - **4.8%** Black
 - **6.7%** Latino
- **48.9** Mean age at dx
- **99%** had health insurance
 - 69% employer plan
 - 11.5% private plan
- **28%** Currently in treatment
- Received treatment at:
 - **38%** Community hospital
 - **29%** Comprehensive cancer center
 - **22%** Private oncology practice
- **68%** had Full/partial mastectomy

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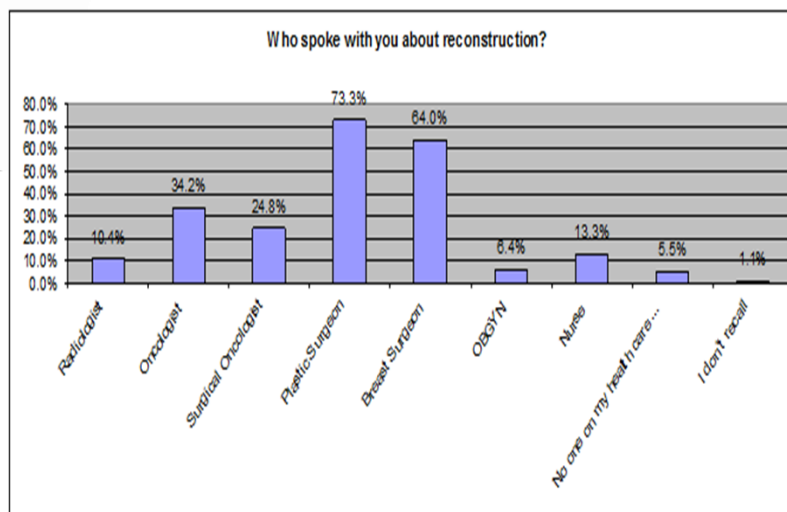
Survey Sample Characteristics: Breast Cancer Status



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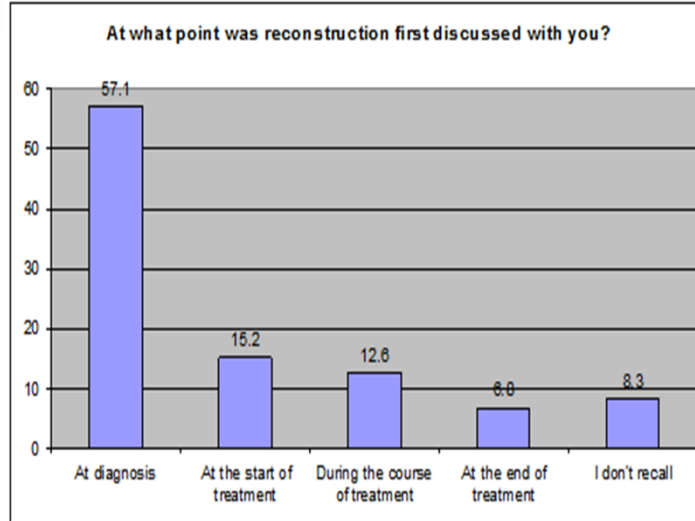
Survey Results



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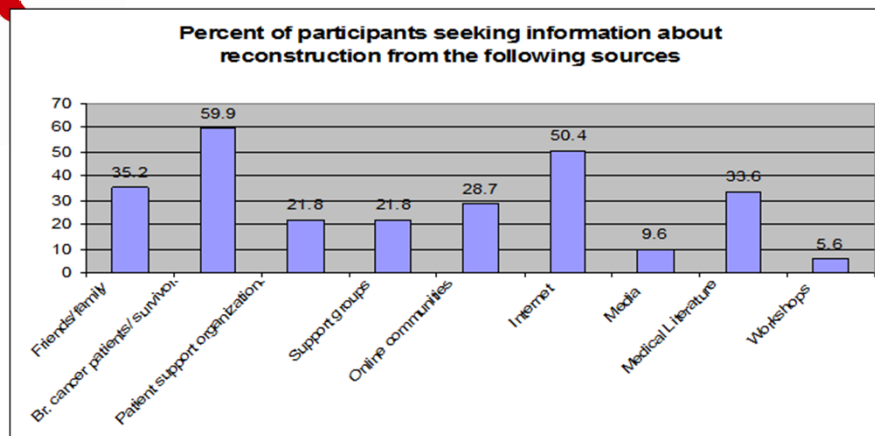
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Survey Results



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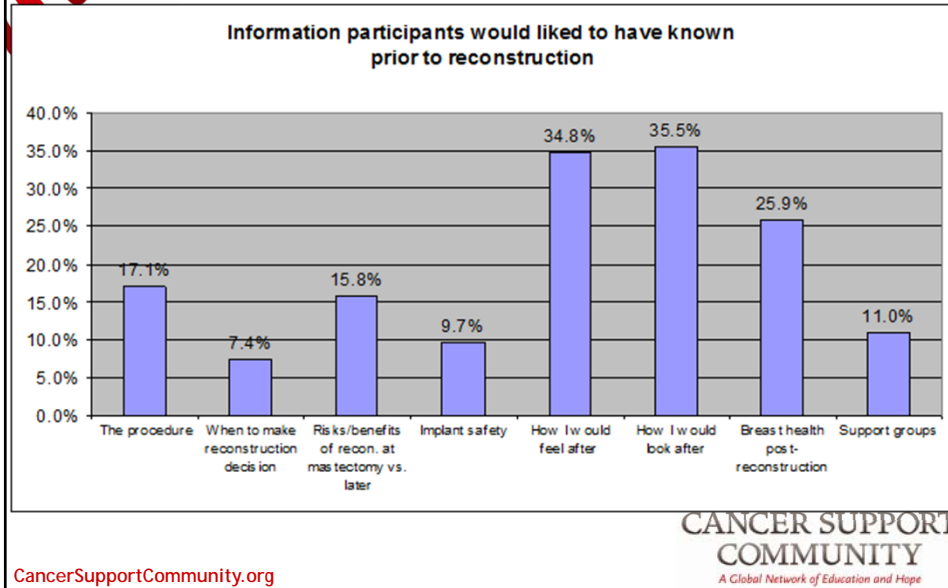
Survey Results



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Survey Results



Survey Conclusions

- Results offer unique insight into many aspects of reconstruction from the perspective of women with breast cancer.
- Though many participants reported satisfaction with the information provided to them about reconstruction, responses suggest that there is work to be done with regard to establishing realistic expectations about the procedures and outcomes, providing comprehensive information at various stages throughout the process, and across various treatment options.

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FSAC: Spotlight on Breast Reconstruction

- Based on survey findings CSC created an educational program designed to empower patients and their families about issues around breast reconstruction.

Program includes:

- print book
- face-to-face workshop
- online content



Program launched in January 2011, and to date:

- Over 600 workshop participants
- 30 workshops provided
- 14,000 books distributed

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For more information,
contact the CSC: 1-888-793-9355
www.cancersupportcommunity.org

Thank You

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