

NOVEL PROGRAMMING TO MEET UNMET NEEDS--FRANKLY SPEAKING ABOUT CANCER: SPOTLIGHT ON BREAST RECONSTRUCTION

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Cancer Support Community

Introduction

- The Cancer Support Community (CSC), uniting The Wellness Community and Gilda's Club Worldwide, is an international non-profit organization that provides free, emotional support and education for cancer patients and their loved ones.
- In 2001, CSC launched Frankly Speaking About Cancer (FSAC), an educational series that provides an in-depth look into a variety of concerns cancer patients and their loved ones face following a diagnosis. Program materials are updated to reflect new advances in knowledge, and include: web-based materials, booklets, and professionally-led workshops held across the country.

Purpose

- The decisions women diagnosed with breast cancer face about breast reconstruction can be complex and overwhelming.
- To better understand the patient experience, CSC conducted a national survey of 840 women. Survey results informed the development of a new patient education and empowerment program, entitled *Frankly Speaking About Cancer: Spotlight on Breast Reconstruction*.

Methods

- 840 U.S. women with breast cancer (762 eligible for breast reconstruction) participated in an online survey or a paper-and-pencil survey at a CSC affiliate site in July or August, 2010
- In addition to demographics, information about their diagnosis and treatment, women provided information about:
 - Knowledge of reconstruction
 - How and when knowledge was communicated
 - Information sources for reconstruction
 - Decision about reconstruction; decisional satisfaction
 - Experiences and satisfaction with reconstruction
 - Details of the decision-making process
 - The influence of psychosocial factors on their reconstruction decision

Sample Characteristics (N=840)

85% Caucasian	Received treatment:
49 yrs Mean age at diagnosis	38% Community hospital
99% were Insured	29% Comprehensive ca center
28% Currently in treatment	22% Private oncology practice
32% Diagnosed >2 years ago	68% had Full/partial mastectomy
68% had Stage I/II disease	63% Opted for reconstruction
10% had a Recurrence	

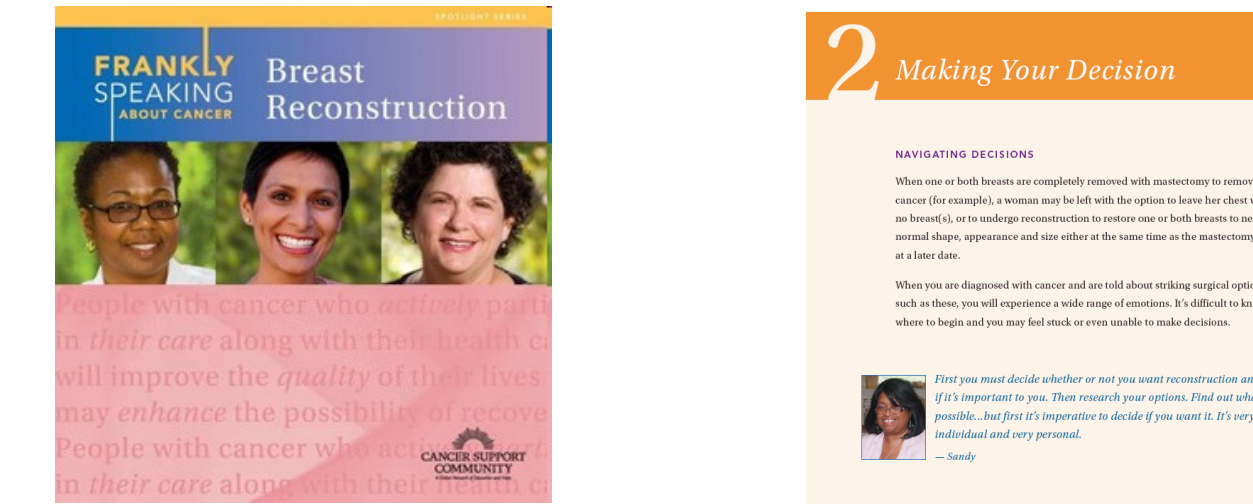
Results

- 43% of patients do not receive information about breast reconstruction options when making treatment decisions at diagnosis
- Women facing breast reconstruction often do not have access to adequate information providing realistic expectations about procedures and outcomes
- Over half of women search for information about reconstruction online and/or ask other women with breast cancer
- A credible, accessible and validated single resource for patients on the topic of breast reconstruction is not currently available
- Women would like to be better equipped with comprehensive information about procedures and recovery
- Participants who chose to have reconstruction (n=762) (63.2% of participants) generally reported body image (70.3%) and physical appearance (73.1%) greatly influenced their decision, whereas financial concerns (69%) and opinions of others (60.3%) were not influential

Program Justification

- Results of this national survey offer unique insight into many aspects of reconstruction, including available sources of information, how information is communicated, and the decision-making process and patient experience for women facing reconstruction.
- Survey has identified a variety of informational needs of women facing reconstruction which have been incorporated into the development of *Frankly Speaking about Cancer: Spotlight on Breast Reconstruction*

Spotlight on Breast Reconstruction



- The program 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. It includes:
 - A community-based patient education workshop
 - A comprehensive patient education guide which educates breast cancer patients eligible for reconstruction and empowers them to make the best personal decision
 - Multimedia education tools and online web content to engage women in knowledgeable discussions around breast reconstruction

Program Evaluation Data

- The Wellness Community of Valley Ventura, CA hosted a professionally-facilitated workshop launch in early 2011. Of 110 attendees, 61 completed an evaluation of the program.

Sample Characteristics (N=61)

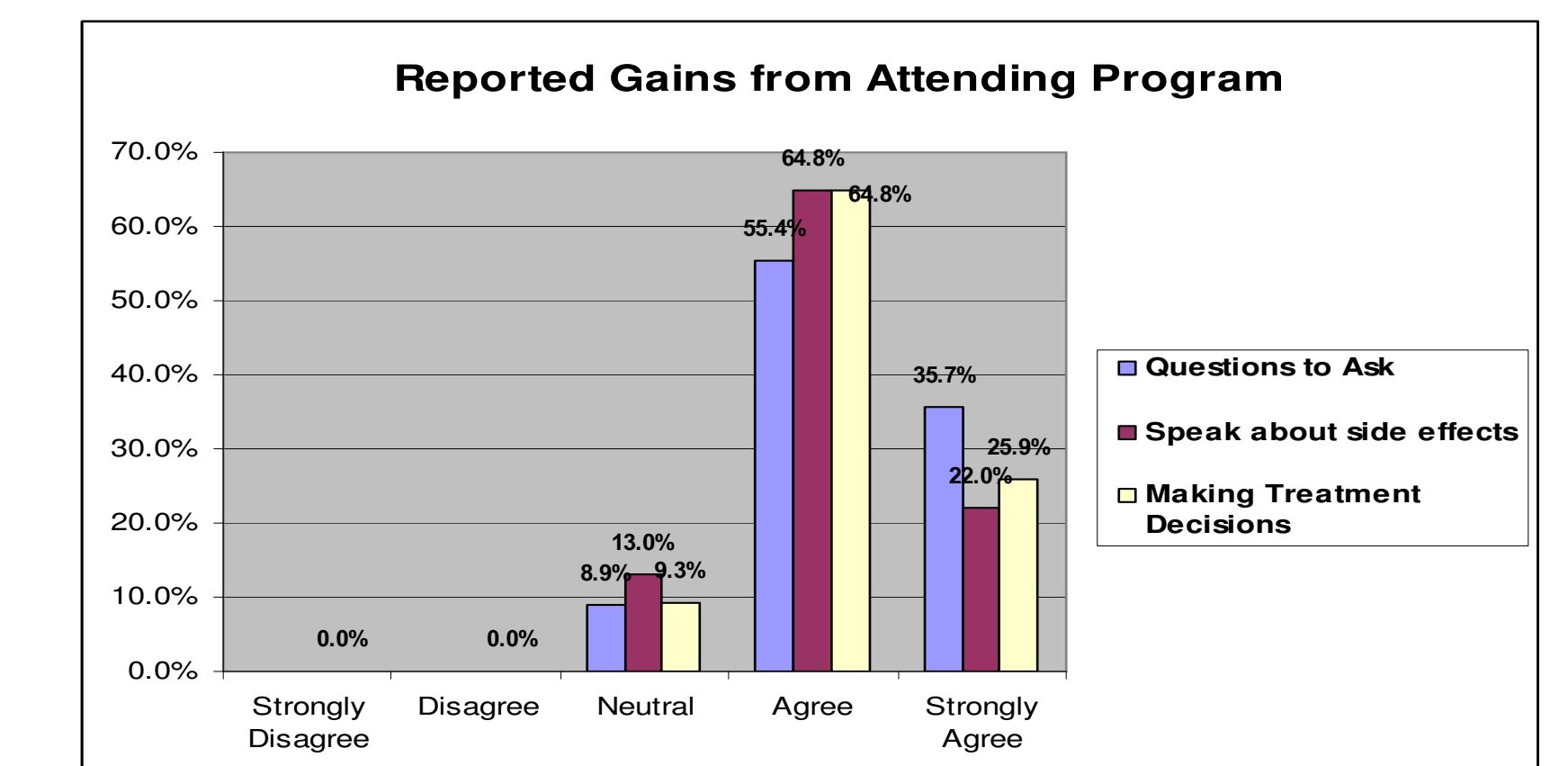
- 84%** were women with cancer/ cancer survivors
- 8%** were friends/family members of women with breast cancer
- Average age: **58 years**
- 76%** were Caucasian

Results

- After attending the program, participants report:
 - a better understanding of what questions to ask the healthcare team to make decisions
 - improved confidence in speaking knowledgeably with healthcare team about side effects and realistic expectations
 - are better able to make decisions with healthcare team

Program Evaluation Data, cont.

- On a 5-point scale (strongly disagree to strongly agree), **every participant** endorsed 'agree' or 'strongly agree' that they **recommended the program and the program booklet to others** facing breast reconstruction.



Knowledge of reconstruction after the workshop was rated as a 4.4 (s.d. = 0.85) on a scale of 1 to 5

Compared to levels of knowledge before the workshop, participants reported a **significant increase in knowledge** about breast reconstruction from attending the workshop.

Conclusions

- Based on the evaluation of existing FSAC programs, the FSAC program model has been successful in both providing the necessary tools to empower patients and supporting effective decision-making tailored to the individual. This model was used to develop the new program as well.
- Pilot program evaluation data indicates the program has been well-received and has successfully met all of its intended goals.

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NOVEL PROGRAMMING TO MEET UNMET NEEDS: FRANKLY SPEAKING ABOUT CANCER: SPOTLIGHT ON BREAST RECONSTRUCTION.

The decisions women diagnosed with breast cancer face about breast reconstruction can be complex and overwhelming. The Cancer Support Community (CSC) conducted a national survey of 840 women to inform the development of a new patient education and empowerment program, entitled *Frankly Speaking About Cancer: Spotlight on Breast Reconstruction*. This program, among other goals, aims to provide the tools necessary to help make the best decision about reconstruction for each individual. Survey findings suggest women facing breast reconstruction often do not have access to adequate information providing realistic expectations about procedures and outcomes, and that women would like to be better equipped with comprehensive information about procedures and recovery.

The CSC, a non-profit organization that provides free emotional support and education for cancer patients and their loved ones, began to offer this program throughout the country in 2011. The program 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 and includes: A community-based patient education workshop; A comprehensive patient education guide which educates breast cancer patients eligible for reconstruction and empowers them to make the best personal decision; Multimedia education tools and online web content to engage women in knowledgeable discussions around breast reconstruction. Available program evaluation data indicates the program has been well-received and has successfully met all of its intended goals.