

Informational needs among women considering breast reconstruction post-mastectomy

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Abstract & Rationale

For many women, the complexity of processing and learning about their breast cancer diagnosis is further complicated by decisions to be made about breast reconstruction post-mastectomy. For women considering reconstruction post-mastectomy, obtaining information about reconstruction procedures and outcomes is a process, and multiple factors may influence the decision-making process. Little is known about the extent to which patient's knowledge and expectations related to breast reconstruction procedures weigh on their decision-making process.

To better understand and meet the needs of women facing reconstruction, the Cancer Support Community surveyed a national sample of 1,185 women with breast cancer in 2010-11. 15.5% of respondents were considering reconstruction options. Many sought information about reconstruction from other women with breast cancer (40.8%), medical literature (45.8%), patient support groups (34.8%), and the Internet (56.1%). Over one-third of those considering reconstruction (34.4%) would have liked more information about the risks and benefits of reconstruction at the time of mastectomy versus at a later time. Results suggest women considering breast reconstruction have a variety of informational needs, some of which are not being met.

Program Background

In 2010, the Cancer Support Community (CSC) took steps to improve access to honest and comprehensive information about breast reconstruction options by developing a national educational program. Guided by the results of a national survey of 840 women with breast cancer, CSC launched *Frankly Speaking About Cancer: Spotlight on Breast Reconstruction*, a clinically-facilitated education program streamlining information about breast reconstruction, emphasizing up-front education and tools for decision-making. This evidence-based program encourages women to speak openly with physicians about whether reconstruction is right for them. In its first year, the program served over 500 women and their loved ones attending 34 workshops nationwide.

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.

Objectives

- To better understand the information-seeking experiences, knowledge, and decision-making about breast reconstruction in women with breast cancer.
- To ascertain the value of specific types of information about breast reconstruction and how it might ultimately affect decision-making

Methods

- Participants:**
 - A national sample of 1,185 women diagnosed with breast cancer answered questions either:
 - online (n=840) in August, 2010
 - via paper and pencil (n= 345) in 2011 after attending CSC's *Spotlight on Breast Reconstruction* workshops
- Surveys assessed:**
 - Demographics, diagnostic and cancer treatment history
 - Knowledge about and decision-making about reconstruction
 - Experience searching for and receiving information about recon.

Respondent Characteristics (n= 1,185)

- 81.6% identified as Caucasian
- 11.4% as African-American; 2.4% as Asian, 10.1% as Hispanic

Breast Cancer History:

- Mean age at diagnosis was 48.9 years
- 21.1% received their diagnosis in the past year
- 30.0% were diagnosed at least five years ago
- 54.4% are currently undergoing cancer treatment
- 27.0% have had a recurrence
- 79.1% were diagnosed with Stage 0-2 disease

Reconstruction Decision:

- Of those eligible for breast reconstruction (91.1% of respondents):
- 18.4% reported they had decided against reconstruction
 - 15.5% were considering their options
 - 57.3% planned to undergo or had undergone reconstructive procedures

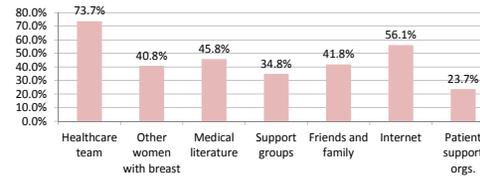
Sampling note:

Online respondents were more likely to be Caucasian, less likely to have been recently (less than one year) diagnosed with breast cancer, and more likely to have already made a decision regarding reconstruction, as compared to workshop attendees, but were similar in all other respects for these analyses.

Information-Seeking

Half of all women (50.4%) currently considering or planning to consider breast reconstruction reported low levels of knowledge about breast reconstruction prior to attending the workshop. These women also reported their information-seeking patterns and informational needs:

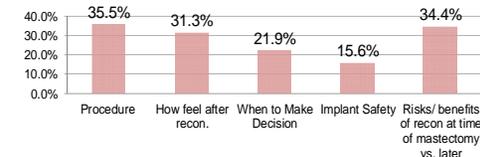
Sources of Information about Breast Reconstruction



Informational Needs and Influential Factors

Women considering breast reconstruction reported they would have liked to have had more information prior to reconstruction about a variety of topics, including:

Desired Information During Decision-Making



Over one-third of respondents considering reconstruction would have liked more information about the risks and benefits of reconstruction at the time of mastectomy versus at a later time (34.4%) as well as information about the procedure itself (35.5%).

These women also reported a number of factors influencing their current point in the decision-making process, including:

- concerns about implant safety (83.3%)
- concerns about additional treatment and recovery (85.5%)
- concerns about failed procedures (91.5%)
- confusion about the reconstruction decision-making process (72.2%).

Summary

- Half of all women considering breast reconstruction post-mastectomy report low levels of knowledge about reconstruction. That said, women search for information about breast reconstruction from a variety of informational sources.
- Findings suggest women considering 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.
- Results suggest that women considering breast cancer experience a multitude of concerns about the procedure and its effects, concerns that are also reflected in the information most desired by women making this decision.

Discussion

- Survey responses suggest women considering breast reconstruction have a variety of informational needs, some of which are not being met. Women are looking to fill these needs by seeking information from a variety of sources.
- Results suggest there is still work to be done with regard to providing comprehensive information at various stages following a diagnosis of breast cancer and throughout the reconstruction decision-making process.
- When making significant health-related decisions, having access to information addressing concerns about the decision is paramount to feeling confident in the decision made.
- The data strongly support the continued relevance of programs developed specifically to meet the informational needs and address the psychosocial concerns of those facing breast reconstruction.

Acknowledgement of Funding

Mentor Worldwide

For more information:

contact the Cancer Support Community at 1-888-793-9355 or www.cancersupportcommunity.org



Informational Needs among Women Considering Breast Reconstruction Post-Mastectomy

For many women, the complexity of processing and learning about their breast cancer diagnosis is further complicated by decisions to be made about breast reconstruction post-mastectomy. For women considering reconstruction post-mastectomy, obtaining information about reconstruction procedures and outcomes is a process, and multiple factors may influence the decision-making process. Little is known about the extent to which patient's knowledge and expectations related to breast reconstruction procedures weigh on their decision-making process.

To better understand and meet the needs of women facing reconstruction, the Cancer Support Community surveyed 1,185 women diagnosed with breast cancer. Women answered questions either: online (n=840) in August, 2010; or via paper and pencil (n= 345) after attending a breast reconstruction workshop held at multiple sites nationwide in 2011. In addition to demographics, and diagnostic and treatment history, women reported their decision regarding reconstruction, experience searching for and receiving information, and expectations about reconstruction.

Respondents were primarily Caucasian (81.9%), and the mean age at diagnosis was 48.9. 21.2% of respondents were first diagnosed with breast cancer in the past year, and 30.0% were diagnosed at least five years ago. Online respondents were more likely to be Caucasian, less likely to have been recently (less than one year) diagnosed with breast cancer, and more likely to have already made a decision regarding reconstruction, as compared to workshop attendees, but were similar in all other respects for these analyses.

Most respondents (57.3%) had either undergone or had decided to undergo breast reconstruction. 18.4% of respondents reported they decided not to undergo reconstruction, and 8.9% reported they were not eligible. Additionally, 15.5% of respondents were currently considering or planning to consider their options for reconstruction at a later time.

Of the women who were currently considering or planning to consider breast reconstruction, information-seeking patterns and informational needs were reported. Aside from their health care team, most women sought additional information about reconstruction from other women with breast cancer (40.9%), medical literature (46.0%), patient support groups (35.6%), friends and family (41.3%), and the Internet (57.2%). Over one-third of respondents considering reconstruction (34.5%) would have liked to have had more information about the risks and benefits of reconstruction at the time of mastectomy versus at a later time. These women also reported a number of factors influencing their current point in the decision-making process, including: concerns about implant safety (83.3%); concerns about additional treatment and recovery (85.5%); concerns about failed procedures (91.5%); and confusion about the reconstruction decision-making process (72.2%).

Survey responses suggest women considering breast reconstruction have a variety of informational needs, some of which are not being met. Results suggest there is still 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 the various choices.