

Patient-Provider Communication and Patient Informational Needs for Breast Reconstruction Post-Mastectomy: Results from a National Survey



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Abstract

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. Existing studies suggest that these women are provided with information about breast reconstruction options of differing depth, breadth, and quality, but little is known about how this information is received by the patient as well as the value of this information.

Guided by Social Cognitive Theory, the Cancer Support Community (CSC) conducted a national survey in an effort to better understand patients' information-seeking experiences, patient-provider communication, and knowledge about breast reconstruction. 840 U.S. women with breast cancer (762 eligible for breast reconstruction who were then eligible to answer survey questions pertaining to their experiences) participated in the survey online or by paper-and-pencil at CSC affiliate sites in 2010. Women rated their experience with receiving breast reconstruction information from their healthcare professionals as well as their experience searching for and receiving information about options and realistic expectations for breast reconstruction.

57% of women reported receiving information about reconstruction at the time of diagnosis, and most found this information at least somewhat useful. Though many participants reported satisfaction with the quality and usefulness of this information, 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.

Survey Objectives

- Understand how women with breast cancer learn about options for breast reconstruction and how this information is communicated by the healthcare team
- Inform the development of a new patient education and empowerment program

Survey Methods

- Participants:
 - 840 U.S. women with breast cancer (762 eligible for breast reconstruction) participated in an online or paper-and-pencil survey in 2010
 - Recruitment through the Cancer survivor registry, advocacy partners, social media, email, flyers, CSC affiliates
- Measures:
 - In addition to demographics, information about their diagnoses, cancer history and treatment, women provided information about:
 - Knowledge of reconstruction and informational sources
 - How and when knowledge was communicated by healthcare team
 - Details of the decision-making process, expectations for and experiences with reconstruction

Participant Characteristics (n=840)

Race/Ethnicity

- **85.2%** Caucasian
- **4.8%** Black
- **6.7%** Latino

48.9 years Mean age at diagnosis

34.7% Diagnosed >5 years ago

28% Currently in treatment

68% had Stage I/II disease

10% had a Recurrence

Received treatment:

- **38%** Community hospital
- **29%** Comprehensive cancer center
- **22%** Private oncology practice

99% had health insurance

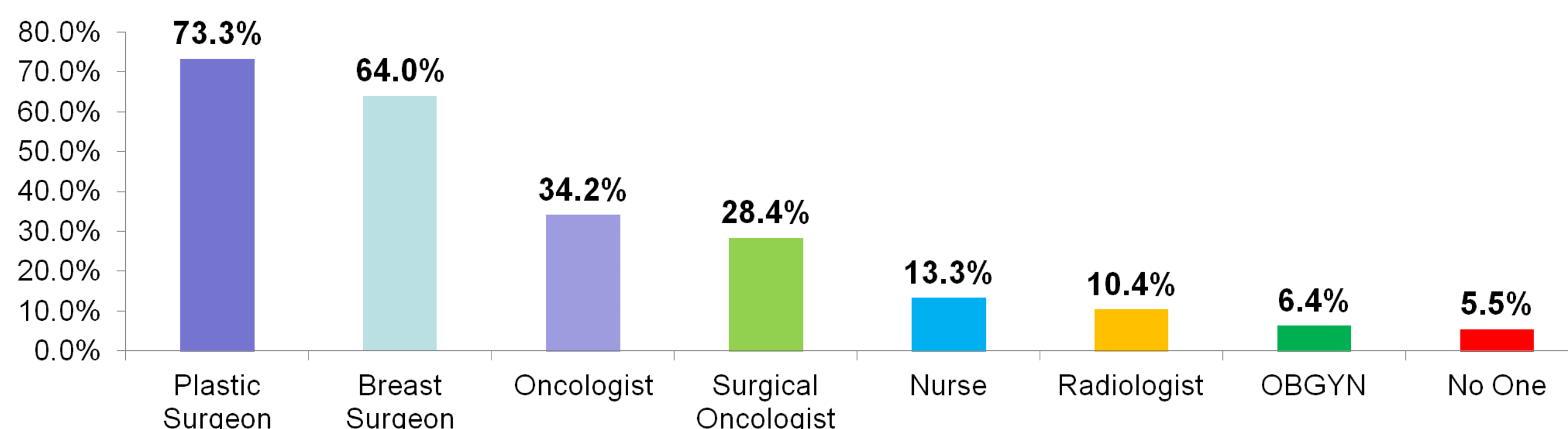
- **69%** employer plan
- **11.5%** private plan

68% had Full/partial mastectomy

63% Opted for reconstruction

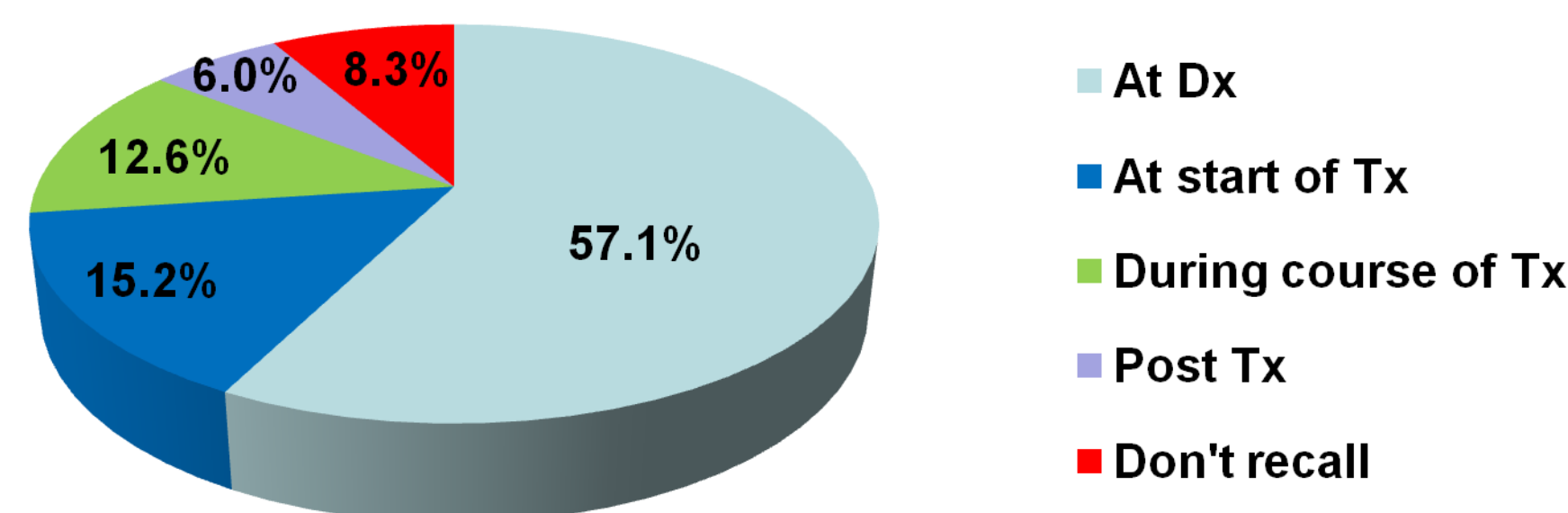
Communication about Breast Reconstruction

Who on your healthcare team spoke with you about reconstruction?



Most women reported that either a plastic surgeon (73.3%) or a breast surgeon (64.0%) had spoken to them about reconstruction.

When was breast reconstruction first discussed?



Of women who received information from their healthcare team, the vast majority perceived that information to be **somewhat (35.1%)** or **extremely (55.5%)** useful.

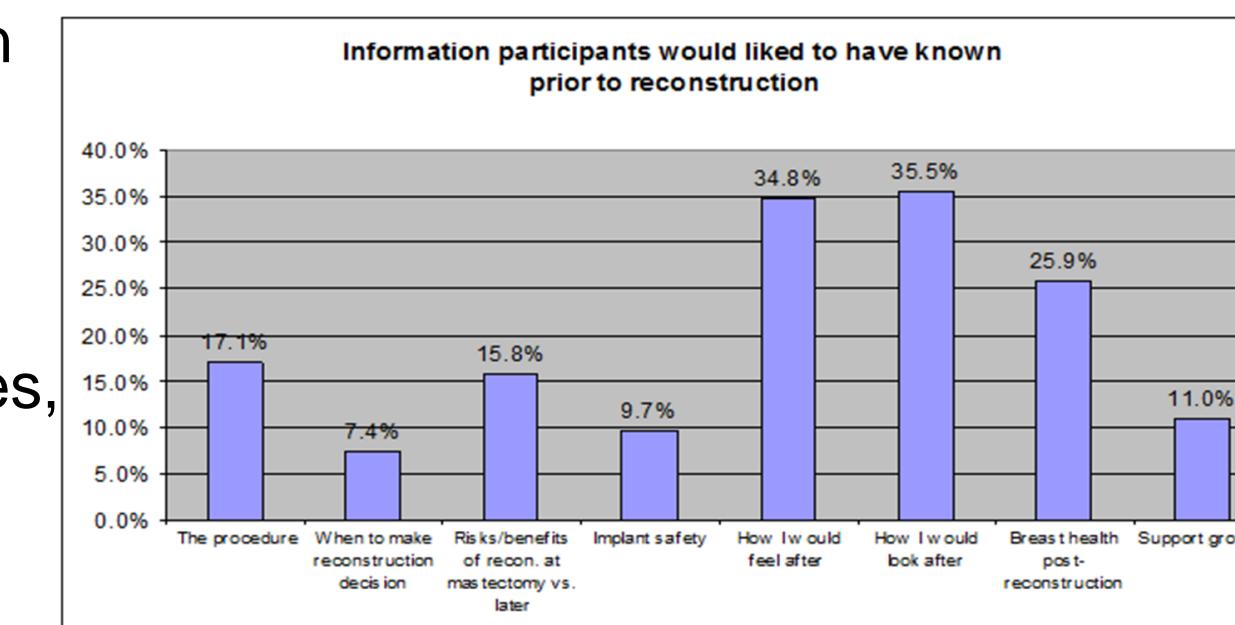
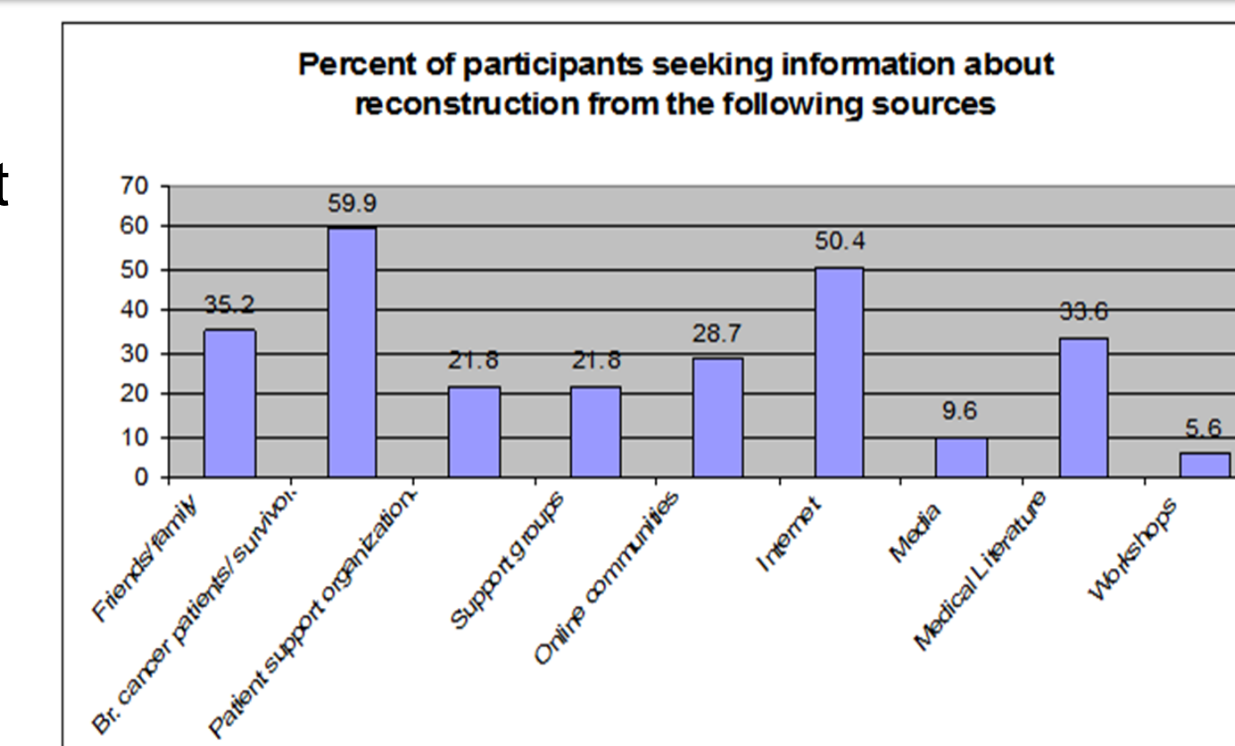
43% of patients do not receive information about breast reconstruction options when making treatment decisions at diagnosis

Patient Knowledge & Information-Seeking

In addition to their healthcare team, most (60%) sought information about reconstruction from other women with breast cancer; half sought information from the Internet.

Participants reported that they would have liked to have had more information prior to reconstruction about a variety of topics, including: how they would look after reconstruction (34.8%), how they would feel after reconstruction (35.5%), and information about their future breast health (25.9%).

Open-ended responses suggest informational gaps in establishing realistic expectations about procedures and outcomes, providing comprehensive information at various stages throughout the process, and across various treatment options.



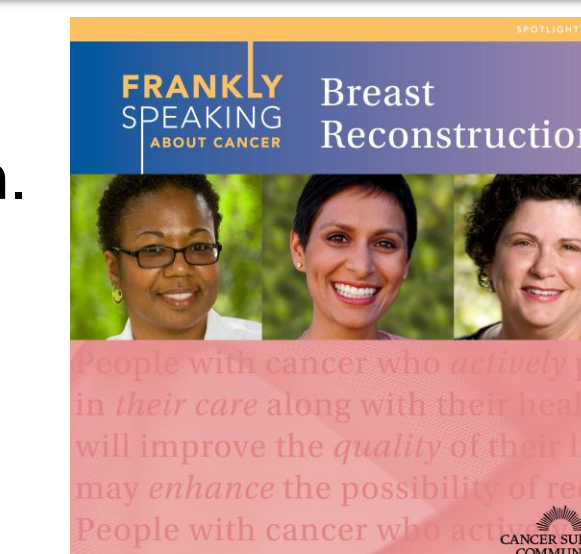
Summary of Findings

- Women facing breast reconstruction often do not have access to adequate information providing realistic expectations about procedures and outcomes and often receive information after treatment has started
- Women would like to be better equipped with comprehensive information about procedures and recovery
- 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

Next Steps

CSC created an educational program, *Frankly Speaking About Cancer: Spotlight on Breast Reconstruction*, designed to empower patients and their families about issues around breast reconstruction. The program launched in 2011, includes: print materials, professionally-led workshops, and online content. Pilot program evaluation data indicates the program has been well-received and has successfully met all of its intended goals.

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Survey participants came from 46 states, were primarily Caucasian (85%), and the mean age at diagnosis was 48.9 years old. Most women reported that either a plastic surgeon (73.3%) or a breast surgeon (64.0%) had spoken to them about reconstruction, followed by oncologist (34.2%) and surgical oncologist (24.8%). Of women whose healthcare team had spoken with them about reconstruction, 57.1% reported that reconstruction was first discussed at diagnosis. Women reported that this information was somewhat (35.1%) or extremely (55.5%) useful, though they sought additional information elsewhere. Aside from their health care team, most women (60%) sought information about reconstruction from other women with breast cancer and half sought information from the Internet. Participants reported that they would have liked to have had more information prior to reconstruction about a variety of topics, including: how they would look after reconstruction (34.8% endorsing), how they would feel after reconstruction (35.5%), and information about their future breast health (25.9%). Open-ended responses suggest many patients experience gaps in information 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.

Though many participants reported satisfaction with how information about reconstruction was provided to them and the quality and scope of this information, 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.