

# Early-stage breast cancer patients lack knowledge; may not receive treatment they prefer

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According to the results of a new study published in the January 2012 issue of the *Journal of the American College of Surgeons*, many early-stage breast cancer survivors lacked knowledge about their disease and were not meaningfully involved in treatment discussions or asked their preferences regarding the approach to treatment. As a result, the study's investigators determined that there is a need for improvements in the quality of the surgical decision-making process for these patients.

The [retrospective study](#) sought to evaluate the quality of the decision-making process regarding the options for surgical treatment. The "quality" for early-stage [breast cancer patients](#) in this study was defined as the degree to which a decision was informed and consistent with patient preferences. Although several other studies have found [knowledge gaps](#) and identified specific patient concerns that affect decisions about [breast cancer surgery](#),<sup>i ii iii</sup> this is the first study that attempted to examine how often treatments actually reflect patient preferences.

Surveys were mailed to adult women with a history of early-stage [invasive breast cancer](#) (stages I and II) treated at one of four [academic medical centers](#): The Dana-Farber Cancer Institute, Boston; Massachusetts General Hospital, Boston; University of California, San Francisco; and University of North Carolina, Chapel Hill. Patients answered about half of the questions right (average knowledge score was 52.7 percent), indicating some large gaps in knowledge for information that providers identified as critical. Less than half (48.6 percent) of study participants reported that their surgeon asked them about their preference regarding surgical treatment.

The data was collected an average of two-and-a-half years following the surgical procedure and

recognized the fact that patients are likely to forget some information over time. However, the knowledge gaps concerned not just detailed information but also basic general concepts. For example, only half of the surveyed patients knew that the survival rate was the same for breast-conservation therapy and mastectomy. In addition, women who had a partial mastectomy were less knowledgeable about local recurrence rates than were women who had a mastectomy.

"This finding was concerning because patients who opt for partial mastectomy need to be aware of their slightly higher risk of local recurrence," said Clara N. Lee, MD, MPP, FACS, lead author of the study and an associate professor and director of surgical research at the University of North Carolina School of Medicine in Chapel Hill. "Patients and providers need to have transparent conversations about treatment options, risks and goals in order to make fully informed decisions."

The study stated that improving the quality of decisions about breast cancer surgery will require interventions to enhance patient knowledge and incorporate preferences into the decision-making process. "Two things are needed to help improve the quality of decisions. First, it is important to have a way to measure decision quality so that providers can get feedback on how they are doing. Second, we need to use decision tools that have been proven to inform and engage patients, more consistently," added Karen Sepucha, PhD, senior study author, assistant professor at Harvard Medical School and director of the Health Decision Sciences Center at Massachusetts General Hospital.

Of the 746 patients identified in the study, 440 participated (59 percent). The data showed that 45.9 percent of respondents knew that local

recurrence risk is higher after breast conservation and 55.7 percent knew that survival is equivalent for the two options. Participants reported more frequent discussion of partial mastectomy and its advantages than of mastectomy, and 83.2 percent reported the provider made a treatment recommendation.

The survey included 10 multiple-choice questions regarding breast cancer knowledge, including treatment options, local recurrence, survival and side effects - six items that were rated on a scale from 0 (not at all important) to 10 (extremely important) in the goals and concerns category - and an additional seven multiple-choice items about the content of discussions with providers and how involved the patient was in the decision-making process. The decision about the type of surgical procedure for early-stage [breast cancer](#) is considered a "preference-sensitive" decision. [Patients](#) in this study were clinically eligible for either option, and an international consensus process has defined the quality of decision-making as the degree to which a decision is informed and concordant with patient preferences.<sup>iv v vi</sup>

**More information:**

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measurable improvements in decision quality. *Health Aff (Millwood)*. 2004;Suppl Variation:VAR54?62.

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