

# Many women report not feeling completely informed about breast cancer treatment options

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Breast cancer is the second most common cancer among women in the United States, with more than 230,000 women diagnosed annually. (Skin cancer remains the most common.) Patients often describe the process of making a treatment decision as worrisome, so one research team wanted to explore how these patients became informed about their treatment options, and why some women might feel less than completely informed.

The researchers found that the majority of women who had [breast cancer](#) operations reported not feeling completely informed about their [treatment](#) options. In a separate study, another research team found a possible solution: using a web-based [decision](#) aid tool, which improved patients' knowledge of treatment options more than standard [cancer](#) websites. Patients using the decision aid were more likely to recognize that waiting a few weeks to make a decision regarding their [breast](#) cancer operations would not negatively impact survival. Results from both studies appear on the *Journal of the American College of Surgeons* website as "articles in press" ahead of print publication.

"We were really interested in providing the patient perspective," said Sunny Mitchell, MD, a breast surgeon in Stratford, CT, and the lead author of the first study, based on a nationwide survey that found the majority of women did not feel completely informed about their treatment options before undergoing [breast cancer surgery](#). "On top of

exploring how women become informed about their treatment options, we also wanted to identify any opportunities for improvement," Dr. Mitchell said.

The study, designed as a post-treatment survey, was administered by an independent public opinion research firm and completed via the Internet in June 2016. Participants were recruited from health advocacy groups, clinics, and other health-related organizations, and were eligible to take the survey if they were female, ages 18-99, received a breast cancer diagnosis, and had undergone lumpectomy, mastectomy, or both procedures. There were 487 respondents who completed the survey.

When asked if researching all their options or making a quick decision was a priority, 35 percent of the lumpectomy-only patients, 31 percent of the mastectomy-only patients, and 22 percent of the group of patients who had both operations, said that making a quick decision was more important. When asked how strongly patients agreed or disagreed that they wished they had more time to explore different breast cancer surgery options, the majority of all three groups agreed somewhat or strongly that they wished they had more time.

The survey also asked participants how informed or uninformed they felt about treatment options before undergoing breast cancer operations. The authors found that, among lumpectomy patients, only 47 percent said they felt completely informed. Among mastectomy patients, 67 percent said they felt completely informed. Among patients who had both operations, only 28 percent said they felt completely informed.

Dr. Mitchell said she was "definitely surprised by the large percentage of women who reported not feeling completely informed." In order to address this deficiency, Dr. Mitchell said that future studies could focus on providing consistent, reliable information in a variety of formats, and measuring which ones are the most effective. Formats could include

brochures, decision aids, and videos to ensure that patients have enough information to make advance treatment decisions.

While many patients will make efforts to educate themselves on their own, the authors wrote, "it is unrealistic to expect that the majority of patients have sufficient health literacy, research skills, information access, and clarity of mind to inform themselves" about all treatment options, and to make the best decision. Therefore, it should be the responsibility of the physician to educate the patient about treatment options and to ensure she's sufficiently informed to make a decision. In addition to providing the information, Dr. Mitchell noted that physicians should also reassure patients. Although timely treatment should be initiated, she said, patients do actually have more time than they think to make a [treatment decision](#).

Like Dr. Mitchell's team, the second research team was also interested in how patients received information about [treatment options](#). These researchers studied decision aids and found that these materials were more effective in informing patients when compared with standard cancer information websites. During their initial surgical consultations, [breast cancer patients](#) who used the web-based decision aid tools were more engaged, better able to articulate their concerns, and quicker to voice their opinions, said lead study author Heather Neuman, MD, MS, FACS, an associate professor in the department of surgery at the University of Wisconsin-Madison.

From April 2014 to June 2016, the research team randomized women newly diagnosed with stages 0 to III breast cancer who were considering an operation within the UW breast program by sending them a web link via email. The link took patients to either a web-based decision aid or to standard cancer websites, including [breastcancer.org](http://breastcancer.org), the American Cancer Society, and the National Cancer Institute. The decision aid utilizes static, didactic information written for an eighth grade reading

level and video clinical vignettes.

"In addition to providing information, the decision aid allows patients to compare choices by presenting the information in a parallel way," Dr. Neuman said. "It includes extra pieces of information that prompt patients to think about their values and preferences."

After receiving the links and reviewing the information, patients received a questionnaire in the clinic prior to their first surgical consultation. Researchers measured patient knowledge, the primary outcome, using a breast cancer decision quality instrument. The instrument presented five items to assess knowledge on key concepts relevant to decision making for a breast cancer operation.

The authors found that patients who received links to the decision aid demonstrated higher overall knowledge (median score of 80 percent on the questionnaire) compared with patients who received links to the standard websites (median score of 66 percent). Additionally, 72 percent of patients who received the decision aid recognized that waiting a few weeks to make a decision about their breast cancer operations would not negatively impact survival, compared with 54 percent of patients who received links to standard websites.

"Patients come in with this urgency, and this finding tells them they can slow down. They don't need to have that anxiety," Dr. Neuman said, adding that her team plans to conduct a similar study on the use of decision aids in an underserved community in Memphis, Tenn.

Decreasing the urgency surrounding the decision-making process may in turn increase the quality of the surgeon-patient consultation, the authors wrote, as patients may be more open to hearing the options and better prepared to consider them. Dr. Neuman emphasized that [patients](#)

receiving information in any form from a physician—rather than having to search for things online themselves—is very helpful.

"This process of sending something by email works, and for a general surgeon in a more rural area, that's something they could do to improve care," she said.

**More information:** How Well Informed Do Patients Feel About Their Breast Cancer Surgery Options: Findings from a Nationwide Survey of Women after Lumpectomy and/or Mastectomy. *Journal of the American College of Surgeons*.

A randomized controlled trial evaluating the impact of web-based information on breast cancer patients' knowledge of surgical treatment options. *Journal of the American College of Surgeons*.

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