

Reliable patient education materials on breast cancer are difficult to access, research finds

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Women with breast cancer must often make complex decisions about surgery and treatment options during an already stressful time in their

lives, and many of these women may turn to the wide variety of materials available online. New research presented at the [American College of Surgeons \(ACS\) Clinical Congress 2023](#) has found that reliable educational materials about breast surgery are not only difficult to assess but are also presented at much higher reading levels than recommended.

Two studies, presented at the Scientific Forum of the annual ACS Clinical Congress, held in Boston, Massachusetts, October 22–25, shed light on the need to develop more accessible materials for women with breast cancer, which is the most common non-skin cancer diagnosed in women in the United States.

"In [breast surgery](#), there are a lot of decisions patients have to make, and sometimes giving a choice to a patient can be really overwhelming, especially if there's not a one-size-fits-all solution," said co-author Emily Palmquist, MD, a [breast surgeon](#) at the University of Washington Medical Center and an assistant professor in the department of general surgery at the University of Washington School of Medicine.

"As much as we as surgeons try to educate patients, there is limited time and patients can only absorb so much in a visit. Some patients may turn to other resources online, such as blogs and non-validated sources that they may find easier to read and understand, which raises concern about the accuracy of materials patients may be accessing."

Dr. Palmquist was part of a group of researchers from the University of Washington who reviewed English-language patient education materials describing breast-conserving surgery, mastectomy, and lymph node surgery from National Cancer Institute-designated Comprehensive Cancer Center (NCI-CCC) websites.

Readability was assessed using five validated assessment scales: the

Flesch-Kincaid Grade Level, Gunning-Fog Index, Coleman-Liau Index, Simple Measures of Gobbledygook Index, and Automated Readability Index. These validated scales use parameters such as word count and sentence difficulty to assess readability.

The team found that patient education materials were publicly available on 78% of NCI-CCC websites, but the average readability score of these materials—defined as the [grade level](#) required to understand the written content—was 11.6 (range 10.1–13.9) across five scales, which is higher than National Institutes of Health (NIH) recommendations and also above national literacy levels in the U.S., where [19% of U.S. adults possess low literacy skills](#).

"Breast surgeons are often one of the first providers that patients meet when they are diagnosed. Even if we do a fantastic job at patient education in our eyes, patients often return home not having asked the questions that they might have asked when they were in a more comfortable environment," said first author Sarah Brennan, a fourth-year medical student at the University of Washington. Brennan was inspired to lead the project after rotating at a large county hospital in Washington that treated many vulnerable patients.

"Many patients may turn to the wide variety of resources available online. I think these findings highlight the importance of making sure the resources that are coming from cancer centers are meeting the needs of patients," she said.

Study co-authors include Claire L. Buchanan, MD, FACS; Kristine E. Calhoun, MD, FACS; Sara H. Javid, MD, FACS; and Meghan R. Flanagan, MD, FACS.

Evaluating the vast landscape of online materials

In another study that will also be presented at the Scientific Forum, researchers from Crozer-Chester Medical Center in Upland, Pennsylvania, evaluated the wide variety of materials available online about breast surgery from accredited organizations or foundations.

The researchers input the search phrase "breast cancer surgery" and "mastectomy" into the three most popular search engines (Google, Yahoo, Bing) and analyzed 108 unique resources for 1) readability, 2) bias, 3) quality, and 4) tone using validated tools that help analyze the quality and tone of information as well as the overall reading level.

The researchers found that most website content exceeded the recommended sixth-grade reading level (most were on average at the 10th grade reading level) and had information deemed either of fair or poor quality, with websites on breast cancer surgery scoring below average for quality evaluation. At least two to three sentences per website had stigmatizing language.

"In addition, most of the tones that were prominent were negative in character. Fear, analytical, tentative, and sadness were the four most prominent tones," said lead author Praveen Satarasinghe, MD, MBA, a third-year resident physician in general surgery at Crozer-Chester Medical Center. Dr. Satarasinghe leveraged his background in [data analytics](#) to design the research study.

"It's surprising that for such a delicate topic like breast cancer, the first piece of information a patient may see online is filled with a negative tone," he added. "In the future, it will be interesting to see how we can shift the resources to capture a positive tone to impact patients who want to seek treatment for [breast cancer](#). I think by going into the details, we can see that there's clearly a problem that needs to be addressed."

"This study highlights the need to provide educational services on a more

accessible level for all patients," added senior author Chantal Reyna, MD, FACS, FSSO, section chief of breast surgical oncology at Loyola University in Chicago. Dr. Reyna previously served as chief of breast surgery and medical director of the Crozer Health Breast Program.

"Our focus needs to be on making sure that there is ease of readability in the materials we hand out, and that the tone of the materials doesn't enhance that fear that many patients may experience in an already stressful time."

Study co-authors include Daniel Kim, MD and Jandie Posner, DO.

More information: Brennan S, et al. Breast Surgery Patient Education Materials: Who Are We Educating?, *Scientific Forum*, American College of Surgeons (ACS) Clinical Congress 2023.

Satarasinghe P, et al. Evaluating Online Information about Breast Cancer Surgery to Improve Quality, *Scientific Forum*, American College of Surgeons (ACS) Clinical Congress 2023.

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