Do You Understand the Terms Found in Electronic Health Data?

If not, you aren't alone according to a study that assessed patient understanding of common terms such as "carcinoma" and "metastatic."

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When the 21st Century Cures Act went into effect in April 2021, health care organizations began releasing electronic health information (EHI) to patients immediately.

An aim of the act is to reduce barriers to patients' timely access to EHI, and previous research has shown that patients sometimes access reports even before clinicians. An ongoing concern, however, is that pathology and radiology reports are written with the clinician, rather than the patient, as the intended audience.

Based on surveys of patients to assess comprehension of breast pathology report terminology, recently published research demonstrates poor patient understanding of terminology and a pressing need to develop and integrate educational tools to support patients.

"Our aims were to get a clearer picture of what patients were understanding and not understanding, and to learn more about what educational tools patients would find most helpful," says Alexandra Verosky, a third-year medical student in the University of Colorado School of Medicine and lead author of the study. "We're seeing this need not just in breast oncology and surgery, but across all areas of health care."

Defining Frequently Used Terms

Verosky and her co-researchers, including research mentor and CU Cancer Center member Sarah Tevis, MD, an assistant professor of surgical oncology, designed a survey to assess patient understanding of eight terms common in breast pathology reports: malignant, benign, metastatic, neoplasm, negative, mass, carcinoma, and high grade.

The 527 study participants who completed the electronic survey were asked to provide free-text definitions of the eight terms, as well as interpret whether the terms are "good news," "bad news," or "could be good news or bad news."

About 80% of patients correctly defined malignant and 73% currently defined benign, but the other terms were correctly defined at much lower rates. While partially correct definitions were tabulated — and 82% of respondents were partially correct in defining carcinoma — more than 40% of respondents didn't know or didn't provide a definition for neoplasm.

"One of the things that was really surprising was we asked on the survey whether the respondent is a health care worker, but the data showed that being one didn't correlate with better understanding of medical terms," Verosky says.

These findings demonstrate "that we need to use definitions and terminology that patients will understand in the clinic and not make assumptions about what they may or may not know based on demographics or their field of work or education level," Tevis says. "This helps us better understand what patients are taking in when they read these reports and that should guide how we talk with patients in general."

Good News or Bad News

In identifying whether the eight terms were "good news," "bad news," or "could be good news or bad news," more than 95% of respondents correctly identified malignant as bad news. The most commonly misidentified term was high grade, though 10% of respondents identified carcinoma as "could be good news or bad news."

Verosky noted that the study was limited in those who responded — a majority were white and college educated — and added that the survey currently is being translated to Spanish so that further research can help broaden understanding of patient comprehension of terms.

In a separate, ongoing study, Tevis and her co-researchers are giving participants a sample medical report and internet access to understand which terms they are looking up and which sites they are using to get that information.

"Another issue we're seeing is if you have a pathology report, you'll see a diagnosis at the top with supporting information, then pages of legalese underneath that," Tevis says. "I've had instances when I've called patients to discuss reports and they're on page five of the small print that even I don't read. So, it's really important that we're gaining a deeper understanding of how patients are seeing and understanding these reports and what educational tools we can develop to support them."

Of the participants in the breast pathology report research, a majority indicated that tools including a brief summary paragraph at the top of pathology reports, as well as an integrated electronic tool that would allow users to hover over phrases for clear definitions, would be the most useful.

"We've developed a Chrome plug-in that will provide the definitions and guide users to a website that we've vetted for both reading level and reliable information," Tevis says. "We're going to pilot

that as a next step, and continue expanding our research to understand how broader populations are receiving this information.”

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