

Breast Cancer Terminology: Understanding Patient Comprehension Amid the Immediate Release of Medical Records

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Abstract

Background: As health care continues to evolve toward information transparency, an increasing number of patients have access to their medical records, including result reports that were not originally designed to be patient-facing. Previous studies have demonstrated that patients have poor understanding of medical terminology. However, patient comprehension of terminology specific to breast pathology reports has not been well studied. We assessed patient understanding of common medical terms found in breast pathology reports.

Methods: A survey was administered electronically to patients scheduled for a screening mammogram within a multisite health care system. Participants were asked to objectively define and interpret 8 medical terms common to breast biopsy pathology reports. Patient perception of the utility of various educational tools was also assessed. Demographic information including health literacy, education level, previous cancer diagnosis, and primary language was collected.

Results: In total, 527 patients completed the survey. Terms including "malignant" and "benign" were the most correctly defined at 80% and 73%, respectively, whereas only 1% correctly defined "high grade." Factors including race/ethnicity and education level were correlated with more correct scores. Patients preferred educational tools that were specific to their diagnosis and available at the time they were reviewing their results.

Conclusion: Patient comprehension of common medical terminology is poor. Potential assumptions of understanding based on patient factors including education, past medical history, and occupation are misinformed. With the newly mandated immediate release of information to patients, there is a pressing need to develop and integrate educational tools to support patients through all aspects of their care.