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Surgical pathology and the patient: a systematic review evaluating the primary audience of pathology reports☆,☆☆

Matthew Mossanen MD[a,*], Lawrence D. True MD[b], Jonathan L. Wright MD, MS[a], Funda Vakar-Lopez MD[b], Danielle Lavallee PhD[c], John L. Gore MD, MS[a]

[a]*Department of Urology, University of Washington, Seattle, WA 98195, USA*
[b]*Department of Pathology, University of Washington, Seattle, WA 98195, USA*
[c]*Department of Surgery, Surgical Outcomes Research Center, University of Washington, Seattle, WA 98195, USA*

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Summary The pathology report is a critical document that helps guide the management of patients with cancer. More and more patients read their reports, intending to participate in decisions about their care. However, a substantial subset of patients may lack the ability to comprehend this often technical and complex document. We hypothesized that most literature on pathology reports discusses reports from the perspective of other physicians and not from the perspective of patients. An expert panel of physicians developed a list of search criteria, which we used to identify articles on PubMed, MEDLINE, Cochrane Reviews, and Google Scholar databases. Two reviewers independently evaluated all articles to identify for detailed review those that met search criteria. We identified the primary audience of the selected articles and the degree to which these articles addressed clarity of communication of pathology reports with patients. Of 801 articles identified in our search, 25 involved the formatting of pathology reports for clarity of communication. Recurrent themes in proposed improvements in reports included content standardization, variation in terminology, clarity of communication, and quality improvement. No articles discussed patients as their target audience. No study evaluated the health literacy level required of patients to comprehend pathology reports. In summary, there is a scarcity of patient-centered approaches to improve pathology reports. The literature on pathology reports does not include patients as a target audience. Limited resources are available to help patients comprehend their reports. Efforts to improve patient-centered communication are desirable to address this overlooked aspect of patient care.

1. Introduction

Cancer remains the second leading cause of death in the United States [1]. For patients and their families, a cancer diagnosis can be a traumatic event. Further aggravating the patient's experience is the complexity of information that a

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* Corresponding author. Department of Urology, University of Washington School of Medicine, 1959 NE Pacific, Box 356510, Seattle, WA 98195.
E-mail address: mnmoss@uw.edu (M. Mossanen).

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patient, his/her family, and their caregivers must absorb as they make decisions about treatment. The complex choices confronting cancer patients require a shared decision-making process, through which information and preferences are discussed by patient and medical provider [2]. Details of the cancer type and other histopathology-related features of importance, that is, tumor stage and grade, are communicated as pathology reports. Thus, to understand the complexities of their diagnosis, delineate their long-term prognosis, and understand relevant management options, patients traditionally rely on the physician's explanation of the pathology report.

The pathology report is relevant to patient-centered care and is important for the comfort, confidence, and mental health of the cancer patient [3-5]. Although patients want access to information about their cancer diagnosis [6], medical terminology is often a barrier to patients understanding their reports [7]. Effective communication is critical. In addition to relying upon their physicians to interpret their reports, many patients also use the Internet, which may be a less reliable and less readable source of information than the pathology report [8].

As health-related technologies are increasingly used in hospital systems, efforts are needed to make patient-related information accessible and comprehensible. The Health Information Technology for Economic and Clinical Health Act of 2009 created "Meaningful Use" criteria to stimulate the creation of medical technology that promotes patient engagement and the exchange of information [9,10]. As hospitals adopt Meaningful Use criteria [11-13] and as patients continue to receive unprecedented access to their medical information, patient-centered approaches to electronic health records, including pathology reports, would both satisfy these requirements and would benefit patients.

From a health policy standpoint, the delivery of patient-centered communication has been highlighted as a key National Cancer Institute (NCI) research priority [14]. The Institute of Medicine released a report titled: "Delivering High-Quality Cancer Care" [15], in which the challenges of achieving quality cancer care due to limited resources (rising costs), growing demand (by 2030, the incidence of cancer is anticipated to increase by 67% [16]), and increasingly complex treatments are discussed. Patient-centered cancer care, which includes effective communication, has been beneficial to patients—to their quality of life, satisfaction with their health care, and their medical outcomes [17].

Efforts to improve patient-centered care highlight communication as a key aspect of the clinical encounter [18]. Recent studies on the effectiveness of different approaches to improve patient-doctor communication acknowledge the challenge of explaining complex information, with empathy, to patients in the context of progressively tighter time constraints on physicians [19].

We reviewed the literature to identify the primary audience of articles that discussed the clarity of surgical pathology reports. In addition, we identified themes in the literature that discussed clarity of these reports, and we looked for citation of patient-centered resources that explained pathology terminology. We hypothesize that most relevant literature, including clarification of report content and synoptic formatting of reports, is primarily directed to a physician audience. The findings of this review may help guide the development of patient-centered cancer education tools and resources including patient-centered pathology reports. Patient-centered pathology reports offer one avenue to increase patient knowledge and retention of important diagnostic cancer-specific information and may increase engagement of patients in the care of their cancer.

2. Methods

2.1. Search strategy

The most common cancers in the United States in 2013 are, respectively, for men, prostate, lung, colon, bladder, and melanoma, and, for women, breast, lung, colon, uterus, and thyroid [20]. The search was done in November of 2013. Using PRISMA [21] guidelines to structure the search, we conducted a systematic review of publications using PubMed, MEDLINE databases, Cochrane Database Library, and Google Scholar. Although we initially intended to limit our review to the top 5 malignancies for each sex, because of a dearth of information, we decided to include data from all malignancies.

The aim of the literature search was to identify the primary audience of articles that discussed clarity of pathology reports. Potential target audiences were patients, clinicians (ie, the surgeon or medical oncologist), and/or pathologists. In addition, we categorized articles by themes. Specifically, we wanted to determine if patient-centered pathology reports or resources had been described for any cancer.

We assembled an expert panel of academic urologists, medical genitourinary oncologists, and genitourinary pathologists to develop a list of search criteria and keywords. An iterative process was conducted using focused interview sessions and electronic surveys. A candidate list of terms to guide the search strategy was made. Each term (ie, *bladder cancer*, *bladder tumor*, *bladder carcinoma*, or *bladder neoplasia*) for each cancer was sequentially combined with selected search terms, which included *pathology report*, *clinical pathology*, *surgical pathology*, *patient-centered*, *readability*, *health literacy*, *meaningful use criteria*, *template*, *synoptic*, *communication*, *patient engagement*, *compassionate*, *primary audience*, *target audience*, and *patient-centered outcomes research*.

2.2. Selection strategy

Two authors (M. M. and J. L. G.) reviewed the articles retrieved from the initial search. MeSH terms and linked