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Patient-centered approaches to creating understandable health information

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Abstract

As care delivery shifts to further include patients in shared decision-making, patient-centered health information can balance the information asymmetry between patients and providers. Patient health literacy, numeracy, and graph literacy must match that of health information materials to create understandable health information that empowers patients to participate in shared decision-making. We consider an iterative approach focused on three key steps: assessment of the specific information needs of the selected patient community, assessment of that community's ability to receive and understand health information, and evaluation of the materials developed to assess effectiveness. This structured approach using validated tools maximizes the likelihood of meeting patient needs to improve health outcomes. Published by Elsevier Inc.

Keywords: Communication; Health Literacy; Patient-centered; Cancer

Introduction

As clinical care shifts toward increased emphasis on shared decision-making, patients face significant knowledge barriers that can prevent them from being effective participants in their own care. Although sources of available information continue to proliferate, providers and researchers have an opportunity to develop patient-centered health information that can improve patient understanding. In Crossing the Quality Chasm, the Institute of Medicine identified patient-centered care as one of the 6 pillars of high-quality care, defining it as care that is "respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" [1]. Importantly, patients should be given adequate information to exercise their desired level of involvement.

Health literacy has been defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" [2]. This contextualizes literacy in the domains of cultural and conceptual knowledge, speaking and listening skills, writing skills, and numeracy. Although understandability often centers on language and literacy, Doak presents a framework for understanding, which also incorporates logic and experience [3]. *Logic mismatch* occurs when patients reach incorrect conclusions from the health information presented, even if there is no literacy mismatch. *Experience mismatches* occur when comparing the physician experience with the patient experience of some health event or interaction. The surgeon experience with a urostomy may not match that of a bladder cancer patient being counseled about urinary diversion options or a patient that has lived with a urostomy for years. Providers can place health care outcomes in the context of their cumulative experience and discuss relative frequencies, but every health care experience for a patient is binary: either they experience the outcome or they do not. In order for patients to truly understand a health concept, the language, logic, and experience must align.

To create understandable health information that empowers patients to participate in shared decision-making, we consider an iterative approach consisting of 3 key steps: assessment of the specific information needs of the

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selected patient community, assessment of that community's ability to receive and understand health information, and evaluation of the materials developed to assess effectiveness.

Assess need

Patients

The decision to develop health information materials for patients often arises from a provider's clinical experience or perception of a health information gap. The patient-provider encounter in clinic can often inspire research questions and highlight patient needs. Although the clinician's experience can be valuable, their perspective of what a patient should know about a specific clinical scenario may differ from the patient's perceived needs. Patients also rely on and involve family and caregivers, and their health information needs should also be considered [1]. The most effective patient-centered health information should incorporate provider, patient, and caregiver perspectives and needs.

Focus groups

Focus groups can be an effective source of different perspectives to understand patient needs. Condition-specific patient-reported outcome measures (PROMs) in urology often rely on focus groups to prioritize important symptoms to measure. Extending this early work on development of PROMs, recent development of prostate cancer PROMs dashboards began with 90-minute focus groups with groups of 6 to 8 patients to generate core goals [4]. Similarly, focus groups comprised of bladder cancer patients were surveyed to identify which elements of pathology reports were important to communicate and their responses were collated and prioritized using a Delphi process [5].

Patient networks

Patient networks can be useful for elucidating the patients' perspectives. These can consist of local disease support groups, patient disease-specific advocacy groups, or online communities. Patient advocacy groups, such as the Bladder Cancer Advocacy Network, the Prostate Cancer Foundation, and the Kidney Cancer Association are powerful allies. In many cases, they have developed patient-focused materials and review of the existing materials may avoid duplication and help identify knowledge gaps. They also have an interested and active membership that appreciates invitations to be involved. There are also many online patient groups such as Patients Like Me (www.patientslikeme.com), Facebook groups, and Twitter communities.

Assess ability

Low health literacy is an independent risk factor for poor health care outcomes, decreased adherence, and higher costs of care [6–9]. Approximately half of Americans between the ages of 16 and 65 are limited to basic literacy [10] and of those with limited literacy, only 15% were born outside the United States [11]. Special attention must be paid to vulnerable populations, who may be at higher risk of low health literacy. Among patients over 65 years of age, 50% reported below basic or basic health literacy [12]. Although a review of urology-specific quality-of-life surveys noted that the average Flesch-Kinkaid reading level grade for urology-specific quality-of-life instruments was grade 6.5 [13], other work has shown that in a cohort of inner city patients, only 16% reported understanding all of the components of the American Urological Association (AUA) Symptom Score index [14]. Kilbridge and colleagues assessed understanding of prostate cancer health-related quality-of-life surveys in an underserved, low socioeconomic status cohort and found that 47% confused bowel and urinary function terms, 32% confused urinary and sexual function terms, and 27% confused bowel and sexual function terms. Fewer than 50% of patients understood "erection" and "impotent," fewer than 5% understood "incontinence," and understanding across all domains dropped dramatically with compound words ("urine" compared to "urinary function") [15].

Numeracy, an often overlooked component of health literacy, is the ability to understand, evaluate, and use numbers in the context of making health care choices [3]. Among Americans aged 16 to 65, over 1 in 4 were reported to have numeracy skills limited to the simple processes, such as counting, sorting, basic arithmetic, and understanding simple percentages such as 50% [10]. It is important not to overestimate our patients' numeracy skills, as many have confirmed similarly low numeracy rates across different cohorts, even showing that in a simple 3-question test, only 77% of first-year medical students answered all 3 questions correctly [16–19]. Innumerate patients have been shown to be equally likely to under and over-report AUA symptom scores when compared with scores obtained by interviewer administration [20].

Graph literacy, the ability to interpret, understand, and extract meaning from graphical representations of data, requires literacy, numeracy, and spatial understanding. Patients must to be able to read the data (extract information), read between the data (compare between groups), and read beyond the data (draw inferences from the graph) [21]. Although graph literacy is built on a foundation of literacy and numeracy, it represents a distinct skillset. In a population of over 500 veterans seen in primary care clinics, the mean Graph Literacy Score was 7.16 of 13 possible points, with lower scores in low health literacy groups compared with high health literacy groups, lower scores in African-Americans compared with whites, and no differences