



Seminars article

Patient engagement in the design and execution of urologic oncology research

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Abstract

Introduction: There have been significant effort and financial support to engage patients in the design and execution of medical research. However, little is known about the relative benefits or potential impact of involving patients in research, most efficient practices and systems to enhance their involvement, and potential barriers and challenges that are involved with engaging patients. In this review, we will discuss the value of patient centered research, review the challenges that many of these studies faced, and highlight potential future opportunities to enhance patient involvement in urologic research.

Methods: An English-language literature search was performed in the electronic databases of Medline (PubMed), EMBASE, Web of Science, Google Scholar, the Cochrane Library, and on the Patient Centered Outcomes Research Institute (PCORI) website. Search items included “patient-centered research,” “patient-reported outcomes” and “patient engagement” in various combinations. Although PCORI has funded almost 600 projects with \$1.6 billion to improve patient centered research, the search revealed 3 studies of patient engagement in the development, management, and execution of urologic oncology research.

Results: Patient engagement in the design and execution of medical research can help align research topics to match patient priorities, improve survey and data collection tools, increase patient recruitment and participation in studies, and improve accessibility and dissemination of clinically relevant results from medical research. However, engagement patients in research requires significant investment of time, financial support, and energy from the patients, stakeholders, and researchers to provide mutual benefit. In the three studies in urologic oncology that involved patients, the patients provided a significant impact on the structure of the studies and helped improve the ability of patients to apply the results from the research studies.

Conclusions: The benefits to involving patients in research to improve the access, understanding, and application of clinical evidence can be significant. Patient engagement in urologic oncology research is limited currently, but is expected to grow as the funding agencies incentivize the practice and the culture shifts toward a greater emphasis on patient centered outcomes. © 2017 Elsevier Inc. All rights reserved.

Keywords: Patient engagement; Patient-centered outcomes; Patient-reported outcomes

Introduction

In 2001, the Institute of Medicine recommended changes to health care to improve quality of care, improve access to care, and contain costs [1]. A major component of this

recommendation was to increase patient engagement in health care decisions, by promoting sharing of clinical knowledge with free flow of information and access to their own medical information, and by instituting flexible systems to accommodate patient preferences and values so that clinical decisions are shared between providers and patients [1]. However, significant barriers to patient engagement remain. Physicians often do not provide the opportunity for patient engagement [2,3], and may rush through

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explanations, limiting the ability for patients to understand their choices and the consequences of their choices [4]. In some instances, there is a lack of evidence to guide decision-making [5]. Patients may have very diverse and firm opinions and beliefs about their health care [6], but often do not know how to bring up their questions or thoughts [7,8], and fear being labeled as “difficult” patients [9,10].

There has been considerable effort to improve physician communication [11], and efforts to improve patient activation with decision aids [12]. In addition, an increased emphasis on shared decision-making in certain clinical scenarios, policy changes toward coordinated and value-based care, and technological advances in electronic health records and data management also contribute to the rise of patient engagement. However, best practice evidence from clinical trials and research studies often do not address patient priorities and are not easily implemented [13,14]. To address this informational gap, the United States Patient Protection and Affordable Care Act of 2010 established the Patient-Centered Outcomes Research Institute (PCORI), a national nonprofit organization designed to financially support patient-centered comparative effectiveness research [15]. Since 2012, PCORI has funded more than \$1.6 billion to almost 600 projects in 45 states [16]. A key component in all these investigations is the input of patients and other stakeholders throughout every phase of research design, implementation, measurement, and dissemination [17,18] to ensure appropriate relevance and value to the patients. However, little is known about the ideal methods and structure for patient engagement, the challenges and barriers facing patient involvement, and the effectiveness or potential impact of patient-centered research. In this review, we will discuss the value of patient-centered research in enhancing clinical care, review the challenges that PCORI

studies have faced, and the effect of patient engagement. In addition, we will review our own experience with patient engagement in the Comparative Effectiveness Analysis of Surgery and Radiation for localized prostate cancer (CEASAR) study.

Materials and methods

An English-language literature search was performed in the electronic databases of Medline (PubMed), EMBASE, Web of Science, Google Scholar, the Cochrane Library, and on the PCORI website [19]. Search terms included “patient-centered research,” “patient-reported outcomes,” “patient engagement,” “Patient-Centered Outcomes Research Initiative” in various combinations. The last search was performed on March 15, 2017. All trial designs were included, and all articles were original articles. This represents a qualitative review of patient engagement in research design, implementation, measurement, and dissemination. Others have performed a review on patient-reported outcomes and its effect on health care and research [20], and will not be covered in this review.

The literature selection process followed the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) method (Fig.). The initial search resulted in 2,633 citations, of which 2106 were unique studies. Initial title and abstract screening excluded 1,762 studies for not meeting core inclusion and exclusion criteria, such as not being related to urology, and not related to patient involvement in research or research outcomes, leaving 344 articles for full-text screening. Of these, 341 were excluded for not being related to urologic oncology and not involving patients in research design, leaving 3 citations for inclusion in the qualitative analysis.

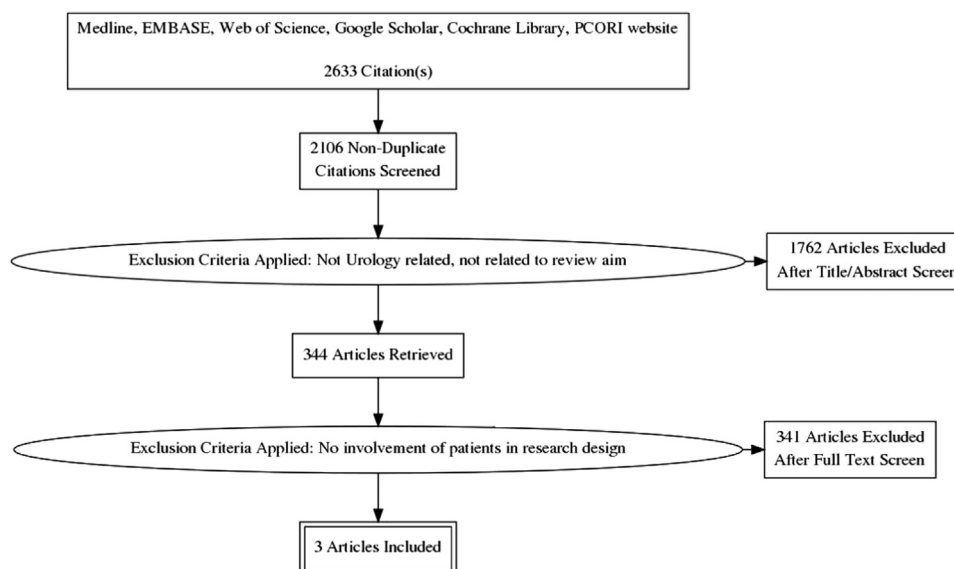


Fig. Literature selection process by the preferred reporting items for systematic reviews and meta-analysis flow diagram.

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