

Seminars article

Engaging patients in complex clinical decision-making: Successes, pitfalls, and future directions

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Abstract

Background: By 2022, there will be 18 million predicted cancer survivors, which is an estimated 30% more than the number of survivors in 2012. In prostate cancer alone, the most common cancer in American men other than skin cancer, 1 in 7 men will be diagnosed during their lifetime. Nevertheless, only approximately 1 in 39 will actually die of the disease. Although life expectancy is often good, these men have multiple treatment management options to choose from, including active surveillance, surgery, or radiotherapy, each of which carries its own array of long-term adverse effects. The same applies to renal cancer where patient have to sift through information to decide among active surveillance, partial nephrectomy, racial nephrectomy, robotic vs. open surgery, and ablation.

Basic procedures: Ultimately, patient, providers, and stakeholders lack high-quality evidence to effectively guide treatment decisions, and these decisions become even harder to discern when considering end-of-life care, palliative care, and the ethics regarding the new End of Life Option Act. As of November 1, 2016, the number of open urologic cancer clinical trials listed on ClinicalTrials.gov was 843.

Main findings: Although we continue to make tremendous strides in urologic cancer care, our options for choosing the best treatment from a patient and provider standpoint are seemingly growing murkier. We need to continue to understand how health-related quality of life varies from patient to patient, and ultimately, incorporate patient preferences and values into the treatment decision in order to make high-quality treatment decisions.

Conclusions: The remainder of this articles will focus on the significant strides made in urologic oncology regarding these difficult decisions from localized disease to end-of-life care and also will detail what needs to be done as we continue to pivot forward. © 2017 Published by Elsevier Inc.

Keywords: Shared decision-making; Palliative care; End of life

Patient decision aids and measuring the quality of shared decision-making

The ability for patients to engage and participate in choosing a path at the crossroads of their complex medical decisions is now essential to providing high-value care [1–5]. Most patients prefer to be involved in treatment decision-making and have better outcomes with improved

satisfaction when they perceive a role in the treatment decision-making [6,7]. Nevertheless, many patients are still not receiving adequate information regarding their various treatment options and quality of life treatment implications [8,9]. As a result, decision aids (DAs) have been created and evaluated for common urologic neoplasms, including prostate, renal, and bladder cancer, in order to incorporate shared decision-making (SDM) into common clinical practice [10]. These aids lower patient anxiety and uncertainty while increasing patient knowledge and involvement in decision-making [4]. Despite their known utility, their

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widespread use and acceptance remains low, as many have a perceived lack of clinical utility or lack the physician familiarity necessary for implementation.

Shared decision-making tools have been best developed for localized prostate cancer, but are lacking for other urologic malignancies and for metastatic disease. These tools have been best studied in localized prostate cancer [11]. In the largest randomized trial in this cohort to date, poor prostate cancer knowledge was associated with increased decisional conflict and higher uncertainty ($P < 0.001$ and $P = 0.001$, respectively). Poor knowledge was also associated with lower perceived effectiveness ($P = 0.003$). This may prove actionable in identifying factors that may be used to distinguish which men are at high risk for decisional conflict, so that they may be targeted for interventions to improve care. Prostate cancer knowledge may represent a modifiable target to reduce decisional conflict, and this may be achieved through widespread installation of decision support interventions. Other studies have supported these claims, including a Scottish randomized controlled trial that found that using a “decision navigation” intervention reduced decisional conflict and decreased decisional regret [12]. Similarly, interventions with health coaches in low-income patients in California have also shown potential promise. By identifying patients most at risk for decisional conflict, clinicians may be able to guide those patients toward effective decision support interventions [13].

Nevertheless, determining which SDM tool best provides accurate information is of critical importance to both the patient and the provider. The Michigan Urological Surgery Improvement Collaborative developed a model to predict the likelihood of finding low-grade, high-grade or no cancer on prostate biopsy and compared this to the prostate cancer prevention trial risk calculator version 2.0 [14]. Using calibration analyses, the prostate cancer prevention trial risk calculator was found to substantially overestimate the likelihood of finding no cancer while underestimating the risk of high-grade cancer. Moving forward, a better understanding of which calculators and nomograms most accurately risk-stratify patients is crucial for designing DAs and enhancing SDM.

Shared decision-making depends on the quality and understandability of the information being shared. Sharing pathology reports, for example, must be done thoughtfully. Those that are patient-centered in terms of format and language, for instance, aid patient-provider communication as well as patients' understanding of their disease [15]. Furthermore, when using DAs, the outcomes relayed to patients must be displayed in a manner that maximizes a patients' understanding of their disease and outcomes. These outcomes are best displayed in a manner centered around how each patient best processes information [16].

Overall, DAs are designed to increase knowledge about specific disease states, estimate adverse effects while incorporating patient risk, help clarify patient goals, and improve patient-provider communication. The use of DAs

prior to the physician encounter often prepares patients for the subsequent SDM consultation by increasing their knowledge of their disease and treatment options while enabling a sense of involvement by the patient and family [17]. DAs alone should not be a replacement for SDM, but rather enhance and facilitate SDM for both physicians and patients [18]. DAs have also been shown to improve risk perceptions, such that patients who have used a DA have a better assessment of the probabilities of various outcomes after treatment [19]. The information collected from patients using DAs can also help physicians tailor their consultations, further facilitating a physician's understanding of patients' concerns [20,21]. When used as part of SDM for prostate cancer screening, the use of DAs improves intent to discuss screening along with knowledge to an extent [22,23]. Of over 10 studies examining prostate-specific antigen screening, 3 demonstrated reductions in screening rates, whereas 7 did not [24]. DAs may improve the patient-physician interaction and help patients discuss their disease with family members [15]. Unfortunately, there is no centralized source of urology-focused DAs [25]. Nevertheless, several online resources exist for a wide spectrum of diseases, including urologic conditions. The “A to Z Inventory” catalog organized by the Ottawa Hospital Research Institute (ORHI) lists urology-focused DAs on circumcision, prostate cancer, prostate-specific antigen screening, benign prostatic hyperplasia management, testicular cancer, undescended testes, and female urinary incontinence [26]. The OHRI also provides resources for research and the development of patient DAs while reviewing them using Cochrane methods. The Urology Care Foundation is another resource that highlights urologic DAs on its website as well and is readily available to providers and patients to access alike [27].

Barriers to implementation of shared Decision-Making

Despite the known benefit of DAs, they continue to remain underused. In a survey of 1,422 urologists and radiation oncologists in the United States assessing attitudes toward DAs on the treatment of prostate cancer, only 35.5% reported currently using a DA in clinical practice [28]. This is in contrast to approximately 84% of respondents believing that DAs were at least somewhat useful, and approximately 78% being moderately confident that they improve treatment decisions. The largest barriers to implementation were the perception that providers could estimate the risk better than DAs, and that patients could not process information from a DA. This discrepancy in perceived usefulness and actual use may result from DAs being difficult to integrate into the workflow of clinical care. DAs are likely best when initially used prior to a physician visit in order for patients to get up to speed about their condition and treatment options, particularly when needing to make complex medical decisions. Even if DAs are

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