

Leveraging Outcomes Research to Optimize Prostate Cancer Care

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Abstract

Introduction: Treatment of localized prostate cancer is subject to patient preference as there are multiple acceptable options with variable side effects. Patient reported outcome measures and decision aids have the potential to improve the decision process by helping patients make high quality decisions. We discuss the importance of and barriers to incorporating these tools into clinical practice.

Methods: We reviewed the literature and summarized key articles and studies of patient reported outcomes and decision aids related to the management of localized prostate cancer.

Results: Multiple high quality patient reported outcome measures that are commonly used in research are beginning to make inroads into clinical practice. We recommend using EPIC (Expanded Prostate Index Composite)-Short Form to measure and track outcomes in patients with localized prostate cancer. Decision aids improve patient knowledge and satisfaction, and decrease patient uncertainty and indecisiveness. Barriers to implementing these tools in clinical practice can be overcome by engaging providers and staff, and establishing office protocols.

Conclusions: Incorporating patient reported outcome measures and decision aids into clinical practice is likely to improve the quality of decision making in patients with prostate cancer but this requires thoughtful implementation.

Key Words: prostatic neoplasms, patient preference, quality of life, questionnaires, decision making

Abbreviations and Acronyms

AUA = American Urological Association

DA = decision aid

EORTC QLQ-C30 = European Organization for Research and Treatment of Cancer Quality of Life Questionnaire

EPIC-CP = EPIC-Clinical Practice

EPIC-SF = EPIC-Short Form

FACT = Functional Assessment of Cancer Therapy

FACT-G = FACT-General Version

P3P = Personal Patient Profile-Prostate

PROM = patient reported outcome measure

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Preference sensitive treatment decisions are those in which strong scientific evidence in favor of 1 specific treatment is lacking and the best choice depends on the value preference of individual patients.¹ Treatment of localized prostate cancer falls into this category as there are multiple options with comparable disease specific outcomes but with variable side effects. To augment our understanding of the value trade-offs that come with these different options a large body of research has focused on quality of life outcomes related to treatment of localized prostate cancer. The use of PROMs in this work has greatly increased in the last few decades, shifting from single center experiences using nonstandardized tools to large prospective cohort studies using rigorously designed standardized and validated PROMs.²

More recently funding agencies have advocated increasing the use of PROMs in research to better define high value health care.³ Using these standardized tools researchers are able to execute psychometrically and methodologically appropriate analyses with outcomes that can be compared across studies and across populations. In addition to the importance of PROMs for research there is increasing interest in developing and incorporating these instruments into daily clinical practice.⁴

A more nascent field of research focuses on helping patients make high quality decisions or decisions based on scientific evidence that are congruent with patient values and preferences.⁵ Making these preference sensitive choices is often difficult when faced with multiple treatment options absent high quality comparative effectiveness research evaluating the benefits and harms of various therapeutic options. There is no better example than the paradigm of localized prostate cancer. DAs, which are standardized tools that offer education and assist with navigation of treatment options for specific disease states, have been demonstrated to be helpful in making high quality decisions.^{6,7}

Although accumulating evidence in support of DAs to counsel patients with prostate cancer advocates for use, less is known about how to successfully implement these tools in daily clinical practice, which tools are most effective and which patients stand most to benefit from use. We discuss the importance of incorporating DAs and PROMs into clinical practice. We reviewed and recommend specific tools as well as common barriers to the incorporation of PROMs and DAs.

Why Use PROMs and DAs

Counseling patients with newly diagnosed prostate cancer involves careful assessment of individualized cancer risk and patient education on possible treatment options,

including the risks, benefits and alternatives. Furthermore counseling necessitates including individual patient values and expectations to facilitate high quality decision. However physicians are often poor judges of patient symptoms and values, and patients often have unrealistic expectations about outcomes and risks.^{1,8} When patients face decisional conflict, ie uncertainty about which action to take, they are more likely to be indecisive, change their minds, regret the decision that they have made and blame the treating physician for bad outcomes.⁵

The Appendix lists the potential benefits of using patient DAs when discussing treatment options. Data suggest that high quality decisions are achieved when DAs are incorporated into practice. Additionally standardized PROMs permit objective assessment of baseline function, which is arguably one of the most important predictors of post-treatment outcomes,⁹ and facilitates discussion about expected posttreatment outcomes. Tracking progress of recovery of and decrease in posttreatment function with standardized PROMs also permits an objective discussion about whether symptoms are in the anticipated range or would fall outside the expected trajectory, potentially facilitating timely intervention(s).

Finally there is a growing movement to collect and report patient level data to national registries to meet CMS (Centers for Medicare and Medicaid Services) requirements for PQRS (Physician Quality Reporting System) and QCDR (Qualified Clinical Data Registry). The AUA is moving forward with the AQUA (AUA Quality) registry as a way to fulfill this requirement. It is not unreasonable to expect that with expert groups calling for the collection of PROMs in addition to disease specific data such as stage, grade and prostate specific antigen, PROMs will become part of these reporting systems.⁴ There is no question that the ubiquitous collection of patient reported data will augment our current understanding of the patient experience and improve our ability to care for patients with urological disease.

General Health PROMs

One approach to measuring patient reported health is to use tools that assess general health and function. Multiple PROMs have been widely studied and several have been suggested for use in patients with prostate cancer.^{10,11}

Medical Outcome SF-36®. SF-36, a generic health status survey developed in the early 1990s as part of the Medical Outcomes Study, addresses a number of domains in general health.¹² These domains include physical and social function, role limitations due to physical and emotional problems, mental health, pain, energy/vitality and overall general

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