Patient-Centered Design and Implementation of Survivorship Tools for Men with Prostate Cancer

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Abstract

Prostate cancer treatment can result in bothersome urinary, sexual, and/or bowel dysfunction. Because providers’ assessments may differ sharply from patients’, patient-reported outcomes (PROs) may provide additional information about treatment results. Yet, to date, PROs have mainly been assessed as part of research registries, without feedback to key stakeholders. Thus, patients and providers need methods for ascertainment and presentation of patient-reported health-related quality of life (HRQOL) in order to facilitate communication about these important prostate cancer treatment outcomes. We have engaged patients, providers, and design experts in human-centered design of “PRO dashboards” that illustrate trends in patient-reported HRQOL following prostate cancer treatment.

We designed PRO dashboards by first capturing the PRO needs of patients and providers through focus groups and interviews. We then iteratively built and refined a prototype PRO dashboard, and we pilot tested dashboards with patients and their provider during follow-up care after radical prostatectomy. We then developed an electronic QOL Tracker that automated survey assessment, construction of HRQOL domain scores (urinary function, sexual function, bowel function), and presentation of domain scores over time contextualized with normative data. We conducted usability assessments with patients to iteratively refine the final prototypes for implementation as a open access, web-based tool for patients with prostate cancer.

Focus groups with 60 prostate cancer patients prioritized needs for PRO dashboards that allow for comparison with pre-treatment scores (i.e., presentation of longitudinal trends), with matched men with prostate cancer (i.e., presentation of “men like me”), and with normative scores that allow for generation of future expectations. Of candidate dashboard designs, 50 patients and 50 providers rated pictographs less helpful than bar charts, line graphs, or tables and preferred bar charts and line graphs. Given these needs and the design recommendations from our Patient Advisory Board (n=7) and design experts (n=7), we built and refined a prototype that charts patients’ HRQOL compared with age- and treatment-matched patients in personalized dashboards. We conducted a small pilot evaluation with 12 patients who completed pre-treatment HRQOL surveys and were returning for post-prostatectomy 3-month and 6-month visits. Exposure to the patient-centered PRO dashboard was associated with improved compliance with quality indicators for prostate cancer care based on patient self-report and review of interview transcripts.

PRO dashboards demonstrate promise as a tool to integrate patient-generated data into clinical prostate cancer care. Work currently underway will improve our understanding of how sites of interaction with PRO dashboards (i.e., home versus clinic)
may impact their effectiveness and how these tools may be enhanced to ensure access independent of patients’ health literacy.