

**The emerging role of patient-reported outcomes in urology**

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In this issue of the *CUAJ*, Vigneault et al published their work validating a French-Canadian version of the Expanded Prostate Cancer Index Composite (EPIC) questionnaire in a French-Canadian population. This represents an important step forward in the quest to incorporate patient-reported outcomes (PRO) into routine clinical practice.

There is a multitude of evidence that we, as prostate cancer healthcare providers, underestimate the treatment-related symptom burden of our patients.<sup>1</sup> Although, we may frequently minimize this symptom burden in the face of the almighty endpoint of oncological cure, the fact remains that impacts on health-related quality of life are significantly associated with satisfaction with care among both patients and their spouses.<sup>2</sup> As such, assessment of a patient's treatment-related symptom burden using a validated questionnaire not only seems intuitive, but has been proposed as a quality indicator in the treatment of early-stage prostate cancer.<sup>3</sup> These PROs are not unique to prostate cancer and recently there has been an explosion in the development of PROs for many benign and malignant disease processes within urology;<sup>4</sup> however, routine incorporation of these instruments into the clinic can be problematic. Studies evaluating integration of these instruments into clinical practice have noted that perceived interruptions in clinic efficiency may represent a barrier to widespread adoption.<sup>5</sup>

Nonetheless, there is objective evidence that systems which maximize the potential of PROs can improve care. Basch et al randomized patients receiving chemotherapy for metastatic cancer to standard of care symptom monitoring or a novel web-based PRO questionnaire platform. If a participant in the PRO group reported a severe or worsening symptom, the clinical nurse responsible for the patient was sent an automated email alert. When compared to the standard of care group, patients in the PRO intervention experienced improved overall survival, improved quality of life, fewer emergency room visits, and a longer time on chemotherapy.<sup>6,7</sup>

Cancer Care Ontario endorses the use of PROs with the measurable target of having 70% of patients complete these questionnaires. "Your Symptoms Matter" kiosks are available at 14 regional cancer centres and 28 partner hospitals across Ontario. A web-based application is also available for patients to use via their home computers (<https://isaac.cancercare.on.ca/>). Currently, more than 27 000 cancer patients are screened for changes in symptom burden each month through the system. The program originally began using the Edmonton Symptom Assessment Scale (ESAS) to track patient health-related quality of life. Realizing that the ESAS

questionnaire might not be universally applicable to all cancer patients at all stages of disease, the program has expanded to include a version of the EPIC questionnaire, the EPIC-CP, for prostate cancer patients. A phase 2 pilot project evaluating the use of EPIC-CP at four Ontario cancer centres demonstrated that 90% of participating patients reported a favourable experience and 62% of patients felt that the addition of the instrument improved their clinical encounter.<sup>8</sup>

Of course, simply applying an individual PRO questionnaire ubiquitously to all cancer patients fails to account for the cultural diversity within our large nation. Cancer Care Ontario's phase 2 pilot project was limited to those who were functionally fluent in English. Although French versions of the EPIC have been previously developed, these were validated in a population in France.<sup>9</sup> Despite a similar language, there are distinct cultural and linguistic differences between French-Canadian prostate cancer patients and those who live in France. As we all strive to improve the quality of care delivered to our patients, it is important that we have PROs available that are validated and applied in a culturally competent manner.

DRAFT

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