The emerging role of patient-reported outcomes in urology

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Cite as: *Can Urol Assoc J* 2017;11(12):411. http://dx.doi.org/10.5489/cuaj.5007

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In this issue, Vigneault et al published their validation of 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 much evidence that we underestimate the treatment-related symptom burden of our patients.[1] Although, we may frequently minimize this symptom burden in the face of the almighty oncological cure, the fact remains that impacts on health-related quality of life are significantly associated with satisfaction with care.[2] As such, assessment of 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.[3] These PRO are not unique to prostate cancer and recently there has been an explosion in the development of PRO for many urological diseases;[4] however, routine incorporation of these instruments can be problematic. Studies evaluating their integration into clinical practice have noted that perceived interruptions in clinic efficiency may represent a barrier to widespread adoption.[5]

Nonetheless, there is objective evidence that systems that maximize the potential of PRO 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 was sent an automated email. When compared to the standard of care group, patients in the PRO group experienced improved overall survival and quality of life, fewer emergency room visits, and a longer time on chemotherapy.[6,7]

Cancer Care Ontario endorses the use of PRO 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 home application is also available (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 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 expanded to include 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% felt the addition of the instrument improved their clinical encounter.[8]

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

Competing interests: The author reports no competing personal or financial interests.

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