

## Advancing the Quality of Care for Newly Diagnosed Prostate Cancer Patients: Novel Uses of Patient-Reported Outcomes

Hillary M. Sedlacek, MS<sup>1,2</sup>, Albert H. Kim, MD, PhD<sup>1</sup>, Wen Min Chen, BS<sup>2</sup>, and Simon P. Kim, MD, MPH<sup>1,2,3,4,5</sup>

<sup>1</sup>Urology Institute, University Hospitals Cleveland Medical Center, Cleveland, OH; <sup>2</sup>Case Western Reserve University School of Medicine, Cleveland, OH; <sup>3</sup>Case Comprehensive Cancer Center, Cleveland, OH; <sup>4</sup>Cancer Outcomes and Public Policy Effectiveness Research (COPPER) Center, Yale University, New Haven, CT; <sup>5</sup>Center for Quality and Outcomes, Cleveland, Case Western Reserve University School of Medicine, Urology Institute, University Hospitals Cleveland Medical Center, Cleveland, OH

Approximately 180,000 patients will be diagnosed with prostate cancer each year in the United States.<sup>1</sup> Overdiagnosis and overtreatment of localized prostate cancer remain a persistent problem with the benefits and harms of screening and treatment of localized prostate cancer far from resolved.<sup>2–6</sup> Nonetheless, approximately a third of men > 50 years old will undergo prostate-specific antigen (PSA) screening of which many will be diagnosed with prostate cancer, continuing to make it the most prevalent male cancer. More importantly, clinicians and patients alike have a clearer picture regarding the risks of progression, mortality, and side effects in the management of localized prostate cancer. Because many patients with localized prostate cancer have extended life expectancy, it is important to consider healthcare-related quality of life (HRQOL) effects in the treatment decision-making process. The recently published American Urological Association (AUA) guidelines stress the importance of shared decision making (SDM) as an important component to high-quality, healthcare delivery, and implores effective SDM to require clinicians to inform patients about immediate and long-term morbidity or side effects of proposed treatment options.<sup>7,8</sup> However, research suggests that surgical practitioners need to be more engaged in the SDM process beyond providing details about conditions and

treatments but focused on adequately addressing patients' emotions and concerns.<sup>9,10</sup>

Most validated questionnaires for HRQOL specific for localized prostate cancer are publically available for physicians and patients to use in the clinical setting.<sup>11</sup> A recent national survey of radiation oncologists and urologists demonstrated that only a quarter used tools to assess HRQOL in clinical practice for their prostate cancer patients.<sup>12</sup> While quality of life represents a key component to informed treatment decisions for patients diagnosed with prostate cancer and their radiation oncologists and urologists, assessing patient-reported outcomes (PROs) and HRQOL requires substantive resources of personnel and ability to incorporate these data into the clinical encounter and electronic medical record. Moreover, it also is essential to acknowledge the time needed from patients to complete these validated questionnaires before during the clinical encounter. To date, it is largely unknown the degree of patient burden, if any, by completing of HRQOL questionnaires, such as the expanded prostate cancer index composite (EPIC), during the clinical encounter.

In this issue, a novel study by Bandaragoda et al. evaluated the use of an innovative machine learning algorithm to extract, analyze, and correlate free text self-reported quality of life and emotional responses in patients and partners from online cancer support group (OCSG) discussions following prostate cancer treatment.<sup>13</sup> Recent prospective studies have shown quality of life differences among patients treated with radical prostatectomy (RP), external beam radiotherapy (EBRT), or active surveillance (AS) using validated PRO questionnaires. The authors sought to measure HRQOL in the context of a more “real life” setting, such as online support groups rather than the

traditional setting of a clinic.<sup>14–16</sup> Using alternative methods to assess HRQOL and satisfaction have obvious appeal; it would reduce the burden to providers and clinical staff to measure PROs and integrate them into a clinical context in a meaningful way, such as the electronic medical record.

Bandaragoda et al. demonstrated that the PRIME framework had 90% accuracy for demographics, 95% for treatment type, and 96% for Gleason score. Further comparative analysis with HRQOL scores in the ProtecT study demonstrated similar patterns of effects by treatment type; urinary incontinence and erectile dysfunction were significant in the RP group, whereas bowel symptoms were significant in the EBRT group. The authors also analyzed patient emotions by age and treatment modality. Patients who received RP consistently expressed positive emotions across all age groups. Patients who received EBRT expressed both positive and negative emotions consistently, and AS patients aged < 40 years were more expressive of all positive emotions but also were high in “depressed,” “helpless,” and “confused” negative emotions. A key finding in their study is that patients aged < 40 years expressed significantly high positive and negative emotions compared with other age groups. Specifically, the age < 40 group had an increased “afraid” emotion as well as higher rates of “depressed” and “helpless.” Further analysis of emotions of patients’ partners demonstrated that partners express more negative emotions than patients and in comparing emotions by treatment modality. Partners of AS patients were significantly more “afraid” and “angry” but less “hurt” than the other two modalities.

The authors should be applauded for devising a new method of capturing PRO measures by utilizing OCSGs to provide additional insight into assessing HRQOL of patients and partners undergoing treatment for localized prostate cancer. Whereas the use of the PRIME algorithm demonstrated almost identical results to recent, large, prospective study about side effects by treatment modality, several key issues warrant further investigation.<sup>14–16</sup> First, the validity of the PRIME algorithm has not been demonstrated. Although this is the first study to incorporate ten concurrent prostate cancer-related OCSGs into a single cohort, further validation of the PRIME algorithm using additional OCSGs in various cancers would increase the generalizability of their results. Furthermore, OCSGs lend to selection bias for patients who have access and awareness of this technology and do not capture those without access to the internet. Indeed, a recent cross-sectional comparison study in Germany of all regional face-to-face support groups and the largest OCSG for prostate cancer showed that younger, better-educated patients with high distress were more likely to use OCSGs, whereas older

patients benefited more from continuous social support in a face-to-face setting.<sup>17</sup> This may be attributable to the OCSG patients’ ability to express freely any feeling or emotional sentiment anonymously and without being confined to the limits of a survey instrument. However, an additional study comparing validated patient reported outcomes questionnaires with PRIME results using the same cohort is warranted.

Second, studies in breast cancer patients comparing differences between OCSGs versus face-to-face support groups demonstrated that OCSG participants had higher emotional expression and advice scores, whereas face-to-face participants scored higher on emotional support and insight.<sup>18</sup> Moreover, in a study examining the role OCSGs play in the cancer survivorship process, most turned to online communities during active treatment and primarily for information and management of adverse effects, and less for emotional support.<sup>19</sup> Thus, while emotions are better expressed in OCSGs, emotional support may be better in a face-to-face setting and patients should be encouraged to utilize both resources. Additional studies examining the effect of face-to-face support groups on HRQOL in the younger cohort of patients identified by PRIME as needing more support would be interesting.

## CONCLUSIONS

Bandaragoda et al. developed a novel machine learning algorithm called PRIME as a new way to assess side effects and emotions of patients treated for low-intermediate risk prostate cancer using OCSGs. Two key additional areas for possible improvement of patient HRQOL were uncovered. Younger patients displayed significantly more negative emotions compared with older age cohorts, and patients’ partners expressed significantly more negative emotions than patients. Regardless of treatment modality, the results suggested that patients age < 40 years could gain the most from additional healthcare resources and discussions focused on treatment decision-making. Also, partners’ burdens of caregiving and anxiety often are overlooked, highlighting the need for better support for partners of patients. Incorporation of the PRIME algorithm into clinical practice has several potential advantages, including monitoring patient HRQOL in real-time rather than at set intervals, reduced burden of data collection on healthcare providers, and the ability for patients to express emotions in a more “real-life” setting. Thus, PRIME is a promising first step in ushering PRO measures into the digital era, but further validation of this mode of communication and capturing PRO as well as incorporating it into the clinical encounter and outcome measurement is needed.

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