



Translating patient-reported outcomes to improve patient care and urogynecologic research

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Patient-reported outcomes (PROs) are critical to the assessment of women with pelvic floor dysfunction (PFD). Originally labeled as subjective measures that lacked the scientific rigor of more objective outcomes, such as urodynamics or Pelvic Organ Prolapse Quantification (POP-Q) system measurements, PROs are now commonly used to diagnose women with pelvic floor disorders and evaluate treatment responses. In their most common form, urogynecologic PROs are obtained via questionnaires that assess symptoms and quality of life (QoL) impact of pelvic floor function and dysfunction.

While the need for calibration of scientific instruments, such as scales and chemical assays, is obvious to even those who do not perform bench research, the importance of PRO calibration is less well understood. The robustness of PROs depends on their validity and reliability, analogous to the calibration of scientific instruments. Simplistically, validity evaluates whether the PRO is measuring what we think it is measuring, and reliability testing establishes whether the PRO obtains the same answer twice between measurements, barring a change in condition. Of course, we could just interview patients and try to extract the same information in an interview, but the accuracy of the information gained would be suspect, as there is no calibration scale used.

In the international arena, the added complexity of language and cultural differences makes PRO measurement challenging. A simple translation of a questionnaire does not ensure that the translated PRO has the same validity and reliability as the original PRO. Robust science has evolved for translating PROs into other languages, which involves extensive patient input evaluating the meaning of translations and robust validity and reliability studies. The International Urogynecology Association (IUGA) is a leader in the development of PROs in multiple languages for PFD. An excellent

example is the IUGA-sponsored project that developed sexual function questionnaires for women with PFDs that could be used across the globe. The Pelvic Organ Prolapse Sexual Function Questionnaire–IUGA revised (PISQ-IR) was developed by an international panel of experts, validated first in English, and now is translated and validated in nine languages [1–3].

The work to incorporate PROs with good validity and reliability properties has come a long way; most clinical research routinely incorporates these outcomes into research trials. However, meaningful integration of PROs into routine clinical care lags behind, in part because of the challenges of presenting PRO data in the electronic medical record and patient burden associated with completing these measures. Future work should focus on refining our PRO instruments to make them more nimble and useful measures of patient outcomes.

In this edition of the *International Urogynecology Journal*, we publish the validation work of scientists throughout the world. This work includes, among others, translations of PROs for Tamil [4], Hebrew [5], Sinhala [6], and Spanish [7] questionnaires. While validation studies may not provide clinical insight to the IUJ reader, our editors have elected to publish the manuscripts because of the important value they bring to the care of women with PFDs and research into these disorders. These validation studies help us understand how well we measure PROs across language and cultural divides and allow us to accurately describe and compare outcomes that are meaningful to patients across the globe.

Compliance with ethical standards

Conflicts of interest R. Rogers receives royalties from Uptodate and travel and stipend from ABOG and IUGA.

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