Special Edition from the Quality Assessment and Safety Committee
Patient Reported Outcomes

Definitions:
Patient-Reported Outcome (PRO): assessment of a patient's health *without* interpretation (e.g. visual analog pain score)

Patient-Reported Outcome Measure (PROM): a tool that has been designed for the purpose of measuring a patient-reported outcome

Note: It is common for these terms to be used interchangeably, and for the purpose of this piece the term PRO is meant to encompass both PROs and PROMs.

What are patient-reported outcomes?

Traditionally, a successful operation has been defined via discrete clinical outcomes, such as wound infection, oncologic completeness, or mortality. However, the patient's definition of success, and thus their satisfaction with the outcome, may differ from his or her surgeon's. Patient Reported Outcomes (PROs) evaluate outcomes from a patient's perspective and generally require dedicated measurement instruments. PROs can be used for clinical care, quality improvement, research and may at some point be used for payment.
PRO instruments most commonly focus on health-related quality of life and can involve either questionnaires or interviews. Many surgeons routinely utilize PROs without even realizing it (e.g. the visual analog scale). Other surveys are less well-known and are more widely used as research tools. The goal of the PRO movement is to use these tools to engage patients and physicians more in a shared clinical decision-making model that appropriately considers outcomes as experienced from a patient perspective. This is especially relevant to the field of colorectal surgery, where many of our procedures have a distinct short- and long-term impact on quality of life. Many clinical scenarios offer more than one acceptable option – e.g. segmental versus subtotal colon resection for HNPCC-associated cancers, TEM versus LAR for T1 rectal cancer, and PPH versus hemorrhoidectomy for severe hemorrhoidal disease.

Ultimately, the goal of PROs is to improve the outcomes of patients undergoing surgical procedures. In this vein, studies have shown that PROs have a higher association with patient satisfaction than clinical outcomes. Data from the oncology literature has shown that improved symptom management in patients with stage IV cancer receiving chemotherapy improves life expectancy by more than 4 months. In addition, data demonstrate that when PROs are used in clinical care, patient satisfaction is higher and clinic visits are shorter. When used appropriately, PROs allow surgeons to better evaluate and inform patients about what quality of life changes to expect, as well as expected clinical outcomes.

Different Types, Examples of PROs

Patient Reported Outcomes (PROs) assess a variety of domains including patient satisfaction, Quality of Life (QoL), and disease-/symptom-specific issues. Some examples and categorizations of different types of PROs are presented below:

Patient Satisfaction

Patient satisfaction/experience is most often measured through established survey mechanisms such as the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), a patient satisfaction survey that is required by the Centers for Medicare and Medicaid Services (CMS). HCAHPS survey results are publicly reported through the CMS Hospital Compare web site. Many institutions have modified the HCAHPS survey or implemented other survey mechanisms in order to better meet their institutional needs.

General Measures of Patient Quality of Life

There are many tools that measure a "global" quality of life, such as the "short form 36" (SF-36), a 36-question instrument that assesses 8 overlapping domains of quality of life. The SF-36 and other similar surveys are widely used in research, but can be challenging to incorporate into clinical decision-making. In the last few years, newer psychometric techniques (e.g. computer adaptive testing) allow for the evaluation of QoL using significantly fewer questions than traditional measures, while still providing useful insights.

Symptom-Specific Measures

PROs can also be symptom-specific, and approaches are already well-established to characterize symptoms including angina, low back pain, hip and knee arthritis, constipation, and bowel incontinence. Shorter sets of measures may also have an important role in characterizing post-operative outcomes.

Disease-Specific Measures

Disease-specific PROs represent a hybrid between general measures of quality of life and symptom-specific measures. An example of a disease-specific measure is the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Colorectal Module (EORTC QLQ-CR38). This survey asks many general quality of life questions, with a focus on bowel function and body image (e.g. issues due to presence of an ostomy).

Barriers to PROs

Historically, PROs and QoL measures have been tools that were predominantly used for research. There are few surgeons, however, who do not consider factors such as quality of life, functional outcomes, and the physiological outcomes of procedures when talking to patients. The great challenge to the PRO movement lies in understanding how to measure and incorporate PRO measurements into a shared decision-making model in a way that is explicit and meaningful. What are the barriers that comprise this challenge?

Infrastructure for collecting PROs is challenging. Real time data collection and interpretation is imperative in order for PRO data to be used in a meaningful way. PROs must be relevant, relatively

short and be able to detect clinically important differences between patients. Clinicians need to be familiar with how to interpret PRO data, in a manner similar to how a blood pressure is interpreted.

The analytic framework for PROs must also allow for appropriate risk-adjustment (as with other clinical outcomes). Understanding how to risk-adjust PRO data when issues like culture, language, sociodemographic variables exist requires more study. Standardized analysis is also an issue with PROs, as these measures are inherently more difficult to quantify compared with traditional outcomes. Patients with seemingly equal outcomes may report different postoperative satisfaction, as a result of varied expectations, preoperative symptoms, medical comorbidities, emotional resilience, socioeconomic factors, and social support structures.

Future Directions

Despite these challenges, the increasing visibility and emphasis on PROs will hopefully drive an understanding of how to use these tools to provide better, more patient-centered surgical care. One of the most important developments is a pilot through the American College of Surgeons' National Surgical Quality Improvement Program (NSQIP). This effort will involve an emailed survey, with results aggregated and analyzed through the NSQIP's existing reporting structure. Another area of emerging innovation is in the use of the Electronic Health Record (EHR) and mobile technology. The ability of these tools to generate a low-cost platform for obtaining and reporting PRO data is powerful but under-developed. Over the next decade, our understanding in how to use PROs will mature and is likely to provide important data for improving the quality of care for our patients.

Selected Resources

1. https://catalyst.nejm.org/implementing-proms-patient-reported-outcome-measures/, Accessed 3/8/2018
2. National Institute of Health Patient Reported Outcomes Measurement Information System (NIHPROMIS). www.nihpromis.org, Accessed 3/8/2018
3. Detmar SB, Muller MJ, Schornagel JH, Wever LD, Aaronson NK. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. Jama. 2002 Dec 18;288(23):3027-34.
4. Valderas JM, Kotzeva A, Espallargues M, Guyatt G, Ferrans CE, Halyard MY, Revicki DA, Symonds T, Parada A, Alonso J. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation. 2008 Mar;17(2):179-93.