Patient-reported outcomes in surgery: Listening to patients improves quality of care

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The American College of Surgeons (ACS) has a legacy of measuring outcomes to improve patient care. The “end result idea” introduced by Ernest Amory Codman, MD, FACS, was simple: follow each patient after an operation to determine whether it succeeded or failed, learn from the negative outcomes, and devise methods to ensure future success.[1] At a time when postoperative morbidity and mortality were commonplace, adverse outcomes were logically the ones most scrutinized. Although it is still vitally important that surgeons and trainees understand the cause of negative outcomes, the advances made in surgical care in the last 100 years have made it possible to measure quality using a broader range of metrics than morbidity and mortality.

Patient-reported outcomes (PROs), which represent the views and perceptions of patients, are becoming widely recognized as important measures for use in improving patient care.[2-4] Although they have their drawbacks, PROs help surgeons and other health care professionals provide patient-centered care. This article is a primer on PROs and how they increase patient engagement and foster shared decision making.

What are PROs and PROMs?

A PRO is an assessment of health status that comes directly from the patient without any interpretation by health care professionals. When patients tell their physicians how they feel or function or about their sense of well-being and their symptoms, they are providing PROs. Each aspect of an individual’s health status, also called a domain, is inherently subjective and differs from patient to patient. The power of PROs is that they can now be collected in a meaningful, rigorous, and scientific manner that accurately translates subjective aspects of health into objective data.

A patient-reported outcome measure (PROM) is the tool that translates the subjective information into objective data. Simply stated, PROMs are questionnaires or surveys that ask patients to gauge their views on their own health. Their responses are then scored, thereby assigning the patient’s perspective a numerical value. An example of this tool is the RAND 36-item Short Form Health Survey (SF-36). This particular PROM survey asks patients about their ability to perform routine daily tasks and queries them on any emotional challenges they may be experiencing. Each domain receives a rating value from 0 to 100—the higher the number, the better the patient views his or her health status. Scores from different patients or groups of patients can then be compared and tracked over time to assess change.

The factors and processes used to develop a PROM are important to understanding the validity of the results it provides. When PROMs are designed in accordance with rigorous scientific standards, they offer meaningful and accurate measurements to compare patient groups and to examine change over time.

We can think of PROMs in much the same way we think of rulers, yardsticks, tape measures, and other tools for assessing length. Objects come in many different sizes and thus there are many different types of rulers to appropriately measure them. Rather than measuring length, PROMs measure quality of life, including physical, mental, or social health and fitness. They can also examine body image, pain, and self-efficacy. Broadly speaking, using a PROM is similar to using other common measuring devices. (See Table 1 for examples of how domains and PROMs fit into other more familiar measurement systems.)

Table 1. Parallels between common measurement systems and PROMs

Concept	Tools	Metrics
Length	Ruler, tape measure, yardstick, odometer	Meters, inches
Heart rate	Fingers and watch, electrocardiogram, pulse oximetry	Beats per minute
Postoperative complications	ACS NSQIP	Raw event rates Risk-adjusted odds ratios
Health-related quality of life	RAND 36-item Short Form Health Survey (SF-36)	Summary physical component score Summary mental component score
Pain and physical function related to osteoarthritis of the knee	Oxford Hip Score (OHS)	OHS
	Hip Disability and Osteoarthritis Outcome Score (HOOS)	HOOS

Guidelines for selecting a PROM

Thousands of different PROMs have been developed. SF-36, EuroQol five dimensions questionnaire (EQ-5D), BODY-Q, Knee Injury and Osteoarthritis Outcome Score (KOOS), and the Pediatric Quality of Life Inventory (PedsQL) are all PROMs designed to measure specific domains from particular patients. For example, the SF-36 was designed to measure the impact that general physical and mental health status has on a person's overall life across different patient populations. In this way, the SF-36 is a "generic" PROM that offers patients with completely different conditions the opportunity to answer the same questions, which allows comparisons between seemingly unrelated groups. For instance, generic PROMs allow the outcomes of ventral hernia repairs to be compared with outcomes for colectomies because generic PROMs only measure those domains that both operations share, such as the ability to complete housework.

Unlike generic PROMs, condition-specific PROMs are focused on a particular disease, set of conditions, or part of the body. The BODY-Q, for example, is a condition-specific PROM that was designed for obese patients and patients who undergo bariatric and cosmetic body contouring operations.[5] Domains measured are specific to this population and include body image, physical appearance, effect of excess skin, psychosocial function, and others. Condition-specific PROMs are especially useful for evaluating outcomes associated with different approaches to treatment for a single disease. For instance, they can provide insight into how the body image of a young adult with Crohn's disease might differ after undergoing an open versus a minimally invasive colectomy.

Choosing whether to use a generic or a condition-specific PROM depends on the intended purpose. [6] Is the objective to gain an overall understanding of the patient's health status, or is the goal to gain a more detailed view of the patient? Frequently, both generic and condition-specific PROMs are used together to get the full picture.

Other attributes of a PROM must be considered before selection. These can include content validity, construct validity, inter-rater reliability, test-retest reliability, responsiveness, and whether it is static or dynamic.[7] "Static" is the technical term for PROMs that are administered on paper—they are static forms. "Dynamic" is the technical term for newer test methods that change depending on how one answers a question. A detailed description of each of these attributes is beyond the scope of this article; however, a good rule of thumb is to simply read the questions posed in

the PROM. If the questions seem irrelevant or unrelated to what you are trying to learn from patients, then you should probably consider another PROM.

How do we collect PROs using PROMs?

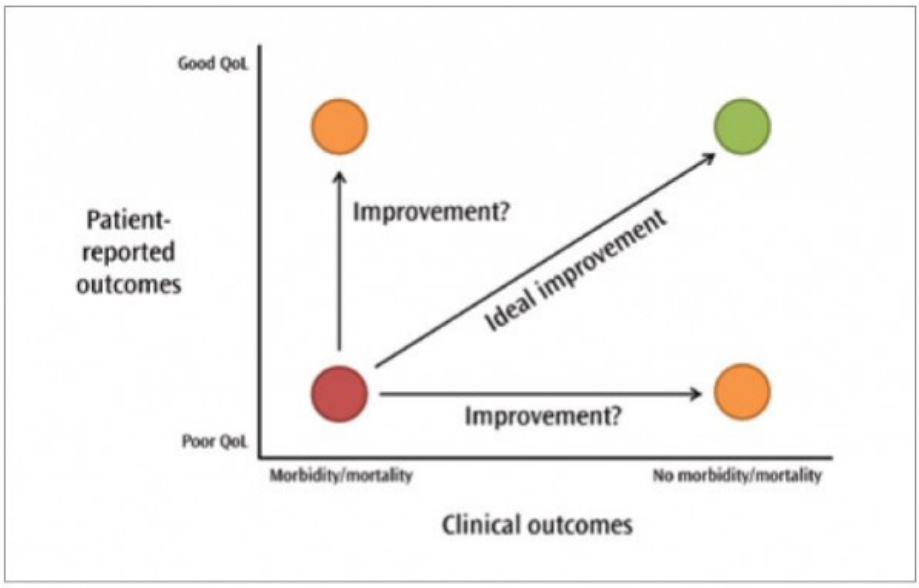
PROMs are available in multiple formats. Traditionally, they were paper-based forms completed by patients during clinic visits or returned via mail. Because computers, and especially smartphones and tablets, are now ubiquitous, PROMs administered in electronic formats and accessible via handheld devices have become increasingly popular.[7-9] For instance, the International Consortium for Health Outcomes Measurement (ICHOM) developed TechHub, an open marketplace that lists health information technology vendors who meet ICHOM's standards for electronic outcomes measurement. Electronically captured PROs, called ePROs, are more efficient, less costly, and are user friendly. Data collected using electronic means have proven to be of equal validity to those collected using traditional methods.[10] In the near future, electronic collection of PROs will be the norm.

Why should we collect PROs?

PRO data have been shown to enhance patient engagement and shared decision making when integrated into clinical care. These data provide an assessment of the patient's experience of illness (such as symptoms, physical function, and vitality), their values and preferences, and their goals of care.[2] For instance, orthopaedic surgeons at the University of Rochester, NY, routinely use PRO data in clinical care to assess whether physical therapy is helpful.[11] If the therapy does not seem to be having a beneficial effect, surgeons can use the PROs to engage a patient in a discussion about whether an operation is a viable option. Similarly, if a patient presents for preoperative evaluation and has PRO scores that are as good as those of postoperative patients, then he or she may not need an operation. As such, PROs can be used to support patient-provider engagement by assessing the severity of symptoms; provide information to track the effect of operations on short-term and long-term patient outcomes; assist patients and providers to set priorities for office visit discussions; and inform treatment decisions through comparative effectiveness and resource utility research.

PROs allow surgeons to understand and measure the benefit of many of the procedures that we perform from the perspective of the patients themselves. Clinical outcomes do not always capture the aspects of health that many patients consider important, and frequently a gap exists between what outcomes matter to surgeons and which matter to patients. PROs complement traditionally measured clinical outcomes with the patient perspective (see Figure 1).

Figure 1. Two-dimensional view of surgical outcomes



Surgical outcomes can be viewed from two perspectives—the clinician's and the patient's. We assume that these two components go hand-in-hand and move in the same direction (ideal improvement: red circle to green circle). However, experience has shown that patients and surgeons sometimes have different definitions of a successful outcome (x-axis). Certain operations can be done solely to improve the quality of life (QoL) from the patient's perspective (y-axis). It is critical that surgeons align our views of success with those of our patients. By measuring patient-reported outcomes, we can be sure we are moving in the right direction.

The outcomes of surgical procedures can thus be viewed from two perspectives: clinical outcomes and PROs. By viewing outcomes in this dual manner, surgeons can gain a clearer understanding of how we can improve patient care. If a patient didn't develop a urinary tract infection or a surgical site infection but lost the ability to dress himself, did he really have a positive outcome?

Significant progress has been made in the areas of survey methodology and quality of life research. For example, modern test techniques, such as those used by the National Institutes of Health Patient-Reported Outcomes Measurement Information System (PROMIS), can reduce the number of questions patients must answer but preserve data accuracy. Patients' perspectives on their health outcomes now can be consistently and reliably measured in most surgical disciplines. The integration of PROs into the clinic and into outcomes assessments only will improve our ability to provide better care.[4]

The ACS will lead the way

The ACS continues to be a leader in surgical outcomes measurement to improve care, particularly through its Quality Programs, such as the National Surgical Quality Improvement Program (ACS NSQIP®). As part of this commitment, the ACS has begun merging all of its clinical databases into one common platform and, in so doing, will begin complementing the rich clinical outcomes data in ACS NSQIP with PROs.

The College has the opportunity to make available the collection of meaningful PROs that will help promote continuous quality improvement, influence clinical care, foster patient engagement, promote performance excellence, and advance patient-centered innovation in surgery. This initiative is being guided by three key principles: (1) minimize patient/ respondent burden, (2) maintain data accuracy, and (3) enable actionable improvements. Complementing the ACS NSQIP with PROs is not without its challenges and limitations. Keeping in mind our guiding principles, we plan to implement this initiative through iterative phases to ensure success and sustainability.

Conclusion

Historically, surgical decision making has been a relatively straightforward process. If a woman had breast cancer, she needed a mastectomy, and her surgeon would perform the operation. Consideration of the procedure's effect on her body image was generally omitted from the treatment equation. Surgery is no longer only about prolonging life, but also about minimizing the negative impact of treatment, optimizing quality of life, and aligning treatment decisions with our patients' goals. Minimally invasive surgery exists today because it can optimize PROs. Only by measuring clinical outcomes and PROs can we ensure the provision of optimal, high-quality, patient-centered surgical care.

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