



The data you've been missing — provided by patients

By Gale Pryor | May 10, 2017

Ask orthopedic surgeon Andrew Jawa, M.D., when his total shoulder replacement patients can expect to put on a jacket without help. His answer is likely to include the exact postoperative week — with evidence-based variations due to each patient's age and condition.

Jawa performs more than 220 total shoulder replacements each year at the Boston Sports and Shoulder Center. And his success relies in part on self-reported data provided by his patients at every visit, from the first preoperative appointment through every follow-up visit for the next five years. That longitudinal data enables him to predict with precision each patient's rate of recovery.

It's an example of the growing use of patient-reported outcome measures, or PROMs: Comprehensive questionnaires for patients measuring their perceptions of their level of pain and degree of function. Once a tool for researchers in clinical trials and to collect data for registries and national benchmarks, PROMs are being adopted by clinicians across the country — from surgeons to primary care providers — to guide and evaluate care delivery.

The process is reshaping patient encounters. The results are guiding clinical decision-making. And, eventually, patient-reported data may even change the way physicians are paid.

"I think that's the way healthcare is going," says Kathryn Sheeran, quality and research manager for The San Antonio Orthopaedic Group. "Doctors that were doing clinical trials said, 'Hey, this could be useful for all my patients, not just the ones in investigational studies.'"

Is patient-reported data valid?

Researchers rely on aggregated patient-reported data to measure perceptions of function, pain, and quality of life, testing results for reliability and validity. PROMs quantify the qualitative.

At the University of Massachusetts Medical School, Patricia Franklin, M.D. and David Ayers, M.D., lead the FORCE-TJR team: Function and Outcomes Research for Comparative Effectiveness in Total Joint Replacement and Quality Improvement.

Since 2010, Franklin and Ayers have collected data from more than 28,000 joint replacement patients of 200 orthopedic surgeons in 28 states to provide risk-adjusted, national benchmarks for outcomes of total joint replacement for surgeons, hospitals, insurers, the Food and Drug Administration, and the Centers for Medicare and Medicaid Services.

“The patient is the only credible source to quantify his or her level of pain, functional limitations, or other symptoms (fatigue, mood, and so on),” says Franklin. “And hospitals or clinicians that do not integrate [what PROM captures] into their routine care path risk ‘poor’ data.”

PROMs in clinical practice

Now, with digital tools that make the questionnaires easy for patients to access and answer, and transfer results automatically to electronic health records, clinicians are adopting PROMs – with orthopedic surgeons leading the charge.

The San Antonio Orthopaedic Group began collecting patient-reported outcomes data in 2016 on their most commonly performed procedures, working with the Arthrex Surgical Outcomes System.

The tool “takes out the interpretation bias,” Sheeran says. Giving patients a quantitative way to converse with their care teams also supports care coordination.

“It eliminates a lot of duplicative work,” she says. “Our physical therapists say, ‘Okay, this patient saw the surgeon yesterday, this is their score, and I know where they are in terms of the therapy plan for today.’ They’re not asking the patient the same questions over and over again.”

At Boston Sports and Shoulder Center, Jawa relies on five questionnaires licensed by Clinical Metrics, a member of athenahealth’s More Disruption Please program. Jawa’s patients spend 10 minutes on a iPad in the waiting room answering questions about their pain, function, and quality of life.

Before each encounter, Jawa glances at his patient’s self-reported metrics for fresh insight on their deficits and recovery status – a real help for a surgeon doing the same procedure for hundreds of patients every year, says Jeremy Lowe, Jawa’s clinical research coordinator.

“If someone reports an issue with an aspect of daily living, he can take a closer look at why they don’t have a certain degree of motion behind their back, why they can’t put on a jacket,” Lowe says.

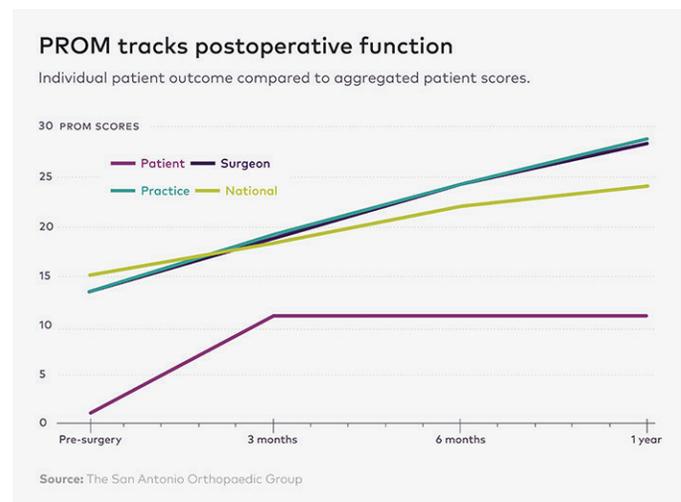
And simply asking patients to complete the questionnaires at every visit, he says, has a positive effect on their relationships with providers.

“They really do appreciate us asking these questions,” Lowe says, “and seeing that we are interested in how they are doing on a daily basis, how their pain is, how their function is. It makes them feel attended to.”

PROMs also give patients clearer expectations for recovery, says Sheeran.

“Instead of saying to patients, ‘We’ve done 800 of these procedures,’” she says, “we can say, ‘In the 800 procedures we’ve done, these are the results we typically see for patients similar to you.’”

And, if an individual patient’s recovery does not proceed at the same rate as benchmarks for their surgeon, the practice, or nationally, PROM data can alert their physician to factors – age or comorbidities, for example – that may be slowing their outcome.



While PROMs allow tailored care of individual patients, aggregating their data enables clinicians to perform original research at the practice level. Data stored in large registries provides national benchmarking, according to these clinicians, but just as useful are measures of outcomes and trends within their own patient panels.

Working with New England Baptist Hospital's institutional review board to develop consent forms and other research protocols, Jawa has established a provider-specific registry for his patients' data.

"He wanted his own system so he would know exactly how it functioned, where he can look and understand his own data," says Lowe.

And Jawa is sharing his results with peers as well as patients. His published studies look at how PROMs can be used to compare outcomes across genders and investigate if asking patients to "recall" their baseline dysfunction is a valid method in outcomes research.

New directions for patient-reported data

With distinct interventions and follow up at regular intervals, surgery is an obvious application for PROMs. But patient-reported data is also being embraced in a less precise field: Behavioral and mental health.

"Being able to screen and measure behavioral health outcomes will be critical to having success in the value-based care environment," says Kevin Spencer, M.D., family physician and chief medical officer of GreenLight, a firm that offers behavioral health PROMs that integrate with EHRs. The startup is also a member of athenahealth's More Disruption Please program.

"Screening all patients is an important data element critical to accurate risk stratification," Spencer says. "We cannot develop and utilize clinical initiatives without measuring and identifying the patients with the most pressing needs."

The evidence for outcome-based reimbursement

Physicians may also be paying more attention to PROMs thanks to MIPS, the CMS quality payment program in which functional outcome assessments are 15 percent of required measures. Commercial payers are not yet asking for PROMs, but "when they do," says Sheeran, "we'll have it ready."

Improving patients' lives, however, is the primary goal, she says. "It's the things they've been wanting to do that they couldn't before – sports or work or getting down on their knees to play with their grandkids. That's really how we like to measure our patients' success."

Gale Pryor is an associate editor for athenaInsight.

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