

Patient-reported Outcome Measures

A Stethoscope for the Patient History

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John Doe stands in the burn clinic waiting room, accompanied by his visibly concerned wife. He is pacing, unable to tolerate the pins and needles in his burned legs that occurs whenever he stands still. Just 3 months ago, John worked 2 jobs to support his family of 5, and there was barely enough money to get by. The factory fire caused burns to half his body. His wife is grateful that he survived and that he is now home. However, life has changed dramatically for both of them. Now they are facing the realities of getting by each day. Their lives are disrupted by financial woes and their future is unclear. John spends his days with therapists and his wife tends to his dressings and medications. They are looking to the doctor to explain what comes next, but the litany of symptoms and the magnitude of the disruption in their lives are difficult for them to verbalize. Their follow-up appointment is booked for 40 minutes. The burn surgeon comes in, asks in general how things are going, asks about pain, typing on the computer as he goes, trying to navigate the electronic medical record, and doing his best to complete the “meaningful use” documentation requirements. Then, he removes dressings, performs the examination, replaces dressings, discusses reconstructive options, reviews medications, obtains surgical consent, discusses scheduling of the next procedure and the visit is over. During the ride home, while they were reassured all was improving, John and his wife had more questions. How long will he have the pain? What can be done for his sleeplessness? They wonder when and if he can ever return to work. John’s wife is concerned that he is not going out in public because of his visible scars and worries how this will affect his self-esteem.

Scenarios such as this are playing out in busy medical offices across the country every day, no matter if it is a burn survivor, a postoperative patient, a pregnant teen, a gentleman with chronic progressive rheumatoid arthritis, or a family struggling with a parent with early-onset dementia. In the era of value-based healthcare and

quality improvement, despite best intentions, physicians face mounting administrative pressures in their daily workflows and the patients feel increasingly shortchanged. Patients may feel lost in a system that churns them in and out of waiting rooms and where their physicians are increasingly preoccupied with the administrative burden of clinical care. Questions are left unasked, anxieties unaddressed. In this taxed and pressured environment, how can we accommodate the need for standardization and efficiency without diminishing the humanity of patient encounters? The vision made in 1988 by Paul Ellwood was to see healthcare from the eyes of the patient. This early concept has been recently introduced into the health system as Ellwood imagined using patient-reported outcome measures (PROMs).¹ PROMs are powerful tools that can bridge the need for data-driven patient information while also strengthening the physician-patient connection. When maximized in clinical settings, PROMs can be leveraged to inform clinical decision making, to improve quality of care, and to foster communication between patients and providers. PROMs are a tool for patient-provider communication and have the potential to be as valuable to the clinical encounter as a stethoscope is to the physical examination. This article is a clarion call for physicians to implement PROMs into their practice and for researchers to study their potential value in the clinical setting.

Imagine if John was e-mailed a series of questions about his physical, emotional, and social recovery progress before the appointment or answered them on a tablet in the office. The data from the survey, structured using technologies similar to academic testing to precisely assess his condition and quality of life in as few questions as possible, is processed using algorithms developed based on large databases. The patient’s scores are compared with the expected scores of people with injuries like his at a similar time after injury, and trajectories of recovery for the population of burn survivors are presented.² His results appear in real time in the electronic medical record. The doctor can quickly scan the report and identify problem areas for discussion during the visit, similar to reviewing a laboratory panel. Appropriate recommendations can be made. John and his wife can be reassured that the usual symptoms associated with his condition were all addressed in the questionnaire, and nothing was forgotten. When the physician reviews the patterns of recovery within the report with the patient, John can see, for instance, that pain is common and that it should subside in a few more months. With PROMs information, the family can organize their thoughts on the timing of recovery and plan for it. PROMs can be selected that are personalized for the patient’s condition, that is, assessing hand function for hand burns or by choosing a select group of PROMs that provide a layered assessment of overall disability according to the conceptual framework of the World Health Organization International Classification of Functioning.³ These data can inform the discussion between the provider, the patient, and his family. Repeated measures can assess changes in outcomes over time. A recent example of this was published in the burn literature

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demonstrating feasibility and potential usefulness of PROMs in clinical situations.⁴

Therein lies the real promise of PROMs: as a roadmap to restructure the clinical encounter by gathering and summarizing the information that is most meaningful to patients and thereby prioritizing clinical information and care needs. Furthermore, the clinical potential of PROM use in prognosis⁵ and identification of at-risk individuals⁶ should also be noted. While PROMs are increasingly recognized as important tools for regulatory and administrative purposes such as performance improvement and resource allocation, these uses should not overshadow the clinical potential of PROMs.

The science of PROMs and the pathway toward implementation of PROMs in clinical care are in their infancy and much work is needed to realize its potential. Clinically focused generalized and condition-specific PROMs need to be developed using a combination of legacy measures and new items derived from the experience of patients and families and from clinicians with rich experience in each condition. This process might be more easily achievable in surgical specialties with a fixed time point of the intervention. General measures can be used such as those within the *PROMIS* (Patient-Reported Outcomes Measurement Information System), a program originally developed through the National Institutes of Health but would also be designed with a condition-specific focus to make granular assessments tailored to the expected outcomes for that particular condition. The design process should involve experts in cutting-edge technologies such as in item response theory and computer adaptive testing similar to the Life Impact Burn Recovery Evaluation (LIBRE) project for burn survivors.⁷ Another major challenge is collection and application of patient data in a way that does not disrupt the workflow of clinicians and assures the privacy and security using cloud-based technologies. The use of contemporary measurement paradigms should be incorporated into the design, analysis, and scoring of questionnaires to ensure that PROMs are efficient and accurate. Electronic medical record systems need to embrace technological solutions to accommodate the seamless flow required for effective clinical PROM use: making data collection patient-friendly, developing capabilities for instant calculations using sophisticated algorithms, and displaying appropriate results in real time for use by patients and clinicians during the visit. Clinical trials and creation of guidelines for implementation of PROMs in a specialty surgical practice would benefit from involvement of the respective professional societies for each condition as well as the overall leadership of the American College of Surgeons to develop an atlas of PROMs. Education of clinicians and patients is essential to

facilitate PROM use. Work needs to be done to harmonize PROMs with billing systems. A body of literature to establish the value of PROMs and to outline best practices needs to be developed. For postoperative follow-up, the surgeon should be able to design a menu of PROMs that would request information directly relevant to and tailored to individual patients. Finally, once patients understand the importance of these metrics to their doctor's decision making and to better evaluate their own health trajectories, they will be motivated to take the time to fill out the questionnaires.

Large-scale studies of PROMs in clinical practice may not be feasible without broad and sustained institutional support. The cost of the development and implementation of these novel technologies has yet to be realized. The NIH has invested heavily in the PROMIS system that capitalizes on computer adaptive testing technologies and is increasingly used in research programs and clinical care. Resources need to be funneled into the study of PROMs in clinical practice if their true potential and value is to be realized for individual patients. Patient's active engagement in medical care through PROMs holds the potential to tailor the care process and overall health to individual biopsychosocial needs.⁸ Ultimately, if physicians and health care systems embrace the opportunity that PROMs present, the dual goals of value-based and patient-centered care can be achieved.

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