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Montreal Accord on Patient-Reported Outcomes Use Series – Paper 4: Patient Reported Outcomes (PRO) Can Inform Clinical Decision-Making in Chronic Care

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Abstract

Background: Providing patient-centered healthcare requires that patient needs, preferences, and valued outcomes are more fully integrated into all decisions. Patient reported outcome measures (PROs) provide unique information from the patient perspective on overall health, symptoms, burden, and treatment response.

Objective: We sought to describe applications of PROs in clinical settings and considerations for implementation from the perspectives of PRO researchers, clinicians, administrators, policy makers, and patients attending a multidisciplinary meeting.

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Discussion: Clinical applications of PROs include individual level use for medical decision-making and aggregate use for comparative effectiveness research, program evaluation, quality improvement, and performance assessments. Considerations of feasibility on work flow impact and patient burden, display of results, and administration frequency are important. PROs with strong psychometric properties, actionable thresholds, and interpretable results should be selected. We provide current exemplars of PRO use in various clinical applications, initial lessons learned, and highlight conceptual, logistical, and consequential considerations of PRO data collection. A research agenda is proposed to address critical knowledge gaps. In conclusion, PROs can be used in clinical settings to support patient-centered care. This requires an assessment of feasibility in the intended setting of use, measurement considerations, and process measures to optimize integration and use.

Keywords

patient reported outcomes; clinical practice; patient care

1. Introduction

As healthcare becomes more patient-centered, there is growing consensus that patient reported outcomes (PROs) should be integrated into clinical management, program development and evaluation, comparative effectiveness assessments, quality improvement, and safety reporting [1, 2]. Obtaining outcomes on patient-valued aspects of health is best assessed through reports that come directly from individuals, collectively referred to as patient reported outcomes (PROs). PROs can help monitor improvements in the health and well-being of individuals, and offer insight into how well clinicians and treatments are meeting patient needs [3]. PROs can also contribute to a learning health system that can better focus care and align resources with patient needs, coordinate services, enhance efficiency, and foster a culture of shared accountability.

To leverage these opportunities, the right PROs must be selected from amongst the thousands of currently available (as discussed in depth by Mayo et al.[4] elsewhere in this supplement). PRO selection must begin with a clear understanding of who will use the data and for what purpose. This paper is the fourth in a series summarizing presentations and small group discussions of PRO researchers, clinicians, administrators, policy makers, and patients attending the Montreal Accord to Accelerate and Harmonize Patient-Reported Outcomes Use held November 5-6, 2014 in Montreal, Canada. Here, we offer a multi-level perspective of considerations around PRO selection and use in clinical settings. Exemplars of using PRO data to guide treatment, evaluate programs, and improve the quality of care are provided. We highlight opportunities and challenges that can arise, initial lessons learned, and propose a research agenda to address knowledge gaps.

2. Understanding who will use PRO data and how

Across settings, the needs, objectives and types of PRO data that will be most informative may differ (Table 1). Optimizing reusability of PRO data by multiple stakeholders is

desirable and increases the likelihood that routine collection of high quality data will be implemented and sustained [5].

2.1 Clinical Management of Patients

2.1.1 Screening and referral—Increasingly, PROs are used to screen across general areas of health to identify problems and needs. Ideally, validated and actionable thresholds are available to guide the next steps. For instance, scores on the PHQ-9 can classify adults >18 years into diagnostic categories of depression severity (see supplemental Table 1 for references for PROs). Guidelines recommend that patients with moderate-severe symptoms receive additional assessment and treatment when adequate staff-assisted care supports are in place [6].

Screening also can occur between visits to identify individuals at greater risk who may need to be seen more frequently, and aid in referral. Recently, a large gynecologic oncology clinic asked 636 patients to complete PROMIS® measures prior to their visit through a patient portal linked to their electronic health record (EHR) [7]. Common symptoms were assessed (fatigue, pain, physical function, anxiety, and depression), with checklists to identify informational, nutritional, and psychosocial needs. Results were automatically integrated into the EHR, and scores that exceeded predetermined thresholds triggered an alert to treating physicians, nurses, social workers, health educators, dietitians, and/or online resources. This enabled the care team to anticipate issues, and facilitated discussions with patients and referrals during the visits. Nevertheless, an important current limitation of many existing PROs is the absence of thresholds that identify clinically meaningful levels of a symptom, or changes in symptoms or impacts.

2.1.2 Diagnosis and prognosis—Collecting PROs as part of clinical care of adults and children can improve communication between providers and patients and increases diagnosis of comorbidities [8, 9]. For example, knee osteoarthritis (OA) is confirmed when reports of pain (of sufficient intensity and frequency) are supported by imaging findings reflecting structural changes. Hence, the Western Ontario McMaster Universities Arthritis Index (WOMAC) can be used to identify knee OA, evaluate severity, and assess treatment effectiveness.

PROs have been used to provide prognostic information beyond sociodemographic and clinical measures in cancer settings [10]. The Oswestry Disability Index (ODI) and Roland Morris Disability Questionnaire (RMDQ) are popular PROs that can classify patients with low back pain (LBP) into prognostic categories; even a simple rating by patients of LBP severity (mild, moderate, severe) correlated highly with disability and lost work productivity [11]. Illness perceptions and patient expectations also reliably predict future disability. In a large UK study of patients 18-60 years of age with LBP, those who perceived they had less control over their back problems, that the back problems would persist, and that this would have serious consequences on their lives had significantly worse outcomes (<30% improvement on RMDQ or reported no improvement on a global measure of change) at 6 months and 5 years later [12].

2.1.3 Assessment and monitoring—There is growing evidence that clinicians underestimate or even miss important patient symptoms. In a study of stable angina patients seen by 207 primary care providers in Australia, physicians often underestimated the extent of angina and impact on health; even among those with frequent angina, many physicians rated these patients as optimally-controlled [13]. In rheumatoid arthritis (RA), composite measures that include physician ratings, laboratory results, and PROs are used to assess disease activity in clinical trials and are used in treatment guidelines. However, the relative contribution of the PROs to the overall score is limited, despite the fact that patient reports of pain, disability, and disease activity are as effective as physician or laboratory measures for predicting morbidity and mortality. For example, the Routine Assessment of Patient Index Data (RAPID3) combines patient ratings of pain, physical function, and disease activity into a simple score that classifies patients as well as composite measures. Because changes in arthritis symptoms often indicate worsening earlier than clinical or laboratory markers [14], there are growing calls to include more PROs in the outcomes used to assess the adequacy of arthritis care [15].

PROs can help capture the personal and societal impact of chronic disease. The WHO's International Classification of Functioning, Disability and Health (ICF) can guide PRO selection and ensure outcomes such as work productivity and participation are assessed as part of chronic disease care. The WHODAS II is a generic instrument that can be used across cultures to assess adults and classify them on standardized ICF disability levels and activity profiles.

2.1.4 Shared decision-making—Patient-centered arthritis research has yielded two important findings: 1) patients and physicians often have different perspectives on outcomes [14, 16]; and 2) patients have additional priorities for treatment [17]. Whereas physicians focus on pathophysiology and functional consequences, patients view their illness within the context of life roles and activities. For example, RA patient priorities for judging the adequacy of treatment include not only the absence of symptoms (pain, fatigue, stiffness, and sleep difficulties) and normalization of function, but also independence and participating in family, work, and other activities [17]. The RA Patient Priorities for Pharmacologic Interventions questionnaire can facilitate discussions about how different treatments may address individual priorities, values, and circumstances. The use of PROs is associated with improved communication, a critical element in shared decision-making in multiple studies [8, 9, 18].

2.1.5 Setting goals and monitoring treatment progress—PROs can be used to identify patient priorities, set goals, and monitor treatment effectiveness. The Wheelchair Outcome Measure (WhOM) incorporates participation goals in specific activities in- or outside the home. One study used automated calls to periodically assess satisfaction with participation and identify problems [19]. When pre-determined thresholds were exceeded, a rehabilitation specialist was alerted to direct patients to appropriate services; adherence to clinical recommendations also increased 79%.

PROs can monitor how patients respond to treatments and identify when additional services may be indicated. Interactive voice response systems (IVRS) are increasingly being used to

promote adherence and monitor drug reactions post hospital discharge [20]. In chronic disease patients prescribed new medications, regularly scheduled IVRS calls were used to identify non-adherence and bothersome side-effects [21]. When predetermined thresholds were reached on a 4-item questionnaire at 3 and 17 days, a pharmacist contacted the patient and forwarded a report and recommendations to the treating physician, influencing clinical management in 40% of cases. In cancer, a 10-point change in the EORTC-QLQ-C30 represents a significant change in supportive care needs, and has been suggested as a threshold for when to engage clinicians [22].

2.2 Developing new programs and matching patients to treatments

Early identification of unmet needs using PROs provides opportunities for risk stratification and stepped care treatments. Increasingly, multidisciplinary rehabilitation programs for LBP use baseline results to identify individuals at risk of persistent pain and disability. Prognostic data from the STarT Back screening tool can be combined with assessment data to match patients to care pathways and therapies. Stratified management can be integrated into primary care, is more cost-effective, and is associated with better short-term outcomes and patient satisfaction [23].

2.3 Assessing performance and creating learning healthcare systems

A recent UK initiative shows how PROs can be used in quality assurance and policymaking. Since 2009, everyone undergoing knee and hip replacement, hernia repair, and varicose vein procedures complete surveys before surgery, and 3 or 6 months later. Sociodemographics and selected PROs and patient experience measures are collected. Much has been learned about how patients are selected for surgery [24], which surgeons are outliers in terms of outcomes [24], and relationships between surgical volumes, competition, and quality [25]. PRO results collected for quality assessments are most likely to be valued by clinicians when objectives for data collection are transparent, including how results will potentially impact current practice and patient care [26].

3. Additional Considerations

3.1 Selecting measures that are “fit for purpose”

Many measures were developed for clinical trials to compare groups receiving different interventions. When these PROs are applied in real-world practices (where there is much greater clinical heterogeneity), they often demonstrate considerable floor and ceiling effects (e.g., many scoring at the highest and lowest levels possible, with little ability to differentiate amongst individuals).

While generic PROs such as the SF36 can facilitate comparisons across populations and interventions, they may not be sensitive and responsive in specific patient populations or for individual patients. Bartlett et al. recently reported that 46% (81/176) of RA patients in their clinic scored zero on the HAQ, the most widely used measure of disability [27]. However, generic instruments can be enriched with new items to meet the needs of specific patient populations. Edwards et al. evaluated the priorities of people living with HIV and developed 16 additional items to supplement existing PROMIS item banks [28] Anytime a PRO is

being considered, there should be evidence of adequate precision, reliability, and responsiveness *in the specific population* (and even subgroup) of interest, and the proposed *context of use* [29].

Information about the *minimal clinically important difference* (MCID) should also be available. The MCID reflects: 1) the minimal change patients perceive as beneficial; and 2) change significant enough to warrant changing patient management [30]. In contrast, the *minimally important difference* (MID)/*smallest detectable difference* (SDD) reflects the smallest change detectable beyond measurement error, which may have little clinical significance. Validated thresholds for clinical action also enhance the usefulness of PRO data [3].

When alternate versions (e.g., translations) are considered, there should be psychometric evidence of cross-cultural adaptation [31], as well as for different modes of administration (interview, telephone, IVRS, etc.).

3.2 Practical considerations

The assessment burden, format (i.e., self-administered vs. interviews), frequency of assessment, and how results will be used are additional considerations [3]. Patient burden is affected by completion time, perceived intrusiveness of questions, and usefulness of the score [32]. Burdensome PROs reduce the willingness of patients to complete repeated assessments, lead to lower response rates, and result in missing data. Factors that influence the perceived burden of PROs by clinicians include simplicity of administration, scoring, and how readily the information can be used to inform treatment.

Potential impact on clinic workflow is an important consideration, along with additional IT requirements. Additional time by patients and staff will be needed to ensure PROs are reliably collected. If results are to be integrated into EHRs, then computer interfaces across multiple formats should be considered (see Ahmed et al. for a more detailed discussion). Consideration should be given to which members of the clinical team will be given PRO results (e.g., physicians, nurses, etc.), and whether, how, when and by whom results will be communicated to patients [3].

Collection of PROs between visits will be enhanced if questionnaires are available on multiple platforms (tablets, smartphones). Consideration must be given to how current PRO results will be displayed. In some cases, the total score will suffice, whereas in others, individual responses to items may also be desired. Interpretation is facilitated when results are displayed in relation to relevant populations (general populations vs. others with the same health condition) along with trends over time. Both the upfront and ongoing costs for IT support including instrument and system updates must be considered. Pilot tests and interviews with patients, clinicians and staff can help identify problems with PRO content, accessibility of results, and potential impact on workflow.

3.3 PRO interpretation and actionability

Clinicians often lack training on how to interpret PROs and integrate PRO data into clinical encounters [3]. Many are skeptical about the validity and value of PRO data and uncertain

how to communicate and act upon PRO scores [26]. It is helpful to have guidance on "actionable" thresholds and meaningful change. Patients and clinicians may differ in their preferences regarding how results are displayed in terms of ease-of-understanding and usefulness.

Table 2 offers a checklist of general considerations when selecting PRO for use in clinical settings. A task force of *The International Society for Quality of Life Research* (ISOQOL) also has developed a *User's Guide for Implementing Patient-Reported Outcomes Assessment in Clinical Practice* (www.isoqol.org/UserFiles/2015UsersGuide-Version2.pdf).

4. Research Agenda

In chronic disease care, patient portals linked to EHRs are increasingly used to capture PRO data between health care visits. As a result, a rapidly growing amount of PRO data over time is now available on many individuals. A number of important questions remain unanswered and additional work is urgently needed on several fronts including: 1) Use case analysis of PRO collection across settings and needs; 2) Methods to automate scoring and optimize the display of results, including changes over time, for different users across teams / settings / diseases; 4) Establishing optimal intervals for data collection; 4) Understanding factors that influence the willingness and confidence of patients and clinicians to use PRO in decision-making; and 5) Using optimal study designs to gather evidence on the impact of PRO collection and reporting, and identify unintended consequences related to communication, patient management, and long-term outcomes on patients, clinicians, and systems. Ultimately, evidence will be needed to demonstrate whether the opportunities envisioned with collecting PRO data to improve patient outcomes can justify the considerable burden and potential risks incurred with routine collection of PRO data. (Arbuckle et al.[33] and Ahmed et al.[34] discuss this elsewhere in this issue.)

5. Conclusion

The systematic collection of PRO data offers new opportunities to enhance clinical care, evaluate programs, identify unmet needs, and engage in quality improvement to improve the health and well-being of patients. While greater adoption of PROs is strongly encouraged, there are critical aspects that should be carefully considered to ensure the buy-in of end-users and meaningful use of PRO data. Embedding formative studies within implementation activities in clinical settings can contribute to the evidence base and address existing knowledge gaps.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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What is New?

Key Points

- Patient reported outcome measures (PROs) provide unique information from the patient perspective on overall health, symptoms, burden, and response to treatment
- PROs can be incorporated at an individual patient level to help in diagnosis and staging of many conditions, and to inform shared medical decision-making
- The systematic collection of PRO data offers new opportunities to enhance clinical care, evaluate and compare programs, identify unmet needs, and engage in quality improvement to improve the health and well-being of patients
- Before widespread implementation it is important to consider feasibility, measurement properties, clinical interpretation, and actionability

Table 1.

Users, uses, and examples of patient reported outcomes.

Users	Importance	Components	Examples
A. Clinical Management of Patients			
Clinicians; Patients / caretakers	Participate in share decision-making and treat what matters to patients	• Screening across domains of health – referral as needed • Diagnosis and prognosis • Assessments of disease activity/severity and monitoring of treatment • Facilitating shared decision-making and matching patients with treatments • Setting treatment and self-management goals and monitoring progress at and between visits	PHQ-9, PROMIS WOMAC, Oswestry Disability Index, Roland Morris Disability Questionnaire RAPID3 ICF frameworks Rheumatoid Arthritis Patient Priorities for Pharmacologic Interventions Wheelchair Outcome Measure, EORTC-QLQ30
B. Developing New Programs and Matching Patients to Treatments			
Multidisciplinary care teams; Health professional organizations; pharma	Ensuring patients get the right treatments for them	• Identifying vulnerable people -- unmet needs and gaps in care • Developing multicomponent and stepped care programs	Monitoring older adults with new drug prescriptions STarT Back screening tool
C. Assessing Performance and Creating Learning Healthcare Systems			
Administrators; Payers; Health service administrators; policymakers	Optimizing equity, efficiency, and cost effectiveness	• Identifying optimal approaches and settings • Continuous quality improvement through benchmarking • Identifying needs and gaps in services	UK PROM in surgery

Note: See supplemental table for references to patient-reported outcome measures

Table 2.

PRO checklist for use in clinical settings.

✓	How will this PRO be used? (e.g., for screening, clinical decision-making, quality assessments, population monitoring)
✓	Has this PRO been used in this setting, and for this purpose?
✓	Has the PRO been validated in this study population?
✓	Has this PRO been compared with other similar measures? Are cross-walks with similar measures available?
✓	Is the administration and scoring feasible in this setting? (Consider cost, IT and other resources, time, and expertise needed over time.)
✓	Have score interpretations been established? Have actionable thresholds been identified? Is there a need for alerts/notifications when critical thresholds are exceeded?
✓	Have the potential consequences of PRO data collection on patients, clinicians, and systems been considered?
✓	Has considerable been given to optimize data export and linkages to facilitate (re)use by multiple stakeholders?