Muddying the Water?: The Role of Verbiage in Patient-Reported Outcome Measures

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Patient-Centered Care

The Institute of Medicine1 considers patient-centered care a priority for providing quality care and defines it as “care that is respectful of and responsive to individual patient preferences, needs, and values, and [ensures] that patient values guide all clinical decisions.” Patient-centered care incorporates shared decision making between patients and clinicians to develop and manage a plan of care that is comprehensive and individualized for each patient. This is important because there are often discrepancies between patient and clinician views.2 The patient may not always be aware of the extent of their condition, and the rehabilitation or management plan may not always correspond with the patient’s preferences and values. Furthermore, care that is not patient-centered has been shown to increase costs, decrease the quality of care, and decrease patient satisfaction.3

In athletic training, we have made a concerted effort to shift from solely evaluating disease-oriented evidence (e.g., range of motion, strength, swelling) to incorporating patient-oriented evidence that matters (i.e., the patient’s perspective on their health).4 Moreover, the profession has recognized that in order to be patient-centered, we need a language that is common among all health care professions. The International Classification of Function, Disability, and Health (ICF)5 describes health, functioning, and disability and provides a framework for this common language. The 2020 Commission on Accreditation of Athletic Training Education Curricular Content Standards6 include a section of standards on patient-centered care, specifically noting the use of the ICF Framework. The members of the Strategic Alliance adopted and/or endorsed the ICF Model in 2015, stating that it “helps to promote patient-centered care by emphasizing the unique needs of each patient.”7 In addition to impacting care at the patient level, the use of the ICF model in practice improves communication with other health care providers, which is integral to both the provision of care (communication between AT and patient) and the continuity of care (communication between AT and other clinicians).

Patient-Reported Outcome Measures

Patient-reported outcome measures (PROMs) are questionnaires that are used to obtain patient-oriented evidence that matters, most often in relation to a particular injury, illness, or condition. They capture impairments, disablement, and constructs such as health-related quality of life and employ standardized terminology (Figure 1) to which the patient compares their experiences. The integration of PROMs into patient care supports communication between clinicians and patients, engages patients as partners in their care, and allows clinicians to obtain the patient’s perspective on aspects of the ICF Model.8 The use of these data can directly improve care by leading to more comprehensive evaluations (i.e., combining internal evidence, research evidence, and patient evidence) and the monitoring of patient progress to determine if improvement has occurred.

While PROMs are valuable tools, it is important to recognize that simply being patient reported does not make a measure patient centered. There are situations in which PROMs may not assess issues relevant to the patient. For example, some validated PROMs do not reflect concepts that patients identify as their primary concerns. Typically, PROMs are developed by experts in the field; however, these experts often cannot articulate or communicate the impact of a particular condition or treatment as a patient would.2 To address this issue, it was recommended in 20122 that patients be involved in the development and evaluation of PROMs to ensure that the instruments capture the patient’s experience. Yet, 5 years later,9 researchers found that the degree to which patients are involved in PROM development varies greatly, irrespective of the health care field. Specifically, many of the instruments with widespread use in athletic training and sports medicine either lack this critical component, or the level of patient involvement, particularly from the targeted population, is unclear.10 This lack of patient involvement leaves researchers and clinicians with two questions: (a) whether the PROM is measuring what it was originally intended to measure, thus potentially impacting its content validity11 and (b) whether the intention correctly addressed patient concerns in the first place.2

In addition, PROMs can transform a patient’s perspective on their condition.12 When completing a PROM, patients follow an appraisal process that involves establishing a frame of reference, selecting relevant experiences from that frame of reference, and comparing those experiences to self-selected standards.13,14 This process requires patients to understand and interpret both the PROM topic and the meaning or connotation of the topic as they select relevant life experiences and standards. Through this reflection or over time, patients may recalibrate or reconceptualize their understanding of how the condition is affecting their life (e.g., symptoms, function, health-related quality of life). This begs the question of whether clinicians should view PROM use as a method of quantifying athlete perceptions of activity and/or participation restrictions, or as a trigger to prompt patients toward self-appraisal in addition to serving as a conversation starter for patient-centered care.

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Furthermore, providing patients with a sample of experiences, such as through functional testing, may improve the alignment between physical performance and PROM scores.\textsuperscript{15,16} While we often use PROMs to gain additional information from a patient, we rarely consider the impact that completing PROMs has on patients or how other rehabilitation activities may interact with PROM completion.

Verbiage in Patient-Reported Outcome Measures

The wording and construction of a PROM can have a significant impact on a patient’s response as definitions and connotations are not always considered. In Table 1, we provide terms commonly found in PROMs in sports medicine and their corresponding definitions.\textsuperscript{17,18} It is often assumed that health care providers have clear definitions for these terms, beyond the lay person, given that they are used frequently in patient care. Interestingly, some of the terms we see most commonly in sports medicine PROMs (i.e., difficult, afraid, strenuous) do not have accepted medical definitions.\textsuperscript{18} This finding could have significant implications as inconsistent terminology and lack of provider understanding have been observed to influence patient preferences.\textsuperscript{19}

In addition, clinicians may be aware of the definitions and connotations of important terms, but they are not often self-evident to the patient. Furthermore, these terms may be influenced by contextual factors, such as environment and culture. Implementing the ICF across health care professions provides a common language and supports communication between providers\textsuperscript{20}; however, without patient involvement in PROM development and with uncertainty surrounding terminology, we are left asking what the common language is for our patients. For example, the term weakness has some notable differences between the lay\textsuperscript{17} (i.e., the quality or state of being weak; fault, defect) and medical\textsuperscript{18} (i.e., fatigue, lack of strength, lack of energy; any structural or functional deficiency) definitions. As clinicians, we may not be aware of how the patient is interpreting or comprehending terms when completing PROMs, which could impact the patient’s perception of the quality of care.

In regard to rehabilitation, while both the athletic training\textsuperscript{7} and physical therapy\textsuperscript{21} professions have adopted the ICF as their common language, patients that an athletic trainer and physical therapist sees may be vastly different. For instance, athletic trainers provide prevention, examination, diagnosis, treatment, and rehabilitation services for emergent, acute, or chronic injuries, and medical conditions in predominantly young and physically active patients. Physical therapists treat the general population, regardless of the level of physical activity. This variability could lead to instances where context and available experiences from which to sample may influence the interpretation of PROM verbiage. However, this is not a limitation of PROMs, rather a benefit. Patients have unique and different experiences, regardless of diagnosis, and PROMs allow health care providers to better understand how a particular injury or condition is impacting the patient from a whole-person perspective.\textsuperscript{8} Through the utilization of these instruments, the clinician is able to incorporate patient evidence into the decision-making process, and ultimately provide patient-centered care.\textsuperscript{8}

Other Considerations

Beyond verbiage, there are other patient-centered factors that should be considered as a part of PROM selection and
development. Patients and clinicians must both perceive relevancy and efficiency in the selected PROMs. Lack of relevance has frequently been cited as justification for the lack of incorporating PROMs into athletic training practice.22-23 Furthermore, responder fatigue can result from the use of multiple PROMs, redundant items within an instrument, or excessively long individual instruments.24 If patients do not perceive that we value their time, they are unlikely to believe that we value their perspective and may not carefully consider their responses. Furthermore, if patients are attentionally fatigued, they are likely to be impulsive and jump to conclusions.25 There is a balancing act at play, where the instruments must ask about a broad enough sample of topics to identify those of value for the patient, but a focused enough sample as to not ask superfluous, potentially irrelevant, and distracting questions. In addition, if a goal of PROMs is to compare outcomes across time or between groups it may be advantageous to select PROMs that specify which experiences should be referenced (e.g., “During the last week, how much pain or discomfort do you have in your arm with daily experiences should be referenced (e.g., groups it may be advantageous to select PROMs that specify which experiences should be referenced (e.g., “During the last week, how much pain or discomfort do you have in your arm with daily activities involving reaching?”)26) and/or provide anchors for comparison standards (e.g., “Strenuous activities like heavy physical work, skiing or tennis”27). However, these efforts to create context from which the patient can provide input can be for not if the provided context is one with which the patient is unfamiliar. For example, questions about handball or sailing would not be relevant for many geographical areas. PROM use can be a key part of patient-centered care, but only if the patient’s perspective regarding context, time, and relevance are factored into instrument selection.

Suggested Ways Forward for Clinicians

In an effort to combat these issues and improve the provision of patient-centered care, we have several suggestions for clinicians. First, ATs must use a systematic process to select a PROM that is suitable for their patients, and consider both the essential elements (i.e., instrument development, reliability, validity, responsiveness, and interpretability, and precision), and clinical utility (i.e., acceptability, feasibility, and appropriateness) of the instrument.28 This process is important, as it provides the clinician with a method to sift through the numerous instruments in the sports medicine field.10,29 Furthermore, through the generation of patient-oriented evidence that matters, ATs are able to engage in shared clinical decision making.22 To ensure that the PROM is appropriate, the readability of the instrument, or likelihood that the written text will be understood by the reader should also be determined and considered during instrument selection. While we’ve identified that certain word choices can impact the patient’s perception or understanding of the PROM, we must also consider that the text may be written at a reading level that is too high for patients to recognize and comprehend.20 These interpretation issues negatively impact the quality of the data and instrument psychometric properties,24 making it difficult for clinicians to confidently integrate PROMs into patient care and clinical decision making. To facilitate health literacy, best practices recommend that PROM selection corresponds with the reading level and education of the patient population, and that materials are written at least two levels below the reading grade level of the patient.12 ATs can easily estimate the readability of a PROM by using formulae (e.g., Flesch Reading Ease, Flesch-Kincaid Reading Level) available on computer software, such as Microsoft Word.51,33

When selecting a PROM for use in patient care, ATs should consider the verbiage and comprehensibility of terms within the instrument. For instance, if a PROM is psychometrically sound but the terminology is seemingly ambiguous, or confusing to patients, it may not be the best choice for the population of interest. To address this concern within clinical practice, clinicians could consider utilizing a focus group to gather information about how patients interpret PROMs. We caution against the modification of PROM verbiage, as this could impact the psychometric properties of the instrument. It may also be of value for clinical and research groups to come to a consensus on the operational

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definition of terms. If no published operational definitions exist, clinicians and researchers should describe how terms were defined for transparency. Furthermore, it would be worthwhile for academic journals to consider requiring operational definitions as a component in publications—particularly for case reports, clinical practice guidelines, and other clinically relevant forms of research evidence. In the event an appropriate applicable existing PROM cannot be identified clinicians may wish to consider a single item measure or a patient-generated outcome measure as alternatives. Single item measures, such as the Single Assessment Numeric Evaluation, allow patients to provide a global rating via single generic item, while patient-generated outcome measures, such as the Patient-Specific Functional Scale, allow patients to identify and evaluate those specific activities or impairments that are relevant to them. Single item measures offer near universal applicability across patients, while patient-generated outcome measures offer patient individualization and specificity.

Conclusion

Our intention is not to drive clinicians away from integrating PROMs into their clinical practice, rather we hope to provide clinicians with information so that they can be conscientious in their decision about which PROM to use. Patient-reported outcome measures are valuable tools that aid in clinical decision making, evaluating treatment effectiveness, and improving patient satisfaction. If clinicians use a PROMs as a conversation starter, they have the opportunity to truly engage patients and instigate the patients’ perception of both the instrument and their quality of life. However, health care providers must consider instrument verbiage and population characteristics when administering these instruments to patients.

References


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