



Patient-reported outcome measures in emergency and acute care: looking beyond the emergency room

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Emergency medical care is a fundamentally important resource across the globe [1]. In the United States alone, more than 130 million visits to the emergency room occurred in 2020, of which 30% were related to injuries and 14% resulted in hospital admissions [2]. The acuity of the condition appropriately directs triage, urgency, resource use, and care intensity [3]. The adage "time is tissue" embodies the philosophy of emergency and acute care: to quickly provide the right care to patients to save their lives. However, mortality and the efficiency with which care is delivered, though incredibly important, should not be the only measures of care quality. Decisions made to treat the medical emergency can have profound short- and long-term consequences for patients, affecting physical function, mental health, well-being, and health-related quality of life.

PROs AND PROMs

Patient-reported outcomes (PROs) are assessments of a patient's health that come directly from them without interpretation by a healthcare provider or anyone else. PROs are health outcomes that only the patient can know and experience, and for which patients are the most reliable source of information [4]. Examples include physical limitations, symptom burden, emotional distress, and social functioning. Measured with psychometrically sound patient-reported outcome measures (PROMs), PROs translate the patient voice into objective numerical data that can help to align the care provided with outcomes that matter most to patients [5,6].

Incorporating PROMs into clinical care improves patients' experiences and satisfaction with care, enhances patient-clinician communication, and facilitates shared decision-making [7-10]. For example, Pusic et al. [11] showed that when patients report their PROs daily after ambulatory cancer surgery and receive immediate feedback based on their PROs, patient anxiety decreased. Patients were reassured that what they were experiencing was "as expected," resulting in fewer phone calls to nurses, reducing nursing workload, and reallocating resources to patients needing nurses most. Beyond reducing unnecessary emergency department use, PROMs can even prolong survival among cancer patients when care teams act on the reported data [11-13]. Perhaps most important, because PROs are the outcomes that matter most to patients, they can help align the care provided with patients' goals for their care.

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In the United States and around the world, PROMs are seeing broader applications in clinical practice, quality improvement, and value-based health care (Fig. 1). For example, the International Consortium for Health Outcomes Measurement (ICHOM) convenes international multidisciplinary working groups of clinical experts and patient advocates to reach consensus on a set of core outcomes that matter most to patients for a particular condition, such as heart failure [14] and colorectal cancer [15]. These standardized core outcome sets include both clinical (e.g., treatment complications, survival) and patient-reported (e.g., urinary function, sexual dysfunction, fatigue) outcomes to provide a comprehensive picture of health outcomes. Other international groups focusing on research and clinical trials, such as the COMET (Core Outcome Measures in Effectiveness Trials) Initiative and the COSMIN (Consensus-based Standards for the Selection of Health Measurement Instruments) Initiative, have also championed consensus-based core outcome sets that include PROMs [16,17]. For example, a core outcome set for out-of-hospital cardiac arrest includes three universal PROMs: the Health Utilities Index Mark 3 (HUI3), Short Form 36-Item Health Survey (SF-36), and EQ-5D-5L [18].

PROMs IN EMERGENCY AND ACUTE CARE

Despite these benefits, the clinical application of PROMs to emergency and acute care has been limited to date. One major roadblock is the methodological challenge to ascertain a patient's baseline status in the emergency room, particularly when a patient is in duress and may not be able to complete PROMs, to allow for comparison. Two strategies have been proposed to circumvent the need to collect PROMs at the time of an emergency event: retrospective PROMs and matched population-based PROMs data.

If patients could accurately recall their pre-emergency health status, retrospective PROMs could serve to establish their baseline health when a pre-emergency measurement is not available. Kwong et al. [19] examined the accuracy of this approach among patients undergoing joint replacement surgery and found intraclass correlation coefficients between 0.61 and 0.80, suggesting high agreement between PROMs completed before surgery and PROMs completed by the same patient after surgery when recalling their presurgery status. They then carried out feasibility studies on patients admitted for two types of emergencies: ST-seg-

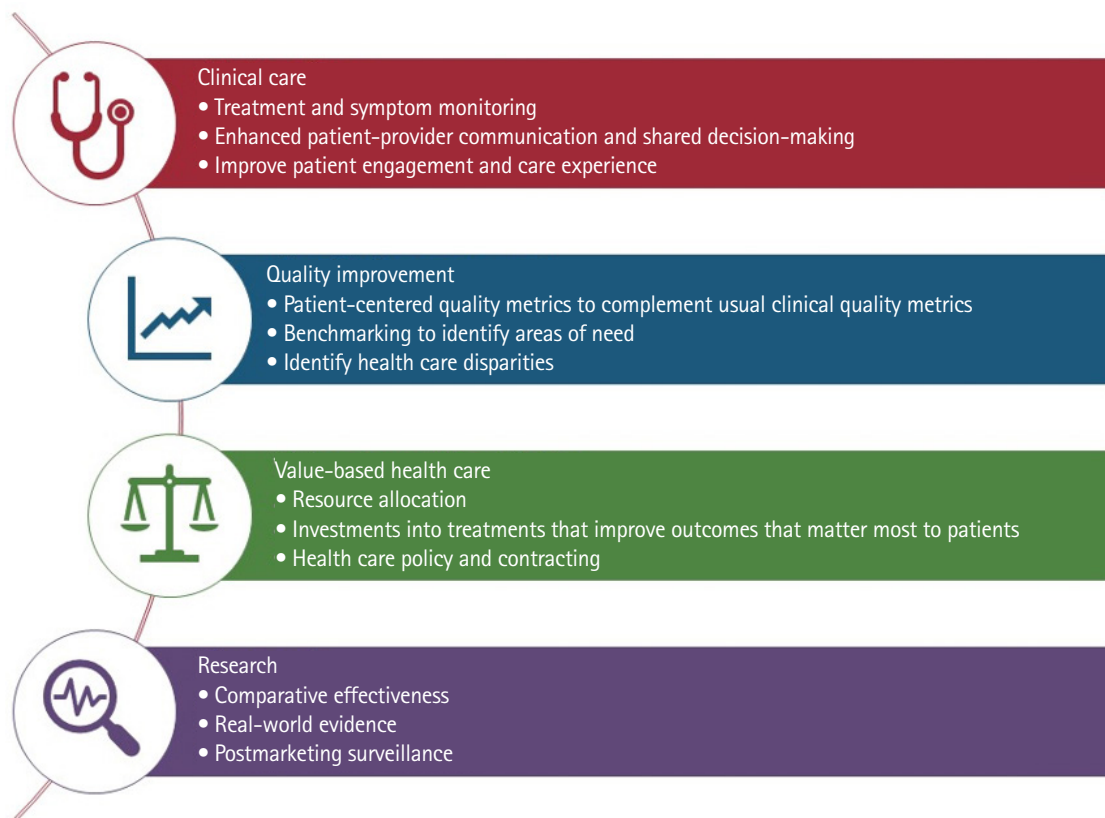


Fig. 1. Multiple roles for patient-reported outcome measures.

ment elevation myocardial infarction managed with percutaneous coronary intervention [20], and gastrointestinal issues treated through laparotomies [21]. Prior to discharge, patients completed PROMs based on recalling their health status 1 month prior to admission. They then completed the same PROMs 3 months after discharge. Though patients were not asked to complete PROMs based upon their current health state at the time of discharge, most patients regained their prior level of recalled health, suggesting that perhaps this retrospective method has potential.

An alternative method for determining the baseline health status of patients who experience unforeseen emergency care involves using PROMs data from similar patients in population surveys as a proxy baseline. Matching patients on demographic characteristics and comorbidities, Kwong et al. [22] also examined this method and found significant discrepancies between the scores from retrospective PROMs and those from the matched patients, indicating that PROMs data obtained from similar patients with similar medical profiles may not serve as a reliable substitute for retrospective PROMs.

These two approaches, retrospective PROMs and matched population-based PROMs data, may be more complicated than necessary. Not all patients will present to the emergency room in extremis, and others are stabilized with treatment. Nowadays, patients have direct access to their medical records through secure mobile applications. Smart health information technology (IT) that recognizes when a patient is in the emergency room could push relevant PROMs to patients to complete while waiting for care or test results. Patients who complete PROMs could be seen faster than others who do not. Indeed, more creative solutions are certainly needed.

However, even without knowing a patient's baseline health, PROMs can offer valuable insights for tracking long-term trauma outcomes, as shown by the FORTE (Functional Outcomes and Recovery after Trauma Emergencies) project [23,24]. This multicenter study in Boston (MA, USA) used phone interviews at 6- and 12-months posttrauma to collect data using PROMs that are universal (i.e., SF-12) and condition-specific (i.e., Trauma Quality of Life). Despite methodologic limitations, the results showed that many patients had lasting physical and emotional impairments, emphasizing the need for ongoing care. Indeed, efforts to integrate PROMs into trauma care are gaining traction, evidenced by the American College of Surgeons (ACS) Committee on Trauma conference on PROMs, which aimed to workshop existing barriers and to better understand how PROMs can evaluate trauma care quality [25].

More important than when to administer PROMs is choosing

the appropriate PROMs with strong measurement properties [6,26,27]. For example, psychometrically sound PROMs tailored for trauma patients are increasingly becoming available, representing a significant step forward. For instance, the LIMB-Q was developed to measure PROs specifically after limb-threatening lower extremity trauma, applicable to patients after either reconstruction or amputation [28]. The LIMB-Q adhered to international guidelines for PROM development and was psychometrically validated using item response theory (IRT) [29]. The application of IRT offers several advantages over classical test theory, such as improved reliability, the ability to handle missing data effectively, and greater precision with shorter assessments [6]. Most importantly, IRT allows for scores to be placed on an interval scale rather than an ordinal one, thus ensuring both the interpretability and clinical relevance of the scores. These attributes make IRT especially suited for clinical care, where quick, accurate, and interpretable evaluations are essential. Nevertheless, there remains an urgent need for more valid and reliable PROMs that are specially designed to address the unique challenges of emergency and acute care environments.

A BROADER PERSPECTIVE

Perhaps a broader perspective that looks beyond acute episodes will be needed to achieve the benefits of PROMs in emergency medicine. A robust healthcare system that integrates PROMs into routine care would enable clinicians to use these metrics similarly to vital signs and laboratory values for informed decision-making, ideally in all settings in which the patient can participate. In this universal model, PROMs would be continuously accrued into the electronic health record, allowing for real-time clinical alerts about concerning symptoms, enabling timely interventions [11,12]. It is especially important to track this information during the long periods when the patient is at home, when we typically have little or no interaction with patients. Emergency, ambulatory, and acute care would punctuate this care, and represent a singular point in time along a patient's entire lifespan.

Achieving this future state is challenging but possible. Large-scale programs to routinely collect PROMs in clinical care are increasing [30], and not only in the United States [31]. For example, Mass General Brigham, an integrated health system in Massachusetts, USA, implemented a standardized PROMs collection program in 2012 [32,33]. Today, more than five million PROMs are completed annually across more than 475 clinics from more than 80 medical, behavioral health, and surgical specialties. Despite these pioneering efforts, more could be done to accelerate

the uptake of PROMs into clinical care. PROMs built with modern measurement theory that can serve multiple purposes, including condition-specific problems and yet retain the ability to compare across diseases, conditions, populations, and systems, need to be developed. These novel, multipurpose PROMs then need to be operationalized by leveraging health IT and interoperability standards [34,35]. PROs data could then "speak a common language" and efficiently track outcomes longitudinally at the individual patient, clinician, community, population, and even global levels.

The fleeting encounter with emergency and acute care makes it challenging to conceptualize how the many promises of PROMs can be applicable. However, the necessary life-saving treatments provided in the emergency setting can result in long-term benefits for patients. Only by measuring PROs can we be confident that patients recover to their baseline, pre-emergency health status to the extent possible. Additionally, innovative PROMs-based solutions in emergency medicine could have a significant, positive impact on patients being treated for mental health issues and alcohol and substance abuse [36]. For now, research into PROMs in emergency medicine remains challenging and needs further work to achieve success. Success, however, may ultimately involve taking a step back from the emergency room to look towards greater healthcare transformation.

ARTICLE INFORMATION

Conflicts of interest

David W. Bates receives grants and personal fees from EarlySense, personal fees from CDI Negev, equity from ValeraHealth, equity from Clew, equity from MDClone, personal fees and equity from Aesop, personal fees and equity from FeelBetter, personal fees and equity from Guided Clinical Solutions and grants from IBM Watson Health, all outside the submitted work. The authors have no other conflicts of interest to declare.

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Data availability

Data sharing is not applicable as no new data were created or analyzed in this study.

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