Engaging Patients and Families in Patient Safety Measurement

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BACKGROUND AND CURRENT LANDSCAPE
Nothing About Me Without Me: Considerations for Measuring the Patient’s Experience of Safe and Effective Care

In 1998 at the Salzburg Seminar, “Through the Patient’s Eyes: Collaboration between Patients and Health Care Professionals” the phrase Nothing About Me Without Me was coined by an English midwife and became the anthem for the seminar and future work to measure and improve the patient’s experience of care. It is even more relevant today as we consider developing new international measures that will include the patient’s perspective on quality and safety and their experience with outcomes that are meaningful to them.

If you were building a house, you would be intimately involved with the architect and the contractor, reviewing all plans to ensure that the design and decor worked for your family. You would bring the knowledge of your family’s needs and preferences, and they would bring the technical skills to build a functional, well-designed home. Co-designing the house through a successful partnership surely increases the likelihood of a positive outcome. How often, however, does this partnership happen in healthcare, when we design new programs, survey tools, or educational materials to improve the quality of health for the people we serve? Typically, the most important experts—ordinary people managing their health—are left out of the development process and treated as objects of care, rather than partners in care.

Researchers and clinicians often assume that they understand the experience of illness. But knowledge about physiology or diagnosis and treatment are not the same as understanding how it feels to be sick, how people define high quality care or what symptom improvement matters most. Clinicians rarely experience the frustrations and challenges of recovering from a surgical procedure or receiving care until they or a family member needs care. Patients bring the lived experience, as well as knowledge about how well the healthcare system functions to meet their needs.

Currently, there are two equally important but different methods to obtain feedback from patients about relevant aspects of quality and safety.

Patient Experience Measures

“Patient experience encompasses the range of interactions that patients have with the health care system, including their care from health plans, and from doctors, nurses, and staff in hospitals, physician practices, and other health care facilities. As an integral component of health care quality, patient experience includes several aspects of health care delivery that patients value highly when they seek and receive care, such as getting timely appointments, easy access to information, and good communication with health care providers.” (Agency for Healthcare and Research Quality)
Measures that evaluate aspects of care that improve patient safety are included in the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys funded by the Agency for Healthcare Research and Quality. These standardized, public domain US surveys are mandated by US government agencies such as the Center for Medicare and Medicaid Services (CMS) and many other payers and regional quality collaboratives. For example, composites are available that focus on clinician-patient communication, communication about medications, cleanliness, preparation for discharge, access to care, responsiveness of staff in the hospital, and shared decision-making. These measures have been correlated with other measures of clinical quality and safety, including reduced readmission rates, and lower mortality. In the inpatient setting, responsiveness of staff has been associated with a reduction in patient falls, and positive results on the Hospital CAHPS surveys are correlated with positive scores on the Survey of Patient Safety Culture. Patient evaluations of hospital cleanliness have also been correlated with MRSA infection rates and in the UK the hospitals that received the best patient experience scores on the UK’s “NHS Choices” website had 42% lower MRSA infection rates, 11% lower readmission rates, and 5% lower mortality rates. In the US, hospitals with the lowest scores on nurse communication had 27% more adverse safety events compared with the top 10% performing hospitals.

**Patient-Reported Outcomes Measures**

PROMs are data about a patient’s functional and cognitive status, their disease-related quality of life, or complications and long-term consequences of care. While used for many years as part of clinical research, PROMs have now become a tool for patients, clinicians, and organizations to improve quality and outcomes of care. Aging populations, the increase in chronic disease, more treatment choices, and changing patient expectations regarding engagement in self management and decision-making, have focused attention on a new priority: maximizing value in health care, understood as the outcomes desired and needed by patients achieved in relation to the money spent over the whole care cycle of a patient’s medical condition.

Funded by the US National Institutes of Health, PROMIS includes over 300 measures of physical, mental, and social health for use with the general population and with individuals living with chronic conditions. PROMIS developed self-report measures for adults for functions, symptoms, behaviors, and feelings. The measures are available in Spanish and many other languages. PROMIS measures are available for free and can be administered in multiple ways.

Currently, more and more health care leaders and politicians are emphasizing the need to measure PROs and to provide transparency about treatment success and failure to caregivers, patients, payers and the public. However, there is no systematic and standardized approach available that can easily be adopted by care organizations. The past few years have seen health care providers, consumer groups, pharmaceuticals and nations (the UK leading the way) take the first steps in implementing PROs. A clear global direction is needed that will align efforts and allow for a common terminology used by all stake holders.

**In summary:**

- Patients are often the only people who can accurately evaluate components of high quality, safe care.
- Respect for patients’ experiences and outcomes should be an integral part of care.
- Health care that promotes good patient experiences and outcomes is important for achieving:
  - Strong provider-patient relationships and trust
  - Continuity of care and treatment fidelity
  - Better outcomes
Reduced harm

- Patient experiences and outcomes are measurable
  - New surveys address conceptual and practical concerns about measuring and improving quality of care.
- Patient experience measures that focus on reports about observable experiences are more actionable than satisfaction (ratings) surveys.
- Valid surveys of patient experience and patient-reported outcomes provide important information to patients and providers:
  - Patient reports discriminate among clinics, systems, markets, regions and countries
  - Patient reports are associated with other indicators of care quality
  - Patient reports are useful for focusing and evaluating improvement efforts

We need to foster a patient- and family-centered measurement system that involves patients and families, systematically, in the development and testing of measures that evaluate the patient’s experience of care with respect to safety and patient-reported outcome measures. To the extent possible, these measures should be available for administration in different modes, available in different languages, available in the public domain, and comparable across different countries.

To accelerate the development and uptake of measures in priority areas, measure developers should work with provider networks and other interested stakeholders to enable large scale testing and validation of measures as part of the development process, thereby enabling consolidation of the measure development, validation, acceptance, and implementation processes.

EXISTING CHALLENGES

1. How to systematically involve diverse patients and families in the design of measures to accurately capture what matters to them.
2. How to balance the cost of data collection with the need to use methodologically sound modes of administration, especially given the relatively low incidence of adverse events.
3. How to improve response rates for PROMs.
4. How to educate clinicians and staff on improvement of patient experience and PROM’s measures.
5. How to achieve clinician buy-in for the use of PROM’s and patient experience measures.
6. How to leverage electronic data collection to reduce the cost and respondent burden of data collection while preserving validity and reliability.
7. How to collect feedback from patients and/or families across health systems and countries in a comparable manner to identify benchmarks and best practices.
8. How to address the myths of what patient-centered experience measures evaluate and why it is important to delivering safer care.
9. Care-delivery processes are rarely designed to systematically elicit PROMS information from patients, and electronic health records are almost never configured to collect patient-reported data that are needed to calculate these measures.
10. Implementation barriers (e.g., how to use these tools in front-line provider offices) must be addressed.
OPPORTUNITIES AND NEXT STEPS

1. How to implement a standardized, valid, reliable, and culturally appropriate measurement system for evaluating engagement, patient-reported outcomes, clinical measures, and patient experiences of care.

2. Potential for creating an international collaboration with public-private partnerships to establishing a network of qualified measure developers that can develop patient experience and patient-reported outcomes measures that would expand upon existing programs.

3. To ensure the development and use of measures that are meaningful to patients, the measure development process must include patients and families at every stage, from identification of priority measure gaps, to measure development, testing, and validation, to ongoing monitoring.

4. Incorporate the ability to routinely collect and use data on race, ethnicity, and primary language to measure, monitor, and improve health equity (i.e., reduce health disparities).

5. Cataloguing outcomes that need to be included in PROM’s measures that are currently missing.

6. How to link patient experience and PROM’s data to transparency initiatives.

7. Identifying and testing new measures of safety that patients can accurately observe and report about:
   - Efficacy of disclosure and apology programs
   - Involvement in root cause analyses
   - Interactions with risk management staff

REFERENCES


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