

# We Respect Their Autonomy and Dignity, But How Do We Value Patient-Reported Experiences?

*MDM Policy & Practice*

1–3

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DOI: 10.1177/2381468318807458

journals.sagepub.com/home/mdm


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Date received: July 10, 2018; accepted: September 12, 2018

Patients are in a unique position to provide insights regarding their health care management and to assess the quality of health care service delivery. Patient-reported experience measures (PREMs) capture patients' objective health care experiences of what actually happened, as opposed to satisfaction-based measures that aim to vindicate patients' expectations. This is in contrast to patient-reported outcome measures, which measure patients' views of their health status.<sup>1</sup> Indeed, it was the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Program that was initiated in the United States in 1995 that highlighted an important transition in assessing health care quality: moving away from measures of patient satisfaction to PREMs for the purposes of obtaining actionable, informed data regarding what actually happens during the provision of health care services.

In recent years, there has been a proliferation of PREMs. While different PREMs across various health care settings and conditions, all with published validation studies, have been identified,<sup>2–4</sup> this does not include unpublished PREMs and those developed for specific institutional use.<sup>5</sup> The explosion of PREMs is partly due to the increasing focus on patient-centered care, and their adoption as an indicator of health care system quality and performance. For example, the CAHPS program is linked with the US Centers for Medicare and Medicaid to inform hospital benchmarking and pay-for-performance/value-based performance schemes, with the core goal of supporting an objective and meaningful comparison of institutions regarding consumer-based priorities.<sup>6</sup> The National Health Service (NHS) of England conducts a similar program called the Overall Patient Experience

Scores in partnership with the Care Quality Commission whereby the experiences of NHS consumers can be compared over time.<sup>7</sup>

Given that PREMs are influential in the assessment of services, it is important to understand what they are measuring. Thematic analysis of the PREMs from a recent systematic review<sup>2</sup> identifies eight themes that best represent patient-reported experience as it is captured by PREMs: access to and the convenience of health care services; the environment and facilities of the health care setting(s); pain and discomfort associated with treatment; patients' perceived quality of care; communication;

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**Figure 1** Themes representative of patient-reported experience as captured by PREMs.

patient-centered care; shared decision making and involvement in care; and the continuity and coordination of care (Figure 1). In general, these themes align strongly with the NHS of England, National Clinical Guidelines Centre (NICE), and Institute of Medicine (IOM) definitions of quality in health care, which promote care that is safe, patient-centric, effective, efficient, and equitable.<sup>8–10</sup>

While PREMs tell us a great deal about the care processes experienced by patients, they fail to capture the weight of patient preferences, or the value that patients place on each element of the care experience. For example, is a patient experience that is characterized by informative communication from medical professionals preferred to one that is characterized by improved access to services? In their current form, PREMs do not elicit preferences for elements of the care experience. Moreover, how do preferences for health care experiences link with the health outcomes related to the care episode?

With the transition from performance-based to value-based health care, which sees service providers rewarded for efficient, high-quality, patient-centered care, the valuation of patient-reported experiences is integral to the improvement, and provision of high-quality health care. No longer is the patient-reported experience viewed solely as a process or intermediate step leading to improved health outcomes or reduced health care costs.

It is recognized as an outcome measure in and of itself, valued by patients and professionals alike. For example, in end-of-life care, patients and their families are likely to value the experience of how they were treated over an increase in life years of unknown quality.

A preference-based PREM scale could be developed not only to reflect the relative value of various attributes that creates the patient experience but also to inform the allocation of resources within a value-based framework alongside health outcomes. This inevitably raises the question of the interplay between different levels of health outcomes, the preferences linked to these, and care experience preferences. This interplay is particularly important where resources are limited and priorities are the key driver in health care decision making. That is, to consider the value of patient experience one must also consider the lost opportunity to invest in alternative strategies that increase health outcomes.

These tradeoffs are not new—policy and decision makers the world over face and make these decisions constantly. So how do we currently value patient-reported experience? Ryan and colleagues conducted a systematic review of studies reporting on the valuation of patient experiences with health care processes, and discovered that current applications of valuation have largely focused on process descriptors (e.g., the attributes of health care associated with structures, access, etc.) and the interaction of staff with patients (e.g., patient involvement in shared decision making).<sup>11</sup> However, two common limitations are evident within this body of research. First, valuation studies have largely focused on the action or characteristics of the health care professionals providing care, not the impact of health care delivery on the patient. Second, valuations have failed to capture a holistic picture of the patient-reported experience associated with health care delivery, due to the focus on only one or two individual experiential attributes. We only partially understand the value that patients place on their experience in the health care system, and know little to nothing of how decision makers balance achieving improvements in health outcomes, patient experience, and costs.

A project to develop a generic preference-based measure of patient-reported experiences of health care using Discrete Choice Experiment (DCE) methods is underway. DCEs are a method where participants are presented with two or more alternatives (e.g., for different care experiences) and are required to choose which alternative they most prefer. This method is based on the assumption that the patient-reported experience can be described by its attributes.<sup>12</sup> Yet although this approach


warrants greater attention, we should keep in mind several considerations.

First, the relative importance of attributes that constitute patient-reported experiences will depend on the context in which a PREM is employed (e.g., PREMs designed for inpatient settings are less likely to include items relative to the theme of access to health care services). This is important for the framing of valuation studies and whether they should value patient-reported experience generally, be specific to a target context or population, or cross the entirety of the care continuum. At the same time, and perhaps more discerningly, the fact that existing PREMs include/exclude certain themes relating to patient experience dependent on the setting for which they are administered may indicate a lack of clarity in our understanding of patient-reported experience as a concept.

Second, there is concern that patient experience, an immediate outcome, may be overly pursued at the expense of non-immediate health outcomes (e.g., reduced HbA1c). This again emphasizes the importance of examining the opportunity costs associated with investing in health care initiatives that promote positive patient experiences.

Providing a complete patient-reported experience picture will have a significant impact on health care decision making, particularly our ability to effectively utilize data collected from PREMs to provide an assessment of patient experience that is reflective of the relative importance of different aspects of the experience. This will also contribute to the assessment and implementation of value-based health care. In the ever-evolving and complex landscape of health care, it is no longer sufficient to base health care policy and funding decisions on health outcomes and costs alone. Incorporating patient experiences is one crucial step toward being able to better determine value in health care.

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