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Evaluation and measurement of patient experience

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Abstract

Despite the increasing presence of a variety of measures of patient health care experiences in research and policy, there remains a lack of consensus regarding measurement. The objectives of this paper were to: (1) explore and describe what is known about measures and measurement of patient experience and (2) describe evaluation approaches/methods used to assess patient experience.

Patient-experience does not simply reflect clinical outcomes or adherence-driven outcomes; rather it seeks to represent a unique encompassing dimension that is challenging to measure. Several challenges exist when measuring patient experience, in part, because it is a complex, ambiguous concept that lacks a common or ubiquitous definition and also because there are multiple cross-cutting terms (e.g., satisfaction, engagement, perceptions, and preferences) in health care that make conceptual distinction (and therefore measurement) difficult. However, there are many measurement and evaluation approaches that can be used to obtain meaningful insights that can generate actionable strategies and plans. Measuring patient experience can be accomplished using mixed methods, quantitative, or qualitative approaches. The strength of the mixed methods design lies not only in obtaining the “full picture,” but in triangulating (i.e., cross-validating) qualitative and quantitative data to see if and where findings converge, and what can be learned about patient experience from each method. Similar to deciding which measures to use, and which approaches to utilize in measurement, the timing of measurement must also fit the need at hand, and make both practical and purposeful sense and be interpreted in light of the timeframe context.

Eliciting feedback from patients and engaging them in their care and health care delivery affords an opportunity to highlight and address aspects of the care experience that need improvement, and to monitor performance with regard to meeting patient experience goals in the delivery of care. The use of core patient-reported measures of patient experience as part of systematic measurement and performance monitoring in health care settings would markedly improve measurement of the ‘total’ patient experience and would heighten our understanding of the patient experience within and across settings.

Keywords

Patient experience, metrics, measurement, evaluation, patient-reported outcomes

Note

The views expressed in this manuscript are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or United States Government.

Over the last decade, increased attention has been placed on measuring and improving the health care experience of patients. This movement was prompted, in part, by the Institute of Medicine report, *Crossing the Quality Chasm*,¹ and further encouraged by the public reporting of measures, such as the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS),² in addition to the increase in use of ‘patient experience’ measures for accreditation and pay-for-performance programs.³ However, in the pursuit of improving patients’

experiences, measurement is necessary, but not always sufficient.

A patient’s experience cannot be viewed in isolation of broader concerns about quality and cost of health care. In health care, big picture goals are to provide health care to large numbers of people at a reasonable cost, but because care should be centered on the patient, this needs to be accomplished with the patient experience at the forefront. This requires inclusion of patients’ perspectives to better

understand how treatment and care impacts the entirety of a patient's life.⁴ The measurement and monitoring of the patient experience in health care poses a number of challenges. For example, an ongoing struggle exists to discern whether and when we should focus on quality, patient-centeredness, satisfaction, and/or other concepts. There is also uncertainty with differentiating among these concepts and their uses. Despite differences, to some degree, these concepts all seek to improve patient experiences and to include patient perspectives about their health care in order to improve overall care delivery. Although patient experience is advocated in health care settings, there is still a poor understanding of how to measure (or even define) its core components. The main purpose of this paper is to explore and describe what is known about measures and measurement of patient experience and evaluation approaches/methods to assess patient experience.

What is patient experience and why is it important to measure?

As articulated by Wolf and colleagues⁵ in this current issue (see pages 7-19), patient experience has generated many definitions. As a global leader on improving the patient experience in health care, The Beryl Institute defines the patient experience as *"the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care."*⁶ Despite the complexity surrounding which definition to embrace or which components/constructs to measure, there is general agreement that patient experience in a health care context incorporates the patient's journey as a whole and that it is a practically, managerially, and clinically important concept to measure.

Measurement of patient experience is important because it provides an opportunity to improve care, enhance strategic decision making, meet patients' expectations, effectively manage and monitor health care performance, and document benchmarks for health care organizations.^{7,8} Measurement of patient experiences can also inform an organization on improvement of processes and clinical outcomes, utilization of resources, and enhancement of safety.⁹ Furthermore, organizations also want patients to return, to refer their friends and family, and to provide positive word-of-mouth (behavioral loyalty) about their health care experience.^{10,11} Although many patient experience measurement initiatives are still in development stages, studies have begun to report improvements after systematic collection of data on patient perspectives and feedback.^{8,12,13}

Measures and Approaches (What, How, and When)

It is imperative to consider whether the right metrics are being used and whether the right methods and evaluation approaches are being employed in order to further progress and improve patient experiences. Wiig and colleagues¹⁴ reported that relevant tools for measuring and using patient experience for quality improvement goals are lacking and that when measures of patient experience were available, there was no meaningful or systematic use of these measures. Because of this uncertainty, many question what reports of patient experiences with their health care actually measure, e.g., Are they a reflection of care quality? Are we measuring the appropriate constructs?¹⁵

What to measure?

The starting point for measuring patients' experiences would ideally include a standardized definition, an established set of standards, and a set of measurable indicators; having this in place would identify essential components of the patient experience construct, as well as set boundaries for what it is not. Measurement items should, therefore, reflect the domains and dimensions of the definition. A key component of a successful strategy for understanding and improving patients' experience is ensuring that what is measured reflects what matters most to patients. In line with the realization that a patient's experience is his/her own, and that it is an interaction that is time bound and ethereal, evaluation techniques can only more or less accurately capture the reality of the experience. Yet, the report of patient experiences must include the patient's perspective.

To study patient experience in current health care delivery models, consideration must be given to whether the metrics and measures that are being used are sufficiently capturing patients' experiences. If the interactions apparent in an organization are intended to collectively and consistently influence patient perceptions, are metrics being used that are too medically-focused without attention to what matters most to patients and their experiences? For instance, in mainstream health care, it is common to use proxy measures for health, such as blood pressure control, while not directly measuring the patient's experience with their health status or health care. Achieving blood pressure within a targeted range is an optimal clinical goal, but is not the same as achieving an optimal state of well-being. In other words, if a patient reluctantly took a medication to successfully reduce blood pressure, but faced a side effect from the medication that adversely affected their quality of life – was the goal achieved? This begs the question, is the right goal being measured and how do we incorporate patient experience measures to optimally achieve (and measure) the best

clinical outcomes and/or subjective goals that matter to the patient?

It is perhaps the quantifiable and unambiguous nature of clinical measures, such as blood pressure, that increase their desirability for use. In contrast, the measurement of patient experience is difficult because precision is absent from its definition (and there is no universal operational definition or set of common components/concepts). As such, patient-experience does not simply reflect clinical outcomes or adherence-driven outcomes, rather it seeks to represent a unique encompassing dimension that is challenging to measure objectively.

Measurement challenges: patient-reported measures, cross-cutting concepts and distinction difficulties

Manary and colleagues¹⁵ highlighted three concerns with patient-reported measures, in general. (1) Patient feedback is not credible because patients lack formal medical training. Critics hold that patient-reported measures, such as patient-satisfaction, actually signify some aspect of “happiness,” and note that these are highly subject to being influenced by factors unrelated to health care. (2) Patient-experience measures could be confounded by factors that are not directly associated with the quality of processes. This would be the case, if patients rated their experiences based on their subjective assessment of their current health status, regardless of the care experience. (3) The third concern is that patient-experience measures may reflect fulfillment of patients' immediate desires, for instance, the receipt of a specific medication, regardless of its benefit. These concerns, in part, reduce the validity of patient perspectives, serving to support a provider-driven model.

In addition to these general concerns about patient-reporting and feedback, challenges specific to patient experience measurement exist as well. Measurement of patient experience is further complicated by the numerous terms and usages that have been applied to, associated with, and become synonymous with the term. Some measure quality of care as an indicator of patient experience, yet others associate access to care (or clinical outcomes as described above) with the measurement of patient experience. For example, in many cases, patient satisfaction is measured and considered one and the same as patient experience. Some common cross-cutting (recurring and arising in most constructs of health care quality and value measures) and potentially overlapping patient-reported measures include:

Patient satisfaction. Patient satisfaction is a predominantly affective judgment formed by the patient alone (again, influenced by both internal and external factors).¹⁶ It is one (perhaps interim) end-state of an individual's

assessment of goal attainment. It is NOT the same as perceived quality; perceived quality is predominantly a cognitive assessment of what happened and how it happened, while satisfaction is how it made the patient feel. Volumes of service research have established that perceptions of quality are drivers of satisfaction, and conceptually distinct.¹⁷ Patient satisfaction is NOT the same as patient perceptions, as patients can perceive aspects of a health care encounter that serve as satisfiers as well as dissatisfiers. Thus, measures such as CAHPS, which capture patient perceptions of what happened, and how frequently things happened, can be drivers of satisfaction, but cannot be conceptually equated with satisfaction. Satisfaction can be measured with items that include the terms “satisfied,” “pleased,” and “happy.” It is important to note that patient satisfaction can be a driver of subsequent outcomes that are most important to health care organizations: loyalty (re-patronage), positive word-of-mouth, referrals, and other behaviors that directly positively impact the bottom line.

Patient perceptions. The view of the patient determines subsequent evaluations of an experience. As mentioned above, the patient's perception is the only input into patient experience. No matter how much an organization or provider wishes to define a patient's experience for him or her, it can only influence patient perceptions through optimizing the quality of actual provision of services. Organizations that keep patient perceptions sacred, and endeavor to minimize factors that may create biased views or interpretations display an honesty and respect for a patient's journey. These organizations are the ones that will benefit from a commitment to patient experience improvement, and display a type of organizational culture that facilitates success in these efforts.

Patient engagement. An engaged patient is one who is emotionally involved, or affectively committed, to their health and well-being.¹⁸ This is the desired patient state for both the patient and his/her caregivers, in that engaged patients are more likely to share important information, engage in productive plans of action, adhere to these plans, utilize communication technologies, engage with other patients/patient communities, and, ultimately, positively influence the course and trajectory of their health status. Thus, patient engagement as a strategy for a health care organization should be focused again on the patient's cognitive and affective processes and states. Patient engagement benefits health care organizations, and can be affected by the plans and actions of care givers, but is not something that is contained within health care organizations; it is owned completely by a patient. Patient activation may be a synonymous term with related measures.¹⁹⁻²¹

Patient participation. Patient participation is a relatively narrow term. It describes the effort that a patient exerts

during a specific health care interaction.²² This may include sharing information, sharing one's self, and engaging in questioning and discussion. Patients participate to varying degrees in various stages of a health care experience, and this can be measured by observation, surveys, and other measures. It has been shown that engaged patients participate more; thus, engagement is antecedent to participation, but this is a non-recursive relationship. That is, over time, each experience that a patient has affects subsequent levels of engagement, which then impacts the level of participation in health care encounters and response to specific requests.

Patient preferences. Understanding patient preferences is a step toward being able to provide an optimal patient experience. Several organizations have begun to collect information on patient preferences for service delivery and modes of communication with regard to their health care. For example, LaVela et al.²³ collected data to understand the communication preferences of primary care patients specific to various health care needs, recognizing that communication preferences may vary by health care needs or encounter reasons (even at the individual level). This measure, of course, is only one piece of the patient experience phenomenon.

Summary of cross-cutting measures/distinction challenges. It is important to make distinctions between patient experience and other potentially cross-cutting measures, and to differentiate between patients' experience of the care process and patient-reported outcome measures. Studies have shown that patient-reported or patient-experience measures and the volume of services utilized are not correlated. For example, increased patient engagement leads to lower health care utilization, but greater patient satisfaction.¹⁵

Measurement concerns exist for each of these concepts; it seems that each has some level of similarity and overlap with one another and 'the patient experience,' yet each alone does not capture the breadth and depth of patient experience. For example, according to Needham,²⁴ the focus on patient satisfaction alone is "short-sighted" and that best practices from other industries should be adopted into health care to move beyond satisfaction to deliver a more "complete patient experience." Limiting patient-experience measurement to a single dimension, such as communication, may discount the interactions that have a powerful effect on experiences and outcomes. Thus, careful and comprehensive approaches to measurement should be employed in attempt to accurately capture patient experience.

Approaches to measurement/evaluation of the patient experience.

In addition to challenges in selecting appropriate measures, it is important to choose study designs and measurement methods appropriate for evaluating the complexity of evolving models of health care delivery and system redesign. In recent years, several individual health care organizations have made attempts to measure patient experience using variety of quantitative and qualitative approaches. Such approaches include ward/department or unit-level surveys, interviews, focus groups, patient forums, and informal feedback through patient advocacy groups or patient service organizations. Other approaches to capture patient experience include formal complaints, commentary on websites, and feedback on the performance of health care providers for appraisal purposes.¹⁴ Although direct feedback and patient-reported outcomes are vital in gathering information about patients' experiences, routine data (e.g., administrative databases and/or charts; performance measures) and staff observations may also be useful data collection approaches. In addition, a variety of observational and ethnographic approaches to gather data about patient experience may also be used, including unobtrusive observation of patients (for example, in a waiting room) and approaches such as patient journey mapping or health care process mapping,^{25,26} mystery shopping,²⁷ rounding and observing,²⁸ video recording,²⁹ and shadowing.³⁰ It is important to examine data collectively from multiple sources and evaluation approaches; in many cases using several different data collection approaches to produce a more informative, rounded picture is preferred (e.g., triangulation). Measuring patient experience can be accomplished using mixed methods, quantitative, or qualitative approaches.

Mixed methods. Mixed methods that incorporate both quantitative and qualitative methods help gain broader perspectives than would be achieved by using one predominant method alone. The strength of the mixed methods design lies not only in obtaining the "full picture", but in triangulating (i.e., cross-validating) qualitative and quantitative data to see if and where findings converge, and what can be learned about patient experience from each method.³¹ Mixed methods also help interpret convergence of the findings to strengthen knowledge claims or explain any lack of convergence.

Quantitative. Quantitative approaches may be used to measure patient experience. Structured questionnaires that collect patient-reported outcomes (PROs) are among the most common form of quantitative measures of patients' experience. These are designed to produce numerical data that can be analyzed statistically to provide patterns, associations, and trends. Quantitative questionnaires can

be used with relatively large samples, providing breadth and the ability for advanced analyses and comparison, but often without much depth due to the predetermined questions and response choices (not necessarily in the patient's words). It is common to collect patient-reported experience measures alongside patient-reported measures of health status, function, health-related quality of life, and some condition-specific measures. This may provide a better picture of patient perceptions of both the process and outcome of care, and information on other factors they may influence the care experience.

There is a great variation in questionnaires as instruments that measure (or claim to measure) patient experience or components of patient experience. However, to date, there are few standardized questionnaires that directly assess patient experience. While some instruments assert direct measurement of patient experience, such as the Picker Patient Experience Questionnaire,³² other instruments measure similar and/or related constructs. For example, CAHPS is a well-known, highly used survey that has been applied to many patient domains: Hospital (HCAHPS), Home Health (HHC CAHPS), Clinician & Group (CG CAHPS), Health Plan (HP CAHPS), In-Center Hemodialysis (CAHPS ICH), Medicare Advantage & Prescription Drug Plan (MA & PDP CAHPS), Nursing Home (NH CAHPS), Pediatric (PHCAHPS), Cancer Treatment (Cancer CAHPS), with others coming soon. Categories of measures in HCAHPS include: Communication with nurses, Response of hospital staff, Communication with doctors, Hospital environment, Pain management, Communication about medicines, Discharge information, Overall rating of hospital, and Patient information/demographics. Press Ganey and other vendors may supplement these CAHPS core measures with additional items in an attempt to gain a broader view of a patient's experience. Press Ganey measures that may be added to HCAHPS instruments include: Admission, Room, Meals, Nurses, Tests and treatments, Visitors and family, Physician, and Discharge.³³ Picker survey categories include: Information and education, Coordination of care, Physical comfort, Emotional support, Respect for patient preferences, Involvement of family and friends, Continuity and transition, and Overall impression.³⁴

Additional constructs that may be related to patient experience, and thus yield insights into how patients perceive their care, include:

1. Health-related quality of life (HRQOL),³⁵ which have been measured by CDC³⁶ and Rand Corporation.³⁷
2. Subjective well-being (SWB). For an outstanding integration of how subjective well-being is a measure of quality in health care, and how it represents perspectives on patient experience, see Lee et al.³⁸ For a view of how SWB impacts life activities, see Diener et al.³⁹ For measures, see Kahneman and Krueger,⁴⁰ and Sandvik et al.⁴¹ Some components of SWB include Life satisfaction, Home satisfaction, Work

satisfaction, Experience measures, and Positive/negative affect and positivity.⁴²

Qualitative. Qualitative methods offer the opportunity to obtain an in-depth understanding of patient experiences. These approaches also allow evaluators to move beyond limitations of structured questions (common in quantitative surveys) through open-ended questions in which patients are encouraged to describe their experiences and perceptions in their own words. In doing so, qualitative methods may elicit a deeper understanding of patient's perceptions and behaviors and the meanings they attach to their experiences. As such, traditional qualitative methods such as interviews and focus groups may be powerful tools in capturing the patient experience.

In addition to traditional methods such as focus groups and interviews, some innovative approaches to evaluating the patient experience have begun to emerge. For example, ethnographic approaches, and novel methods such as photovoice and guided tours may be used to measure and better understand patient's perspectives while engaging them in improving their health and health care.

Ethnographic Approaches. Shadowing and mystery shopping are ethnographic approaches that allow researchers to join patients in order to embed themselves in the patient's experience. Notes are taken based on observations, and are then compiled across experiences in order to provide insights into how to improve or redesign a care delivery process in order to improve clinical quality, process measures, save money and resources, and to improve patient perceptions of care.³⁰

Photovoice. For the photovoice approach, participants are provided with cameras and invited to take pictures to visually interpret a particular subject. Guided by questions and prompts on the topic of interest, participants are given the opportunity to take pictures of elements in their environment - capturing objects, landscapes, and events meaningful to them. Once participants have taken their pictures, in-depth interviews are conducted to examine their photographs in detail. During follow-up interviews, the pictures create a platform to stimulate discussion on the topic and allow participants to share their unique narrative and experiences. Participants are encouraged to elaborate on the meaning of their photographs and describe how they represent their perspective. This may be shaped by individual beliefs as well as sociocultural context and physical environment. Through this process, evaluators can get a deeper understanding of patient's perceptions, preferences, and needs. Studies have found this technique to be beneficial in extracting rich data on perceptions and needs defined by an individual patient's viewpoint.⁴³ One recent study used photovoice to measure patient experience; patients were asked to take photographs that captured salient features that represent

their experiences and perceptions of care, followed by interviews to explore the intended meanings of photographs.⁴⁴

Guided Tours. Guided tours, in which participants lead the evaluator through their environment while commenting on thoughts and experiences,⁴⁵ is another participatory methodology that can be useful for capturing the patient experience. Using a guided tour approach to assess the patient experience in a health care setting, a patient leads the individual who is collecting data through the hospital environment, as they describe their surroundings, thoughts, and feelings⁴⁴ related to their individual health care experience. This method is able to capture a multi-sensory (e.g., sights, sounds) insight into the patient experience. Locatelli et al.⁴⁶ describe the use of guided tours to measure patient experience of a US Veteran cohort at the point of care. In this work, Veteran patients walked through the hospital as they would during “a typical visit” and described their patient experience in real-time as they walked.

Advantages/disadvantages of approaches to evaluating patient experience. An obvious strength in using quantitative methods is the ability to have bigger sample sizes, which allows the use of more advanced statistical testing of associations and greater comparability. Quantitative data are also beneficial for benchmarking and documenting quantifiable, measurable change. It should be noted, that some of the patient-reported measures used to capture patient experience may be affected by bias. Even a patient’s own recall of an experience is only an approximated representation of the actual experience, because it is subject to bias. This could result from a number of different sources: faulty memory and recall, perceptions that become altered after the experience due to internal factors (emotions, re-evaluations, etc.), as well as external factors (measurement effects, family discussions, organization-provided communication, etc.). Nonetheless, evaluation techniques are employed to capture the reality of a patient’s experience, and should be combined to triangulate on the phenomenon under study. Although qualitative methods use smaller samples, they often have rich in-depth data. It is more difficult to make concrete comparisons or generalizations using qualitative data, but strength lies in that these data are in the patient’s own words. Furthermore, qualitative evaluative approaches, such as guided tours, often have fewer regulatory restrictions; which may help avoid delays in obtaining actionable results. The innovative participatory methods such as ethnography, photovoice, and guided tours allow the examination of patients’ real-world experiences and identification of areas in need of improvement. Other advantages of qualitative participatory approaches lie in the ability of these methods to (a) foster a sense of partnership between evaluators and patient participants, and (b) give patients a voice to help

improve health initiatives tailored around their needs.⁴⁷ Qualitative data may be challenging to summarize and interpret, and can be especially susceptible to bias. Ideally, using mixed methods with both quantitative and qualitative measures can often provide an informative depiction of the patient experience. In this case, the quantitative data measures would be interpreted alongside the qualitative data, which provides context. Together, these approaches can provide the most rounded, fruitful understanding of patient experience.

When to measure?

There are several considerations for deciding “when” to measure patient experience. Studies that have examined the timing of measuring patient experience using their feedback about health care received have produced contradictory findings.⁴⁸ Evaluation approaches can be used either at the time of care or at some time after a health care encounter or care was received. For example, the HCAHPS questionnaire is collected within 42 days after a patient is discharged. Conversely, surveys conducted by health plans and primary care providers often require patients to consider interactions that occurred during the previous year or more, which may introduce considerable recall inaccuracies and bias.¹⁵ Patient experience can also be measured at the point-of-care or using regular monitoring (continuous feedback strategies). Increasingly, technology is allowing organizations to collect “real-time” feedback from patients, including quick tablet-based surveys prior to exiting a facility, using apps to collect data during a visit, and other creative methods of decreasing data collection effort and feedback timing. Similar to deciding which measures to use, and which approaches to utilize in measurement, the timing of measurement must also fit the need at hand, and make both practical and purposeful sense and be interpreted in light of the timeframe context. Bjertnaes and colleagues⁸ found that patients report worse experiences for 3 of 6 patient-reported experience scales when survey is conducted a lengthier time from their clinical encounter. Individual response time was also negatively related to patient-reported experiences, suggesting that regardless of the reason, more time that passed since an encounter occurred resulted in poorer patient-experience reported. This suggests that many organizations support the collection of patient experience as close to the care encounter as possible.

Application and impact of successful patient experience measurement.

The intent of this paper was to serve as a starting point for various stakeholders to think broadly about how patient experience measurement can impact patient care, and an organization’s culture, strategy, and care models/designs. Eliciting feedback from patients and engaging them in

their care and health care delivery affords an opportunity to highlight and address aspects of care that need improvement and to monitor performance with regard to meeting patient experience goals in the delivery of care. Regardless of method or measures, efforts to better understand patients' experiences allow organizations to identify gaps in service, to gain insights into issues that are causing negative effects on patient care, and to innovate and/or redesign processes in order to better deliver care with patients. Patient experience measurement efforts help health care researchers and administrators gain insight into patient/family experiences.⁴⁹ Additionally, incorporating the voice of the patient into strategic decisions can help streamline processes, save costs, and facilitate teamwork.⁵⁰ Moreover, collecting patient experience measures can provide feedback on quality improvement efforts. Patients can report on what is going well, what is not, and mixed method research designs can give direction to the priorities that an organizations should have when embarking on QI programs. Finally, delivering on the mission of health care for all can only be achieved through a more complete view of what is important to patients. Patients value health, well-being, quality of life, respect and dignity, independence and autonomy – aspects of health that cannot be found completely in clinical measures. Thus, collecting measures of patient experience, broadly construed, is essential to realizing the mission of health care.

Conclusion

As illustrated in this article, measures of patient experience vary widely, and measurement is not routinely conducted in a standardized way. Several challenges exist to measurement of patient experience, in part, because it is a complex, ambiguous concept that lacks a common or ubiquitous definition, to date, and also because there are multiple cross-cutting terms in health care that make conceptual distinction (and therefore measurement) difficult. However, there are many measurement and evaluation approaches that can be used to obtain meaningful, actionable findings. Effective measurement of patient experience can be used: (a) to compare the care experiences delivered by different providers/systems, (b) to facilitate patient decision-making about their care, e.g., provision of comparable data to help patients decide which health care provider/system they will use, (c) by health care oversight committees/organization to monitor care delivery and patient experience 'ratings,' and (d) by health care organizations to successfully meet their mission of health care delivery. The use of core patient-reported patient experience measures as part of systematic measurement and performance monitoring in health care settings would markedly improve measurement of the 'total' patient experience and would heighten our understanding of the patient-experience within and across settings.

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