Curr Treat Options Peds (2016) 2:267–279
DOI 10.1007/s40746-016-0072-6



# Patient and Family Experience in the Healthcare Value Equation

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Published online: 15 November 2016
© Springer International Publishing AG 2016

This article is part of the Topical Collection on *Quality Improvement*

**Keywords** Quality · Value · Outcomes · Experience · Family

## Opinion statement

As outlined in the 2001 Institute of Medicine landmark paper "Crossing the Quality Chasm," the overarching goal of healthcare is to provide safe, efficient, effective, equitable, timely, and patient-centered care (Crossing the Quality Chasm: A New Health System for the 21st Century, 2001). In addition to these six aims, the cost of care must also be considered and VALUE, our ability to achieve these aims at an affordable cost, is at the forefront of discussions across the nation. VALUE is often defined in terms of the equation: VALUE = QUALITY/COST. This definition prompts important questions about the meaning of quality and cost in healthcare. Traditionally, VALUE in medicine highlights quantitative metrics of quality such as access to services, patient safety measures, preventable conditions, peri-operative complications, re-admissions, resource utilization, and mortality. Metrics such as these are OUTCOMES that define the QUALITY of the care provided. When QUALITY is assessed, patient and family experience measures are often viewed as secondary to clinical outcome measures and relegated to a minor role or excluded all together from the value equation. We assert that in the current medical landscape, the role of patient and family experience should be considered paramount in delivering the best

quality, outcomes, and safety at the lowest cost and, therefore, providing the greatest VALUE for the consumer. As such, any discussion of VALUE should include patient and family experience in the equation:

$$\text{VALUE} = \text{QUALITY}\ (\text{Experience} + \text{Clinical Outcomes} + \text{Safety})/\text{COST}$$

## Introduction

### Introduction to patient and family experience

In today's healthcare arena, patients are presented with more healthcare treatment, cost options, and decisions than ever before. In addition to navigating complex medical systems and diseases, patients are now faced with financial pressures and endless access to online medical resources providing diagnostic and treatment options and social media ratings of care. Healthcare consumers feel pressured to balance these insights from multiple sources to attain the highest value care. Patients today assume that care will be safe and effective, and as such, view healthcare as a commodity, demanding that the clinical and service aspects of healthcare meet their expectations. Depending on the resources they access, patients will come to care with varying levels of realism in their expectations [2]. Patient satisfaction encompasses the superficial markers of how well a patient "liked" their healthcare encounter; how well even their most unrealistic expectations were met. Patient and family experience (PFE), however, encapsulates the principles of patient- and family-centered care (as defined by the Institute for Patient and Family Centered Care: focusing on enhancing dignity and respect, communication, collaboration, and participation), making patients and families partners in every aspect of care, in every setting, by every care provider, every day [3]. It is also important to recognize that patients and families do not fragment the care they receive by service line, provider type, encounter, or location—they instead view medical care as a fluid entity. As such, the Beryl Institute defines PFE as, "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care" [4]. Focusing on PFE is a fundamentally essential goal [5], because as the recipients of care, patients provide unique insights into hospital quality as a whole. Patient's impressions and feelings educate us on how the care we think we provide compares to the patient perspective of that care and therefore, provides a true gauge of the value our healthcare systems deliver [6].

### Measurement of the patient and family experience

Numerous modalities have been used in the past to gauge patient and family attitudes and perceptions about healthcare delivery systems with varying levels of success [6, 7] (Table 1). We now recognize that any tool assessing PFE must deliver valid, reliable, and reproducible results if we are to accurately report metrics. The best studied and most widely used tool today is the Hospital Consumer Assessment of Healthcare Providers and Systems Survey Tool (HCAHPS), a 32-item validated survey based on 11 domains (Table 2) that was developed by the Department of Health and Human Services as a method to assess the patient's perceptions of the healthcare system. The HCAHPS program is funded and overseen by the US Agency for Healthcare Research and Quality (AHRQ) and the survey itself is administered by hospitals directly or through a third party vendor. The data is analyzed and reported by the Centers for Medicare and Medicaid Services (CMS). HCAHPS Survey data have been collected in the adult inpatient setting since 2006 and became publically reported in 2008. CAHPS surveys have also been developed and validated for use in many other healthcare environments, such as outpatient clinics and pediatric inpatient settings [8].

**Table 1. Patient experience tools**

| Patient experience tools |
|---|
| Government-mandated surveys |
| Patient satisfaction/experience surveys |
| Calls to patients/caretakers after discharge |
| Bedside surveys/instant feedback |
| Patient and family advisory committees |

# PFE in the value equation

## PFE and quality

Measuring, improving, and sustaining quality at affordable cost in healthcare is a challenge shared by healthcare institutions across the country. Quality dashboards often do not include measures of PFE and instead focus on the clinical/clinician perspective of safety, outcome-based measures, costs, and the elimination of waste. As explicitly stated by Don Berwick in his paper "The Triple Aim: Care, Health, And Cost," improving the experience of care is one of the three components of the triple aim. This, along with improving the health of populations and reducing the per capita costs, are interdependent and believed by many to be essential if the quality of health care in the USA will improve [9]. Though we recognize that no single measurement can capture the complexity of

**Table 2. HCAHPS domains**

| HCAHPS domains |
|---|
| Nurses' communication |
| Physician's communication |
| Responsiveness to needs |
| Management of pain |
| Communication about new medications |
| Key information at discharge |
| Transition to the post hospital setting |
| Cleanliness |
| Quiet |
| Hospital's overall rating |
| Likelihood to recommend |

our healthcare systems [6], PFE is the overarching connection between quality and cost and patient experience should be viewed as a vital component of hospital quality and outcomes [10]. Quality in healthcare is best defined as the amalgam of Experience + Outcomes + Safety, where outcomes and safety are strongly influenced by PFE. We discuss these relationships further below.

$$\text{Value} = \text{Quality (EXPERIENCE} + \text{Clinical Outcomes} + \text{Safety)}\Big/\text{Cost}$$

## Clinical outcomes

Superior clinical outcomes are undeniably the primary focus of healthcare. Improving and maintaining clinical outcomes cannot be addressed in a vacuum [11]. Just as superior outcomes are dependent on safety, so are they dependent on an excellent experience. Excellence in PFE requires empowered patients, activated families, and engaged caregivers such that all work together to combine technical and clinical aspects of medicine with the needs and goals of the patient. When this happens, all parties are working toward a common solution, optimizing care and ultimately achieving better outcomes.

There is robust evidence linking a patient-centered approach to improvement on a number of clinical outcomes. Hospitals that are rated more highly in PFE also show higher adherence to clinical guidelines, lower risk-adjusted mortality rates, and lower readmission rates [5, 12, 13]. Patients who have positive health care experiences have improved outcomes and more efficient utilization of the healthcare system [6, 14]. As an example, one meta-analysis of surgical outcomes revealed that hospitals with higher scores in patient experience had more efficient care, shorter lengths of stay, lower readmission rates, and lower mortality rates. This positive relationship between patient experience and composite measures of surgical quality provides evidence that there is alignment between experience and quality of care [15].

Some have suggested that focusing on patient experience is dangerous and that it leads to increased testing and overtreatment, which results in negative health outcomes [16–18]. One of the more frequently cited studies looked at patient experience in conjunction with healthcare utilization and mortality [18]. In this study, higher scores on patient experience measures were associated with greater inpatient utilization, higher overall expenditures for health care and prescription drugs, and increased mortality [18]. In addition to concerns about the methodology used (experience and cost were measured over an extended time period instead of as specifically linked to unique events), the sicker patient population assessed in the study raised questions about the generalizability of the data [19]. Sicker patients may be more grateful for the care they receive, confounding their perception of the overall experience. Sicker patients also inherently use more healthcare resources and have worse outcomes [19]. Overall, this study conflicts with an impressive body of literature showing a positive association between higher patient experience scores and important markers of positive clinical outcomes.

The totality of the evidence is strong and consistent—there is no need to trade technically excellent care for care that is attentive to the needs of the

patient and family [12, 28]. Outcomes are optimized when balance is achieved between the clinical aspects of care, attention to the patient's perceptions of the care, and partnership between the care providers and the patient.

## Safety

From the perspective of patients and families, safe care and service components of care are inextricably linked. Numerous studies demonstrate that when patients are engaged in care, the safety of the care they receive is improved, and conversely, patients who reported service quality issues perceived risks to their safety [20, 21–23]. Patient-reported service quality deficiencies are associated with adverse events and medical errors, and engaging patients as partners in identifying medical errors have been found to enhance patient safety [22, 23]. Frequent and effective communication in a mutually supportive environment is crucial to both service and safety, which may help explain this relationship. In a systematic review including data from 55 studies, Doyle et al. found impressive positive associations between patient experience, patient safety, and clinical effectiveness for a wide range of disease states [14]. Just as safety is a central pillar of quality in health care, so too is PFE [14]. Furthermore, it is important to remember that patients and families do not identify experience and safety as distinct entities; providing the safest care without embracing the tenets of patient- and family-centered care will not result in a positive experience.

## Patient and family experience and cost

As mentioned, patients and families are increasingly aware of the cost of care. In an effort to cut overhead, employers are switching to high-deductible insurance plans that cover basic services, including preventative care, but other services result in "out of pocket" expenses until deductibles are met. Consumers are now more responsible for the billed costs of medications, laboratory tests, imaging, procedures, physician fees, and facility use and are responding by demanding transparency in pricing. Internet resources are becoming more popular as patients seek to balance the cost with the quality of care (best value for their money). These sites synthesize patient impressions of organizations (the experience) and are readily available to patients who are researching options for treatment, services, and location of care [3]. A recent survey of more than 500 members of the American College of Healthcare Executives and the Society for Healthcare Strategy and Marketing (*Futurescan*) examined the perspectives of hospital leaders across the country on how certain trends are likely to impact their organizations over the next 5 years. Almost 80 % of these leaders agreed that the majority of patients will have compared the experience scores of their hospital to those of other hospitals before choosing where to receive care [3].

Hospital systems are also beginning to recognize the impact of PFE on cost. In an analysis by the Deloitte Center for Health Solutions, hospitals with high patient-reported experience scores have higher profitability [24].The patient perspective is an important mediator of reduction in professional liability claims [5]. With CMS reimbursement strategies, experience scores have become a factor in the financial viability of institutions. In 2012, CMS integrated HCAHPS data into the Hospital Value-Based Purchasing (HVBP) program, one of the domains of the total performance score (TPS) used to determine payment to healthcare systems. In 2015, the Patient Experience of Care domain

comprised 30 % of the HVBP's TPS and affected 1.5 % of total CMS payments to hospitals. It is projected that with ongoing healthcare reform, the Patient Experience of Care domain will have increasing importance in the HVBP Program [25]. An overwhelming majority of *Futurescan* survey leaders agreed that at least 10 % of hospitals' total possible reimbursement will depend on HCAHPS scores in the next 5 years. *Futurescan* leaders also agreed that hospital leaders will begin to measure organizational performance primarily using PFE metrics [3].

When considering value in health care, quality and cost have been the classic foci of measurement. Certainly, any discussion of the quality component of value must include mention of safe care that results in excellent clinical outcomes. Patients and families include their experiences across the continuum of the care journey when judging the quality of care they were provided. This makes it essential that PFE also be included in our definition of quality care because value is not just defined by the healthcare system but is also defined by patients and families. In addition to its independent contribution to quality care, PFE also has a profound impact on safety, clinical outcomes, and cost as discussed above. As such, one cannot underestimate the effect of experience on value in health care. Any efforts to improve value in healthcare will need to focus on improving the experience of patients and families.

## Improving the patient and family experience

In a 2011 Institute for Healthcare Improvement report, Balik et al. described three themes for improving PFE:

1. An integrated system in which efforts to improve quality, safety, and experience are mutually reinforcing.
2. Leadership behavior at all levels (executive, middle, and front-line) demonstrating commitment to creating an environment that nurtures and improves the patient and family experiences.
3. Achieving excellence in experience requires "dynamic, positively reinforcing actions" [26].

   Efforts to enhance PFE need to be systematic, wide-spread, and involve changes in culture, processes, and accountability. The culture of an organization is highly ingrained and defines the manner in which an organization operates. Any strategy that does not take into account the culture of an organization will not succeed, yet culture change is possibly the most challenging component of any improvement effort [27]. In leveraging the strengths of the culture while addressing opportunities to refine the culture, leaders can affect true change. Leaders must set the expectation of high performance in patient experience [34]. Leadership that values healthcare employees and inspires a workforce that embraces a culture of excellence are fundamental to developing a superior PFE milieu [28].

### Human-centered design/design thinking

To attain maximum value in care, innovation targeting patient/family experience must enhance patient/family engagement, improve outcomes, and embrace safety while lowering costs. That being said, innovations in patient/family

experience need to originate from a place outside traditional improvement science methodology and take advantage of the voice of the ultimate user. Innovation of this sort is best approached through a process called human-centered design or design thinking. Design thinking is an approach that is well suited to PFE innovation as it is powered by a deep user understanding, thorough knowledge of what people want and need, and is achieved through direct observation of users in their daily lives [29]. Empathy is a cornerstone of design thinking.

Design thinking involves a system of three overlapping spaces:

1. Inspiration—frame the problem that motivates people to search for solutions. Observe your user in their daily lives; empathize with them.
2. Ideation—distill themes and insights from the observations made during the discovery/inspiration phase and come up with as many ideas as possible.
3. Implementation—turn the best ideas generated during ideation into concrete, fully conceived plans with prototypes which allows the designers to test and refine them. Start a pilot program, followed by plans to scale.

Design thinking results in real-world solutions that produce better outcomes for the people they serve [29]. Areas in healthcare where innovation will lead to enhanced patient/family experience include:

### *Development of centers of excellence with multidisciplinary teams caring for patients*

The best safety, clinical outcomes and experience are achieved by comprehensive, disease-specific interdisciplinary teams that deliver consistent outcomes over time [3]. With diverse resources, these teams have the ability to focus on the needs of the patient/family, not just on the needs of the institution. One example is the MD Anderson Cancer Center's Head and Neck program which has developed an integrated system. Caregivers, testing, and treatment are all available in a single facility, thereby increasing access, experience, and efficiency, thus reducing cost [30]. A team-based approach enhances communication, which is a domain of the HCAHPS experience metric. In order to form a center of excellence in a cost-efficient way, hospitals that were competitors will need to collaborate and pool resources. Hospitals that adopt principles of human-centered design to innovate around experience and push the envelope in the development of Centers of Excellence will be uniquely positioned to excel in the provision of high value health care.

### *Enhanced employee engagement*

Engaged and experienced providers at all levels improve patient outcomes, experience, and cost. Engaged providers are more likely to be retained, decreasing costs across the system. In a 2014 survey of the Patient Experience Officers, hospitals that reported physician engagement as a barrier to improved patient and family experience had significantly lower patient experience scores when compared to those hospitals that did not identify

physicians as a barrier [31]. Holding physicians and hospitals accountable for patient experience builds trust with the healthcare system from the perspective of the patient, protects against the withholding of vital services, and promotes collaborative practice between clinicians and patients [12]. In turn, hospitals that build a collaborative culture have higher experience scores, highlighting the importance of engagement and teamwork in the healthcare setting [31]. There are many ongoing efforts to better engage physicians in experience. In 2016, Boissey et al. described improvement around CGCAHPs scores for physician communication and respect after an 8-h physician-directed curriculum including interactive didactics, skill demonstrations, and practice sessions using a relationship-centered model. This training also resulted in significant improvement in empathy and provider burnout, including all measures of emotional exhaustion, depersonalization, and personal accomplishment [32]. Similarly, empathy training may be the key to engaging physicians in experience initiatives. A study in 2013 found that physician empathy is directly correlated with patient experience and that empathic providers lowered patients' anxiety and distress, ultimately delivering better clinical outcomes [33].

### *Embracing transparency, consumerism, and technology*

Hospitals must embrace the growing culture of technology, consumerism, and transparency. As previously mentioned, more and more consumers are "shopping" for medical services, comparing prices and patient ratings before committing to a hospital for non-emergent care. Medicare Hospital Compare has become a powerful tool for patients as they chose the provider best suited for them, in terms of cost, outcomes, and physician characteristics. Other hospitals have gone farther and have made all of their provider's experience data, including HCAHPS scores and comments, available online [34, 35]. Such transparency will only continue to grow as it provides an impetus for hospitals and providers to improve outcomes, experience, and reputation. Researchers are investigating social media platforms to obtain patient and family experience data that may not be reflected in formal surveys. Developers are looking at Twitter, Yelp, Facebook, and other social media sites to better understand user observations and to gain additional insights into patient/family perceptions of care [36, 37].

Technology is also being used to enhance access to care and to fully engage the patient and family in their care. Online list-serves and electronic patient and family advisory councils provide a means for feedback without requiring travel to the institution for conventional meetings. Telemedicine also provides opportunities for providers to reach patients at a distance and new smartphone apps allow timely virtual physician consultations without the cost of travel to patients. Online patient portals provide immediate access to laboratory results, imaging results, and a means to communicate with providers via email. At the hospital bedside, tablets are being used to enhance communication with nurses. Providers are discovering new ways to obtain data and ways to use it to improve scores. In 2015, Indovina et al. described a system in which patients were asked to provide

feedback on physician communication and empathy daily. Physicians were then presented with this data and provided one-on-one coaching on value-based purchasing, the importance of PFE, and on etiquette-based medicine to improve experience scores [13, 38]. Using technology, hospital leaders, clinicians, and policy makers will continue to refine experience measurements to capture real-time patient experience data thereby gathering feedback that allows for more active improvement of current practices. Scoring and interpretation of metrics will also continue to be refined to ensure that we are truly incorporating the needs of our consumers [12].

### *Define excellence in PFE and develop best practices*

There is no recipe guaranteed to yield the ideal patient/family experience. Future work will need to use human-centered design to continue to identify components of an excellent experience, to prototype and refine that experience, and to optimize our understanding of how to assure that experience with every encounter. This approach when deployed in the setting of strong leadership and an engaged workforce, and coupled with known best practices (Table 3), will more rapidly advance and improve PFE [4, 11, 26, 28, 39, 40].

## The pediatric experience

The obvious difference when considering experience in pediatric populations is the fact that the care involves not only the patient but also the family, where "Patient Experience" must become the "Patient and Family Experience." In order to care for a child and attain the best possible outcomes, engagement with both the child and their caregivers is imperative. Understanding what patients and their families want and value is an integral part of the experience of care for pediatric patients [41].

In 2015, the American Academy of Pediatrics released a report describing a number of important aspects of family-centered care (Table 4) [42].

Recognizing that pediatrics is a unique population, Child CAHPs was introduced in 2015 with the purpose of measuring the patient-centeredness of hospital care for pediatric patients (ages 17 and younger). As the family unit is absolutely essential in any discussion of pediatric experience, these themes are imbued throughout the Child CAHPS. This tool is used by most major children's hospitals and, like Adult HCAHPS, focuses on aspects of inpatient care that are important for patients and their parents. The pediatric survey contains 62 items that assess the following themes: communication with parents, communication with children, attention to safety and comfort, hospital environment, and global rating [43]. Information is obtained from parents, who act as a proxy for their child in answering questions. While Medicare has instituted value-based reimbursement for experience scores for

**Table 3. Known best practices**

| Known best practices |
|---|
| 1.Seeking the voice of the patient |
| ○ Patient and family advisory committees |
| ○ Patient and family advocates |
| ○ Using human-centered design for processes, procedures, and physical space |
| 2.Developing a welcoming physical space |
| ○ Wayfinding and signage |
| ○ Culturally sensitive |
| ○ Consistent |
| 3.Creating a culture that focuses on EXPERIENCE |
| ○ Inspiring leadership the values the patient and family experience |
| ○ Clearly expressed mission, vision, and values within the organization |
| ○ Entire TEAM with interpersonal training |
| 4.Structuring care around patient experience |
| ○ Access to care (results, meds) |
| ○ Prompt greetings/initiation of care |
| ○ Timely updates of delays, next steps |
| ○ Rounding by staff and leadership |
| ○ Handoffs of care at the bedside |
| ○ Visible care plan and CARE TEAM |
| ○ Post visit follow-up to assist with aftercare and next steps |
| 5.Key moments of truth |
| ○ Identifying barriers to excellent experience |
| ○ Identifying communication lapses, mistakes, and inconveniences |
| ○ Strong service recovery |

**Table 4. Important aspects of family-centered care**

| Important aspects of family-centered care |
|---|
| Family presence |
| Cultural sensitivity |
| Communication |
| Shared decision making |
| Coordination with the medical home |
| Discharge planning and instructions |

adult medicine, Medicaid has not yet done so. It is anticipated, however, that the principles of VBP will inform Medicaid payment models in the near future.

## Conclusions

With increasing demand that health care systems focus on providing higher value health care, defining value itself becomes more and more important. Consumers today have more information available at their fingertips and are more interested in high quality care at low cost than ever before. They come prepared to be engaged, active, participants in their care; care that they presume will be safe and effective. When patients detect disconnection between the safety, outcomes, or engagement that they desire, they perceive poor value care. As such, any discussion of value in health care must include the perceptions of our customers; their experience is the only experience that matters. We know also that using the principles of patient- and family-centered care has profound impacts on clinical outcomes, safety, and cost. The power of the patient and family experience cannot be underestimated.

Governing bodies have already recognized this power, incorporating experience scores into value-based purchasing measures that affect reimbursement rates. It is anticipated that this influence will only grow as years pass. In order to remain competitive in the market, hospital systems will need to focus on PFE, the common denominator in all components of the value equation. Those hospitals that use human-centered design to implement changes will be the most effective.

$$\text{Value} = \text{Quality}\ (\text{EXPERIENCE} + \text{Clinical Outcomes} + \text{Safety})/\text{Cost}$$

## Compliance with Ethical Standards

**Conflict of Interest**

Patricia Chambers, Lisa Benz, and Anne Boat declare that they have no conflict of interest.

**Human and Animal Rights and Informed Consent**

This article does not contain any studies with human or animal subjects performed by any of the authors.

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