

The Patient Experience: An Essential Component of High-Value Care and Service

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"We cannot direct the wind but we can adjust the sails."

—Author Unknown

Abbreviations

AAIM	Alliance for Academic Internal Medicine	HCAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems
ACP	American College of Physicians	HRQL	Health-related quality of life
AHRQ	Agency for Healthcare Research and Quality	HVC	High-value care
ARRA	American Recovery and Reinvestment Act	NCCN	National Comprehensive Cancer Network
CAHPS	Consumer Assessment of Healthcare Providers and Systems	PCORI	Patient-Centered Outcomes Research Institute
CER	Comparative effectiveness research	PRO	Patient-reported outcomes
FACIT	Functional Assessment of Chronic Illness Therapy	PROMIS®	Patient Reported Outcomes Measurement Information System
		PROMS	Patient Reported Outcome Measures
		SPORT	Spine Patient Outcomes Research Trial

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By the year 2020, healthcare expenditures are projected to reach nearly 20% of the gross domestic product, a spending rate described as highly unsustainable by economists. Approximately 30% of healthcare costs (over \$750 billion annually) has been identified as wasteful spending that if eliminated would not negatively affect care quality [1]. Examples of waste include preventable hospitalization and rehospitalization, overuse and misuse of diagnostic testing, and excessive use of emergency department services [2]. A myriad of factors are influencing rising healthcare costs, including the aging population, novel devices, drugs, tests, and procedures. However, healthcare innovations are

also contributing to improved patient outcomes; thus evaluating the value of healthcare services is of great importance and necessary for reducing extraneous healthcare spending [3].

For decades, efforts to enhance quality and safety practices and slow the rate of increasing healthcare costs have been undertaken. Due to the exorbitant spending projections, scholars, organizations, and practitioners have endeavored to shift healthcare reform efforts from a fee-for-service model to one that places emphasis on the delivery of high-value care. Value-based health care is a reform effort that aims to control unnecessary healthcare expenditures by focusing on the value of healthcare interventions and services determined by evaluating the costs in light of benefits and risks while considering quality care outcomes prioritized by patients [4]. Screening protocols, procedures, and interventions are now being chosen or disregarded based on their ability to produce good value (medical benefits commensurate with costs) based upon patient preferences [4]. An intervention is deemed high value when the health benefits justify the costs. The higher the benefit, the more justifiable the cost of the intervention that delivers that benefit. High-cost interventions in which the net benefit outweighs the costs could therefore be considered a good value. Conversely, low-cost interventions that provide little to no net benefits are considered to have low value, in spite of the low price tag [3]. Although the cost of care is important, value-based healthcare delivery is organized around the patient by aiming to meet a set of defined patient needs [5]. In short, the objective of high-value care is to improve health outcomes that are important to patients in a cost-effective and efficient manner. This chapter provides an overview of high-value care, reviews the patient's role in value-based care, and outlines the integral role of patient-reported outcomes (PROs) while highlighting specific tools for outcome assessment.

What Is High-Value Care?

Considerations of restructuring into a value-based healthcare system began with Porter and Kaplan's pioneering work at Harvard Business School, and

called for an overarching strategy to reduce healthcare costs by improving value for patients [6]. Within their seminal works, the authors defined value as patient outcomes relative to the amount of money spent [7–10]. Since Porter and Kaplan's initial call for systematic change, many healthcare organizations and national institutes have begun to support value-based initiatives and are in the process of developing and implementing plans for restructuring healthcare organizations and care processes—the ultimate goal being a reconfiguration of the US healthcare delivery system to reduce costs while simultaneously enhancing quality and efficiency.

Growing support for value-based health care is evidenced by the American College of Physicians (ACP) High-value Care (HVC) initiative, a broad program that aims to enhance physicians' ability to provide optimal patient care while simultaneously reducing unnecessary healthcare costs. The goals associated with the HVC initiative involve providing recommendations to clinicians regarding best available practice, to notify clinicians when evidence is lacking, and to assist clinicians in providing the best possible health care [11], including development and dissemination of condition-specific recommendations for high-value diagnostic services [12]. Increasingly, medical professionals are taking on more responsibility to reduce healthcare costs by becoming cost-conscious and decreasing unnecessary interventions that provide little to no benefit. The need for training in value-based care is further evidenced by a recent proposal to include medical resident training on practicing high-value, cost-conscious care as a seventh core competency for physicians by the Accreditation Council for Graduate Medical Education [2]. Likewise, in a joint endeavor, the ACP and the Alliance for Academic Internal Medicine (AAIM) developed an High-value care (HVC) Curriculum, which aims to help internal medicine residents in providing value patient care by teaching them how to identify system-level opportunities to reduce wasted costs and improve patient outcomes. In addition to learning how to balance benefits with potential harms and costs, medical residents actively learn methods of practicing evidence-based shared decision making with patients [13].

Further, the American Recovery and Reinvestment Act of 2009 (ARRA) allocated over \$1 billion to support comparative effectiveness research (CER), defined by the Institute of Medicine as "... the generation and synthesis of evidence that compares the benefits and harms of alternative methods to prevent, diagnose, treat, and monitor a clinical condition, or to improve the delivery of care." The goal of CER is to promote informed decision making by consumers, clinicians, purchasers, and policy makers to improve healthcare delivery [14].

In order to fully comprehend value-based care, one must first understand the value equation. The *value* in high-value care is defined as the following: value equals quality over cost or $V=Q/C$ [15]. *Cost* (the denominator) refers to the economic cost over the full cycle of care for a medical condition, not simply the cost of individual services [9, 15]. When conducting value and/or cost assessments, health organizations and providers must consider any and all downstream costs (e.g., subsequent testing, treatment, follow-up, conditions due to treatment complications) in the equation [3, 4]. *Quality* (the numerator) in the equation represents outcomes of importance to patients (e.g., health status, care cycle and recovery, health sustainability).

Porter and Kaplan outline a six-component strategy for the effective implementation of a value-based healthcare system: (1) organize into integrated practice units; (2) assess outcomes and costs for every patient; (3) bundle payments for care cycles; (4) integrate healthcare delivery systems; (5) expand geographic reach; and (6) develop an information technology platform to enable and support the above. This chapter focuses on component two as it relates to the scope of this chapter—outcomes of importance from the patient's perspective (for further information on the other five components, see [16]).

Measurement of outcomes and costs is essential to improving value; without these data, clinicians do not have the information required to validate choices, guide advancement, learn from others, or encourage collaboration and change [5]. To date, our healthcare system does not measure outcomes and costs by medical condition for individual patients. Instead, outcomes are assessed in

terms of process measures (e.g., emergency department visits, hospital admissions, readmission rates, mortality rates), safety measures (e.g., medication errors, central line infection rates, postoperative complications), and patient-reported satisfaction [15, 17]. Current standards for outcome assessment cover little breadth in terms of the outcomes that are actually important to patients. To enhance value, outcome measurement must include health circumstances identified by patients as most relevant to their quality of life [9]. While the above is important when investigating organizational process outcomes, in order to assess the true value of health care, clinicians must gain insight into the outcomes that are of concern to patients [18].

This is why one of the most emphasized strategies for implementing a value-based care model centers on the measurement of health outcomes and costs for each patient over the full cycle of care. Value-based initiatives support outcome assessment by medical condition rather than by intervention or specialty. In 2010, Porter recommended a three-tier hierarchy for assessing health outcomes of concern to patients. The hierarchy tiers include health status achieved, recovery process, and health sustainability [17]. The first level of recommended outcomes include health status achieved that involves mortality rates and functional status, which are top concerns for patients. The second outcome tier refers to the cycle of care and recovery, which includes the level of discomfort during treatment, diagnostic errors, delays in the treatment process, duration of hospital stay, treatment-related discomfort, complications, adverse events, and the time required to resume normal activities, including work. The third tier relates to the sustainability of health including the nature of recurrences, level of function maintained, and long-term consequences of therapy (e.g., care-induced illnesses). For further details on the three-tier outcome hierarchy, see Porter [9].

Ideally, patient outcomes will be measured and publicly reported. Public reporting of outcomes provides a level of transparency not currently available which will benefit patients and providers [19]. The publication of condition-specific outcomes enables patients to become

informed healthcare consumers armed with choice in deciding a provider, but it also increases pressure on providers to adopt best practices and improve care practices based on what actually matters to patients. The standardization of outcome measures by condition will enable comparisons to be made across providers and organizations which will then stimulate improvements in practice and patient outcomes on both a national and global scale [16]. Efforts to develop, standardize, and distribute efficient outcome measures are currently under way and have made great progress, and will be highlighted later in this chapter.

In its current state, our healthcare system is unable to assess condition-specific costs for each patient for a full cycle of care. Healthcare organizations are currently reimbursed on a fee-for-service basis and are department based rather than patient or condition based. Moreover, healthcare accounting systems based on overall department budgeting are unable to provide accurate estimates of service costs on a patient or even condition level [16]. To ascertain value, it is recommended that healthcare providers calculate costs based on the medical condition over the full cycle of care. Tracking expenses incurred over the full care cycle involve recognizing all resources utilized to care for the patient (e.g., equipment, facilities, personnel), capacity costs of supplying resources, and care-associated support costs (e.g., administration, IT). Only then can the actual cost of condition-specific care be compared with quality (patient outcomes) to determine the value of healthcare services [16].

Research conducted within the Spine Center at Dartmouth-Hitchcock is a good example of value-based health care. Dartmouth's Spine Center conducted a 5-year, multisite study, Spine Patient Outcomes Research Trial (SPORT), to compare the three most common back conditions (i.e., intervertebral disc herniation, spinal stenosis, degenerative spondylolisthesis) and PROs to gain insight into whether surgery produces better outcomes over nonsurgical therapies (i.e., physical therapy, medication, other noninvasive therapies). Results of the trial in intervertebral disc

herniation patients revealed that both surgical and nonsurgical groups improved posttreatment; however, patients who received a discectomy recovered more quickly [20]. Results of the spinal stenosis trial uncovered that surgical intervention resulted in better pain and function PROs than nonsurgical therapies [21]. Likewise, the surgical patients in the degenerative spondylolisthesis trial reported greater improvements in pain, function, and disability than those receiving nonsurgical therapies [22]. For all three conditions, the results of a 4-year follow-up study showed that patients maintained the reported gains from surgical intervention 4 years after surgery [20, 22, 23]. Further cost-benefit analyses of longitudinal PRO data on productivity loss, use of resources, and health-related quality of life (HRQL) revealed that when assessed over 4 years, surgery provides good value for patients in the three diagnostic groups [24]. Currently, the Spine Center at Dartmouth-Hitchcock implements these principles in the practice of spinal care, by conducting detailed intake assessment that incorporates PROs and visual decision aids, and engages in shared decision making with their patients to develop a personalized plan of care in light of patient priorities to determine whether patients are more likely to benefit from nonsurgical therapies or surgery [25].

What Is the Patient's Role in High-Value Care?

Many efforts at healthcare reform have focused the structure and design around physicians and institutions; however, in these efforts, the patient was commonly left out. In 2001, the Institute of Medicine's landmark report, *Crossing the Quality Chasm*, presented patient-centered care as a fundamental step towards improving US healthcare quality. Patient-centered care is defined as "care that is respectful and responsive to individual patient preferences, needs, and values" [26]. The report further recommended that patient values should be considered as guides to all clinical decisions. Patient-centered care involves ensuring

that treatment decisions align with the patient's values and preferences. When faced with making a decision among treatment options, patients often experience a state of heightened uncertainty, also known as decisional conflict [27]. The quality of a decision involves the degree in which a patient's decision is congruent with their values and evidence-based knowledge. One way to practice patient-centered care and to enhance the value of health care is to invite patients and family members to actively participate in clinical decision making in ways that reduce decisional conflict and enhance decision quality.

Shared Decision Making

In order to achieve optimal decisions in line with the patient's values and preferences, both providers and patients must engage in a process of shared decision making [28]. Shared decision making involves active collaboration among patients and providers for the development of a mutually agreeable plan of care [27]. To enhance patient participation in shared decision making, patients need more information, such as guidance for personalized care planning and self-management, resources for decision support, and social support from family and peers [29]. When given these resources and opportunities for active participation, the result is often better health outcomes and reduced waste, resulting from increased participation, better treatment adherence, more appropriate use of services, reduced elections for major surgery, more realistic risk perceptions, improved knowledge and understanding, enhanced self-management and coping skills, reduced decisional conflict, and greater match between chosen treatments and patient values and priorities [27, 29, 30]. In fact, shared decision making was investigated in the context of elective surgery—the results revealed that shared decision making improves patient decisions to undergo elective surgery and helps reduce decisional conflict and overuse of surgical care [27]. While the use of shared decision making in elective surgery appears promising, future research is

needed to obtain more information regarding the impact on surgical utilization.

Shared decision making has been championed as a successful method of enhancing patient- and family-centered outcomes while reducing waste—and therefore is one method of practicing value-based care [27]. The Agency for Healthcare Research and Quality (AHRQ) and the Patient-Centered Outcomes Research Institute (PCORI) both increased funding for research aimed at developing shared decision making support tools, testing implementation, and reporting results [31, 32]. Likewise, the Informed Medical Decisions Foundation provides resources and guides to help patients understand the importance of engaging in shared decision making and information to assist them in that process [33].

A well-informed patient is one who is both aware of and understands the potential risks and benefits of diagnostic and treatment options. Patients tend to overestimate benefits and underestimate harms when faced with a choice of treatments [34]. These results support the need for providers to actively engage patients in healthcare decisions by clearly communicating the benefits and potential risks associated with different choices. Clinicians, therefore, have an important role in encouraging and inviting patients to actively participate in healthcare decision making; however, this is not necessarily a straightforward task.

Patient understanding is a fundamental component of value-based care. Patient knowledge and understanding require that clinicians engage patients in direct discussions of diagnosis, prognosis, treatment options, and end-of-life care preferences (e.g., palliative, hospice care) [35]. In order to educate patients and engage them in shared decision making, providers must be able to effectively communicate with their patients. To implement value-based care by engaging patients in shared decision making, physicians must be effective at not only assessing risks, but also communicating those risks to patients in an intelligible manner. However, physician competencies in communication skills and risk assessment have been described as poor and thus require training

to improve their skills in communicating numerical information to patients which is necessary if providers are to effectively discuss risks and benefits of different treatment options. Patient perspectives and input should be included in efforts aimed at enhancing provider communication skills, especially the skills needed to intelligibly discuss risk. Inclusion of patient voices in these efforts will reinforce the central role of the patient in creating value. In value-based health care, medical decision making is inherent to value, and patient understanding of risks versus benefits is essential in these efforts [35].

Decision Aids

Decision aids are useful tools that aid physicians in communicating objective information about treatment options, ensuring that the patient understands that a decision must be made, and providing the patient opportunities to make decisions about their care, if desired [36]. Decision aids are commonly used when more than one option for screening or treatment exists [28]. In addition to helping doctors discuss important information, decision aids are also used to help educate patients by informing them of the risks and benefits of treatment options and providing them with tailored evidence to consider in light of their particular condition. Sometimes, decision aids include a section aimed at clarifying patient values, which benefits both patients and providers when discussing and deciding upon the most appropriate options based on patient preferences in light of evidence-based knowledge [27]. Decision aids can be delivered through different modalities (i.e., video, online, paper), and are used to enhance patient understanding of treatment options and the potential outcomes and to further assist patients in developing and discussing educated preferences with their clinicians.

Like shared decision making, decision aids provide many benefits including improvements in patient-provider communication and collaboration, information exchange (i.e., risks, benefits, options), treatment adherence, patient satisfaction,

and ultimately closing the gap between patient values and choices [36–38]. When outcome probabilities are included in decision aids (particularly when presented quantitatively) patients have more accurate perceptions of risk [38].

Decision aids have received support among surgeons, although there has been minimal progress towards incorporating decision aids into standards of care. Despite the lack of nationwide progress for integrating decision aids into health-care delivery, a few research hospitals are leading the way [36]. One example is the Spine Center and Adult Reconstruction division of the Department of Orthopaedics at Dartmouth-Hitchcock Medical Center. Together, this team is working with the Center for Shared Decision-Making to implement the use of shared decision making tools into standard care by providing orthopaedic patients opportunities to engage in informed choice by encouraging them to borrow a DVD and take home a symptom-rating worksheet. The worksheet asks patients questions about their preferences, values, and decisional conflict to aid them in choosing the most appropriate treatment option [39]. Decision aids, like those utilized by Dartmouth's Orthopaedics department, provide a structure for discussing the benefits and risks of treatment options in light of patient priorities and values. Use of decision aids provides patients a voice by enabling them to become informed participants when choosing care options that provide optimal value. In addition to decision aids, supportive services should be available to aid patients and families when communicating with clinicians about their preferences and values while they are learning about, processing, and deciding among treatment options [28]. Only through communication and understanding of evidence-based knowledge can patients have realistic expectations regarding their healthcare options.

Barriers to Shared Decision Making and Value-Based Care

Despite the vast benefits and avenues for enhancing value in health, there are barriers to shared

decision making and barriers to value-based care implementation efforts for both clinicians and patients. An investigation into clinician readiness to openly discuss high-value care during patient and family consultations revealed that although physicians held favorable views of high-value care, they commonly chose to avoid explicit references to value in their interactions with patients [40]. Likewise, while evidence suggests that most patients are open to participating in healthcare decision making [27, 29], some groups may be less open to the idea. For example, disadvantaged groups and older adults are less likely than young educated adults to report wanting an active role in shared decision making; however, many of the former claim that they would like the opportunity to learn about choices from their doctors [29]. On the other hand, evidence suggests that when patients know that they have treatment options, most want to engage with their physicians to make an optimal choice [28].

Although open communication and transparency regarding a need to weigh benefits in light of potential costs are standard recommendations for implementing value-based care, a qualitative investigation into patient thoughts on discussing cost with healthcare providers as part of making treatment choices suggests that these conversations may be more difficult than anticipated. Results from a large focus group study revealed that insured patients were resistant to the idea of considering costs when deciding among similar treatment or diagnostic options. Analysis of the focus group data uncovered four barriers to patients considering cost when making healthcare decisions: preference for no risk versus minimal risk, assumptions that cost is indicative of quality, a belief that choosing a more expensive option is a way to get back at insurance companies, and misperceptions that rising healthcare costs can be reduced through federal budgeting rather than individual action [41].

The results of the focus group study are at odds with numerous reports of the positive outcomes associated with shared decision making. One potential reason for this discrepancy is that discussing hypothetical situations about cost consid-

erations when making healthcare decisions may have heightened anxiety, especially in light of the pervasive rhetoric concerning healthcare rationing. Research into patient perspectives might produce different results if interviews are conducted following a clinical encounter in which the provider incorporated cost discussions. More qualitative research is needed to investigate patient perceptions of value-based healthcare initiatives and practices. Qualitative methods are a useful approach for learning about patient preferences to aid cost-reduction efforts and enhance the value of care based on patients' lived experiences that influence outcome priorities [42]. Insights gained through qualitative studies will aid researchers, clinicians, and policy makers in developing the most appropriate decision aids, communication training for medical practitioners, and protocols for sharing information regarding risks and benefits that are based upon patient values. Moreover, public perceptions concerning cost considerations in healthcare decision making must undergo a significant shift for both patients and providers, in order to set the stage for informed patient-provider value-based decision making in light of risks, benefits, and patient priorities.

How Do We Measure Quality?

Armed with information and opportunities for open dialogue concerning health decisions, patients can become active participants in their own health management ensuring that choices made are in line with their preferences and priorities and thus obtain value in health care. As previously discussed, a key component of high-value health care is patient perspectives of the quality of healthcare practice and delivery [43]. Value means that the medical benefits or outcomes (quality) are commensurate with economic costs. While qualitative methods are important for designing and aiding in the implementation of value-based care practices, it is not a reasonable approach for assessing, public reporting, and comparing quality on a national scale. As previously discussed, assessment of patient outcomes is vital to the practice of high-value care.

In order to achieve high value, the outcomes assessed must represent those prioritized by patients [9], but how do we measure quality?

Patient-Reported Outcomes

Provision of patient-centered care promotes low cost and high-value care [44]. Patient-centered care is associated with reduced healthcare utilization [45], fewer hospitalizations and readmissions [46], fewer diagnostic tests and specialty referrals [47], and reduced costs. Thus, measurement and public reporting of PROs is regarded as a necessary means for promoting and enhancing patient-centered care by advancing accountability and quality endeavors towards care that is truly centered around its patients [48]. In order to extend assessment of patient outcomes beyond survival, clinical efficacy, and adverse events, we must assess PROs to determine the impact of the disease and treatment upon patient function and overall well-being [49].

PROs are representations of how patients feel and/or their functional abilities within the context

of their own health and daily life. PROs include self-report of symptoms, functional status, and more general perceptions of general health and well-being. Common PRO domains include health-related quality of life, functional status, symptoms and symptom burden, and experience of care. For an overview of PRO characteristics, see Fig. 7.1 [50]. PROs can be used in a variety of ways to promote value in health, including, but not limited to, aiding patients and providers in making informed healthcare decisions, monitoring outcomes and the progress of care, enhancing healthcare service quality, tracking and reporting performance of healthcare delivery systems, and for use when developing policies for health service reimbursement and coverage [50].

PROs are tools that enable the elicitation, collection, and assessment of PRO information. A PRO measure, referred to by some as PROM, is “any standardized or structured questionnaire regarding the status of a patient’s health condition, health behavior, or experience with health care that comes directly from the patient” [50]. PRO measures are standardized tools—developed through qualitative methods to identify top

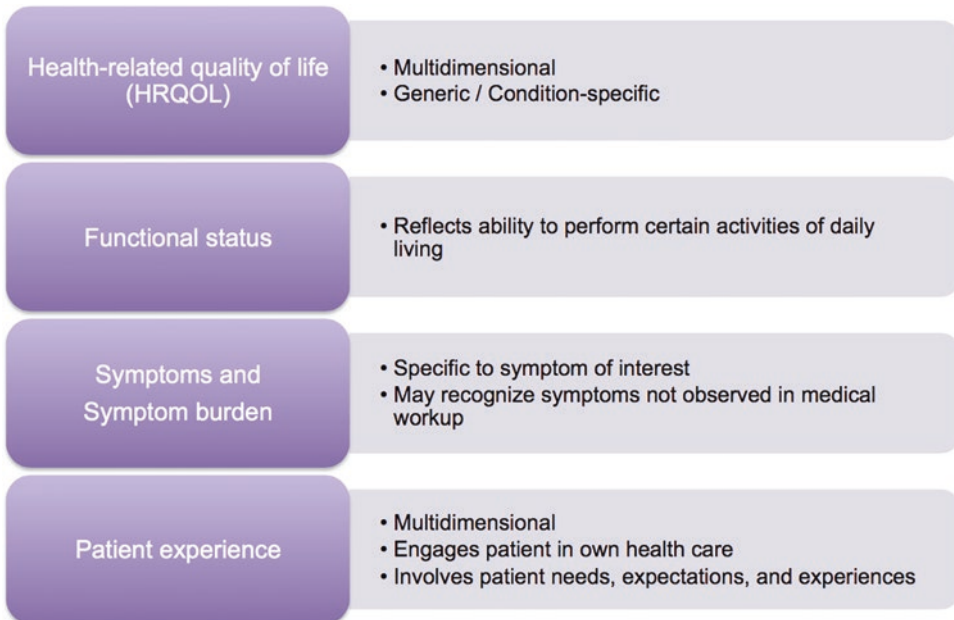


Fig. 7.1 Characteristics of patient-reported outcomes

patient concerns—that allow comparison of quantitative data across patient groups and/or providers [50]. The use of PRO measures has been described as critical to enhance understanding of how treatments impact patient functioning and well-being from the perspective of patients themselves [49]. They show immense promise for enhancing value in health by strengthening supportive care, improving symptom control, and enhancing the quality of healthcare delivery [51]. Moreover, implementation and discussion of actual patient reports during clinic visits can help facilitate shared decision making, resulting in improved patient satisfaction with provider communication, particularly regarding emotional concerns [51, 52].

Health-related quality of life (HRQL) measures are multidimensional and commonly encompass the physical, emotional, and social well-being associated with illness and/or treatment [50]. The Patient Reported Outcomes Measurement Information System (PROMIS[®]) is a good example of an HRQL measurement tool that provides patient-reported health status measures for physical, mental, and social well-being [53]. PROMIS tools are available for use across various conditions and chronic diseases and in the general population. Clinicians can use PROMIS measures to understand how treatments affect patient function and the symptoms they experience. Such information is useful for enhancing patient-provider communication, informing treatment plan design, and improving chronic illness management [53]. Neuro-QOL is another HRQL measurement system that captures different areas of functioning and well-being in adults and children with neurologic diseases [54]. Neither PROMIS nor Neuro-QOL specifies a disease within the item phrasing, making possible a comparison across conditions [54, 55]. In order to assess the value of healthcare services, patient HRQL must be included in the calculation.

Functional status is included in Porter's three-tier outcome hierarchy. Functional status measures assess the patient's ability to perform basic and advanced activities of daily living.

For example, functional status could include cognitive function, physical function, and sexual function [50].

Symptoms and symptom burden are also important outcome measures for assessing value. Symptom assessment should be conducted prior to beginning treatment and should be continually assessed throughout recovery to determine treatment effectiveness. Patient symptoms commonly occur in clusters rather than in isolation. Symptom burden is a concept that refers to the impact of multiple symptoms on the patient, encompassing both the severity of symptoms and the impact of the symptoms from the patient's perspective [56]. For example, the PROMIS Pain Interference is a highly reliable and valid measure that enables quantification of the impact of pain on functioning that can be used across conditions [57].

Likewise, the Functional Assessment of Chronic Illness Therapy (FACIT)-Fatigue questionnaire can be used to accurately measure symptoms and symptom burden. The FACIT-F is not condition specific, and therefore can be used for comparisons between a variety of conditions [58, 59]. There are, however, disease-specific FACIT questionnaires such as FACIT-Dyspnea, which is a measurement tool that has been specifically tailored to assess dyspnea for chronic obstructive pulmonary disease [60]. Additional examples of disease-focused symptom assessments tools can be obtained from the National Comprehensive Cancer Network (NCCN), which catalogues disease-specific symptom indexes for various types of cancer. In collaboration with the NCCN, Cella and colleagues addressed the need for brief and clinically relevant measures by creating a series of 11 disease-specific symptom indexes (bladder, brain, breast, colorectal, head and neck, hepatobiliary, kidney, lung, lymphoma, ovarian, prostate) that reflect the highest priority symptoms and concerns of patients [61, 62]. While HRQL, functional status, and symptom PROs are necessary to assess the quality of health care, the patient experience is another type of PRO that must be included as a measure of quality in high-value calculations.

Patient Experience of Care

Patient ratings of healthcare experiences are central to the provision and promotion of patient-centered care, which in turn enhances the value of care. Patient experience involves the perceived needs, care expectations, and actual experience of care received [63–67]. In the past, patient experience and healthcare quality were assessed through patient satisfaction PROMs. Patient satisfaction is a construct that includes multiple dimensions such as evaluations of patient-provider communication, level of trust or confidence in physicians, treatment affordability, service availability, quality-of-care facilities, and satisfaction with treatment explanations and medications [68, 69]. However, in recent years, the construct of patient satisfaction has been criticized for its lack of clarity in how it is defined and its basis upon subjective patient experiences, which are largely influenced by patient care preferences and expectations [43, 70]. Today, patient-reported experience has been distinguished as a more objective measure of patient experience and care quality. Often, patient satisfaction is conflated with patient experience creating confusion between the two; yet the two concepts are distinct [43].

Patient experience is a multidimensional construct that involves patient feedback on what actually happened during the course of care including observable processes and outcomes, objective experiences, and subjective experiences [48]. Patient experience, therefore, involves a range of variables including experiences with scheduling appointments, wait times, facility cleanliness, provision of information, and interactions with all healthcare staff (e.g., doctors, nurses, assistants, receptionists). Thus, patient experience consists of patient reports of what happened as well as the patient's evaluation or ratings of the experience reports [43, 48].

Patient-reported experience measures are tools used to evaluate the patient-centeredness and quality of health care. They obtain patient feedback on specific care experiences that capture key components of patient-centered care [48, 71]. Experience of care measures yield valuable insights into the

quality of healthcare delivery from the patient's perspective. Moreover, enhanced patient experience is associated with promising outcomes, such as increased adherence, improved clinical outcomes, improved patient safety, enhanced clinical effectiveness, and reduced healthcare utilization [48, 72, 73]. In 1995, AHRQ began the Consumer Assessment of Healthcare Providers and Systems (CAHPS) project, a multi-year initiative to promote and support assessment of patients' healthcare experiences through the development of standardized questionnaires and resources that provide both patients and providers with intelligible and comparative information [74].

Likewise, in a joint effort, Centers for Medicare and Medicaid and AHRQ developed the CAHPS Hospital Survey (i.e., HCAHPS). HCAHPS is the first standardized, publicly reported, national survey of patients' perspectives of hospital care in the US. HCAHPS is a 32-item standardized survey of patient perspectives regarding hospital care that enables objective comparisons of hospital performance on topics important to patients. HCAHPS measures nurse and doctor communication, level of responsiveness to patient needs, pain management, communication regarding new medications, provision of critical information at discharge, patient understanding of care needed following discharge, reports on patient room cleanliness and quietness, likelihood to recommend to friends and family, and an overall hospital rating. HCAHPS survey results are publicly reported four times per year on the Hospital Care website, which allows comparisons across national, regional, and local hospitals. The website also provides HCAHPS Star Ratings that summarize and legibly report results to make it easier for consumers and patients to identify and compare hospitals on healthcare quality and excellence. HCAHPS is among the measures identified in the Patient Protection and Affordable Care Act of 2010 for use in calculating value-based incentive payments in the Hospital Value-Based Purchasing program [75]. Both the CAHPS and HCAHPS are measures that assess patient experience on healthcare dimensions for which patients are the only or best informational source [70].

Measuring Quality in Surgical Care

To date, no validated measurement system of surgical care quality exists. In order to align health care with efforts to improve quality, Mayer and colleagues (2009) suggested a multidimensional approach to assess the quality of surgical care that incorporates measures of both clinical and PROs over the full cycle of care [76]. Clinical pathway measures include structured measures (e.g., ratios of doctors to population served, doctors and nurses per bed, management capabilities), process measures (e.g., preoperative, intraoperative, postoperative facets of care), clinical outcome measures (e.g., procedure-specific outcomes, 30-day mortality, follow-up diagnostics, length of stay, readmission rates), and economic measures (e.g., the amount of cost created per unit of quality-adjusted output). In addition to measuring clinical pathways, the quality framework must include PRO measures. For Mayer and colleagues, these measures include patient-reported treatment outcome measures (e.g., patient reports of treatment outcomes including symptoms and/or functional status), HRQL measures (e.g., general, physical, social/family, emotional, functional well-being), and patient satisfaction/experience (e.g., patient expectations and characteristics, psychosocial determinants, interpersonal aspects, care accessibility and convenience, care environment, care continuity).

While great strides have been made in outlining high-value care principles and priorities, much work is yet to be done. The transformation into a high-value healthcare delivery system will require participation from every stakeholder in the healthcare system. Clinicians must open their minds beyond traditional clinical practice and begin to prioritize the needs and values of patients, which should be a central focus of healthcare delivery regardless. Patients too must be open to change in how health care is delivered and be open to considerations of cost when choosing among screening or treatment options. Patients play a significant role in producing high-value care, which involves engaging in shared decision making with providers, becoming well-informed participants, and taking a more active role in their

health and healthcare planning. Incorporating PRO measures into standard care practice will not only help providers assess the impact of treatments on patients, but it will also give providers an opportunity to facilitate shared decision making and to practice medicine that is centered around the patient. Most of all, the priorities and preferences of patients must be considered when determining the value of screening or treatments, and PRO measures are valuable tools for achieving such goals. In sum, high-value care enables the practice of patient-centered care by ensuring that healthcare decision making and choices are both responsive and considerate of individual patient needs and priorities while simultaneously enhancing efficiency and reducing costs.

References

1. Institute of Medicine. The healthcare imperative: lowering costs and improving outcomes: workshop series summary. Washington, DC: National Academies Press; 2010.
2. Weinberger SE. Providing high-value, cost-conscious care: a critical seventh general competency for physicians. *Ann Intern Med.* 2011;155(6):386–8.
3. Qaseem A, Alguire P, Dallas P, Feinberg LE, Fitzgerald FT, Horwitch C, et al. Appropriate use of screening and diagnostic tests to foster high-value, cost-conscious care. *Ann Intern Med.* 2012;156(2):147–9.
4. Owens DK, Qaseem A, Chou R, Shekelle P. High-value, cost-conscious health care: concepts for clinicians to evaluate the benefits, harms, and costs of medical interventions. *Ann Intern Med.* 2011;154(3):174–80.
5. Porter ME, Pabo EA, Lee TH. Redesigning primary care: a strategic vision to improve value by organizing around patients' needs. *Health Aff.* 2013;32(3):516–25.
6. Institute for Strategy & Competitiveness Harvard Business School. Value-based health care delivery—measuring and managing costs. n.d. <http://www.isc.hbs.edu/about-michael-porter/affiliated-organizations-institutions/pages/vbhcd-initiative.aspx>.
7. Porter ME. A strategy for health care reform—toward a value-based system. *N Engl J Med.* 2009;361(2):109–12.
8. Porter ME, Teisberg EO. Redefining health care: creating value-based competition on results. Boston: Harvard Business School Press; 2006.
9. Porter ME. What is value in health care? *N Engl J Med.* 2010;363(26):2477–81.
10. Kaplan RS, Porter ME. How to solve the cost crisis in health care. *Harv Bus Rev.* 2011;89(9):46–52.

11. American College of Physicians. High value care. 2016. <https://hvc.acponline.org>.
12. Chou R, Qaseem A, Owens DK, Shekelle P. Diagnostic imaging for low back pain: advice for high-value health care from the American College of Physicians. *Ann Intern Med.* 2011;154(3):181–9.
13. American College of Physicians. High value care: curriculum for educators and residents. n.d. <https://hvc.acponline.org/curriculum.html>.
14. Sox HC, Greenfield S. Comparative effectiveness research: a report from the Institute of Medicine. *Ann Intern Med.* 2009;151(3):203–5.
15. Mayo Clinic. A foundation for health care reform legislation: Mayo Clinic's point of view. 2008.
16. Porter ME, Lee TH. The strategy that will fix health care. *Harv Bus Rev.* 2013;91(12):24.
17. Porter ME. Measuring health outcomes: the outcomes hierarchy. *N Engl J Med.* 2010;363:2477–81.
18. Flink M, Hesselink G, Barach P, Öhlen G, Wollersheim H, Pijneborg L, Hansagi H, Vernooij-Dassen M, Olsson M. The key actor: a qualitative study of patient participation in the handover process in Europe. *BMJ Qual Saf.* 2012;1–8. doi:10.1136/bmjqs-2012-001171.
19. Barach P, Lipschultz S. The benefits and hazards of publicly reported quality outcomes. *Prog Pediatr Cardiol.* 2016;45–9. doi:10.1016/j.ppedcard.2016.06.001.
20. Weinstein JN, Lurie JD, Tosteson TD, Tosteson AN, Blood E, Abdu WA, et al. Surgical versus non-operative treatment for lumbar disc herniation: four-year results for the Spine Patient Outcomes Research Trial (SPORT). *Spine.* 2008;33(25):2789.
21. Weinstein JN, Tosteson TD, Lurie JD, Tosteson AN, Blood E, Hanscom B, et al. Surgical versus nonsurgical therapy for lumbar spinal stenosis. *N Engl J Med.* 2008;358(8):794–810.
22. Weinstein JN, Lurie JD, Tosteson TD, Zhao W, Blood EA, Tosteson AN, et al. Surgical compared with nonoperative treatment for lumbar degenerative spondylolisthesis. *J Bone Joint Surg.* 2009;91(6):1295–304.
23. Weinstein JN, Tosteson TD, Lurie JD, Tosteson A, Blood E, Herkowitz H, et al. Surgical versus non-operative treatment for lumbar spinal stenosis four-year results of the Spine Patient Outcomes Research Trial (SPORT). *Spine.* 2010;35(14):1329.
24. Tosteson AN, Tosteson TD, Lurie JD, Abdu W, Herkowitz H, Andersson G, et al. Comparative effectiveness evidence from the spine patient outcomes research trial: Surgical vs. non-operative care for spinal stenosis, degenerative spondylolisthesis and intervertebral disc herniation. *Spine.* 2011;36(24):2061.
25. Bohmer RM. The four habits of high-value health care organizations. *N Engl J Med.* 2011;365(22):2045–7.
26. Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington, DC: National Academy Press; 2001.
27. Boss EF, Mehta N, Nagarajan N, Links A, Benke JR, Berger Z, et al. Shared decision making and choice for elective surgical care a systematic review. *Otolaryngol Head Neck Surg.* 2015;153:405–20. doi:10.1177/0194599815620558.
28. Barry MJ, Edgman-Levitan S. Shared decision making—the pinnacle of patient-centered care. *N Engl J Med.* 2012;366(9):780–1.
29. Coulter A, Collins A. Making shared decision-making a reality. London: King's Fund; 2011.
30. Flink M, Ohlen G, Hansagi H, Barach P, Olsson M. Beliefs and experiences can influence patient participation in handover between primary and secondary care—a qualitative study of patient perspectives. *BMJ Qual Saf.* 2012;1–8. doi:10.1136/bmjqs-2012-001179.
31. Selby JV, Beal AC, Frank L. The Patient-Centered Outcomes Research Institute (PCORI) national priorities for research and initial research agenda. *JAMA.* 2012;307(15):1583–4.
32. Agency for Healthcare Research and Quality. The SHARE Approach. Rockville. 2015 <http://www.ahrq.gov/professionals/education/curriculum-tools/shared-decisionmaking/index.html>.
33. Informed Medical Decisions Foundation. Shared decision making resources. n.d. <http://www.informed-medicaldecisions.org/what-is-shared-decision-making/shared-decision-making-resources/>.
34. Hoffmann TC, Del Mar C. Patients' expectations of the benefits and harms of treatments, screening, and tests: a systematic review. *JAMA Intern Med.* 2015;175(2):274–86.
35. Korenstein D. Patient perception of benefits and harms: the achilles heel of high-value care. *JAMA Intern Med.* 2015;175(2):287–8.
36. Weinstein JN, Clay K, Morgan TS. Informed patient choice: patient-centered valuing of surgical risks and benefits. *Health Aff.* 2007;26(3):726–30.
37. Eden KB, Scariati P, Klein K, Watson L, Remiker M, Hribar M, et al. Mammography decision Aid reduces decisional conflict for women in their forties considering screening. *J Womens Health.* 2015;24(12):1013–20.
38. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev.* 2011;10, CD001431.
39. Weinstein JN, Brown PW, Hanscom B, Walsh T, Nelson EC. Designing an ambulatory clinical practice for outcomes improvement: from vision to reality—the Spine Center at Dartmouth-Hitchcock, year One. *Qual Manag Health Care.* 2000;8(2):1–20.
40. Vegas DB, Levinson W, Norman G, Monteiro S, You JJ. Readiness of hospital-based internists to embrace and discuss high-value care with patients and family members: a single-centre cross-sectional survey study. *CMAJ Open.* 2015;3(4), E382.
41. Sommers R, Goold SD, McGlynn EA, Pearson SD, Danis M. Focus groups highlight that many patients object to clinicians' focusing on costs. *Health Aff.* 2013;32(2):338–46.
42. Hesselink G, Flink M, Olsson M, Barach P, Vernooij-Dassen M, Wollersheim H. Are patients discharged with care? A qualitative study of perceptions and

- experiences of patients, family members and care providers. *BMJ Qual Saf.* 2012;21 Suppl 1:i29–49. doi:10.1136/bmjqs-2012-00116.
43. Ahmed F, Burt J, Roland M. Measuring patient experience: concepts and methods. *Patient.* 2014;7(3):235–41.
 44. Cosgrove DM, Fisher M, Gabow P, Gottlieb G, Halvorson GC, James BC, et al. Ten strategies to lower costs, improve quality, and engage patients: the view from leading health system CEOs. *Health Aff.* 2013;32(2):321–7.
 45. Bertakis KD, Azari R. Patient-centered care is associated with decreased health care utilization. *J Am Board Fam Med.* 2011;24(3):229–39.
 46. Boulding W, Glickman SW, Manary MP, Schulman KA, Staelin R. Relationship between patient satisfaction with inpatient care and hospital readmission within 30 days. *Am J Manag Care.* 2011;17(1):41–8.
 47. Epstein RM, Franks P, Shields CG, Meldrum SC, Miller KN, Campbell TL, et al. Patient-centered communication and diagnostic testing. *Ann Fam Med.* 2005;3(5):415–21.
 48. Price RA, Elliott MN, Zaslavsky AM, Hays RD, Lehrman WG, Rybowski L, et al. Examining the role of patient experience surveys in measuring health care quality. *Med Care Res Rev.* 2014;71(5):522–54.
 49. Acquadro C, Berzon R, Dubois D, Leidy NK, Marquis P, Revicki D, et al. Incorporating the patient's perspective into drug development and communication: an ad hoc task force report of the patient-reported outcomes (PRO) harmonization group meeting at the Food and Drug Administration, February 16, 2001. *Value Health.* 2003;6(5):522–31.
 50. Cella D, Hahn EA, Jensen SE, Butt Z, Nowinski CJ, Rothrock N, et al. Patient-reported outcomes in performance measurement. Research Triangle Park: RTI Press; 2015.
 51. Kotronoulas G, Kearney N, Maguire R, Harrow A, Di Domenico D, Croy S, et al. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J Clin Oncol.* 2014;32(14):1480–501.
 52. Søreide K, Søreide AH. Using patient-reported outcome measures for improved decision-making in patients with gastrointestinal cancer—the last clinical frontier in surgical oncology? *Front Oncol.* 2013;3:157.
 53. Patient Reported Outcomes Measurement Information System. n.d. <http://www.nihpromis.org/>.
 54. Cella D, Lai J-S, Nowinski C, Victorson D, Peterman A, Miller D, et al. Neuro-QOL Brief measures of health-related quality of life for clinical research in neurology. *Neurology.* 2012;78(23):1860–7.
 55. Neuro-QOL. n.d. <http://www.neuroqol.org/Pages/default.aspx>.
 56. Cleeland CS. Symptom burden: multiple symptoms and their impact as patient-reported outcomes. *J Natl Cancer Inst Monogr.* 2007;37:16.
 57. Amtmann D, Cook KF, Jensen MP, Chen W-H, Choi S, Revicki D, et al. Development of a PROMIS item bank to measure pain interference. *Pain.* 2010;150(1):173–82.
 58. Yellen SB, Cella DF, Webster K, Blendowski C, Kaplan E. Measuring fatigue and other anemia-related symptoms with the Functional Assessment of Cancer Therapy (FACT) measurement system. *J Pain Symptom Manage.* 1997;13(2):63–74.
 59. Smith E, Lai J-S, Cella D. Building a measure of fatigue: the functional assessment of Chronic Illness Therapy Fatigue Scale. *Phys Med Rehabil.* 2010;2(5):359–63.
 60. Yount SE, Choi SW, Victorson D, Ruo B, Cella D, Anton S, et al. Brief, valid measures of dyspnea and related functional limitations in chronic obstructive pulmonary disease (COPD). *Value Health.* 2011;14(2):307–15.
 61. Rosenbloom S, Yount S, Yost K, Hampton D, Paul D, Abernethy A, et al. Development and validation of eleven symptom indices to evaluate response to chemotherapy for advanced cancer: measurement compliance with regulatory demands. In: Farquhar I, Summers K, Sorkin A, editors. *The value of innovation: impacts on health, life quality, and regulatory research, Research in human capital and development, vol. 16.* Bingley: Emerald Group Publishing Limited; 2008.
 62. Cella D, Rosenbloom SK, Beaumont JL, Yount SE, Paul D, Hampton D, et al. Development and validation of 11 symptom indexes to evaluate response to chemotherapy for advanced cancer. *J Natl Compr Canc Netw.* 2011;9(3):268–78.
 63. Hall JA, Dornan MC. Meta-analysis of satisfaction with medical care: description of research domain and analysis of overall satisfaction levels. *Soc Sci Med.* 1988;27(6):637–44.
 64. Lewis JR. Patient views on quality care in general practice: literature review. *Soc Sci Med.* 1994;39(5):655–70.
 65. Pascoe GC. Patient satisfaction in primary health care: a literature review and analysis. *Eval Program Plann.* 1983;6(3–4):185–210.
 66. Williams B. Patient satisfaction: a valid concept? *Soc Sci Med.* 1994;38(4):509–16.
 67. Oberst MT. Methodology in behavioral and psychosocial cancer research. Patients' perceptions of care. Measurement of quality and satisfaction. *Cancer.* 1984;53(10 Suppl):2366.
 68. Speight J. Assessing patient satisfaction: concepts, applications, and measurement. *Value Health.* 2005;8(s1):S6–8.
 69. Ware JE, Snyder MK, Wright WR, Davies AR. Defining and measuring patient satisfaction with medical care. *Eval Program Plann.* 1983;6(3):247–63.
 70. Lehrman WG, Friedberg MW. CAHPS surveys: valid and valuable measures of patient experience. *Hastings Cent Rep.* 2015;45(6):3–4.
 71. Luxford K. What does the patient know about quality? *Int J Qual Health Care.* 2012;24(5):439–40. doi:10.1093/intqhc/mzs053.
 72. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open.* 2013;3(1), e001570.

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73. Black N, Varaganum M, Hutchings A. Relationship between patient reported experience (PREMs) and patient reported outcomes (PROMs) in elective surgery. *BMJ Qual Saf.* 2014;23(7):534–42. doi:10.1136/bmjqs-2013-002707.
74. Agency for Healthcare Research and Quality. The CAHPS Program n.d. <https://cahps.ahrq.gov/about-cahps/cahps-program/index.html>.
75. Centers for Medicare and Medicaid Services. HCHAPS: Patients' Perspectives of Care Survey. 2014. <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-instruments/HospitalQualityInits/HospitalHCAHPS.html>.
76. Mayer EK, Chow A, Vale JA, Athanasiou T. Appraising the quality of care in surgery. *World J Surg.* 2009;33(8):1584–93.