

# Concept and Measurement of Pediatric Value



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Publication of this article was supported by the US Department of Health and Human Services and the Agency for Healthcare Research and Quality.

The views expressed in this article are those of the authors and do not necessarily represent the views of the US Department of Health and Human Services or the Agency for Healthcare Research and Quality.

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Received for publication November 1, 2013; accepted March 29, 2014.

## ABSTRACT

In the new health care marketplace, families will be making important decisions concerning choice of health plan, health provider, and even accountable care organizations. Ideally, they would make these decisions using information on health care value, which comprises the relationships between patient/family-centered outcomes (the outputs of health care services) and costs of providing care to achieve these outcomes. Providing information on pediatric value will require new investments in data collection systems that include outcomes

that matter to children and families and costs measured at the level of the child. The analysis of these data must account for the perspective of the user of the information. In the case of families, direct standardization should be used to contrast care in one health care system with another according to the unique characteristics of each family and child.

**KEYWORDS:** health care; outcomes; pediatric; quality; value

**ACADEMIC PEDIATRICS** 2014;14:S33–S38

AS A RESULT of tremendous strides in improving insurance coverage through expansions of Medicaid and the creation of the State Children's Health Insurance Program, child health policy makers have begun shifting their focus from access as a primary concern toward issues related to quality and costs. The Kaiser Family Foundation estimated that 90% of children in 2012 had insurance coverage,<sup>1</sup> and that successful implementation of the Affordable Care Act (ACA) will expand children's access to insurance to levels that approximate universal coverage.

Although access to insurance thus dims as a concern for families and providers, there are several reasons to believe that they are paying more attention to health care costs. Many large employers are considering switching from providing defined health benefits to providing defined contributions for health insurance.<sup>2</sup> The health insurance exchanges created by the ACA tier health plans according to costs to the consumer. Prices for specific health care services are being made transparent and available to the public, which further increases cost sensitivity. At the same time, insurers have already established large price differentials between in-network and out-of-network use.

Families desire more than just cheap health insurance. They want access to health care that keeps their children healthy and restores their children's health as rapidly as possible when illness strikes. If competitive forces are to improve health care, we will need information on not just costs or even quality of care, but perhaps more importantly information on the outputs of health care that matter to families most. Similarly, purchasers in both the public and private sectors want to know the value of the health care that they are obtaining on behalf of families.

Because pediatric value is a relatively new concept, we sought to address the questions of what pediatric value is, how it differs from adult health care value, and how challenges related to its measurement can be overcome.

## CONCEPT OF PEDIATRIC VALUE

Porter's work on health care value has been influential in defining what value is and how to measure it.<sup>3</sup> Porter argues that value is defined by the relationship between patient-centered outcomes (the outputs of health care services) and costs of providing those services. Although clinicians and managers may be interested in the services delivered, their technical quality, and the interpersonal factors involved in service provision, Porter argues that the proper focus of value assessment is on outcomes that matter most to patients—improvements in health status, timeliness of care and recovery, and long-term effects of health services.<sup>4</sup> Patients pay to get better or to prevent disease. Thus, value-driven health care should seek to optimize patients' short- and long-term health status with as much efficiency as possible.

We believe that Porter's conceptualization of health care value is a reasonable starting point for conceptualizing value in pediatrics. However, there are additional considerations for defining pediatric value. These relate to the unique attributes of children's health, such as rapid development and the effects of children's health-related experiences on adult health, and the critical role that families play in setting the future trajectories of children's lives.<sup>5</sup> Furthermore, to optimize decision making in the Porter model, measurement of value must be done with the perspective of the user—the child/family or society—in mind.

Table 1.

Domain (Child or Parent)	Outcome	Measure
1) Recovery from acute exacerbation		
Physiological (Child)	Lung function	- Pulmonary function testing
Signs (Child)	Tachypnea	- Respiratory rate
	Wheezing	- Clinical evaluation of wheezing
		- Self-reported wheezing
Symptoms and Feelings (Child)	Asthma-specific symptoms	- PROMIS Pediatric Asthma Impact*
	Fatigue	- PROMIS Pediatric Fatigue*
	Anxiety	- PROMIS Pediatric Anxiety*
	Depression	- PROMIS Pediatric Depressive Symptoms*
	Stress experiences	- PROMIS Pediatric Psychological Stress Experiences*
		- PROMIS Pediatric Somatic Stress Experiences*
Feelings (Parent)	Positive affect	- PROMIS Pediatric Positive Affect*
	Fatigue	- PROMIS Fatigue*
	Anxiety	- PROMIS Anxiety*
	Depression	- PROMIS Depression*
	Stress experiences	- Perceived Stress Scale†
Functioning (Child)	Positive affect	- NIH Toolbox Positive Affect
	Mobility	- PROMIS Pediatric Mobility*
	Physical activity	- PROMIS Pediatric Physical Activity*
		- Accelerometry
	Sleep	- Actigraphy
Functioning (Parent)	Sleep quality	- Pediatric Sleep Questionnaire‡
	Wakefulness	- PROMIS Sleep-related Disturbance*
General Health (Child)	Global health	- PROMIS Sleep-related Impairment*
General Health (Parent)	Global health	- PROMIS Pediatric Global Health*
		- PROMIS Global Health*
2) Quality of acute exacerbation management		
Timeliness of treatment (child)	Time to treatment for acute exacerbation	- Time from entry to ED to receipt of first treatment
	Time to resolution of acute exacerbation	- Time from entry to ED to resolution of an exacerbation
Timeliness of recovery (child)	Time to return to baseline physical functioning after acute exacerbation	- Repeated assessment of physical functioning* and physical activity* using PROMIS measures
	Time to return to school after acute exacerbation	- Missed school days due to asthma exacerbation
Timeliness of recovery (parent)	Parental time to return to work after acute exacerbation	- Parental missed work days due to asthma exacerbation
(3) Quality of chronic care management		
Effectiveness (child)	Asthma control	- PROMIS Pediatric Asthma Impact*
	Acute exacerbations	- Acute asthma exacerbation rates
		- Time between acute exacerbations
	Emergency department use	- Emergency department utilization
	Hospital admission	- Inpatient or short stay admission rates
	Length of hospital stay	- Asthma admission length of stay
(4) Long-term Outcomes		
Disease Progression (child)	Chronic asthma	- Chronic asthma incidence rates
Friends (child)	Peer relationships	- PROMIS Pediatric Peer Relationships*
Friends (parent)	Loneliness	- PROMIS Social Isolation*
Family (child)	Family relationships	- PROMIS Pediatric Family Belonging*
		- PROMIS Pediatric Family Involvement (child edition) *
Family (parent)	Family relationships	- PROMIS Pediatric Family Involvement (parent edition) *
School (child)	School engagement	- PHP School Engagement§
	Absenteeism	- Annual days missed from school
	Academic performance	- PHP Academic Performance§
		- Grade point average
		- Standardized achievement testing
Work (parent)	Job engagement	- Utrecht Work Engagement Scale
	Absenteeism	- Annual days missed from work
Well-Being (child)	Life satisfaction	- PROMIS Pediatric Life Satisfaction*
	Meaning and purpose	- PROMIS Pediatric Meaning and Purpose*

(Continued)

**Table 1.** Continued

Domain (Child or Parent)	Outcome	Measure
Well-Being (parent)	Life satisfaction Meaning and purpose	- NIH Toolbox Life Satisfaction¶ - NIH Toolbox Meaning and Purpose¶

\*For more information on the measures developed by the NIH's Patient Reported Outcome Measurement Information System (PROMIS) initiative, see <http://www.nihpromis.org>, where detailed descriptions of each measure and supporting references can be found. These measures are freely available as fixed-length forms or computerized adaptive tests.

†Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. *Journal of Health and Social Behavior*. 1983; 24(4): 385–396.

‡Chervin RD, Hedger K, Dillon JE, Pituch KJ. Pediatric sleep questionnaire (PSQ): validity and reliability of scales for sleep-disordered breathing, snoring, sleepiness, and behavioral problems. *Sleep Med*. 2000;1(1):21-32.

§Bevans KB, Riley AW, Forrest CB. Development of the healthy pathways child-report scales. *Quality of Life Research*. 2010;19(8):1195–1214.

||Schaufeli WB, Salanova M, González-Romá V, Bakker AB. The measurement of Engagement and burnout: a confirmative analytic approach. *Journal of Happiness Studies*. 2002;3:71-92.

¶For more information on NIH Toolbox measures, see: <http://www.nihtoolbox.org>. Like the PROMIS, Toolbox measures are freely available for users.

## FAMILY CONTEXT

Children grow, develop, and flourish in the context of their family. This interaction between children's development and their families is a distinguishing characteristic of childhood. Pediatric illness affects not only children but also their parents, who play essential roles in accessing and implementing health care treatments on behalf of their children. Because of the enmeshment between children and their parents, pediatrics has adopted models of family-centered care, which integrate the perspectives and voices of parents and children themselves into clinical operations and governance of pediatric institutions.<sup>6</sup> Children's dependency on their parents, therefore, is the rationale for extending Porter's concept of patient-centered outcomes to include family- and parent-centered outcomes as well. Assuming that child outcomes and costs are the same between 2 providers, the one that does a better job addressing parental outcomes (eg, parental anxiety, social isolation, job engagement) related to the child's illness provides higher-value care.

## DATA COLLECTION

Measurement of a portfolio of patient/family-centered outcomes will require that we collect data from a variety of sources, including directly from children and parents. We are just beginning to envision and design data collection systems that obtain outcome data, inclusive of clinical outcomes, biomonitor data, and patient-reported outcomes, on a routine basis.<sup>7</sup> The types, manifestations, and frequency of various diseases as well as the adverse event profile for medical treatments often differs between adults and children in important ways, and, sadly, conditions such as hypertension and metabolic syndrome once considered to be of adult onset have infiltrated childhood. Maturation of children's physiology influences the qualitative and quantitative effects of medical treatments, which calls into question the use of "hand-me-downs" from studies

done among adults.<sup>8</sup> It is now well established that children as young as age 8 years can provide self-reports on their health, and parents can provide proxy or observational reports for younger children.<sup>9</sup>

Although pediatric quality assessment has been hampered by a lack of reliable and valid measures, this situation is rapidly changing. Pediatric outcome assessment has matured to a point where we now have a large set of biochemical, physiological, biomonitor, clinical examination, self-reported, and parent-reported measures. Table 1 illustrates this for pediatric asthma, one of the most common chronic conditions in childhood. Table 1 shows a patient/family-centered outcome measure portfolio that is arrayed by outcome dimensions and domains adapted from Porter.<sup>4</sup> Each of these outcome measures has been extensively evaluated and is ready for use in pediatric value assessment. It is worth noting that most of the outcomes in Table 1 are not disease specific but rather are universally applicable to all pediatric conditions. Thus, the approach we present is relevant across many pediatric disorders.

## SELECTING THE PATIENT/FAMILY-CENTERED OUTCOMES

It should be evident from Table 1 that measuring pediatric value is complicated by choice of outcome measures. It would not be feasible to measure every possible outcome for a child with asthma, for example. There is little empirical information to guide decision making on which ones to select. Longitudinal validation studies are needed that contrast the sensitivity of the various measures to true change in clinical status. The measures that are most responsive to health care services would be most desirable. Patient and family priorities are not always aligned with clinician priorities for treatment outcomes.<sup>10</sup> Thus, we also need to obtain patient and family preferences, which can be done using such methods as analytical hierarchical

process<sup>11</sup> or conjoint analysis,<sup>12</sup> which provide quantitative assessments of treatment and outcome priorities.

### CONSIDERING PERSPECTIVE IN ASSESSING VALUE

A key feature in assessing health care value is to determine the perspective of the analysis: children themselves, their parents, health benefit purchasers, and society. There is a great deal of economic literature that examines value from the societal perspective or group purchaser perspective.<sup>13</sup> From the societal perspective, it matters which and how many resources were consumed; who actually pays is less relevant. For example, when Medicaid pays for an admission, it is a shared burden between the federal government, the state, and the hospital if reimbursement is lower than costs. From the societal perspective, we care about how efficient the hospital was, and we assume that less resource consumption for the same outcomes suggests better value. As for societal health benefits, we can assume society profits when a death is averted, or when a child is treated well so that they grow up to be productive adult citizens.

The perspective of the family varies markedly from that of society. Measuring value such that it is meaningful to families holds the potential for providing information that would be a strong determinant of a family unit's actions. The perspective of the family is the personalized perspective. Families using the newly created health insurance exchanges must decide which health plan to choose; thus, the family perspective on pediatric value will likely become a major force in making insurance selection decisions.

The classic way economists have modeled the family decision making process has been by defining a utility function, which places the benefits of alternative options on the same scale. Becker<sup>14</sup> has suggested that altruism is part of the parental utility function, which may help explain why parents choose to provide gifts to their children in the form of health and educational resources. Of course, parents must make decisions for the child subject to a family's budgetary constraints. From an altruistic perspective, parents want the best possible care for their children, but from a fiduciary perspective, they may decide that the opportunity cost of not funding some other family expense is greater than the benefit derived from investments in children's health care. This type of decision making is likely in play when the costs but not outcomes of health care systems are provided to families.

The child's perspective is often missing in discussions of pediatric value because it is assumed that parents always act in the best interests of the child. There is extensive literature suggesting that decisions on health care benefit from a shared parent-child perspective and that parent and child assessments of health status are not always congruent.<sup>15,16</sup>

### ANALYTIC CHALLENGES

In order to compare value across provider settings or insurance plans, we must use a standardization method that

**Table 2. Assessing Dimensions of Value With Appropriate Standardization**

Outcome by Category	Recovery From Acute Exacerbation	Quality of Acute Exacerbation Management	Quality of Chronic Care Management	Long-Term Outcomes	Row-Weighted Aggregates
Outcomes (direct standardization)	For each dimension: Provide a personalized sample of patients that are specifically of interest to the family. Answers the question: "In specific patients relevant to my child, eg with a specific type of asthma severity, what were the costs and outcomes for my health system compared to other health systems available to our family?"				
Outcomes (indirect standardization)	For each dimension: Provide a sample of all children in the system. Answers the question: "How well does my health system perform with respect to costs and outcomes on the children they see in their system, compared to how these same patients would be performing at other systems available to my family?"				
Patient-reported outcomes (direct standardization)	For each dimension: Provide a personalized sample of patients that are specifically of interest to the family. Answers the question: "In specific patients like my child, eg with a specific type of asthma severity, what were the patient reported outcomes for my health system compared to other health systems available to our family?"				
Patient-reported outcomes (indirect standardization)	For each dimension: Provide a sample of all children in the system. Answers the question: "How well does my health system perform with respect to patient reported outcomes of the children they see in their system, compared to how these same patients would be performing at other systems available to my family?"				
Financial cost to family/society (direct standardization)	For each dimension: Provide a personalized sample of patients that are specifically of interest to the family. Answers the question: "In specific patients like my child, eg with a specific type of asthma severity, what were the costs for 1) my family and 2) the health system compared to what 1) my family's costs and 2) what other health systems costs would be in other systems available to our family?"				
Financial cost to family/society (indirect standardization)	For each dimension: Provide a sample of all children in the system. Answers the question: "In general patients that my health system sees, how well does my system perform with respect to 1) family costs and 2) health system costs, on the children they see in their system, compared to how these same children would be accruing costs for 1) the family and 2) the system at other systems available to our family?"				

addresses differences in patient mix and disease severity in order to level the playing field. The adjustment method used must be consistent with the perspective of the analysis (eg, society or family). Most commonly, analysts use indirect standardization,<sup>17</sup> which answers the question, “How would the outcomes and costs of patients seen at the index health system compare with those outcomes and costs if these same patients were treated at a typical system?” Value is assessed by analyzing the outcome–cost trade-offs among alternative health care systems, which are benchmarked to the typical system.

The fundamental problem with indirect standardization for families is that each family has unique decision-making dimensions, such as morbidity burden, finances, outcome priorities, and trade-offs between outcomes and costs. From a societal perspective, indirect standardization is useful; society may wish to know whether a health system is producing good outcomes at a reasonable level of costs. However, the family wants to know how children like theirs benefit from a given health plan or health care provider and what the costs (charges) are to the family for this care (eg, copayments, deductibles, and potentially out-of-pocket expenses). The family perspective suggests the use of direct standardization,<sup>18</sup> which answers the question, “How is this health system doing relative to other systems on patients just like me or my child?” From the perspective of measuring value and choosing a specific plan or provider, direct standardization allows for a fair evaluation with an examination that has targeted questions relevant to the specific patient or family—or a personalized mix of relevant patients that reflect the needs of the family or child. From a societal perspective, a directly standardized report on value, based on a specific family’s needs, would be difficult to use because it will not reflect the typical mix of patients in a region or state. From the family perspective, the directly standardized approach is essential to making an informed choice.

Table 2 integrates the dimensions of perspective, measurement, and analysis needed to assess value across health systems. Columns represent outcome dimensions and rows define the method of standardization needed to allow appropriate comparisons across systems, both from the perspective of the family/child (focusing on direct standardization) and of society (focusing on indirect standardization). A description of each interaction between outcomes measurement and perspective is provided. Note that the final column in Table 2 suggests that different outcomes may be weighted to form summary measures (something that may also vary by perspective).

## CONCLUSION

In the new health care marketplace, families will increasingly be making important decisions concerning choice of health plan, health provider, and even the newly created accountable care organizations. Ideally, they would make these decisions on the basis of a patient/family-centered approach to assessing pediatric value. Making

such decisions will require the collection of outcome and cost (and charge) data that go well beyond standard reports now used to compare health care systems or hospitals. Understanding pediatric value requires information systems that include outcomes that matter to children and families, costs and charges measured at the level of the child, and directly standardized reports tailored to the priorities of the family unit. Future research is needed to develop methods for promoting pediatric value in ways that do not lead to new disparities among vulnerable populations because of unequal access or ability to use this type of value-based information.

Pediatric value assessment is no longer aspirational. We now have the conceptual frameworks, measures, and methods to make what once was a vision a concrete reality. We believe that the time has come for families, providers, purchasers, and child health policy makers to start demanding that resources be obtained to fund the collection of appropriate data and implementation of appropriate analytic methods to support value-based decision making for children’s health care.

## ACKNOWLEDGMENTS

This work was funded by Pediatric Quality Measures Program grant U18HS20408 from the Agency for Healthcare Research and Quality.

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