Curr Treat Options Peds (2016) 2:311–317
DOI 10.1007/s40746-016-0069-1

Quality Improvement (J Anderson, Section Editor)

Identifying and Improving Value in Patients with Chronic Disease

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

Keywords Value · Outcomes · Chronic conditions · Quality · Healthcare costs · Metrics

Opinion statement

More than 10 million children in the USA have a chronic condition that requires healthcare. Children with chronic illness require distinct strategies to achieve best outcomes. Value, defined as outcome and patient experience divided by the cost of health care value, has emerged as a critical metric in health care and may be very applicable to the population of children with chronic conditions. With increased value, the patient, provider, and payer should benefit. While the concept of a value metric has face validity, the definition and application face challenges. The perspective of the payer, provider, health care system and the patient and family are not always aligned. Patient-centered care requires that the provider respect patient's preferences and that care is integrated and coordinated. Quality of life, plays a critical role in decision-making especially with chronic disease management. At the population level, a value metric, if validated, might be able to forecast the impact of distinct improvement efforts and help to prioritize their efforts. The role of value as a driving force in health care is clear both at the individual and at the population level. Understanding value will improve decision-making but the details of the metric must be carefully validated at the condition level.

Introduction

Childhood chronic illness includes a multitude of diverse conditions which impact growth, development, physical health, emotional well-being and/or cognitive function. Despite the diversity of diseases and conditions, children and families face common challenges when living with any chronic health problem. The chronic care model proposed by Wagner almost 20 years ago offers a framework which identifies the critical structures and care processes that are needed to optimize outcomes and has proven reliable across conditions, demographics and national borders [1]. To achieve best outcomes bidirectional interaction between informed patients and a prepared, proactive health care team is required. The chronic care model focuses on having a system that is proactive and focused on keeping a person healthy rather that reactive and only responding when patients are sick. Moreover, the outcomes depend on six fundamental areas including effective self-management, decision support, a reliable clinical information system, a reliable care delivery system and community support.

Advances in medical science, operative procedures, and pharmaceuticals over the past three decades, have been associated with increased costs both to the health care system and the consumer. While medical science has marched forward, the impact of many advances on patient care and outcomes outside of clinical trials remains murky. Concurrently with increasing health care costs, there has been mounting focus on the quality of care, perhaps still best defined using the dimensions outlined by the Institute of Medicine in 1999 Report Crossing the Quality Chasm [2] (Table 1 [2]).

So as complexity of care has increased, health care costs have skyrocketed. More recently, value or value-based health care has emerged as a critical term in health care [3••]. The meaning is similar to that for other industries and in the end, represents quality of the product as perceived by the consumer divided by cost. In health care, value might be considered to be defined as outcome and patient experience divided by the cost of health care. With increased value, the patient, provider, and payer should benefit. So if efficiency is increased and waste is reduced, the cost of care decreases and the value of the product increases. Alternatively, if a new therapy that is costly becomes available and dramatically improves outcomes, then value may also increase. While the value metric has face validity, the definition of value and its application face challenges. Stakeholders in the healthcare industry struggle with adequate definitions for both outcomes and costs. The perspective of the payer, provider, health care system and the patient are not always aligned [3••]. What is the definition of best outcome or quality of care? Can quality be measured? How do we define costs? Is it the cost of care and/or the cost to the patient from out of pocket expenses? Does it include lost wages related to health care? So at some level, the metric varies according to the eyes of the beholder. In the end, measurement of value if proven reliable would [1] permit us to trend over time and show improvement to insurers and families and [2] guide opportunities for strategies to reduce waste and assess the impact of novel therapies.

While recognizing that there are multiple stakeholders in value-based health care, our focus will be primarily on the perspective of children with a chronic condition and their families at the individual and population level. By focusing on two critical components of the chronic care model, patient outcomes and the challenges of self-management, we can better define outcomes as it pertains to value in health care. We will then examine components of cost. After addressing these issues, we will look at specific examples of value-base health care as it pertains to specific challenges faced by children with chronic and/or complex conditions.

The value metric

For value to be meaningful, a metric must reflect the impact of care on the patient's health status and cost of care. Furthermore, the metric must be objective, understandable, accurately reflect the patient's health, distinguish among patients, and be valid, reliable and retrievable [3••]. Lastly, the metric should identify and prioritize opportunities for improvement and research. As a first step, we can consider measures of outcome. The outcome metric will vary according to condition, the perspective of the patient, provider and payer and the phase of care. So while the concept of value is attractive,

Table 1. Dimensions of quality [2]

Dimension of quality	Definition
Effectiveness	Appropriate care based on systematically acquired evidence
Efficiency	Reduce waste in the system
Equity	Reduce the burden of illness across the population
Patient-centered	Respect for patients values and preferences with real integration of care
Safety	Patients should not be harmed by care intended to help them
Timeliness	Avoid delays

the definition and application requires clear definition. Complexity is further compounded when we consider chronic conditions.

Value at the population level

The value metric links to the dimensions of quality [2] (Fig. 1). While the individual dimensions of quality impact both outcome and cost, some dimensions like effectiveness may be more aligned with outcome and efficiency may be more aligned with cost. At the population level, a rational construct permits patient, providers, program leaders, health care administrators and payers to forecast how changes in a dimension of quality might impact value and perhaps allow stakeholders to prioritize areas for improvement.

Components of value in chronic conditions

As a first step, we can consider measures of outcome. Traditionally used single outcome metrics such as patient survival rates or cancer remission do not adequately represent the results of care and certainly do not reflect the dimensions of quality. The tiers of outcomes as defined by Michael Porter may describe the goals for patients and for their providers. The tiers are categorized as (1) health status achieved (2) process of recovery and (3) sustainability of health [3••]. Tier 1 is defined by improvement in health status or the failure to have expected decrease in health status. Tier 2 is defined as disutility in the system, delays and complications directly related to care. Tier 3 is defined as sustainability which includes freedom of disease recurrence, sustained functional health and freedom from complications of therapy. The outcome metric will vary according to condition, the perspective of the patient, provider and payer and the phase of care. So freedom from disease recurrence and absence of complications from therapy are critical for a long term cancer survivor, but the perspective of a newly diagnosed patient may be different. Complexity is further compounded when we consider chronic conditions.

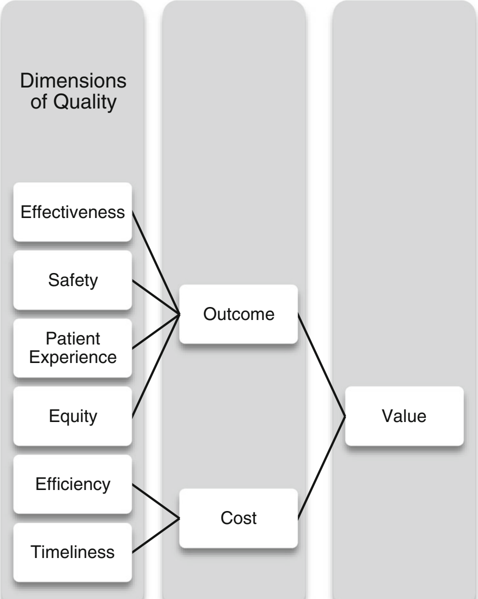

Fig. 1. Dimensions of quality care.

Patient reported outcomes are a critical component of functional health and can be examined by assessment of health related quality of life (HRQOL). Measurement of HRQOL is focused on five aspects of health as defined by the World Health Organization; physical health, mental health, social functioning, role functioning, and general health perceptions [4, 5]. HRQOL may be measured using preference or non-preference based approaches, the latter divided into generic or disease-specific measures. Preference-based instruments ask the respondent to choose between two health alternatives such as maintaining their current status or a therapy which may improve function at the risk of increased morbidity. These instruments provide patients and their providers with a framework for comparison of risks, benefits and outcomes. Preference-based instruments have not been broadly used in children. Non-preference based instruments address the specific domains of HRQOL identified by the World Health Organization. Measurement of HRQOL in children must take into account changes in expected role functioning with growth and the need to use a parent as a proxy for the child. Over the past 20 years, generic and disease specific tools to measure HRQOL for children and adolescents have been developed, validated and applied across diverse conditions [6].

While instruments which help to assess HRQOL from the patient's perspective are necessary, they do not provide an overall perspective of the health care experience, more specifically the interaction of health care system with patients and families. The behavior change counseling model known as the 5 A's Cycle (Assess, Advise, Agree, Assist, Arrange) has been used a guide to organize self-management interventions [7]. The 5A's Cycle provide a framework to examine the interface between health care system and family and patient. Effective self-management requires that medical assessment be done in the context of sociocultural factors including but not limited to ethnicity, literacy, health beliefs and economic factors. The health care team may give their advice in the context of this assessment and base the advice on best available evidence. Agreement on the path forward reflects shared decision-making taking among providers and patients and families permits understanding of benefits, risk, potential complications and family preference. Providers may help patients and families identify and mitigate problems related to social, environmental and community barriers. Finally coordination of care within and across systems completes the process. So the behavior change counseling model, while developed to promote self-management, can also provide a framework to understand the process of health care delivery in a child with a chronic condition from the perspective of the patient and the family. Failure to consider the 5A's will remove the experience of the patient and family from the value equation, a critical issue especially as it relates to chronic conditions.

Costs: Health care costs vary based on phase of care. The costs associated with chronic medical conditions may be categorized into direct and indirect costs [8, 9] Direct costs reflect medical resource utilization attributed to the health care delivery system. From the perspective of the individual patient and family, i*ndirect costs* reflect the loss of income resulting from decreased work productivity and/or the expenses incurred from accessing the health care system (travel, gas, and lodging). For a patient in the acute phase of care, Tier 1, costs may be estimated by hospitalization. Depending on the length of hospitalization, indirect costs can be very substantial. In Tier III, poor coordination and delays in care may increase out of pocket expenses for patients, and these factors may exceed the direct health care costs. Effective coordination of care can markedly decrease indirect costs with minimal impact on the medical resource utilization and direct costs.

Examples

To put concept of value into a more practical context, a series of scenarios will be provided. First, consider value at the patient population level and second at the individual patient and family level. The examples will provide some understanding of the complexity of the metric.

Value at the patient population level

A metric for value might help to organize the quality initiatives that are increasingly abundant in health care. The value metric if proven reliable would (1) trend value over time (2) guide improvement and identify critical leverage points and (3) permit the team to show improvement to insurers and families and to meet regulatory requirements.

Scenario 1: life-threatening condition requiring immediate intervention and follow-up chronic long-term care (examples—complex congenital heart disease, cancer, solid organ or bone marrow transplantation)

For these and similar conditions, patients face a life threatening illness which requires a major intervention from an interdisciplinary team. Patient selection for the high risk, high cost intervention is based on survival benefit and absence of any specific contraindications such as infection, malignancy not corrected by the intervention, or irreversible end organ damage distinct from the primary problem. The time before treatment is not without risk and survival is a critical early endpoint of the intervention. Nevertheless by one year after the procedure, patients move into a chronic management phase in which the goals are avoidance of disease recurrence and sustained health without complications of therapy.

Example: Solid organ transplantation is a well-established and effective treatment for irreversible and end-stage organ disease. The goal for providers, families and the recipient is to ensure optimal graft function, functional health and freedom from the complications of immunosuppression. With advances in organ preservation, operative techniques, immunosuppression and prevention of infection, one and three-year patient and graft survival have markedly improved. Consequently, patient or allograft graft survival rates do not adequately represent the results of care. In summary, the field might consider diverting focus from survival to sustainability of allograft health and avoidance of complications.

At a population level, one year outcomes after transplantation might be considered. Outcomes at one year reflect selection decision, donor organ quality, operative complications, and early complications of immunosuppression. Much of this care is delivered at the primary transplant center. Outcomes at year one certainly influence long-term outcomes across all solid organ transplant recipients [10]. For a one year value metric, the sum of direct hospital costs and an estimate of outpatient medication cost may be used as the denominator. For the numerator, a composite measure based on weighted Tier I, Tier II and Tier III metrics according to Porter may be used [3••]. Once the composite metric is validated, program leaders would be able to forecast the impact of distinct improvement efforts and prioritize their efforts. After year one, care parallels the complexity of other chronic conditions and as such, implementation of the components of the chronic care model is critical to achieve best outcomes [1].

Scenario 2: chronic progressive condition: examples—diabetes, inflammatory bowel disease

For these and similar conditions, the population has an illness or condition which requires an intervention to stabilize health. While care is provided by a specialist and requires a team to optimize outcome, the intervention can often be provided as an outpatient. The time from identification of the condition to stabilization can be short and the treatment is associated with much less risk than for the first scenario. Yet by one year after diagnosis, challenges for the conditions merge according to the chronic care model [1] and patients move into a chronic management phase in which the goals are avoidance of disease recurrence and sustained health without complications of therapy.

Example: Inflammatory bowel disease is a relapsing and remitting condition which is common among adolescents, occurring with a prevalence of approximately 1/1000 persons. The goal for providers, families and the recipient is to improve functional health, decrease disease activity and be free from the complications of treatment. Single outcome metrics such as survival do not represent the results of care for this patient population since mortality is rare. Outcomes at one year reflect disease severity, co-morbidity and the effectiveness of initial therapy. Patient perception of their health, morbidity and markers of disease activity are critical measures to be considered. For pediatrics, much of the care is coordinated through a specialty practice but may delivered at the primary center or at a distant center. Measurement of costs outside of the primary center and the costs of coordination of care may be challenging. The differences in determination of value compared to those with life threatening conditions emphasize the condition specific nature of the metric. Even so, after one year, implementation of the components of the chronic care model is critical to achieve best outcomes regardless of the condition [1].

Value at the individual level

Patient-centered care requires that the provider respect patient's preferences and that care is integrated and coordinated. HRQOL and the patient and family experience, plays a critical role in decision making but more so with chronic disease management than during the acute phase of case. Assessment of value during the phase of stabilization or complex intervention can drive improvement efforts at the population level, but improvement and innovations are usually focused on care processes and costs on the provider side. In contrast, for individual patient with chronic conditions, preference plays a critical role and value is integral to the preference for the patient and family.

Contrast the first two cases with the third case and consider the relative impact of patient preference on the plan of care.

Case 1: 14-year-old adolescent girl with type 1 diabetes. She has been controlled with insulin injection. Her HGB A1C is 6.4. She seeks to use an insulin pump since she and her parents think it will give her improved quality of life.

Case 2: *15-year-old liver transplant recipient with normal liver tests on twice daily treatment with tacrolimus. She underwent liver transplantation 12 years old for biliary atresia. She is a soccer player and leads an active life style. She seeks to change treatment to once daily tacrolimus since the second dose interferes with her quality of life.*

In both cases, the young women have managed their chronic condition without complications. The issue at hand is outlined in level 3 of the hierarchy of outcomes and is related to the sustainability of health. The outcome desired is better patient experience and perhaps better adherence to medical regimen. The cost is related to the risk of acute and chronic damage associated with change in therapy the cost of increased monitoring.

Case 3: *18-year-old girl who underwent a Fontan procedure for single ventricle anatomy. She has now developed liver enlargement and chronic kidney disease, both of which suggest end-organ injury. Her cardiologist suggests that she have imaging studies and be seen by a nephrologist and hepatologist. The patient and family would like to coordinate the consultations so as to avoid costs of travel and missing work and missing school. They would also like to ensure that their perspective is considered in decision-making across specialties*

In this case, coordination of care and the experience of the family are critical. The components of the behavior change counseling model (Assess, Advise, Agree, Assist, Arrange) are especially critical and play a central role in the patients and family experience.

Case 4: *2-year-old girl with refractory heart failure requires placement of a left ventricular assist device as a bridge to heart transplantation. The family seeks to understand* *what can be done to avoid complications associated with mechanical circulatory support and transplant and increase the chance for survival.*

In this case, the family is focused on survival and risk of complications, levels 1 and 2 in the hierarchy of outcome. Most of the costs will be borne by the third party payer. So the discussion and alternatives for treatment are less flexible and probably reflects provider expertise and recommendations.

Case 5: *15-year-old adolescent boy suffered a severe head injury after skate boarding. He was in medically induced coma and has been transferred to a rehabilitation hospital. He is walking and doing self-care and is improving each day. The family would like to understand what can be done to optimize his functional health in the future.*

In this situation, the young man will survive and the family is not certain if there will be significant complications from the injury. The family seeks to optimize his functional health through rehabilitation. They are asking for a forecast for function in the future and the impact of rehabilitation, the direct health care costs and indirect costs related to the family. Perhaps the choice between similar facilities will be impacted by indirect costs. In this case, we have a hybrid case. The final outcome is best functional health but the choices may be influenced by the quality of the facilities, the care experience and the cost to the family or indirect health care costs. So this case contrasts to the first two cases.

Conclusion

What will it take to incorporate value into decision-making?

The role of value as a driving force in health care is clear both at the individual and at the population level. Understanding value will improve decision making but the details of the metric must be considered at the condition level. The outcome metric must be valid and reliable and reflect the phase of care for the patient or population. Comparison across programs and conditions must be done with caution since populations may vary according to disease severity and or demographics. The denominator will reflect cost, both direct and indirect, to the payer, providers, health system and patient may not always be aligned. Given these caveats, it is a daunting task but one that will certainly help care strategy across the system.

Compliance with Ethical Standards

Conflict of Interest

Angela Lorts declares that she has no conflict of interest.
John Bucuvalas declares that he has 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.

References and Recommended Reading

Papers of particular interest, published recently, have been highlighted as:
•• Of major importance

1. Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? Eff Clin Pract. 1998;1(1):2–4.
2. Institute of Medicine. Crossing the Quality Chasm: a New HEalth System for the 21st Cnentury.; 2001.

3.•• Porter ME. What is value in health care? N Engl J Med. 2010;363(26):2477–81. doi:10.1056/NEJMp1011024.

The perspective provided by Michael Porter gives a clear framework for the value metric in health care and provides the reader with a way to deconstruct the challenge for individual patients and for populations of patients.

4. Aaronson NK. Assessing the quality of life of patients in cancer clinical trials: common problems and common sense solutions. Eur J Cancer. 1992;28A(8–9):1304–7.

5. Ware JEJ, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care. 1992;30(6):473–83.

6. Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. Med Care. 1999;37(2):126–39.

7. Manley M, Epps RP, Husten C, Glynn T, Shopland D. Clinical interventions in tobacco control. A National Cancer Institute training program for physicians. JAMA. 1991;266(22):3172–3.

8. Nelson EC, Batalden PB, Huber TP, et al. Microsystems in health care: part 1. Learning from high-performing front-line clinical units. Jt Comm J Qual Improv. 2002;28(9):472–93.

9. Harvard. Healthcare Delivery-Deconstructin the Costs.

10. Soltys KA, Mazariegos GV, Squires RH, Sindhi RK, Anand R, Split Research Group. Late graft loss or death in pediatric liver transplantation: an analysis of the SPLIT database. Am J Transplant. 2007;7(9):2165–71. doi:10.1111/j.1600-6143.2007.01893.x.