Title: Measuring Quality of Primary Care in Complex Pediatric Patients

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Structured Abstract (194 words)

Purpose: The main objective of this project was to develop a set of rigorously designed quality measures that can be used to assess the quality of primary care for complex pediatric patients.
Scope: Evidence showed that there are known gaps in healthcare quality. Assessing and improving quality are key steps to better patient outcomes.
Methods: We conducted a systematic literature review with MEDLINE and the National Quality Measures Clearinghouse (NQMC) for existing measures as well as evidence to inform the development of new quality measures. All eligible articles were reviewed for Oxford CEBM level of evidence and for relevance to primary care of complex pediatric patients. A national expert panel was convened to rate candidate quality measures using the RAND/UCLA Appropriateness (Delphi) Method.
Results: We presented 74 quality measures to the expert panel. The panel rated and accepted 35 measures as valid and feasible for assessing primary care quality in complex pediatric patients. The final set of quality measures was grouped into the following domains: general primary care; patient-/family-centered care; chronic disease management; and coordination of care.

Key Words: quality measure; quality indicator, primary care; complex patients; quality of care; patient-centered medical home.

PURPOSE

The overarching objective of this project was to develop a set of rigorously designed quality measures that could be used to assess the quality of primary care for complex pediatric patients, using the Patient-Centered Medical Home as the conceptual framework. The specific aims were as follows:

1. To develop comprehensive and clinically meaningful primary care quality guidelines for pediatric patients with complex developmental conditions. Quality measures under this Aim focused on:
    a. Prevention and early detection.
    b. Family-centeredness.
    c. School/education coordination.
2. To develop comprehensive and clinically meaningful primary care quality guidelines for pediatric patients with two or more chronic medical conditions. Quality measures under this aim focused on:
    a. Accessibility of care.
    b. Continuity of care.
    c. Coordination of care.
3. To determine the feasibility of implementing our medical home-driven quality measures in pediatric primary care setting.
4. To produce a quality scorecard using our medical home-driven quality measures, in combination with established disease-specific standards of care, for a complex developmental condition – Down syndrome.

SCOPE

Background

There are growing concerns that traditional models of care may not be effective for children with complex medical conditions.[1-5] Children with complex medical conditions are often managed by multiple providers, including generalists, specialists, school healthcare personnel, and therapists. The chronic and complex nature of these conditions, coupled with fragmented interaction and communication across multiple providers, can lead to inconsistent and poorly managed care. Traditional encounter-based approach is often insufficient for prevention, disease monitoring, or promotion of self-management and collaborative decision making.[1, 4-5]

The "medical home model," defined by the American Academy of Pediatrics (AAP) as accessible, continuous, comprehensive, family-centered, coordinated, compassionate, culturally effective care, has been adopted by the pediatric community as a promising primary care model for children with complex conditions and special healthcare needs.[6] The medical home is a primary healthcare setting that facilitates partnerships between patients and their physicians as well as the patient’s family.

Context

This project was not a prototypical hypothesis-driven research project. This was type II translation research, in which the application and implementation of “clinical study results into everyday clinical practice and health decision making” was realized.[7]

With the current national focus on delivering high-quality care for all patients, type II translation is vital for translating research and knowledge to actual improved care for patients.[7]

Settings

The quality measures are intended for use in primary care pediatrics clinics across the United States. The first quality report card using this set of quality measures was calculated using data from the Children's Hospital Los Angeles (CHLA) general pediatrics clinics.

Participants

Two types of participants were involved in the project: 1) nine nationally nominated experts that participated in the modified Delphi panel to rate the proposed quality measures and 2) 50 children with Down syndrome seen at CHLA during the study period. (Their charts were abstracted as an example of complex pediatric patients for quality scorecard reporting.)

Incidence

The definition of complex pediatric patients has yet to be standardized, and true incidence estimates will depend on the specific definition. One of the AHRQ-funded CHIPRA Centers of Excellence on Quality of Care Measures is tasked with standardizing the definition of complex pediatric patients.

The estimated incidence of Down syndrome is between 1 in 1,000 to 1 in 1,100 live births worldwide.[8]

Prevalence

There is currently no clearly documented prevalence of complex pediatric patients, due in part to the lack of a standardized definition (as mentioned above). The prevalence of Children with Special Health Care Needs (CSHCN) as defined by the Maternal and Child Health Bureau (MCHB) is 13.9% of U.S. children under 18.[9]

METHODS

Study Design

Using the RAND-UCLA modified Delphi method, a well-established and valid method for developing quality measures,[10-14] we developed measures for primary care of complex pediatric patients. We began with a focused systematic review of the literature and existing clinical guidelines, followed by the compilation of existing quality measures. Then we convened a multidisciplinary national expert panel to interpret the evidence detailed by the literature review and to assess the validity and feasibility of the candidate measures. Nine expert panelists were selected through official nominations from the American Academy of Pediatrics (AAP), Academic Pediatric Association (APA), and the National Association of Children's Hospitals and Related Institutions (NACHRI). We solicited nominations from these professional organizations because of their strong interest and work in the areas of primary care, chronic care, and PCMH. The modified Delphi method consisted of two rounds of anonymous ratings for *validity* and *feasibility* and a face-to-face panel meeting between rounds (held on July 23, 2010, in Los Angeles).

We sent each panelist 74 candidate quality measures and relevant references/data. We asked the panelists to rate the validity and feasibility of each measure on a scale of 1-to-9, in which 1 was "definitely not valid" (and similarly for feasibility, "definitely not feasible") and 9 was "definitely valid" (and similarly for feasibility, "definitely feasible").

A measure was considered valid if 1) there is adequate scientific evidence or professional consensus to support a link between what it measures and improved patient outcome; 2) a provider performing the actions described by the measure would be considered to deliver better care than a provider who did not perform those actions; and 3) the provider or the practice could “control” the process specified by the measure. A measure was considered feasible if it could be assessed using data sources currently available in most pediatric primary care setting – these include paper medical charts/ records, administrative/billing data, laboratory and pharmacy data, or Electronic Medical Records (EMR).

The panelists submitted their first round of ratings prior to the face-to-face meeting along with their comments and any additional references or sources they chose to provide. We incorporated additional sources suggested by the panelists to include unpublished or not yet published material. We then prepared summaries of the first-round ratings for distribution at the panel meeting. The summary was individualized for each panelist and included 1) the actual rating submitted by the individual; 2) a histogram of anonymous ratings by all panelists; 3) the median rating, as a measure of central tendency; 4) the mean absolute deviation from the median, as a measure of dispersion; 5) a statistical classification of “agreement” or “disagreement” among the panelists; and 6) whether each measure was accepted, rejected, or of indeterminate disposition after the first round of ratings. Agreement among the panelists was defined as the inability to reject the hypothesis that 80% of the hypothetical population of repeated ratings would be within the same three-point region (i.e., 1-3, 4-6, or 7-9) as the median; disagreement was defined as otherwise. A measure was accepted if the median validity was in the 7-9 range, the median feasibility was in the 4-9 range, and there was agreement for the measure. A measure was rejected if the median validity or feasibility was in the 1-3 range and there was agreement. Measures that were neither accepted nor rejected after the first round of ratings were classified as indeterminate.

During the panel meeting, all measures of indeterminate disposition after the first round were discussed first. Then, each panelist was asked to bring to attention any measure they would like the group to discuss regardless of its disposition. Some measures were re-worded or clarified by the panel, and two new measures were suggested based on the additional sources provided by panelists. Following the panel meeting discussions, each panelist was asked to re-rate all measures for validity and feasibility; the median, mean absolute deviation, and agreement/disagreement were subsequently re-calculated based on these second-round ratings. A measure was accepted to the final set if its median validity was in the 7-9 range, its median feasibility was in the 4-9 range, and there was agreement after the second round of ratings. Any measure not accepted after the second round of ratings (i.e., those that were rejected or of indeterminate status) was dropped from further consideration.

Last, we pilot tested the panel accepted quality measures by operationalizing the numerator and denominator for each chart-based measure and constructed a chart abstraction form. We then abstracted 50 randomly selected patients with a known diagnosis of Down syndrome (ICD-9 code 758.0) at CHLA General Pediatrics clinic and computed the quality scorecard for the clinic.

Data Sources/Collection

Systematic Literature Review

We conducted a literature review of published evidence (up to the publication date of December 2009) in order to identify factors linking processes of care to pediatric patient outcomes.

First, we searched MEDLINE using the following search terms, alone and in conjunction with one another: *primary care; patient-centered care; family-centered care; medical home; chronic care model; disease management; care coordination; coordination of care; continuity of care; comprehensive care; chronic conditions; complex conditions; developmental conditions; and quality measures/indicators.* Citations were retained if they were available in English; were relevant for infants and children under age 18; and were reviews, practice guidelines, meta-analyses, randomized controlled trials, cohort studies, case-control studies, quality measure reports, or expert consensus, opinion, or "first principles" research. Then, we searched the National Quality Measures Clearinghouse (http://www.qualitymeasures.ahrq.gov), including the HEDIS – Healthcare Effectiveness Data and Information Set, for existing quality measures pertaining to the above italicized constructs.

We reviewed all citations using the follow steps: 1) the titles of the articles were reviewed for relevance; 2) the abstracts of the articles passing step 1 were then reviewed for contents; and 3) articles passing step 2 were obtained and reviewed in full. Articles were excluded if they did not meet the retention criteria described above. Quality measures that were redundant (i.e., with similar constructs and processes) or inappropriate for primary care settings were removed in step 3. We also performed "reference mining" of the full articles by examining the cited references and identifying additional sources. Every article was reviewed by two independent reviewers to identify established guidelines/recommendations and quality measures. Disagreements were resolved by discussion until consensus was reached. We gave priority to studies with the strongest designs based on the Oxford Centre for Evidence-Based Medicine Levels of Evidence.[15] At the end of literature review, we identified 36 existing quality measures appropriate for the primary care of complex pediatric patients. Additionally, by combining clinical evidence/practice guidelines obtained in the literature review with parent focus group data, we constructed 38 new quality measures. Patient and family inputs on care were represented as focus group data aimed at addressing the patient-centeredness component of the PCMH – this was collected through two semi-structured, hour-long focus groups using a convenience sample of parents of chronically ill children at Children's Hospital Los Angeles (N=7 per group).

At the end of this process, we had a total of 74 quality measures. Each measure was assigned a content *type* (process, structure, or outcome) and an anticipated *data source* (medical record/chart, practice-based survey, or patient survey).

Chart Abstraction

Using a standard chart abstraction form, a trained research assistant reviewed 50 ambulatory patient charts and abstracted information needed to populate the numerators and denominators of the operationalized measures. Data from the abstraction forms were entered into Microsoft Excel for tabulation and calculation of the quality scorecard.

Interventions

N/A – this project proposed no intervention.

Measures

Measure #	Measure Text	LOE*	Content Type	Data Source
General Primary Care				
1	Children should be screened by the primary care team for developmental delays (at the 9-, 18-, and either 24- or 30-month visits) using validated instruments.	I	Process	Chart
2	When a primary care team ordered a blood test, x-ray, or other tests, a follow-up discussion with parents to provide those results should be documented.	IV	Process	Chart
3	Primary care team should have coverage to provide help or advice to parents after hours: "In the last 12 months, when you called your child's primary care provider's office after regular hours, how often did you get the medical help or advice you needed?"	IV	Process	Patient Survey
4	The primary care team should have a standardized and clear procedure for communicating with parents/families (e.g., call-in hours, phone triage for questions, or provider call-back hours).	IV	Structure	Practice-based Survey
5	The primary care team should have an established protocol that enables parents/families to access their child's medical record.	IV	Structure	Practice-based Survey
6	The child's length/height and weight should be measured and documented at every well child visit or note a reason for not doing so.	I	Process	Chart
7	If a child is 2 years or older, the child's body mass index should be calculated and documented at every well child visit or note a reason for not doing so.	I	Process	Chart
8	If a child is 3 years or older, the child's blood pressure should be measured and documented at every well child visit or note a reason for not doing so.	I	Process	Chart
9	At the 4-year well child visit, office-based vision screen should be performed and documented or note a reason for not doing so.	I	Process	Chart
10	At the 4-year well child visit, office-based hearing screen should be performed and documented or note a reason for not doing so.	I	Process	Chart

11	The primary care team should administer annual influenza vaccination to all pediatric patients 6 months and older, or note a reason for not doing so.	V	Process	Chart
12	The primary care team should document a discussion with parents about the child's dental health and/or referral to a dentist by the 15-month well child visit.	IV	Process	Chart
13	The primary care team should provide guidance on growth and nutrition: "In the last 12 months, did your child's primary care provider or his/her staff talk to you about your child’s growth and nutrition?"	IV	Process	Patient Survey
14	The primary care team should have administered 4 DTap, 3 IPV, 1 MMR, 3 HiB, 3 Hep B, 1 VZV, 4 Pneumococcal conjugate, 2 Hep A, and 3 Rotavirus vaccines to all pediatric patients by 2 years of age, or note a reason for not doing so.	I	Process	Chart
Patient/Family-Centered Care				
1	Primary care provider should explain things in a easy to understand way: "In the last 12 months, how often did your child's primary care provider explain things about your child’s health in a way that was easy to understand?"	V	Process	Patient Survey
2	The primary care team should actively involve patient or parent(s) in decision making: "When there was more than one choice for your child’s treatment or healthcare, how often did your child's primary care team ask which choice you thought was best for your child?"	V	Process	Patient Survey
3	The clinic or medical home should have a formal process in which patient/parent-partner(s) can provide their perspective on family-centered strategies, practices, and policies.	IV	Structure	Practice-based Survey
4	The primary care team should describe treatment options adequately: "In the last 12 months, when there was more than one choice for your child's care, did your child's primary care team give you enough information about each choice?"	V	Process	Patient Survey
5	The clinic or the medical home should obtain feedback from families regarding care through systematic methods (e.g., surveys, focus groups, or interviews).	IV	Process	Practice-based Survey

6	The primary care team should provide guidance on other support services: "Does your child's primary care team suggest support services & resources outside of the practice when specific needs arise (e.g., diagnosis specific support groups, disability rights organizations)?"	IV	Process	Patient Survey
7	The primary care team should document the need for interpretation services (if appropriate) when making referrals.	V	Process	Chart
8	The primary care provider should be sensitive to the family's cultural background and beliefs: "Do you think your child's primary care provider is sensitive to your family’s cultural background and your beliefs about health?"	IV	Process	Patient Survey
Chronic Care				
1	The primary care team should work with the patient's family to specifically develop a management plan that includes visit schedules and communication strategies.	IV	Process	Chart
2	The primary care team should document counseling about nutrition when a child's BMI is ≥ 85 percentile for age and gender or note a reason for not doing so.	III	Process	Chart
Coordination of Care				
1	The primary care team or the medical home should track lab tests and referrals to subspecialists.	V	Process	Practice-based Survey
2	The primary care team should give timely referral to patients: "In the last 12 months, when your child needed a referral to a specialist, how often were you able to get the referral from your child's primary care provider?"	IV	Process	Patient Survey
3	The primary care team should help patient/parent(s) coordinate care: "In the last 12 months, how often did you get as much help as you wanted with arranging or coordinating your child’s care?	V	Process	Patient Survey
4	The clinic or medical home should have a designated person responsible for care coordination.	IV	Structure	Practice-based Survey
5	The primary care team should follow up with parents on visit to specialists: "How often did your child's primary care provider or staff talk with you about what happens during visits to a specialist doctor?"	III	Process	Patient Survey
6	At every visit, the primary care team should have the patient's medical record available.	IV	Process	Practice-based Survey

7	The clinic should maintain a list (updated yearly) of children with special or complex healthcare needs with diagnoses.	IV	Process	Practice-based Survey
8	The primary care team should clearly and specifically document if a patient has special or complex healthcare needs.	IV	Process	Chart
9	The primary care team should document in the chart about community-based services that the child and family use.	V	Process	Chart
10	When the patient is 16 years of age or older, the primary care team should document a discussion with patient or parent(s) on transitioning to adult healthcare providers.	V	Process	Chart
11	At the point of transfer, the primary care team should document the adult care provider that has been identified to eventually take over care.	V	Process	Chart

* LOE – Level of Evidence based on one reviewer’s grading using the Oxford CEBM criteria.

Limitations

At the time when this project started, because there was no consensus definition of complex patients, we used the simple definition of patients with two or more chronic conditions (consistent with AHRQ’s definition - Special Emphasis Notice 2008) as complex. This is not an all-inclusive approach, and our results cannot be generalized to all children with medically complex issues. Second, our expert panel nomination process resulted in an under-representation of safety-net providers, which may have skewed the panel ratings. Finally, the quality scorecard used measures that were chart based. Although this approach increases the accuracy and validity of the clinical data obtained, chart-based data can be very expensive in large scale, which, limits its applicability.

RESULTS

Principal Findings

Literature Review and Panel Results

The literature review identified 165 articles for a full text review, of which 37 articles were removed based on the inclusion/exclusion criteria. The expert panel accepted 35 measures of 74 candidate measures as valid and feasible for assessing primary care quality for complex pediatric patients. We grouped the measures into the following four domains: general primary care (n=14); patient-/family-centered care (n=8); chronic care (n=2); and coordination of care (n=11). Among the panel-accepted quality measures, 11% were structure measures; the remaining 89% were process measures. Nearly half of the measures (49%) would require medical record or chart abstraction, 23% would require an assessment of the clinic operation/resources using practice-based survey, and the remaining 29% would be based on patient survey.

The Institute of Medicine (IOM) committee emphasized four components of healthcare quality: safety; effectiveness; patient-centeredness; and timeliness. Among the 35 accepted quality measures, four focused on the safety aspect of primary care, tracking and following up on laboratory findings and diagnoses as well as ensuring proper hand-offs between providers.

Fourteen focused on the effectiveness of care, ensuring the delivery of appropriate evidence-based best practices; eight focused on the timeliness of care, emphasizing coordination of care (the IOM *Future Directions for the National Healthcare Quality and Disparities Reports* also identified care coordination as a system-wide priority area along with infrastructure) and the provision of services in a timely manner. The rest addressed patient- or family-centeredness in care, encouraging shared decision making and partnership.

Quality Scorecard

For a sample of 50 children with the diagnosis of Down syndrome (Trisomy 21) seen at Children's Hospital Los Angeles pediatrics clinic, an actual quality scorecard derived from the operationalized chart-based quality measures is presented in the table below.

Quality Measure	***Eligibility***	***Rate***
General Primary Care		
When a primary care team ordered a blood test, x-ray, or other tests, a follow-up discussion with parents to provide those results should be documented.	Children with either a blood test or radiographic test (eligible n=36)	33 %
The child's length/height and weight should be measured and documented at every well child visit or note a reason for not doing so.	All children (eligible n=50) at all well child visits	100 %
If a child is 2 years or older, the child's body mass index should be calculated and documented at every well child visit or note a reason for not doing so.	Children age ≥ 2 (eligible n=42)	50 %
If a child is 3 years or older, the child's blood pressure should be measured and documented at every well child visit or note a reason for not doing so.	Children age ≥ 3 (eligible n=37)	59 %
At the 4-year well child visit, office-based ***vision*** screen should be performed and documented or note a reason for not doing so.	Children with a 4-year well child visit (eligible n=18)	61 %
At the 4-year well child visit, office-based ***hearing*** screen should be performed and documented or note a reason for not doing so.	Children with a 4-year well child visit (eligible n=18)	61 %
The primary care team should administer annual influenza vaccination to all pediatric patients 6 months and older, or note a reason for not doing so.	Children age ≥ 6 month (eligible n=47)	70 %
The primary care team should have administered 4 DTap, 3 IPV, 1 MMR, 3 HiB, 3 Hep B, 1 VZV, 4 Pneumococcal conjugate, ***2 Hep A, and 3 Rotavirus*** vaccines to all pediatric patients by 2 years of age, or note a reason for not doing so.	Children age ≥ 2 (eligible n=42)	57 % ***19 %***
Patient/Family-Centered Care		
The primary care team should document the need for interpretation services (if appropriate) when making referrals.	Children with noted language barrier and had a referral (eligible n=21)	14 %
Chronic Care		
The primary care team should document counseling about nutrition when a child's BMI is ≥ 85 percentile for age and gender or note a reason for not doing so.	Children with BMI ≥ 85 percentile (eligible n=13)	69 %
Coordination of Care		
The primary care team should clearly and specifically document if a patient has special or complex healthcare needs.	All children (eligible n=50)	6 %

When the patient is 16 years of age or older, the primary care team should document a discussion with patient or parent(s) on transitioning to adult healthcare providers.	Children age ≥ 16 (eligible n=5)	20 %
At the point of transfer, the primary care team should document the adult care provider that has been identified to eventually take over care.	Children with notes documenting ready for transfer to adult provider (eligible n=3)	0 %
Down syndrome-specific recommendations		
Annual lab screening for TSH	All children with Down syndrome (eligible n=50)	94 %
Annual eye exam	All children with Down syndrome (eligible n=50)	78 %

Outcomes

Based on the quality scorecard, it was evident that, for children with Down syndrome, at the site (CHLA) where quality was assessed using the quality measure set we developed, children received high-quality care 44% of the time (averaged over all measures scored). The worst measure was scored at 0% when, at the point of transfer from pediatric care to adult care (coordination of care/ transition of care), no adult provider was identified and documented in the chart. Other poorly performed care included the identification of children with Down syndrome as children with special healthcare needs (with higher health services needs) at 6%, the documentation of the need for an interpreter on the referral form for those with limited English proficiency (14%), and complete recommended vaccines by 2 years of age, including two hepatitis A vaccines and three rotavirus vaccines (19%). The highest-performing areas were the measurement of height and weight (but not the calculation of body mass index or BMI) at well child visits (100%) and vaccinating Down syndrome children against influenza (70%). Of note, providers appeared to adhere to guidelines specific to Down syndrome care and performed better in those services (94% for TSH screening and 78% for vision/ophthalmologic exam) than in primary care services for these complex children.

Discussion

Our final set of quality measures can be categorized into four domains of care: general primary care; patient- or family-centered care; chronic care; and coordination of care (including transition to adult providers). General primary care is of enormous importance to complex pediatric patients and their families. The primary care team is often responsible for guiding patients/parents and advocating for them. There is also some evidence linking primary care to improved outcomes and reduced costs.[16]

There is also broad consensus on the emerging need to provide patient- and family-centered care; for example, researchers have noted with concern the rarity with which patient and family perspectives are considered valid evidence to inform quality measures or guidelines,[17] and the AAP has explicitly urged pediatricians to establish partnerships with families of medically complex children in planning and executing care.[18] In the family-centered care domain, the expert panel selected several quality measures that empower patients and families with shared decision making (measures #2 and #4) and inputs into the functioning of the medical home (measures #3 and #5). Moreover, the panel also placed emphasis on cultural sensitivity and the provision of language services (measures #7 and #8).

Chronic diseases represent perhaps the largest burden on our heathcare system today.[19] Unlike care for acute illnesses, which is usually contained in a finite number of visits, medical care for chronic illnesses is a long-term process that requires multi-faceted care.

Wagner commented in his papers that the needs of patients with chronic illnesses are unlikely to be met by an acute care system.[20-22] In the chronic care domain, the expert panel placed importance on defining a management plan that includes regular assessments and interactions between patients and their primary care team (measure #1).

Coordination of care is also an important component of care for clinically complex patients. A recent Commonwealth Fund report suggested a “roadmap” for coordination of care, advocating that it should be proactive, planned, comprehensive, support/rely on team care, and jointly developed (with patient/family) to ensure effective communication and collaboration.[23] The expert panel selected several quality measures that place the responsibility of the care coordination on the provider-patient partnership (measures #3-6). For chronically ill children, another facet of care involves the effective transition to adult care providers. The panel selected measures that promote early initiation of care transition and placed the responsibility of identifying future adult providers on the primary care team.

The expert panel focused on several key areas when evaluating quality measures. First, they supported the importance of preventive care for all complex pediatric patients; this includes a comprehensive range of services, from immunizations to timely developmental assessments, as well as dental health screening and obesity prevention. Second, they emphasized that primary care should be delivered by a team of providers, and this is reflected by the consistent use of the term “primary care team.” Last, patient- and family-centeredness are viewed as integral parts of the care delivery process. The panel endorsed making medical records available and accessible to families, building a culturally sensitive environment, and forming a patient-provider partnership of shared decision making.

Conclusions

Quality measures can be used to assess care delivered to patients and to identify deficiencies in care. The development of medical-home-model-driven, comprehensive, family-centered, coordinated, and culturally effective care quality measures is a first step toward improving primary care for complex pediatric patients. The quality scorecard derived from these measures currently showed poor performance and low quality of care at a tertiary children’s hospital ambulatory pediatric clinic. Although not generalizable to all pediatric clinics, this may be an indication of potentially poor-quality care for children with complex disease and needs.

Significance

Complex pediatric patients represent a disproportionately heavy burden on the healthcare system[24-25]; moreover, studies have found that quality of care delivered to these children may be inadequate. Specifically, children with special healthcare needs receive fewer preventive services than otherwise healthy children,[25] and only 53.4% of children with chronic conditions receive recommended care.[14] The quality measures developed in this study would enable providers, health plans, payers, and policymakers to evaluate how well the needs of children are being met and identify aspects of care needing improvement.

Implications

This project provided a conceptual framework as well as the approach to develop primary care quality measures centered on medical-home, patient-centered care. The quality measures published from this project reflect current best practices for providers to deliver high-quality care to children.

Chart-based quality measures provide valuable information regarding the process of medical care and the outcomes associated with care. They also can be useful in monitoring healthcare trends and in identifying deficiencies in care. The progress made here is an important initial step toward providing comprehensive coordinated primary care for complex pediatric patients.

LIST OF PUBLICATIONS

Chen AY, Schrager SM, Mangione-Smith R. Quality measures for primary care of complex pediatric patients. *Pediatrics* 2012: 129(3); 433-45. Epub 2012 Feb 13.

A subset of the quality measures we developed has also been accepted for inclusion in the National Quality Measures Clearinghouse (NQMC), sponsored by AHRQ.

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