ABSTRACT. The movement to measure medical care quality has been accelerating, spurred on by evidence of poor quality of care and trials of interventions to improve care. Appropriate measurement of quality of care is an essential aspect of improving the quality of care, yet some quality measures may be influenced by patients’ attributes unrelated to quality of care. Risk adjustment is the term commonly applied to those methods that account for patient-related attributes, making measurement of health care quality as comparable as possible across providers or organizations seeing different mixes of patients.

The measurement of quality of care for children poses specific challenges. In addition to these measurement challenges, analysts must ensure that quality comparisons among doctors, groups of doctors, hospitals, or health plans are not adversely affected by the likelihood that different types of patients seek care in different places. Although some techniques designed to adjust performance measures for case mix were developed for both adults and children, other systems are specific to childhood circumstances. The theoretical issues involved in risk-adjusting childhood outcomes measures for newborns in the neonatal intensive care unit were reviewed recently. Here, we go beyond the neonatal intensive care unit setting to consider risk adjustment for pediatric quality measures more broadly. In particular, we 1) review the conceptual background for risk-adjusting quality measures, 2) present policy issues related to adjusting pediatric quality measures, and 3) catalog existing risk-adjustment methodologies for pediatric quality measures. We conclude with an overall assessment of the status of risk adjustment for pediatric quality measures and recommendations for additional research and application.

Quality indicators (QIs) are usually described as either outcome or process measures. For example, if we measure health care quality for children with chronic conditions, we may choose 2 different approaches. Process measures examine whether the right care was delivered. In contrast, outcome measures evaluate how well children do after receiving care. Distinguishing process and outcome measures is important for risk adjustment: Both the policy implications and the methods used generally differ between these types of measures.

Quality measures should isolate factors under the control of the unit of observation (eg, providers or hospitals). Risk adjustment involves accounting for patients’ characteristics that influence the quality measure but are not under the control of the provider. To the extent that risk-adjustment techniques are able to adjust for differences in the population that is served, risk adjustment will insure that quality comparisons are valid. The rationale for risk adjustment is generally obvious for outcome measures. However, even some process indicators (eg, vaccination) are not entirely under the control of providers.

Risk adjustments typically include adjustment for health status (and may include socioeconomic status) and other intrinsic patient factors. The technique used can vary by the unit of observation (eg, provider or institution), outcome/process measure of interest, and the type of data used. Decisions regarding when to use risk adjustment for quality measures often can be made on conceptual grounds. Ideally, comparisons of patients’ outcomes should account for all factors that predispose the patient to a better or worse outcome. In practice, the inclusion of all factors is neither practical nor necessary.
because some factors matter more than others, and inclusion of the most predictive factors in statistical models generally accounts for a majority of the adjustment.

The appropriateness of adjusting quality measures for process-of-care (eg, giving an immunization) measures is more complicated. Many process measures require a positive action by patients (eg, bringing an infant for immunization). These measures raise special concerns. Education, motivation, where-withal (eg, transportation, child care, and time off work), preferences for care and outcomes, cultural concerns, and a variety of other factors influence these patient actions. Different health plans and providers see different mixes of patients along these critical dimensions. Because these factors affect immunization rates and they are largely out of the control of the provider, one might argue that risk adjustment is indicated. Yet, an accreditation body making this measure public knowledge in the interest of accountability may want to hold all providers to the same standard of care regardless of the patient population (eg, all children should be immunized). In this context, risk adjustment may be viewed as either unnecessary or even counterproductive. Nevertheless, providers with the more disadvantaged patient population may be required to invest more resources per patient to achieve comparable immunization rates. These providers therefore may be unable to focus equally on other issues (eg, counseling for smoking cessation) or may need more funds to cover the additional work necessary to achieve similar performance.

There are alternative ways of creating comparable groups without risk-adjusting quality measures. Risk stratification refers to splitting populations into specific policy-relevant groups to facilitate comparisons. Risk stratification is an alternative to risk adjustment and is desirable when a patient characteristic that is a potential risk factor could also result from differences in the way that patients are treated (ie, their quality of care). Assuming that data are available on the patient characteristic by which the quality data should be grouped (eg, race), it is preferable to perform risk stratification first (eg, compare performance across plans or providers separately for patients grouped by racial categories). If performance is similar for different plans or providers within each patient stratum, then it would be reasonable to combine patients across strata and risk-adjust for that characteristic, assuming that the conceptual model provides a valid, causal rationale for that characteristic being a risk factor (see Romano for a discussion of the policy issues).

Even when risk adjustment is applied, it does not adjust perfectly for all factors. Thinking about potential risk factors that were not accounted for will assist in interpreting comparisons across plans or providers. Identifying risk factors for poor outcomes or processes also assists in the process of improving care by providing targets for quality-improvement interventions.

### Issues in Risk-Adjusting Pediatric Quality Measures

Many characteristics make children special: relatively low mortality and morbidity rates; specialized pediatric services (eg, neonatal intensive care unit [NICU] care); use of providers and institutions outside the traditional health care delivery system (eg, school health clinics); and the need for adult help and supportive environments. These considerations often make risk adjustment more challenging for children than adults. Importantly, these factors also complicate efforts to define pediatric quality measures regardless of risk. Several factors are especially important when designing risk adjustment for pediatric quality measures.

The first factor is the epidemiology of childhood disease and chronic conditions. Except for specialty clinics, the number of children with any particular serious health condition is likely to be small, especially for individual providers. Even for relatively common chronic conditions such as asthma, numbers of patients may be too small for individual providers to support QIs or adjust for risk. Most children are hospitalized relatively rarely; hospital-based quality measures will be less useful than for an adult population. Nonetheless, comparisons between hospitals or hospital units are still useful in children, especially when their care is concentrated (such as comparing NICU outcomes or the results of congenital heart disease surgery). These comparisons require appropriate adjustments.

Second, the meaning and use of diagnoses, drugs, and procedures are sometimes different for children compared with adults. Although diagnoses can serve as important risk adjusters for the high percentage of older adults with multiple conditions, symptoms, developmental milestones, and functional status may be more pertinent for children. The standard diagnosis coding nomenclature in administrative databases, the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) does not contain codes for many of these developmental or functional attributes. ICD-9-CM codes for symptoms and signs give little indication of condition severity or chronicity. In addition, the meaning of codes may be different for children and adults (eg, murmur and sleep disturbance). Most studies of coding completeness and accuracy have targeted Medicare populations, as have most regulations involving auditing and oversight of coding and medical record documentation. Diagnosis coding and medical record documentation may be even less accurate and clinically meaningful for children than adults.

Researchers recently developed risk-adjusted tools based on pharmacy claims. Patterns of medication use are different in adults and children. Many drugs are not tested in children, and as such, pediatric use is less evidence-based. As for adults, some conditions are undercoded (eg, acquired immunodeficiency syndrome and mental health conditions); whether this impact is greater in children for whom socially disadvantaged labels may have long-lasting effects is unknown. On the other hand, parents...
may seem healthier than they actually are simply because existing data sets do not include all health-related information. These potential biases could compromise risk adjustment.

A related concern is that children use both the pediatric care system (including pediatric subspecialists, general pediatricians, and children’s hospitals) and the adult care system. Because the pediatric care system likely serves children with more severe conditions, risk adjustment may be particularly important when comparing pediatric and adult providers.

Finally, family and community factors strongly influence child utilization and health status. Risk therefore should be measured, at least in part, at the family or parental level. Familial attributes may be particularly important for process-of-care measures. Because of the complexity of identifying and quantifying child outcomes, process measures are likely to be used more commonly than outcomes measures as QIs for children. Timely delivery of preventive services is measured easily and is a common QI for children. Although virtually all children should be immunized, characteristics of the family (eg, living with mother and maternal grandmother, cash assistance eligibility, father living in home with child, presence of an additional preschool sibling, and use of Supplemental Nutrition Program for Women, Infants, and Children) are associated with reduced immunization rates. As noted above, stratification may be the appropriate first step for analyzing differences in process measures, but few databases contain information on these critical familial and environmental risk factors. One promising possible solution makes use of data on socioeconomic status obtained from the census to adjust performance measures such as physician profiles.

The prominent role of the family and environment in which children live is tied to the concerns about equity in the delivery of medical care raised by the Institute of Medicine. Unless these contextual factors are recognized and adjusted for, providers and plans seeing disproportionate numbers of relatively sick and vulnerable children could fare poorly in quality measurement; they may seem as if they are giving substandard care. This could unfairly penalize some providers and make others less inclined to care for disadvantaged children. On the other hand, as noted above, one would not want to hold providers to a lower standard of care for any subpopulations. As such, the decision about risk adjustment depends on both the conceptual model guiding its use and the quality measure’s purpose. Because the requisite data on these risk factors are generally unavailable, comparisons of performance among providers caring for children across the socioeconomic spectrum must proceed cautiously.

**RISK-ADJUSTMENT METHODOLOGIES FOR CHILDREN**

Here we briefly review existing techniques and examples for adjusting pediatric quality measures. Risk adjustment varies depending on the specific quality measure; we present several available pediatric quality measures only as examples. A more complete review of pediatric quality measurement per se is in Beal et al. We consider risk adjustment in 3 categories: 1) generic risk adjustment using administrative data; 2) risk adjustment for specific conditions or settings using administrative or clinical data; and 3) risk adjustment found in major quality-measurement data sets.

**Generic Risk Adjustment**

Several risk-adjustment methodologies use ICD-9-CM diagnosis codes and/or pharmacy claims from administrative data to create predictions of future costs for a defined population. These methodologies, sometimes called “case-mix adjustments,” were originally intended to assist in setting capitated payment levels. Although they have been used primarily to predict costs, they sometimes have been used to assess provider performance (such as comparing hospitalization rates across physicians). Examples of these risk-adjustment systems include the Adjusted Clinical Groups, Diagnostic Cost Groups, the Chronic Illness and Disability Payment System, and the Clinical Risk Groups. Most of these adjustment techniques were developed with the involvement of pediatricians in specifying the clinical algorithms (eg, grouping together clinically homogeneous ICD-9-CM diagnosis codes). Some specifically tested their algorithms on child populations (eg, by using Medicaid or private insurance databases).

One strength of these methodologies for adults is their ability to quantify the combined effect of multiple, coexisting conditions. Because children typically do not have as extensive comorbidities as adults, comorbid diagnoses may not be as useful for adjusting pediatric performance measures. Yet, these risk-adjustment methodologies have been shown to predict subspecialist visit use in adult and child populations. Perrin et al. used these adjustment tools to predict child hospitalizations and emergency department visits. On the other hand, these adjustments have only marginal influence on quality comparisons for which care processes for a single disease (eg, asthma) are being considered.

The Chronic Disease Status (CDS), developed at Group Health Cooperative of Puget Sound, WA, scores individuals based on their pharmacy claims to reflect the number of chronic diseases, the complexity of the regimen, whether the condition is potentially life-threatening, and whether the medications treat diseases and not symptoms. CDS excludes med-
ications for the treatment of diseases of children. Fishman and Shay used the CDS methodology to develop a pediatric-specific model. The increasing ease of obtaining pharmacy information make this risk adjustment with pharmacy data a potentially important tool for populations with health insurance plans (public or private) that offer prescription drug benefits.

Risk Adjustment for Specific Conditions or Settings

Risk Adjustment for Neonatal Outcomes

Morbidity and mortality for newborns, particularly those admitted to NICUs, are important child outcomes. Richardson and colleagues reviewed the literature on neonatal risk-scoring systems that were designed to predict neonatal mortality, length of stay, and total costs. More recently, Richardson et al reviewed issues of risk adjustment for performance measurement in the NICU. Several illness-severity measurement systems for adjusting neonatal outcomes have been developed, and two, the Clinical Risk Index for Infants and the Score for Neonatal Acute Physiology, have undergone rigorous independent evaluation. Some systems (including the Neonatal Therapeutic Intervention Scoring System and the Berlin score) include treatments as part of the score, whereas others (including the National Institute of Child Health and Human Development neonatal network model) include race. The inclusion of treatment and race variables may create unwanted biases in application of these systems to quality comparisons. Despite publications documenting multiple uses for these systems, they have not been extensively applied to compare provider performance outside of a limited set of research studies. Nonetheless, these studies suggest several important considerations if they are to be applied broadly to compare NICU performance. First, these systems have been used successfully to adjust performance comparisons between different NICUs. Second, the performance of these systems varies by both the population of newborns and the time period to which they have applied. Empirically calibrated adjustment systems such as the Score for Neonatal Acute Physiology reflect ICU practices that were common when the system was developed or recalibrated. These systems require updating and recalibrating with therapeutic advances. Third, these systems require data from blood tests (eg, arterial blood gas), and differences between institutions in the timing of blood draws might affect the risk-adjustment scores.

Despite these caveats, risk adjustment for neonatal outcomes is sufficiently well developed and validated to be ready for more widespread use in NICU performance comparisons. Considerable improvements in NICU care would likely result from widespread adoption.

Risk Adjustment for Pediatric ICU Outcomes

Methods for predicting mortality in the pediatric ICU (PICU) have also been developed and studied extensively. The most commonly available tools include Pediatric Risk of Mortality (PRISM), Dynamic Objective Risk Assessment, Pediatric Logistic Organ Dysfunction, and Paediatric Index of Mortality. Dynamic Objective Risk Assessment is an adjustment system that permits daily updating of mortality risk as assessed by the PRISM system. The Societe Francaise d’Anesthesie et de Reanimation maintains a web site at which risks of mortality from each of these instruments can be calculated and compared (http://www.sfar.org/scores2/scores2.html).

PRISM and subsequent revisions (PRISM III) have undergone the most extensive testing and use. PRISM scores, similar to the neonatal scores, rely primarily on data from physiologic measurements made within the first half or full day of admission to a PICU. PRISM has been used to understand differences in PICU admissions between teaching and nonteaching hospitals and the effect of pediatric intensivists on mortality rates. PRISM also has been used to compare hospital length of stay between different institutions. The PRISM system permits comparison of outcomes between different PICUs, and although not currently widely used, PRISM or a system similar to it could be widely used to compare quality of care across PICUs.

Risk-Adjusting Surgical Mortality for Congenital Heart Disease

Surgery for congenital heart defects in children is relatively common at regional centers and, similar to adult cardiac procedures, is technically demanding. For these reasons the outcomes of congenital heart surgery are a logical target for comparisons between institutions. Several groups of researchers have examined mortality after surgery for congenital heart defects. Risk of mortality after surgery for congenital heart defects. Risk of mortality seems to be most closely related to the type of procedure.

Jenkins and et al developed a method of risk-adjusting in-hospital mortality for children <18 years old undergoing surgery for congenital heart disease. They derived the Risk Adjustment for Congenital Heart Surgery measure by using a combination of expert consensus and empirical methods to determine relative risks of in-hospital death based on specific surgical procedure and other clinical characteristics. This system is relatively new and therefore has not been extensively tested, but it may be applied to comparisons of cardiac surgery, which then could be used to help improve care as was done for coronary artery bypass graft surgery in New England.

Risk Adjustment Using Major Quality-Measure Sets

Here we discuss risk adjustment for selected pediatric quality measures found in commonly used measurement sets. Again, our review is not exhaustive but illustrative, focusing on commonly used measures or those for which the risk-adjustment technique illustrates a salient point.

Health Employer Data and Information Set

The Health Employer Data and Information Set (HEDIS), widely accepted as the quality metric for managed care plans, includes several pediatric qual-
ity measures. As with the adult quality measures, HEDIS does not use risk adjustment in the way we have used the term throughout this article. For some measures, instead of including an entire population or condition (such as all persons with asthma) within a measure, HEDIS restricts the denominator to include only those who meet strict definitions of eligibility. For example, the diphtheria-tetanus-acellular pertussis immunization measure excludes patients with encephalopathy. This approach minimizes the need for posthoc risk adjustment. But, because denominators are restricted, the measure applies to only a fraction of the population. HEDIS measures do not adjust for socioeconomic risk, although they can be reported by insurance plan (Medicaid versus private).

HEDIS also includes the Consumer Assessment of Health Plans Study (CAHPS) survey. The publicly reported CAHPS scores results are not risk adjusted, although the survey does contain questions about respondent (parent) and child characteristics that could be used to adjust responses (eg, parental education or child health status). The CAHPS team found that including these elements for adjustment of pediatric CAHPS scores does have a small but significant impact on CAHPS scores. Risk adjustment of adult CAHPS data has been shown to have small but significant effects on quality scores.

Rand's Pediatric Quality Measures

Rand developed a comprehensive set of indicators for quality of care for children and adolescents as a part of a larger effort to collect quality-assessment tools addressing many dimensions of performance for conditions/events such as preventive services, family planning, otitis media, sickle cell disease, and acne. Risk adjustment is largely absent from Rand’s approach, although similar to the HEDIS measure set, indicators of treatment and assessment are conditional on diagnoses and previous treatments. In other words, the Rand measures tightly define to whom the measure should be applied and therefore greatly reduce the need for risk adjustment. For example, “in patients requiring chronic treatment with oral corticosteroids, a trial of inhaled corticosteroids should have been attempted.” In addition, they restrict denominators, eliminating children with contradictions to treatment (eg, contradictions to immunization).

Health Care Cost and Utilization Project QIs

The Health Care Cost and Utilization Project (HCUP) QIs were created in 1994 by the Agency for Healthcare Research and Quality and rely on hospital administrative discharge data. The HCUP QIs use all patient-refined (APR) diagnosis-related groups (DRGs) to risk-adjust certain hospital quality measures. In choosing their risk-adjustment methodology, the Agency for Healthcare Research and Quality considered: the classification and analytic approach; how the method was developed; costs and feasibility; empirical performance (discrimination and calibration); whether the method is “open” (ie, has published logic detailing the methodology); and whether the methodology had achieved official recognition. The choice of APR DRGs was driven in part by Medicare’s reliance on DRGs.

Only selected HCUP QIs are risk adjusted. Risk adjustment is applied by using regression techniques. HCUP identifies 7 pediatric QIs. For pediatric heart surgery volume, the instructions do not recommend risk adjustment. For 5 child measures, HCUP recommends adjusting by age and sex (pediatric asthma admission rate, pediatric gastroenteritis admission rate, hospitalization for bacterial pneumonia, hospitalization for urinary tract infection, and perforated appendix). Risk adjustment using APR DRGs is recommended only for pediatric heart surgery mortality.

GAPS AND IMPORTANT RESEARCH AREAS FOR PEDIATRIC RISK ADJUSTMENT

How much risk adjustment is adequate to “level the playing field?” The answer to this question is: It depends on the quality measure itself and how the information will be used. Even with the relative sophistication of risk-adjustment methods for NICU, PICU, and congenital heart disease deaths, for example, it is still probably unwise to make final decisions about the quality of NICU, PICU, or heart surgery programs on this basis alone. Unmeasured risk factors may still differ across providers (eg, differences in “do-not-resuscitate” practices, at least partially a reflection of patients’ preferences for life-sustaining care). Risk-adjustment methods that account for the most important risk factors are more likely to facilitate drawing inferences about quality of care than methods that account minimally for pertinent risk factors.

Risk adjustment for pediatric quality measures has received little scrutiny. The areas that have generated more attention (NICU and PICU outcomes) represent acute, high-technology care, rarely needed by children. Nonetheless, these adjustment systems are, in general, well tested and validated. Given the well-developed status of ICU outcomes adjustment methods, large-scale risk-adjusted comparisons of ICU outcomes could be used to motivate improvement in the quality of NICU and PICU care. On the other hand, more work is needed on applying risk adjustment to diverse practice settings, in different sociodemographic populations, and across a variety of quality dimensions. As new quality measures are derived, developers must consider which risk factors are pertinent and produce risk-adjustment strategies appropriate to each particular measure.

Despite the conceptual rationale for risk adjustment specific to individual quality measures, reality intervenes. Developing risk adjusters de novo can be expensive, often requiring extensive clinical and methodological expertise, creation of large databases for empirical testing and validation, or data that are difficult or impossible to collect. It therefore may be reasonable to examine the utility of existing risk adjusters for a particular quality measure, recognizing the conceptual limitations and therefore interpreting results with appropriate caveats. An example involves the risk adjusters developed for predicting...
future resource consumption and setting capitated payments. Considerable effort has gone into their development and statistical validation; they rely on readily available administrative databases. Testing their validity for risk-adjusting pediatric quality measures seems reasonable, especially for measures relating to resource consumption (eg, hospitalization rates). One attraction of these approaches for pediatrics is their consideration of the totality of all diagnoses: because relatively few children might have one specific diagnosis, these risk adjusters overcome problems of small disease-specific sample sizes. The obvious drawback is their focus on resource consumption.

As noted at the outset, risk adjustment becomes necessary when people with different risk profiles are not assigned randomly to the “unit of observation” (ie, the groups whose performance one wants to compare). Relevant units of observation for children may differ from those for adults. For children we may care more about schools, health department jurisdictions, provider groups, or communities than hospitals. In addition, we need to better understand the impact on health risks and thus risk adjustment of the large numbers of children with no health care or with care only for prevention and/or acute illness or injuries. Given current data and information systems, it may prove impossible to capture pertinent risk factors for children across different units of observation. Therefore, research must consider how unmeasured risk factors affect perceptions of relative quality across diverse units of observation.

Closely related is the need to know more about the role of family and community characteristics as risk adjusters for pediatric quality measures. As noted above, children depend heavily on their families and communities, and these factors therefore are potentially important risk adjusters. Information from the census and other sources can provide important community information. Parental information may be available in the same data sets as child information when parents and children are insured by the same plan. When parents report on quality, parents can answer questions about themselves and their families.

Linking data systems among institutions that could provide information about child health, such as schools, public health departments, and children’s hospitals, would be an enormous undertaking. However, sharing data will be important to obtaining community-level views of child health quality and various risk factors. Defining relevant roles for various organizations (eg, school and public health departments, Medicaid programs, State Children’s Health Insurance Program, pediatric health centers, and children’s hospitals) and the data available from each might be a good starting point. These issues extend beyond the narrow topic of risk adjustment, highlighting barriers to obtaining comprehensive information about child health, let alone the quality of pediatric care. Risk adjustment is limited inherently by inadequate or unavailable data.

A variety of technical issues also need more study. Many efforts to compare provider performance must contend with small sample sizes; individual providers frequently treat too few patients of a given type each year to generate accurate and stable estimates of their long-term average performance with such patients. Better ways to estimate expected outcomes, such as empirical Bayes and hierarchical modeling, need more investigation. Simultaneous concerns about risk adjustment and small sample sizes can trap comparative efforts between “a rock and a hard place.” The main strategy for increasing the accuracy of estimates is including more cases, but this generally increases population heterogeneity and makes risk adjustment both more necessary and more problematic.

Thinking about valid risk adjustment is premature without assuring the validity of the quality measure to be risk adjusted. Risk adjustment aims to control for patient factors outside provider control so that residual differences in performance could, potentially, reflect quality differences. Few measures currently used as ostensible QIs have undergone such scrutiny. For example, risk-adjusted NICU and PICU mortality rates are putative quality measures, but no one really knows whether differences across institutions reflect quality problems that, if resolved, would lower mortality rates. Research about validity of quality measures themselves should be linked directly to risk-adjustment research: they should go hand in hand. Methods must be validated across time and settings of care (eg, academic health centers versus community facilities). Changes in patterns of care (eg, diagnostic testing or therapeutic interventions) and differences across settings could affect the type of data available for risk adjustment and the relationships between the risk factors and outcome of interest. Risk adjusters should generally be updated periodically, requiring an ongoing research commitment and investment.

Finally, we need to better understand how risk-adjusted quality measures will be used and disseminated. Risk adjustment will never be perfect; it is impossible to adjust for all relevant risk factors. Understanding better how to disseminate admittedly imperfect information to clinicians, parents, plans, purchasers, and even older children requires more study. Given the ultimate goal of improving child health care, it is critical that battles over measurement methods not unduly divert resources and attention, as has happened sometimes in adult settings.

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