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Quality of Health Care in the United States: Implications for Pediatric Inflammatory Bowel Disease

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Abstract

The Institute of Medicine's publications **To Error is Human** and **Crossing the Quality Chasm** publicized the widespread deficits in U.S. health care quality. Emerging studies continue to reveal deficits in the quality of adult and pediatric care, including subspecialty care. In recent years, key stakeholders in the health care system including providers, purchasers, and the public have been applying various quality improvement methods to address these concerns. Lessons learned from these efforts in other pediatric conditions, including asthma, cystic fibrosis, neonatal intensive care, and liver transplantation may be applicable to the care of children with inflammatory bowel disease.

This review is intended to be a primer on the quality of care movement in the United States, with a focus on pediatric inflammatory bowel disease. In this article, we review the history, rationale, and methods of quality measurement and improvement, and we discuss the unique challenges in adapting these general strategies to pediatric IBD care.

Keywords

Crohn's disease; ulcerative colitis; healthcare quality; quality improvement

A. Introduction

The quality of health care in the United States has received considerable attention in both scientific journals and the lay press in recent years. There is now abundant evidence that the U.S. health care system is facing a widespread quality problem, involving nearly every aspect of medical care including pediatric inflammatory bowel disease (IBD). Fortunately, a number of quality improvement strategies have been developed and applied over the last several decades, and lessons learned in other medical specialties may be applicable to pediatric IBD including Crohn's disease (CD), ulcerative colitis (UC), and inflammatory

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bowel disease unspecified (IBDU). The objectives of this article are 1) to provide an overview of quality of care research in the United States, 2) to review examples of quality measurement and improvement from the pediatric literature, 3) to underscore the need for quality improvement (QI) in inflammatory bowel disease, and 4) to discuss specific issues related to pediatric IBD quality improvement and review the early work in this area..

B. Overview of Quality of Care in the United States

Early History

While the topic of health care quality has received significant attention in recent years, the concept of measuring and improving the quality of care began over one-hundred years ago with the American College of Surgeons (ACS) employment of Earnest Codman's "end-result system" [1] to track patient outcomes. The ACS was later joined by the American College of Physicians (ACP), the American Hospital Association (AHA), the American Medical Association (AMA), and the Canadian Medical Association (CMA) to form the Joint Commission on the Accreditation of Hospitals in 1951. Since then, the quality of care movement in the United States has grown and evolved.

Principles of Quality Measurement

Avedis Donabedian, one of the founding fathers of the quality of care movement, outlined a framework for measuring quality of care along three dimensions—Structure, Process, and Outcomes [2] (Table 1). *Structural Measures* are characteristics of the setting in which care is delivered (nurse/patient ratio, use of electronic medical record system, practice type, level of accreditation). *Process Measures*, largely developed from evidence-based practices, indicate the steps taken by health care providers in the care of an individual patient (timely prescription of medications, ordering appropriate screening exams). *Outcome Measures* indicate what happens to patients as the result of an intervention (disease activity, quality of life, etc.).

Though outcome measures have the most intrinsic value, numerous factors complicate their use. First, factors outside the control of the health care provider (e.g. disease severity, comorbidity, socioeconomic factors, adherence) contribute to patient outcomes. Although the process of "risk-adjustment" attempts to take many of these factors into account, it is an imperfect science. Thus, the relationship between process measures (*i.e. doing the right thing*) and outcome measures (*i.e. having the desired result*) is not always linear. A second limitation to outcome measures is that disease outcomes may not occur until several years after treatment has begun. This is especially true for a chronic illness such as IBD, creating difficulty in studying and measuring quality of care.

Consequently, process measures have been the most widely-studied quality measure. They are more sensitive [3], more responsive to change, more accepted by physician groups, and more resistant to bias from imperfect risk-adjustment strategies (if exceptions are allowed for contraindications such as co-morbidities). However, if process measures are to be meaningful, strong evidence linking clinical processes to improved health outcomes is necessary. Thus, the use of process measures for conditions such as pediatric IBD, for which

broadly applicable, evidence-based practices are few and clinical practice guidelines do not exist, is challenging.

Pioneering Studies

The 1970's work of John Wennberg and Alan Gittelsohn kindled the quality of care movement by demonstrating small-area variations in the utilization of health services and associated expenditures.. Variation in care has the potential to affect quality when it results in underuse, overuse, or misuse of diagnostic and therapeutic interventions, and is frequently cited as a marker for "serious and widespread quality problems" (Table 2) [4] [5]. In performance variation, a difference exists between what is considered optimal performance and observed performance [6] [7]. Several studies in the mid-1990's demonstrated that beneficial therapies were often withheld [8], risky or unnecessary therapies were given [9], [10], or preventable complications/mortality were experienced by an unacceptable number of American patients [11, 12]. Prominent examples include the publication of hospital mortality rates by the Health Care Financing Administration (Medicare predecessor) in 1986–1991 [13] and of coronary artery bypass surgery outcomes by the New York State Department of Health in 1989 [14].

Institute of Medicine Reports

In the years 2000 and 2001, the Institute of Medicine published two reports,***To Err is Human***[15] and***Crossing the Quality Chasm***[16], which thrust quality of care into the public eye and resulted in public demand for accountability from the health care profession. In 1990, the IOM defined quality of care as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." [17] Over a decade later, the Institute of Medicine's Committee on Quality of Health Care in America found "strong evidence" that Americans were not receiving health care that was based on the best available scientific knowledge [4]. *To Err is Human*, reported that "tens of thousands of Americans die each year from errors in their care, and hundreds of thousands suffer or barely escape non-fatal injuries". Fifteen months later, the *Crossing the Quality Chasm* report concluded that "between the health care we have and the care we *could have* lies not just a gap, but a chasm." The IOM reports were a call to action—implying that quality can be defined, should be measured, and that the entire health care system must be involved to substantially improve care.

Further evidence of the quality chasm

Many subsequent studies published over the last five years have reinforced the findings of the IOM reports. McGlynn and colleagues, in a large study of outpatient quality of care, demonstrated that adults receive only 54.9% of recommended care [18]. Unexpectedly, they found little racial and socio-economic disparities in the provision of care: all groups experienced deficient care at essentially the same rate [19]. Children faired worse than adults, receiving only 41% of preventive services and 53% of recommended vaccinations [20]. Inpatient care also has quality deficits. In a study of 10 widely-accepted hospital quality indicators for acute myocardial infarction, congestive heart failure, and pneumonia,

Jha et al observed that the quality of hospital care in the United States varies widely across different quality indicators [21]. Numerous additional studies have echoed these findings of on-going deficiencies in inpatient and outpatient care [22] [23] [24].

Key Stakeholders

Several key stakeholders, each with a vested interest in improving the quality of care delivered to Americans, have emerged in response to these reports of deficits in health care quality. These stakeholders include: 1) government and other regulatory bodies, 2) foundations, 3) patients, 4) payers (Medicare, Medicaid, and commercial insurers), and 5) providers (physicians, hospitals, etc.) Understanding their roles and perspectives helps to shed light on some of the drivers of the quality of care movement.

Governments and Foundations: “Determined Leaders”—Preceding the IOM reports, the US Government’s Department of Health and Human Services made quality a priority in 1989, with the establishment of the Agency for Health Care Policy and Research. Later renamed the Agency for Healthcare Research and Quality (AHRQ), its mission includes promoting high scientific standards for quality improvement and patient safety, outcomes and clinical effectiveness research, clinical practice and technology assessment, and the study of health care organization, delivery systems, and financing [25]. Furthermore, the Center for Medicare and Medicaid Services (CMS) has been on the leading edge of quality improvement since the 1970's, promoting transparency in health care reporting and adoption of novel health-care financing strategies. In addition to government involvement, many private foundations and business collectives have also added force to the healthcare quality revolution, each unique in its scope and goals but with the welfare of the patient in mind.

Patients & payers: "Motivated Consumers"—Many patients receive health care access through employer-provided health insurance. Concerns with escalating costs and gross medical errors have motivated patients and insurers to speak out against gaps in the healthcare system. Together, employers, patients, and insurance companies are one of the largest “purchasers” of health care and have become a formidable bargaining collective, demanding both accountability and value for their product. Patients want the highest quality care; however, insurers are reluctant to pay for expensive care unless it is effective. An emerging concept is “value based purchasing” [26], where interventions are ranked and reimbursed according to cost and effectiveness. Insurers have also begun to develop their own measures and rewards of quality, including designating “preferred providers” and publicly ranking hospitals based on quality indicators. A notable exception at the present time is the treatment of rare diseases, including pediatric IBD, for which limited clinical evidence precludes these standardized approaches.

Providers: “Reluctant Partners”—Physicians have often approached the subject of quality of care with a mixture of “anger, skepticism, or simply disinterest” [27] due to concerns with the validity, reliability, and accuracy of quality measurement [27] [28]. There is also the fear that quality assurance measures are “disguised … efforts to control costs rather than improve quality” [29] [28] [30]. However, physician groups are now realizing

that active participation is required to ensure valid, systematic application of quality measurement. For example, in 2004, the American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP) joined the commercial insurers of America's Health Insurance Plans (AHIP) and the Agency for Healthcare Research and Quality (AHRQ) to form the Ambulatory Quality Care Alliance. Similarly, the American Medical Association has created the Performance Improvement Collaborative partnering physician specialty organizations with experts in methodology and data collection to create performance measures for the CMS's Physician Quality Reporting Initiative (PQRI) [31]. The American Academy of Pediatrics, has also established its own quality improvement infrastructure to address quality issue specific to pediatric disease.

Approaches to Quality Improvement

Approaches to quality improvement are varied in scope, design, and target. Ranging from simple to complex, they target health services delivery at multiple points along the process of care. The following paragraphs review several of the commonly used QI methods.

The chronic care model—In its *Crossing the Quality Chasm* report, the IOM concluded that "the changes needed to realize a substantial improvement in health care involve the health care system as a whole". Re-designing delivery systems to support coordinated, multidisciplinary chronic illness care is a major component of this change. The chronic care model is a proposed framework for such delivery system changes [32]. This model posits that improved patient outcomes result from carefully designed systems of care that include patient and family self-management support, delivery system design, decision support, and clinical information systems working in concert with the greater health care organization and community resources (Figure 1). Self-management support emphasizes the patient's central role in managing their health, utilizing motivational interviewing, goal-setting, action planning and problem solving. The delivery system design component involves defining roles and distributing tasks among the medical team, using planned interactions to support evidence-based care, and ensuring regular follow up. Decision support embeds evidence-based guidelines into daily clinical practice. Clinical information systems 1) provide timely reminders for needed services, 2) summarize data to track and plan care, 3) identify groups of patients needing additional care, and 4) facilitate performance monitoring. Incorporation of these chronic care model components encourages productive interactions between informed, activated patients and prepared, pro-active practice teams. Not surprisingly, interventions designed with this framework have resulted in improved outcomes in a number of pediatric [33] and adult chronic conditions [25].

Improvement collaboratives—Quality improvement collaboratives have emerged as a widely endorsed approach to organizing improvement efforts at hospitals and/or ambulatory practices. [34] These collaboratives date back to the mid-1980s, with some of the earliest and most successful examples including the Northern New England Cardiovascular Disease Study Group, the US Veterans' Affairs National Surgical Quality Improvement Program, and the Vermont Oxford Network. These ongoing initiatives have improved care and saved many lives [35] [36] [37]. Improvement collaboratives bring together multidisciplinary teams from multiple sites focusing on a common problem. Experts in clinical and

performance improvement provide the group with training in quality improvement methods. Teams review the evidence for recommended care practices, set measurable targets, track their performance and receive feedback, study effective changes from other sites, and adapt and expand these changes at their own centers. Although this model has considerable face validity and has been popularized by the Institute for Healthcare Improvement and similar organizations, the evidence to support their widespread use remains limited and the impact on outcomes has been moderate, at best [38].

Health Information Technology (HIT)—Adoption of HIT is a major priority for healthcare leaders [4, 7, 16]. The *Crossing the Quality Chasm* report underscored the importance of improving the information technology infrastructure, and HIT has been incorporated into the CMS Quality Roadmap [39]. Examples of HIT QI interventions include computerized order entry [40, 41] [42] [43], clinical decision support systems [44] [45], automated patient and physician reminder systems [46], chronic disease management tools [47], telemedicine [48], and electronic health records [49] [50].

In 2005, Garg and colleagues published a review of computerized decision support tools [44]. They examined 100 randomized and non-randomized trials where a control group was employed, including systems for diagnosis, disease management, reminders for preventive services, drug dosing and prescribing. A significant proportion of the trials showed statistical improvement in provider performance; however, improvement in patient outcomes remained marginal. Another example of HIT is the use of automated provider reminders for childhood vaccination [51]. In a non-randomized trial, automated reminders were associated with significant improvements in captured immunization opportunities at sick visits (from 11.3% to 32.0%) but only modest improvements at well visits (from 78.2% to 90.3%).

Although the concept of using HIT to improve health care is appealing, the effectiveness of such interventions is difficult to evaluate due to methodological concerns (i.e. small sample size, contamination bias from non-randomized designs [49], and the concern for publication bias [46]), and the strong public pressure to rapidly adopt HIT without rigorous study.

Report Cards and Pay for Performance—Report cards and Pay for Performance (P4P) are two related quality improvement strategies that have been recently promoted [52] [53] [54]. Report cards, also known as “peer-comparison feedback” [55], provide physicians with a direct comparison of their performance relative to their peers. P4P is a financial incentive strategy linking performance to reimbursement. Advocates of reports cards and P4P hope to promote transparency in the health care system, empower patients to make more informed healthcare choices, and provide a mechanism to reimburse physicians for providing quality care.

The CMS, private foundations, health care leaders, and payers quickly embraced report cards and P4P, hoping that identifying and reimbursing high-performance could resolve the tension between cost, quality, and effectiveness [30] [7] [56]. To date, the evidence for the effectiveness of report cards and P4P has been modest. Hannan et al analyzed the impact of New York State’s coronary artery bypass graft reporting and concluded that report cards had

reduced risk-adjusted mortality by 41% [14]; however, a meta-analysis of peer-comparison feedback interventions found a statistically significant but clinically unexceptional odds ratio of 1.091 (confidence interval 1.045 – 1.136) [57]. A systematic review of seventeen P4P interventions found that 13 of 17 demonstrated a partial or positive effect on some aspect of care, one demonstrated a negative effect, and four led to unintended consequences [58].

A number of additional concerns with report cards and P4P potentially limit their effectiveness. They have been criticized for providing incentives to avoid care for severely ill or complex patients [59] [7]. Physicians may be tempted to exaggerate the initial severity of their patients' condition to reap financial rewards for “miraculous” recoveries [60] or claim that an improvement in medical history documentation (immunization or tobacco use history) is an improvement in intervention (administering vaccines on schedule or promoting smoking cessation) [61] [62]. Finally, P4P and report cards have the potential to widen, or at least fail to correct pre-existing racial and ethnic disparities [52] [63]. Despite these criticisms of P4P and report cards, their popularity among the purchasers of health care and the lay public will likely ensure their place in quality improvement in the years to come. [64] [65] [30].

Industrial Approaches—A number of industrial quality improvement strategies, initially developed to monitor the manufacturing process have been adapted for use by the health care sector. The "model for improvement" stems from the work of Walter Shewart [6] and provides a framework for process improvement: (Figure 2) [66] [67]. First, time-sensitive and measurable aims are established, quantitative measures are developed to determine whether specific changes lead to improvement, and changes most likely to result in improvement are identified. These changes are then tested on a small scale using the Plan-Do-Study-Act (PDSA) cycle—planning interventions, trying them, observing the results, and acting on what is learned. Successful changes are refined through several PDSA cycles, implemented on a broader scale, and spread to other parts of the organization or in other organizations.

C: Pediatric Health Care Quality and Quality Improvement: Lessons learned from general pediatricians and other subspecialists

As in adult populations, the pioneering work on quality of pediatric health care began with descriptions of variation in care. In 1989, Perrin et al described variation in the rates of discretionary, but not emergent, medical and surgical conditions in 3 geographic locations [68]. Since that time, a limited number of published reports suggest that quality problems are as widespread in pediatric care as in they are in adult care. Mangione-Smith et. al. examined hundreds of pediatric indicators of outpatient quality, including preventive care, care for acute conditions, and care for chronic conditions. According to data in the medical records, children in the study received 46.5% of the indicated care [20] consistent with prior studies of pediatric quality of care [69], as well as a recent report from the Commonwealth Fund [70]. These deficits provide a clear message that the current U.S. health care system is not meeting the needs of the pediatric population, including those with chronic conditions.

Fortunately, a number of tools for measuring and improving pediatric chronic illness care have been developed by pediatric generalists and sub-specialists alike. Lessons learned from work in conditions such as asthma, cystic fibrosis, neonatal intensive care, and liver transplantation may serve as models for pediatric IBD.

Despite the availability of effective asthma medications, hospital admissions for this condition have been increasing over the last 20 years [71]. The underuse of effective controller therapy is a primary example of the quality gap in pediatric chronic illness [72]. In a recently published evaluation of an asthma improvement collaborative, the intervention group outperformed the control group in a number of process and outcome measures including peak flow monitoring, use of written action plans, and quality of life, yet no differences in the use of long-term controller medications were observed [73]. In a second collaborative which incorporated the concept of P4P, the percentage of patients receiving "perfect care" (controller medications and influenza vaccination) increased from 4% to 88% over a three year period [74]. This collaborative also demonstrated improvement in asthma outcomes including prevention of ED visits, hospitalizations, and missed school. Other QI interventions have been associated with reductions in oral steroid requirements [33] re-admission rates [71], medication prescribing errors, and inpatient length of stay [75].

Cystic fibrosis (CF) is perhaps the best known example of pediatric quality improvement [76]. Since the 1960's, the CF Foundation has maintained a national patient registry containing demographic and clinical data on patients attending accredited CF care centers. This registry data has been used to raise awareness of center-based differences in both the process and outcomes of care. For example, in an observational study ranking CF centers on the basis of median FEV1, widespread differences in lung health were observed between centers. Notably, patients from higher ranking centers had more frequent monitoring of their clinical status, measurements of lung function, respiratory cultures, and use of intravenous antibiotics for pulmonary exacerbations [77]. Additional research revealed variation in the prevalence of nutritional failure ($< 5^{th}$ percentile for age) and life expectancy between centers that could not be explained by differences in case mix alone. Though the response to this data was mixed, most CF providers have accepted such variation as an opportunity to learn from high-performing centers to improve care at all centers [78] a process known as benchmarking [79]. Recognizing this, the CF Foundation has established an infrastructure to promote the development and spread of QI methods in the CF community. A number of QI collaboratives have been formed, based on the principles described above, and preliminary results have been encouraging [80] [81].

A third example of outstanding quality improvement in pediatric subspecialty care is the Vermont Oxford Neonatal Network (VON), a nonprofit organization of over 440 member neonatal intensive care units (NICUs) participating in a range of network activities (randomized controlled trials, outcomes research, and a variety of QI projects). VON maintains a database tracking the treatment and outcomes for high-risk infants receiving neonatal intensive care. The database provides members with quarterly and annual reports documenting performance and providing comparisons of each NICU with the entire VON network. These reports allow identification of opportunities for improvement and the tracking of changes over time. A series of QI collaboratives organized by the VON have

resulted in improved outcomes, including reductions in the number of nosocomial infections, chronic lung disease, and overall healthcare costs. Internet-based QI collaboratives have continued and expanded upon these efforts [82].

A final example of pediatric QI involves the care children following liver transplantation. Therapeutic drug monitoring of calcineurin inhibitors in post-transplant patients is a key driver of graft survival. Yet, in a single-center study, Bucuvalas et al demonstrated that > 50% of calcineurin inhibitor trough values were outside of the target range. Using the model for improvement discussed previously, a series of changes were tested including 1) developing consensus of target levels, 2) development of a protocol for therapeutic drug monitoring, 3) use of provider feedback through statistical process control charts, and 4) implementation of a protocol workflow sheet aligned with the protocol (decision support tool). These changes increased the proportion of trough levels within target range to 77% and reduced wide fluctuations of trough levels [83]. Work in pediatric liver transplantation also recognizes the need to expand outcome assessment beyond patient and graft survival, but also to quality of life years restored, resource utilization, and improved care delivery. Further understanding of these outcomes will help guide future research and care improvement initiatives [84].

D. Quality of care and quality improvement in pediatric inflammatory bowel diseases

Defining the need for improvement

Inflammatory bowel disease (IBD), including CD, ulcerative colitis and inflammatory bowel disease unspecified (IBDU), affects greater than 100,000 US patients less than 21 years of age [85]. The financial impact of IBD is substantial, with combined estimated adult and pediatric health care cost exceeding $1.7 billion annually [85]. Pediatric IBD also poses a unique social burden on children and their families, often at a time of fragile personal development during adolescence [86, 87]. Consequently, efforts to improve the clinical outcomes for these children are needed.

As with other chronic conditions, variation in care often is a signal that the health care system can improve (Table 2) and recognition of this variation is often the initial step in quality improvement. A small, but growing body of literature is beginning to demonstrate variation in the management of both adult and pediatric IBD. Ersrailian recently found extreme variation in adult provider opinion regarding treatment decision-making in CD, including the appropriateness of 5-ASA therapy, the use of immunomodulators and infliximab in perianal and fistulizing disease, and the indications for antibiotics in newly-diagnosed and steroid-refractory CD [88]. This variation may be secondary to the wide range of available treatment options and paucity of broadly-applicable practice guidelines. Thus, it is no surprise that an adult study of IBD practice guideline implementation yielded only modest improvement in guideline use and thus reduced practice variation [89]. A recent qualitative study of adult gastroenterologists' attitudes and practices assessed some of the drivers of IBD practice variation. The authors describe a number of themes that cluster around the belief that optimal treatment strategies for IBD have not been well defined and

that issues of disease variability and patient preference are not adequately captured by existing practice guidelines [90].

Although the lack of sufficient evidence on which to base treatment decisions may be one driver of practice variation, there are other examples of unwarranted variation resulting from underuse, overuse, or misuse of health care services. In a retrospective study of 67 adult patients referred to a tertiary care center, 64% of patients treated with 5ASA had received suboptimal dosing, 60% receiving chronic steroids had not attempted steroid-sparing medications, and 82% of those treated with steroid sparing regimens received suboptimal dosages. This study also found gaps in colorectal dysplasia surveillance and in screening/treatment for osteopenia/osteoporois in patients treated with chronic steroids. Although this study may be limited by referral bias, the data presented reveals a quality gap in IBD care [91]. A subsequent study examined 6 quality indicators based on recently published guidelines from the British Society of Gastroenterology for adult IBD patients treated in general GI and IBD specialty clinics in London. Based on these process measures, the specialist IBD clinics provided higher quality care than the general gastroenterology clinics with regard to screening laboratory studies during immunosuppression initiation, bone protection at times of steroids use, and surveillance colonoscopy; however, gaps in performance were also noted in the specialist clinics [92]. Further quality deficits in care provided to IBD patients have been observed and continue to be evaluated in an ongoing, nationwide UK audit of inpatient and outpatient IBD management [93].

A recent analysis of data from the Pediatric IBD Collaborative Research Group, an ongoing inception cohort of children diagnosed with IBD, demonstrated substantial variation among centers in the initial treatment of CD. Such variation persisted, even after adjusting for potential confounders such as severity, age, and disease location [94]. As with other chronic illnesses, clearly a gap exists between ideal IBD care and actual patient care. Application of the principles of quality improvement discussed above, including measuring processes and outcomes of care, and designing and implementing interventions to improve the processes of care, will be an essential step in improving the outcomes for patients with IBD. Thus, it appears that clinicians caring for IBD patients are in a remarkably similar position to physicians who cared for critically ill neonates or CF patients one decade ago. Hence, there is a clear opportunity for collaborative learning and building new knowledge through the formation of networks that foster outcomes research, including studies of comparative efficacy and clinical effectiveness, and quality improvement.

Challenges to QI in pediatric IBD

As with other complex, chronic conditions with variable phenotypes and clinical progression, measuring and improving the quality of care in pediatric IBD is challenging on a number of levels. First, there is a lack of evidence to support best practices. Few randomized trials have been performed, studies of comparative efficacy are lacking, and the risk-benefit ratio of many therapies including thiopurines, methotrexate, and infliximab has not been adequately quantified. Thus, defining optimal care is near impossible. For these reasons, the *North American Society for Pediatric Gastroenterology and Nutrition* has not published IBD treatment guidelines, and other guidelines, while providing a framework for

medication use, do not precisely identify which patients to treat with which medications [95]. Therefore, defining evidence-based process measures is a significant challenge to quality measurement. However, this challenge is not insurmountable and a number of other aspects of IBD care might be amenable to the development of process measures including standardized assessment of growth, nutrition, and disease severity, preventative measures including influenza vaccination and opthomological examinations, and monitoring for medication toxicity (TB screening prior to infliximab, monitoring of complete blood count and liver enzymes while on immunomodulator therapy, etc.). Indeed, the selection of less controversial process measures has been well established in quality improvement programs for other chronic conditions (eg., annual lipid screening for diabetic patients).

A second challenge is the difficulty in selecting appropriate outcome measures. The ideal outcome measure would be clinically meaningful, easy to measure, applicable to all patients, and responsive to short-term changes. For these reasons the measurement of surrogate outcomes are widely used measures in other chronic conditions. Examples include a hemoglobin A1C in diabetes, or pulmonary function tests in cystic fibrosis. Unfortunately, no surrogate markers exist for IBD. Outcomes such as hospitalization are limited by the fact that indication for hospitalization is often subjective. The use of surgery as an outcome is similarly fraught with difficulty because, in many instances, surgery is an appropriate treatment (to avoid medication toxicity, to improve growth in ileal Crohn's, etc) rather than a negative outcome. Growth is an appealing outcome measure. Growth failure is a significant complication of pediatric IBD, may be correlated with disease activity, and thought to be amenable to medical, nutritional, or surgical interventions. However, the risk of growth failure may vary by disease type (CD versus UC), phenotype, and location, and thus may not be a good outcome measure for all patients. Furthermore, a number of practical issues complicating growth measurement include the difficulty in adjusting for pubertal stage and the need to exclude post-pubertal patients (a sizable proportion of pediatric IBD patients). Ultimately, measures of disease activity, quality of life, and other patient-centered outcomes may be the most appropriate for quality improvement purposes; however, the feasibility of measuring these outcomes in the context of routine clinical care will need to be addressed.

A related challenge is that the drivers of clinical outcomes are often multifactorial and thus may require more complex improvement strategies. For example, HIT interventions may be useful in preventing medication errors through automated drug interaction prompts, and improving health maintenance and immunization through automated reminders. However, improving disease activity and quality of life will likely require simultaneous attention to a number of areas including changing physician practice patterns, enhancing family self-management, and promotion of medication adherence.

A third challenge in pediatric IBD quality improvement is that risk adjustment remains an imperfect science. The heterogeneity of pediatric CD and ulcerative colitis and the lack of reliable prognostic indicators at the present time make risk adjustment especially problematic. However, IBD physicians look forward to the day when clinical, genetic, immunological, and microbial markers will help to more precisely define clinical prognosis and, in turn, facilitate risk adjustment.

Early improvement work and future directions

Given these challenges, pediatric IBD quality improvement can be a daunting task. Nevertheless, it appears that QI (along with basic, translational, and clinical research) is a necessary step to improve outcomes for patients with these conditions. Fortunately, momentum for pediatric IBD quality improvement is building. Increasing numbers of healthcare providers and IBD centers have started to discuss and begun to take actions to improve the care of their patients. Patients and families, many who have been inspired by widely publicized success in cystic fibrosis, are continuing to advance the quality dialogue and have volunteered considerable time serving on the advisory panels of several centers. A number of non-profit organizations have recently become engaged in pediatric IBD quality improvement. The North American Society for Pediatric Gastroenterology and Nutrition has formed a task force on quality improvement within the IBD committee, the Crohn's and Colitis Foundation of America has listed quality improvement as one of the challenges in pediatric IBD and has formed a Quality of Care Initiative, and the American Gastroenterological Association Task Force on Quality has identified CD as one of its key targets. Perhaps the most exciting step in pediatric IBD QI was the formation of the first quality improvement collaborative, the Pediatric Inflammatory Bowel Disease Network for Research and Improvement (PIBDNet) Trailblazer Collaborative in 2007. Preliminary results demonstrate improvement in a number of process measures, including the monitoring of growth and nutritional status [96]. This work is expected to lead to improvement in growth outcomes of affected patients.

Proceed with caution: possible threats of quality improvement

There is now abundant evidence that the quality of medical care in the United States is not nearly as high as desired and limited evidence suggests the same problem exists in pediatric IBD care. As momentum continues to build and further improvement work is initiated, it is imperative that pediatric gastroenterologists, improvement leaders, and other stakeholders pause to consider several pragmatic and methodological issues. First, it is essential to be mindful that not all quality improvement interventions are effective. There are numerous reports in the literature of negative QI studies, or studies that show moderate improvement at best. Furthermore, QI studies are typically not held to the same high standards as other clinical studies. Because randomized trials of QI interventions are uncommon, secular trends and/or co-interventions represent a major threat to the validity of published studies [97]. Given that quality improvement work often consumes a large amount of resources, including human capital, it is important to weigh the potential benefits of quality improvement against the costs involved and the alternative uses of these resources. Another consideration is that of unintended consequences of QI. For example, measuring and rewarding certain aspects of care may encourage those practices at the expense of other, non-measured but equally beneficial practices [98]. Other unintended consequences of QI may arise from changes in the organization of complex systems. These consequences, such as prescribing errors resulting from computer order entry, are often difficult to anticipate [97]. Despite these caveats, the upside for quality improvement work can be tremendous and the pay-offs can be seen over a relatively short period of time (5–10 years). When compared to the investment of resources, risk of failure, potential for harm, and time course required for the

development and testing of medical and/or surgical technologies, quality improvement appears to be a reasonable and necessary step in the effort to improve patient outcomes.

E. Conclusion

The future is bright for quality of care in the United States. After a half-century of slow progress, the quality of care movement was galvanized by two provocative IOM reports. Key stakeholders-providers, purchasers, and the public-have emerged and are shaping the landscape of quality improvement. Momentum and experience using QI methodology (multi-center collaboration, adaptation of the chronic care model, information technology interventions, and public reporting) to improve patient outcomes are growing in a number of primary care and subspecialty settings, most notably cystic fibrosis. As a consequence, pediatric gastroenterologists will have opportunities (and perhaps some pressure) to use similar strategies to assess and improve the care delivered to children with IBD. Quality improvement in pediatric IBD faces a number of unique challenges which will require thoughtful consideration by all stakeholders. Nevertheless, pediatric gastroenterologists have the obligation to patients and the profession to embrace these challenges.

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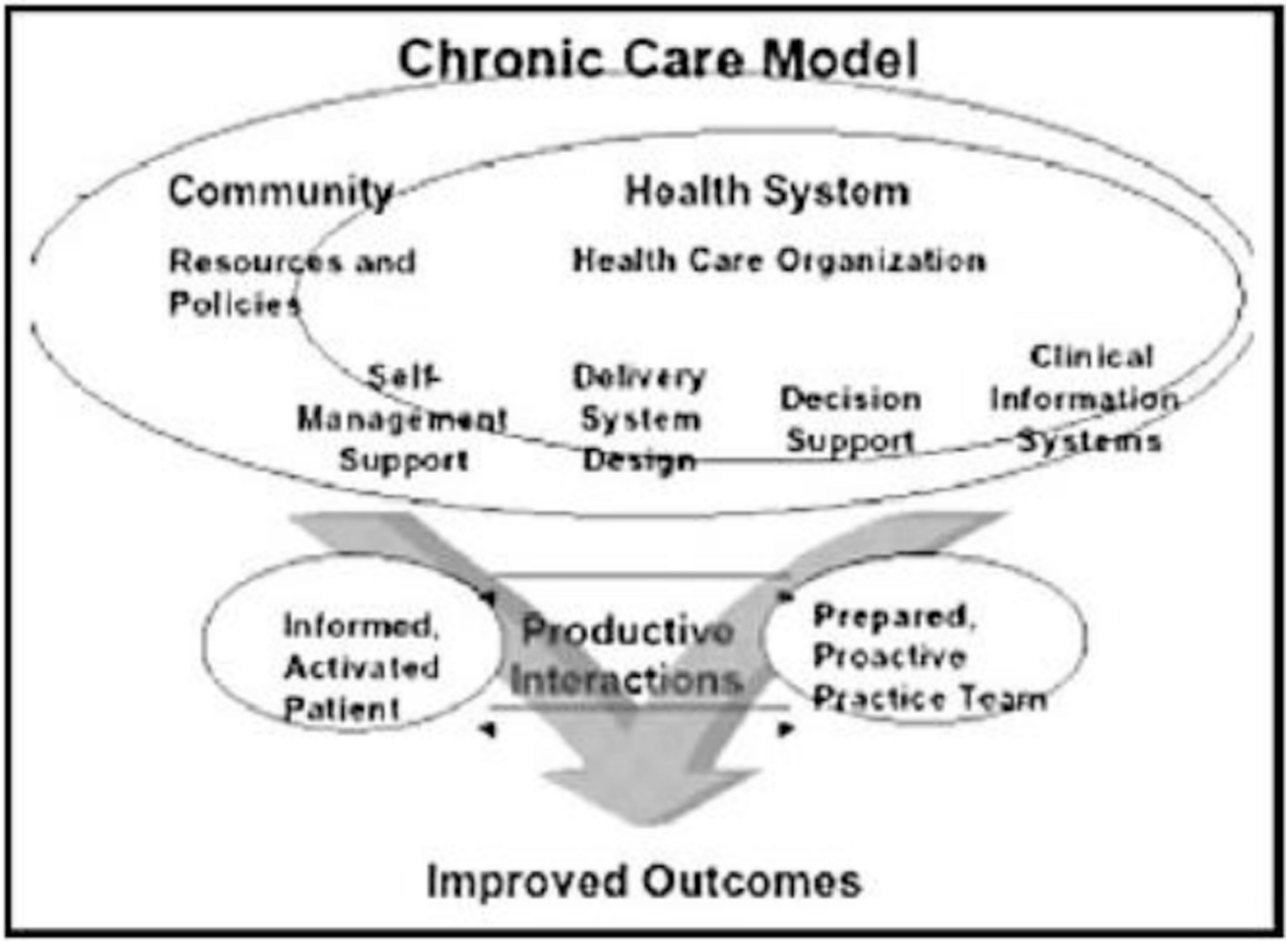

Figure 1. The chronic care model

The chronic care model, a useful framework for delivery system design, posits that improved patient outcomes are the result of carefully designed and coordinated systems of care that include patient and family self-management support, delivery system design, decision support, and clinical information systems working in concert with the greater health care organization and community resources.

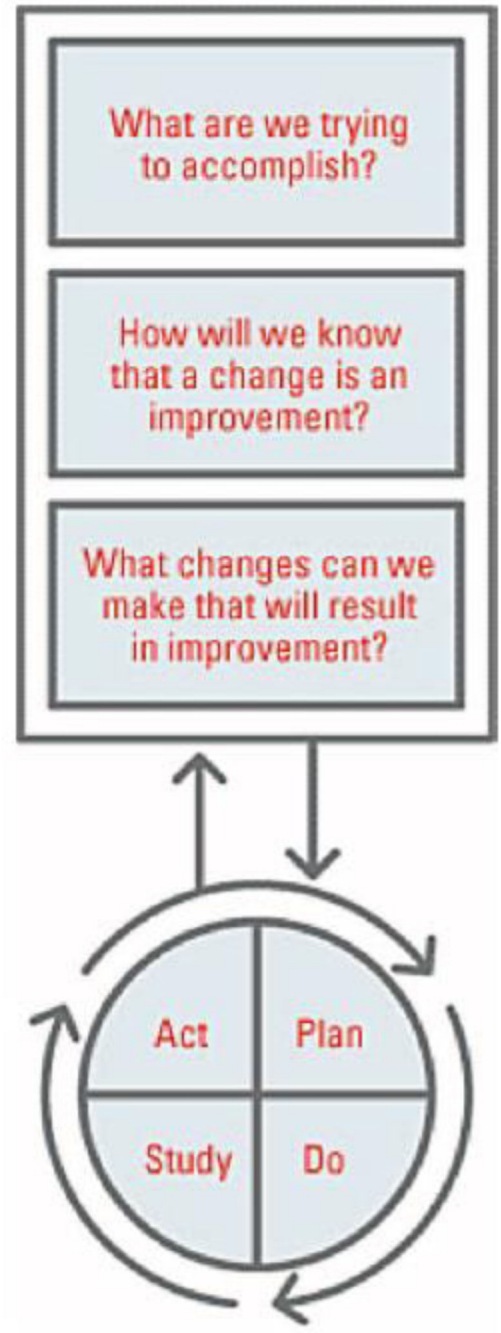

Figure 2. The Model for Improvement

The Model for Improvement describes a stepwise process for process improvement. Time-sensitive and measurable aims are established, quantitative measures are developed to determine whether specific changes lead to improvement, and changes that are most likely to result in improvement are identified. Changes are then tested on a small scale using the Plan-Do-Study-Act (PDSA) cycle-planning interventions, trying them, observing the results, and acting on what is learned.

Table 1

Methods of Measuring Health Care Quality

	Structure	Process	Outcome
Definition	Characteristics of the setting in which the care is delivered.	Indicate what steps health care providers took in the care of an individual patient.	Change in a patient's current/ future health status that can be attributed to antecedent health care
Examples	**1** Nurse to patient ratio **2** Use of electronic medical record system **3** Practice type **4** Level of accreditation	**1** Timely prescription of medications **2** Ordering appropriate screening exams, monitoring for medication toxicity	**1** Disease activity assessment **2** Quality of life **3** Functional status
Advantages	**1** Easiest to measure **2** Reflect attributes of the health system as an entire unit **3** Indicate opportunities for system re-design	**1** Direct measure of care **2** Can be condition specific **3** Can reflect evidence-based care **4** Measurable in a timely manner **5** May influence actual practice (P4P as example)	**1** Intrinsically the most meaningful quality indicator (to patients and providers)
Disadvantages	**1** Do not measure care at the level of the individual patient **2** Relatively weak association with patient outcomes	**1** Costly to develop and collect **2** Often do not reflect comprehensive care **3** May encourage over-utilization **4** Rely in documentation of services performed which may not be in clinical records.	**1** Factors outside of the provider's control may influence outcomes; risk adjustment remains problematic **2** Often a long time must elapse before outcomes occur

Table 2

Reasons for Variation in Care

Type of Variation	Definition and types	Examples
Warranted	**1** Variation due to characteristics of the illness itself (disease type, severity, phenotype, etc). **2** Variation driven by patient/family preferences.	- Use of budesonide in mild to moderate ileal Crohn's disease but not in pancolitis - Use of enteral feeding as induction therapy in a patient/family who prefers NG feeds to corticosteroid side effects
Unwarranted	**1** *Variation in effective care and patient safety*—failure to provide care consistent with evidence based practices (underuse) or medical errors (misuse) **2** *Variation in preference-sensitive care*—failure to incorporate patient/family preference in decisions in which two medically acceptable options exist **3** *Variation in supply-sensitive care*—variation in healthcare utilization driven by the per capita quantity of healthcare resources (overuse)	Failure to perform TB screening prior to initiation of biologics Inappropriate medication dosing; failure to consider drug interactions Failure to involve patient/families in selection of maintenance therapy Greater frequency of MRI imaging in hospitals with more scanners and/or radiologists with body imaging expertise in IBD