Using conjoint analysis to assess pediatric gastroenterologists’ preferences regarding the management of pediatric Crohn’s Disease

By

Shilpa Saxena McManus

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Desmond Runyan, MD, MPH

Peter Margolis, MD, PhD

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Abstract

Background: Difficulties in diagnosis, treatment, and chronic management of Crohn’s Disease (CD) may explain the variation in diagnostic evaluation and treatment therapies seen among providers. Our systematic literature review shows that published guidelines do not fully address management of pediatric CD. Therefore, using the Quality Improvement Model, we can systematically gather data from experts on the best way to change current CD management.

Objective: To determine if conjoint analysis can summarize current beliefs among pediatric gastroenterologists on the relative importance of implementing evidence-based changes to improve outcomes of children with CD.

Methods: We administered an online survey, Physicians Beliefs on Crohn’s Management, to a convenience sample of 12 members of the Pediatric Inflammatory Bowel Disease (PIBD) Network. We asked participants to rank 16 different clinic scenarios based on which ones were most likely to improve patient outcomes and analyzed the ranking through conjoint analysis.

Results: One physician completed the survey for a response rate of 8.3%. Results suggest that decreasing steroid use is most likely to improve outcomes while planned care and optimizing nutrition are least likely to improve outcomes. We found the largest effect of interaction to be between standardizing diagnostic evaluation and planned care.

Conclusion: Conjoint analysis has the potential to summarize current beliefs among pediatric gastroenterologists regarding CD management, but before it can be used reliably, it needs to be tested on a larger sample.
Introduction

Pediatric inflammatory bowel disease (IBD) is a chronic, destructive inflammatory disease of the gastrointestinal tract. Children with IBD can be further described as having either Crohn’s disease (CD) or ulcerative colitis (UC). CD is characterized by ulcerations and scarring of the terminal ileum and proximal colon, but can affect any part of the gastrointestinal tract. Patients typically complain of abdominal pain, diarrhea and weight loss, but can also present with blood or mucus in stools, fatigue, growth failure, delayed puberty, or extraintestinal symptoms (erythema nodosum, aphthous ulcers, arthritis, ocular disease, etc.). The estimated incidence of pediatric CD in the United States is 4.56 cases per 100,000 children for all racial and ethnic groups. Approximately 80% of cases are diagnosed after age 10, with an average age of diagnosis of 13.5 years. Only 12% of cases are in children with a positive family history of CD.

Managing children with CD can be difficult. Although characteristics of CD and UC are very different in adults, they are not as distinct in children. For example, adults with CD typically present with diarrhea while those with UC present with rectal bleeding. However, children with either CD or UC present with abdominal pain. This suggests that clinical symptoms may not be helpful in diagnosing children with CD. Secondly, our understanding of the etiology of CD is limited. Development of this disease depends only partially on genetic factors. Potential nongenetic factors include smoking, use of nonsteroidal anti-inflammatory drugs, or the presence of certain microflora in the gut. We cannot
explain how these environmental factors lead to the development of CD, making it difficult to find effective treatments. Finally, CD is a chronic disease, affecting individuals throughout their childhood and adulthood. To manage such individuals, it is important to provide self-management support, coordinate proper interdisciplinary care, and follow evidence based clinical practice guidelines.\(^5\)

Together, difficulties in diagnosis, treatment, and chronic management may explain the variation that Colletti et al. found in diagnostic evaluation and treatment therapies for pediatric CD patients at 30 different IBD clinics.\(^6\) For example, only 75% of pediatric gastroenterologists completed stool cultures to rule out an infectious process,\(^6\) despite the fact that this is recommended for all patients.\(^3\) Similarly, 63% used mesalamine for treatment,\(^6\) but this drug is considered first line treatment for all patients with mild CD.\(^7\) Although variation in care often exists because we do not know the best way to care for a disease, variation may also exist because we know the best way to manage the disease, but not all practices have implemented it. For this second reason, consensus based and evidence based guidelines can improve quality of care by assisting all physicians in providing the best care to patients.\(^8\)

To address this variation in care, we completed a two part study. We first conducted a systematic review on current recommendations for diagnosing, treating, and managing pediatric CD. We then surveyed pediatric gastroenterologists and, using conjoint analysis, summarized their current beliefs on the best way to change current CD management to improve patient outcomes.
Quality Improvement

Definition of Quality Improvement

Quality Improvement (QI) is a set of methods designed to improve the performance of systems. A system is “A network of interdependent components that work together to accomplish a shared aim”. For example, the network of activities performed in a CD outpatient clinic is a system that creates a particular set of outcomes. To meaningfully improve these outcomes, we cannot make changes such as hiring more nurses for each clinic or asking doctors to work longer hours because these are merely ways of adding resources. Instead, QI involves changing the way components of a system work together.

In order to conduct QI, we need to understand the following theoretical and methodological principles of QI. The four principles are: 1) appreciation of the system; 2) learning from variation; 3) building knowledge through testing; and 4) human reaction.

Appreciation of the System

This first principle means that to improve outcomes, you must first understand that they are the result of a system or a set of care processes. Therefore, to improve the result you need to identify the system. One way to describe a system that is applicable to CD patients is to use Wagner’s chronic illness care model. In this model, community resources and policies interact with the health care system, which is defined as family and self management, delivery system design, decision support, and clinical information systems. As the name implies, family and self management is when CD patients and their families
manage their chronic illness. Delivery system design describes the roles and activities of staff within CD clinics. Decision support refers to processes that support the use of evidence based care by the provider. Finally, a clinical information system aids providers in monitoring the overall care of each patient as well as all the patients in the practice.

*Learning from Variation*

If all systems are not standardized then we will observe 2 types of variation in the results.\textsuperscript{11,12} The first type of variation is variation due to chance, which typically falls within ±3 standard deviations of the mean. The second type of variation is due to differences in systems and is defined as >3 standard deviations from the mean. For example, not all outpatient CD clinics have the exact same infrastructure. Depending on location or funding, the clinics may have different services or referral resources. This variation between systems may lead to significant variation in outcomes for CD patients. By studying the second type of variation, we can learn which changes to a system may lead to improvement in patient outcomes.\textsuperscript{12}

*Building Knowledge through Testing*

QI methods represent a means of applying the scientific method to learn rapidly in a complex organizational system. An example of such a tool is the model for improvement created by Langley et al.\textsuperscript{11} The two component model is designed to help individuals apply the scientific method to the improvement of systems. The first component is the planning component, which is comprised of three main questions: 1) What are we trying to accomplish? 2) How will we know
that a change is an improvement? and 3) What changes can we make that will result in improvement? The second component, the action component, was first developed by WE Deming for quality management and is comprised of continuous Plan-Do-Study-Act cycles. During the Plan phase, we identify the problem and the changes we would like to make. In the Do phase, we implement a change, often on a small scale, and then during the Study phase we evaluate the effects of the change in comparison to our aim. Finally, during the Act phase, we formalize the change and consider implementing it on a larger scale. QI should be a continuous process because our environment is constantly changing. Therefore, after the Act phase, we return to the Plan phase to decide what other changes should be made.

*Human Reaction*

The last principle of QI is anticipating how individuals will react to the changes. For example, providers may react positively to a new standardized diagnostic protocol because they feel that it simplifies diagnostic evaluation and leads to proper diagnoses of all their patients. On the other hand, they may react negatively because the new protocol may influence long established habits.

**Applying Quality Improvement Models to Pediatric CD Management**

*Significance of QI*

In 2001, the Institute of Medicine (IOM) concluded that a large chasm exists between the health care we have and the health care we could have. This lack of quality health care is from underuse, overuse, and misuse of health care
services. The root of these three problems are the increase in prevalence of chronic diseases, the growing complexity of science and technology, and our poorly organized health care delivery system. To address the health care chasm, the IOM created 10 “rules” that would redesign our current health care system. Rule number 5 encouraged the use of evidence based care because systematic reviews and clinical guidelines along with reminder systems can improve patient care. To provide consistent, high-quality care to patients with CD, we can use QI methods to identify and develop clinical guidelines.

**Idealized Design**

To identify the best way to manage pediatric CD, we need to first develop a theory or hypothesis for which changes in management of pediatric CD will improve outcomes. As the systematic literature review below will show, we have very few published guidelines on CD management that we can follow. Since we cannot use the literature to define our recommended changes in management, we must systematically gather data from experts in the field. The protocol that we will follow is based on the Idealized Design Process described by Ronald Moen in “A Guide for Idealized Design”. This explicit process for design improvement is based on prior strategies used in industry. Moen describes 6 phases, starting from Phase 0 and ending with Phase 5. During Phase 0, which is the focus of this study, we generate new ideas for restructuring the current system in such a way that we improve the quality of care patients receive. During Phases 1 through 4, the new ideas are tested and, finally, during Phase 5, the ideas are disseminated.
The first Idealized Design project was led by the Institute for Healthcare Improvement (IHI) in January 1999. The IHI wanted to redesign the health care system by starting with the clinical office practice. The Idealized Design of Clinical Office Practice (IDCOP) initiative involved 42 practices that tried to improve patient satisfaction, access to care, and the quality of outpatient care. One practice increased their overall percentage of high patient satisfaction from 72% to 95%. They increased access to care by decreasing their waiting time for an appointment from 59 days to 1 day. Finally, they improved clinical outcomes by increasing the percent of diabetic patients who monitor their blood glucose at home from 54.3% to 72.4%.

Change Concepts

Using the steps in Phase 0 of the Idealized Design Process outlined in Appendix A, experts in quality improvement and pediatric gastroenterology identified 5 changes to CD management that they hypothesize will improve outcomes. As the first step, our sponsors, the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) and the American Board of Pediatrics, selected pediatric CD as the topic of interest and provided funding. Next, 2 experts in quality improvement and 3 experts in pediatric gastroenterology formed a team to address this topic. Using questions from the planning component of the model for improvement, the team developed a charter with the goal of improving outcomes for children with CD. For the 5th step, the 5 experts reviewed both research based evidence and anecdotal evidence on managing Crohn’s disease. They used the Chronic Illness Care model by
Wagner as a framework to organize the evidence.\textsuperscript{5,19} Next, the team selected a large hospital in the northeastern US and observed how patients were managed at the CD clinic. They then held a meeting to brainstorm ideas for improvement based on their observations. Next (step 9), they held a meeting of 20 pediatric gastroenterologists who are recognized experts in CD to narrow down the ideas.

At the meeting, experts identified 5 changes to CD management and 5 outcomes to measure improvement in care. The 5 change concepts were the following: 1) standardize diagnostic evaluation; 2) optimize nutritional assessment and management; 3) planned care; 4) promote patient and family self-management; and 5) decrease use and duration of steroids. For details on the definitions of each change concept, please refer to Appendix B. The outcomes were reducing overall disease activity, increasing quality of life, achieving normal growth, decreasing complications of IBD, and decreasing medication side effects. Quality of life would be measured using IMPACT 35, which is a validated 35 question survey designed for children and adolescents that determines the effect of IBD on health.\textsuperscript{20} To determine what pediatric gastroenterologists hypothesize is the effectiveness of each of the 5 change concepts for improving patient outcomes, we will conduct a conjoint analysis, as recommended in Phase 0 (Appendix A).

\textit{Conjoint Analysis}

Conjoint analysis has been used traditionally in marketing research to determine consumer preferences by assessing the relative importance of groups of attributes.\textsuperscript{21} This allows us to calculate which attribute is the most important and which less important attributes consumers are willing to give up for their most
important attribute. We can then predict which trade-offs consumers will make when purchasing a product. This indirect method is more effective than directly asking the consumer because, similar to real life, it forces the consumer to make trade-offs.23

In clinical trials, interventions are done one at a time. This allows us to compare one single intervention to placebo or standard care and determine which is better. However, in clinical practice, many interventions are made at once, making it difficult to identify which change had the largest effect. Sometimes two interventions interact synergistically such that the effect of both changes is greater than the effect of each on its own. Similar to real clinical settings, a conjoint analysis allows us to hypothesize which intervention has the largest effect and which two changes work synergistically when many changes are made at once.

Three types of conjoint analysis exist and depending on the type of research, one is usually more appropriate than the others. Choice-Based Conjoint (CBC) uses interview questions that mimic the process for purchasing competing products. CBC is appropriate for predicting product choices and for measuring interactions between attributes that have more than 3 levels. For example, 5 different sedans may be described by 4 attributes: price, gas mileage, safety rating and color. Each attribute can then have different levels. An attribute with more than 3 levels could be car color because the sedan may come in blue, green, red and gray. Rather than rank the 5 cars, respondents are asked to choose the one they would purchase. For this study, we were more interested in the
importance of attributes rather than predicting product choices. Therefore we decided that CBC was not appropriate for this study.

The second type of conjoint analysis is Adaptive Conjoint Analysis (ACA), which asks respondents to first rank all of the attributes and then compare pairs of products with different levels for each attribute. ACA is computer administered because interview questions are adapted to the respondents’ previous answers. This allows respondents to evaluate 8-15 attributes without being overloaded by seeing all attributes at once. ACA also allows the researcher to have a smaller sample size because the estimates of the respondent’s preferences are more accurate. Since this study only has 5 change concepts or attributes, we felt that the complexity of ACA was unnecessary.

Traditional Full-Profile Conjoint Analysis (CVA) is the third type of conjoint analysis and is the most appropriate type of analysis for this study. Respondents are asked to rank products with different levels for each attribute. CVA can only be used to evaluate up to 6 attributes because respondents must see all the products and their attributes at once. If respondents are asked to evaluate more than 6 attributes, they cannot process them effectively. Similar to CBC, CVA can measure interactions between attributes, but the attributes must have less than 3 levels. For this study, we chose CVA because we have 5 attributes and each attribute has 2 levels. There are only two levels because each change concept is either implemented or is not implemented.

At the end of the conjoint analysis, we will determine if CVA is an appropriate method for identifying which change or changes pediatric
gastroenterologists hypothesize will most improve outcomes for CD patients. With this expert generated hypothesis, NASPGHAN and the American Board of Pediatrics will enter the Plan phase of the PDSA cycle, where they will develop an intervention to test the hypothesis. After several PDSA cycles, they can provide evidence either supporting or refuting the hypothesis from our conjoint analysis.

Systematic Review of Clinical Recommendations for Crohn’s Management

To identify standard practices for CD management, we conducted a systematic review of the literature regarding current guidelines on the diagnosis, treatment and management of pediatric CD. Only some of the articles provided guidelines on our 5 concept changes (Appendix B). We critically appraised the selected articles using the 25 item questionnaire developed by Shaneyfelt, Mayo-Smith, and Rothwangl.25

Article Selection

We searched Pubmed, Ovid and Clearinghouse Guidelines databases for relevant articles using different combinations of the following search string: pediatric, IBD or Crohn’s disease, and recommendations or guidelines. Articles were limited to those published in English before March 2006 and included a list of guidelines or recommendations for pediatric Crohn’s disease. As Figure 1 shows, our online search resulted in 73 articles, 9 of which had potentially relevant titles. Of the 9 abstracts, only 7 were relevant to this topic. This author (SM) reviewed the 7 articles and identified 4 of them that met inclusion criteria.
The hand search of bibliographies from relevant articles and consultation with experts in the field of pediatric gastroenterology led to acceptance of one other article for the systematic review.

*Literature Appraisal Methods*

The 25 item questionnaire for guidelines uses a yes or no format to measure how well published guidelines follow standards on guideline format and development (10 questions), on identification and summary of evidence (10 questions), and on formulation of recommendations (5 questions). Each question is worth 1 point, such that the ideal guidelines would have all 25 items and would receive 25 points. Shaneyfelt, Mayo-Smith, and Rothwangl reviewed 279 guidelines which had a mean score of 10.77 with a standard deviation of 3.7. Using these results, we defined a set of guidelines as good if they were more than 1 standard deviation above the mean, fair if they were ± 1 standard deviation from the mean, and poor if they were more than 1 standard deviation below the mean. Therefore, poor guidelines would have a score less than 8, fair guidelines would have a score between 8 and 14 and good guidelines would have a score above 14 (see Table 1).

*Standardized Diagnostic Evaluation*

Of the five articles that met inclusion criteria, only one suggested guidelines on how to diagnose children with Crohn’s disease. Published by the IBD working group of the European Society for Paediatric Gastroenterology, Hepatology, and Nutrition (ESPGHAN), this article describes a protocol consisting of laboratory tests, endoscopies, biopsies, and imaging for diagnosing
Crohn’s disease. The guidelines received a score of 7 for following standards on
 guideline format and development, a score of 1 for identification and summary of
evidence, and a score of 2 for formulation of recommendations (see Table 2).

Unlike the other articles, these guidelines did not discuss health
outcomes. This may be because they were focused on appropriate diagnosis for
furthering epidemiological data on this disease. Indirectly, the authors are
suggesting that by gathering more data on this disease, we may be able to
understand it better and hence improve treatment and outcomes. However, the
authors did not suggest that, by standardizing the diagnostic evaluation, patients
will be appropriately diagnosed, which would improve health outcomes.

ESPGHAN’s recommendations for diagnosis did not describe their guideline
development or their procedure for identifying evidence, which explains their
poor score for the second section of the questionnaire. For the last section, the
recommendations were flexible and specific to the goals of the guidelines.

However ESPGHAN did not formally grade the recommendations, nor did they
discuss patient preference or the role of value judgments.

Based on the Porto criteria and the limited articles on diagnosing IBD,
there seems to be some controversy on how to differentiate children with CD and
UC. Since it is unclear in the literature on how to best diagnose CD in children,
pediatric gastroenterologists may disagree on the impact of a standardized
diagnostic evaluation.

*Optimize Nutritional Assessment and Management*
Only one article addressed nutritional assessment and management. The American Society for Parenteral and Enteral Nutrition (ASPEN) recommended nutrition screening for all children with IBD and provided guidelines for usage of enteral or parenteral nutrition. For guideline format and development the ASPEN guidelines received a score of 9, for identification and summary of evidence they received a score of 3, and for formulation of recommendations they received a score of 3 (see Table 2).

For the first section of the questionnaire, the ASPEN guidelines discussed everything except an expiration date. Authors did report that ASPEN would continue to review the guidelines and update them on a certain schedule, but then they did not publish this schedule. For the second section, the guidelines cited and graded evidence and discussed harms and benefits, but did not define their methods for data extraction and consolidation. Finally, for the third section, ASPEN did not describe the role of value judgments and patient preference.

The guidelines on nutritional assessment and management, although sparse, seem very clear. Most pediatric gastroenterologists should agree that all physicians should optimize nutrition for pediatric CD patients. However, the feasibility of optimizing nutrition may be limited and may decrease its impact for improving outcomes.

Planned Care

Planned care is when an interdisciplinary team meets regularly to review a patient’s chart and any other patient information and plans what to do next. Typically, the review focuses on disease activity, nutritional status, functional
activity, and the medication list. Then, the team identifies problems in one or more of these areas and creates a plan for patient interaction. No published guidelines addressed the issue of planned care in the management of CD. There are no recommendations on who should be involved in the meetings, what areas of disease management should be discussed, and even if planned care should be implemented in all practices. Since there are no recommendations, it is difficult to predict what most pediatric gastroenterologists believe is the impact of planned care.

Promote Patient and Family Self Management

We found no guidelines that encouraged or discouraged the promotion of patient and family self management. Similar to planned care, it is difficult to predict what pediatric gastroenterologists believe is the impact of self management.

Decrease Use and Duration of Steroids

Only one article reviewed the evidence for various medical therapies, described side effects, and suggested usage and dosage for each medical therapy.\(^7\) These recommendations received a score of 7 for following standards on guideline format and development, a score of 2 for identification and summary of evidence, and a score of 3 for formulation of recommendations (see Table 2).

For the first section of the questionnaire, Escher et al. did not mention their intended audience or users, their external review process, or an expiration date for their guidelines.\(^7\) Similar to the diagnostic recommendations, the treatment recommendations did not clearly explain their guideline development or
their procedure for identifying evidence. Escher et al. did summarize the potential side effects of each treatment in detail. They did not, however, describe how they identified the evidence, what time period it came from, how it was extracted and combined, or if the evidence was of high quality. While we know the benefits and harms of the treatments, we are not told how much they cost. Although the authors of this article gave recommendations for treatment, they may describe this article as a review rather than a set of guidelines. If this is true, then they may not have felt it was necessary to grade their recommendations or explain how they combined their evidence. This does not explain why they did not describe their methods for data extraction. Finally, Escher et al. described how they created their recommendations, but they did not mention patient preference or the role of value judgments.

Besides this one article on recommendations for CD treatment, there are many reviews in the literature discussing treatment options. There seems to be some consensus on which class of drugs is best for CD treatment and the importance of limiting steroids. Therefore, pediatric gastroenterologists are likely to agree on the impact of steroid reduction on patient outcomes.

*Other Aspects of CD Management*

The remaining two articles did not address any of our 5 change concepts, but they did address other important management issues. One article addressed whether routine childhood vaccinations are safe for children with Crohn's disease. For guideline format and development, the guidelines received a score
of 7, for identification and summary of evidence they received a score of 2, and for formulation of recommendations they received a score of 3 (see Table 2).

Similar to the treatment recommendations by Escher et al., the vaccination guidelines did not mention their intended audience or users, their external review process, or an expiration date for their guidelines. Authors cited their evidence and discussed the harms and benefits of vaccination in depth. However, the authors did not explain in detail how they identified their evidence or how they developed their guidelines. Lastly, the guidelines were flexible and specific to guideline goals, but did not discuss patient preference or grade the immunization guidelines.

The other article not addressing any change concepts described strategies for preventing and treating osteoporosis in IBD. The guidelines received a score of 8 for following standards on guideline format and development, a score of 6 for identification and summary of evidence, and a score of 5 for formulation of recommendations (see Table 2).

For the first section of the questionnaire, Scott et al. explained their external review process but did not give an expiration date for their guidelines. For the second part, they described how they identified, extracted and graded their evidence and discussed the harms and benefits of treatment. For the last part, these guidelines met all the criteria.

Overall Findings of Systematic Review

The diagnostic recommendations by ESPGHAN met 10 of the guideline standards. The medical treatment recommendations and the immunization
guidelines each met 12 of the standards. The ASPEN guidelines met 15 of the standards and the osteoporosis guidelines met 19 of the standards. Based on these results, the ESPGHAN, medical treatment, and immunization guidelines were fair while the osteoporosis and ASPEN guidelines were good (see Table 2).

For guidelines to be useful, they need to be up to date. On the other hand, determining how long they will be accurate can be difficult because we cannot often predict when medicine will change. This may explain why none of the articles published an expiration date for their recommendations. Another explanation may be that the group that publishes the guidelines must constantly review the literature and make changes to guidelines on a regular basis. Except for ASPEN, none of the other groups were willing to make such a commitment.

None of the 5 articles attempted to quantify benefits and harms or health care costs. These results are similar to findings by Shaneyfelt, Mayo-Smith, and Rothwangl, who reported that only 14.3% of 279 guidelines quantified health care costs.25 We believe practice guidelines can play a role in decreasing health care costs because they have the potential to decrease mistakes and decrease misuse, overuse, and underuse of medical care. However, very few guideline developers attempt to prove or disprove this belief. This may be because most guideline developers are physicians who have minimal expertise in running cost benefit analyses. Costs may be overlooked because physicians are more focused on providing patients with proper medical care. Finally, authors may not quantify costs because they believe they are not responsible for lowering health care costs.
All five articles describe flexible guidelines that allow the health care provider to use his or her judgment before finalizing a plan of action. However, only one article suggests that the provider should consider their patient’s judgment when deciding appropriate medical care. Guidelines developers may not discuss patient preferences because they believe that by giving health care providers flexibility, providers can then take into account patient preferences. On the other hand, guideline developers may believe that patient preferences should not influence care decisions.

Significance of this Study

Currently, published guidelines do not fully address management of pediatric CD. The systematic review shows that guidelines for the diagnosis and treatment of CD are of limited quality, and the good guidelines that do exist only address osteoporosis and nutrition. We do not have any recommendations discussing patient education or interdisciplinary care, which play a large role in managing chronic diseases. Since current literature on CD management is limited, we would like to begin an improvement collaborative that develops information about what combination of the 5 change concepts improves outcomes for CD patients the most. This will be a $2^{5-1}$ factorial, time series study where each practices adopts one or more of the 5 change concepts and then measures each patient outcome for improvement. Before we conduct the study, however, we would like to formally determine which change concept(s) pediatric gastroenterologists hypothesize will improve outcomes the most.
To determine if conjoint analysis can summarize pediatric gastroenterologists' beliefs on the relative importance and feasibility of implementing evidence-based changes to improve outcomes of children with CD, we administered a survey and conducted a conjoint analysis according to the methods of QI. Based on the literature review, we would expect there to be variation in providers' beliefs on diagnosing children with CD, but not for optimizing nutrition or decreasing steroid use. For planned care and patient and family self management, it is difficult to predict provider beliefs.

Study Methods

Study Population

The Pediatric Inflammatory Bowel Disease (PIBD) Network for Research and Improvement is a collaborative network that allows all physicians in North America who are board certified in pediatrics and gastroenterology to work together to improve the health care of children with IBD. This network provides a secure online system that stores and analyzes data. As of March 2006, there were a total of 72 pediatric gastroenterologists who had entered patient data into the PIBD database. There were 58 males and 14 females ranging in age from approximately 30 years to 70 years old. Race and ethnicity of providers was not reported in the PIBD database. Physicians that played a role in designing and testing the survey were not included in our study.

Rather than contacting all 72 members to volunteer for our study, we gathered a convenience sample of 12 physicians by asking the leaders of one large
academic practice and one small private practice if they would be willing to join our study. Although a random sample of volunteers would have been ideal, we felt we could increase our response rate by asking groups that were more likely to respond.

Survey Development

To determine which of the 5 change concepts pediatric gastroenterologists view as most important for improving outcomes of children with CD, we used CVA to develop a survey for PIBD network members. The first question in the Physicians Beliefs on Crohn’s Management Survey asked physicians to rank clinic scenarios from 1 to 16, based on most likely to improve outcomes for children with CD. Scenarios that were ranked closer to 1 had a higher ranking and were more likely to improve outcomes, while scenarios that were ranked closer to 16 had a lower ranking and were less likely to improve outcomes. Each clinic scenario either did or did not implement each of the 5 change concepts. For example, in one scenario the physician may evaluate a patient using a standardized diagnostic tool and may promote patient and family self management but may not implement the other three change concepts. Table 3 summarizes the descriptors for each change concept used in the clinic scenarios. The second question in the survey asked physicians to rate the feasibility of each scenario with 1 being the most feasible and 5 being the least.

There are 5 change concepts and each change concept has two levels because either the change is implemented or it is not implemented. Therefore, there are $2^5$ or 32 different clinic scenarios. Based on our moderate knowledge on
managing CD, investigators decided to do a screening study to evaluate the impact of the changes and how they interact.\textsuperscript{32} They determined that the survey needed to incorporate only \(2^{16} - 1\) or 16 different clinic scenarios to give a preliminary sense of which combination of change concepts is most important. The non-shaded columns of Table 4 summarize the 16 clinic scenarios in matrix form and Appendix C shows the 16 scenarios in paragraph form. Therefore, to interpret scenario A in row 1 of Table 4, please refer to “Scenario A” in Appendix C. In the survey, the 16 scenarios were presented in a random order, and within each scenario the change concepts were also presented in random order.

Before administering the survey, we piloted the survey twice. The first time, we provided 17 physicians and nurse practitioners with 16 scenarios in matrix form and in paragraph form. The matrix form quickly summarizes all of the scenarios in one table, but it may not be clear what it means to implement a change concept. Therefore, we developed a paragraph form for each scenario to describe only the changes that were to be implemented. We provided participants with both forms of the scenarios to ensure that each participant understood the scenarios. Pilot participants were then asked to rank the scenarios according to most likely to improve outcomes and to rate the feasibility of each scenario.

In general, people reported that they were able to understand and rank the scenarios. Some of the participants reported that the survey only took 15 minutes because they looked at the matrix and based on the number of changes implemented, they ranked the scenarios. Other participants reported that they
preferred the paragraphs, but then to rank the scenarios they would extract how many changes were implemented in each scenario.

The results showed that the survey had good face validity, because the scenarios we expected to improve outcomes were given a ranking between 1 and 5 rather than 11 and 16. Figure 2 shows a dot diagram of the effect size of each change concept and the effect size of the interaction for each pair of change concepts. According to the dot diagram, decreasing steroid use (RX) is the change concept with the largest effect size because it is the furthest away from zero. When looking at the effect size of each pair, all of the pairs are around zero, suggesting no interaction between change concepts. In other words, no 2 change concepts seemed to work synergistically. The response plot in Figure 3 shows this lack of interaction graphically because the two lines are almost parallel. When decreasing use and duration of steroids is added to a scenario, the average ranking of the scenario is 6 points higher. Then, if patient and family self management is added to the scenario, the average ranking is about 3 points higher, independent of the presence of steroid use.

Although we had no hypothesis for which two change concepts would have an interaction, we expected to find at least one interaction. We believe we saw no interaction because by ranking scenarios based on number of changes implemented, participants are not focusing on the scenario as a whole. They are not thinking that 2 specific changes, such as self management and reducing steroids, are more effective at improving outcomes than standard diagnostic evaluation, planned care, and optimal nutrition management.
To address the lack of interaction, we piloted the survey a second time on 2 different providers (1 physician and 1 nurse practitioner). We provided this group with the 16 scenarios in paragraph form only. This time, the scenarios described both change concepts that were implemented and not implemented. We felt that by only providing the paragraph form and by describing both the implemented and not implemented change concepts, providers would have a harder time determining how many changes were implemented. Providers would be forced to look at the scenarios as a gestalt and give a ranking rather than systematically comparing the changes in each scenario. To discourage participants from taking the paragraph form of the scenarios and creating their own matrix, we asked them to spend no more than 30 minutes on the survey.

The conjoint analysis showed that the survey had good face validity and, as expected, showed an interaction between 2 change concepts. Figure 4 shows a dot diagram of the results from the 2 providers. Similar to the first pilot study, the change concept with the largest effect size is reducing steroid use (RX) because it is the furthest away from zero. The largest interaction is between decreasing steroid use and self management because this effect size is furthest away from zero. This interaction can be seen visually by the intersecting lines in Figure 5. The response plot shows that the effect of decreasing steroid use is dependent on patient and self management and vice versa. Therefore, adding decreasing steroid use to a scenario increases ranking by 6.5 points if self management is absent but only by 1.5 points if self management is present. Similarly, adding self
management to a scenario increases ranking by 6.25 points if decreasing steroid use is absent but only by 1.25 if decreasing steroid use is present.

Although both participants in the second pilot study recommended that the scenarios be shortened or provided in bullet format, we believed that the long scenarios accurately measured which change concepts were most important and had the ability to detect an interaction between 2 change concepts. Therefore, the survey format for this study is the same as the survey in our second pilot study. The University of North Carolina at Chapel Hill Institutional Review Board approved this final version of our survey.

Data Collection

Participants were emailed a cover letter which explained the purpose of this study, a copy of the questionnaire, and the definitions of the change concepts (Appendix B). If participants chose to enter the study then they consented to the study and filled out the survey anonymously at www.zoomerang.com. At the end of one week, each potential participant received an email reminding them to complete the Physicians Beliefs on Crohn's Management Survey if they have not already done so and thanking those that had already responded. At the end of 3 weeks, participants completed the study and were no longer contacted. Participants did not receive any incentive to complete the survey. Data was collected by www.zoomerang.com and then exported to Microsoft Excel.

From the first two questions, we gathered data on the rank order and feasibility of the scenarios. The next two questions collected data on participant gender and race. The fifth question asked participants how long they had been
practicing pediatric gastroenterology. The last 3 questions gathered the following data on the practice: 1) practice location; 2) practice setting; and 3) number of new patients with CD the practice sees in a year.

Data Analysis

To analyze the rankings, we used StudyIt software 33, which is a statistical package for running conjoint analysis. We first calculated the average ranking and average feasibility rating for each scenario. Then we determined the effect measurement of each change concept, and the effect measurement of the interaction between change concepts.

Results

Participant Characteristics

Of the 12 physicians that were contacted, 1 physician completed the survey for a response rate of 8.3%. The participant is a white male who has been practicing pediatric gastroenterology for 15 years. He currently works for an urban group practice that sees about 20 new patients with Crohn’s disease every year.

Conjoint Analysis Data

The reported rankings and feasibility for each scenario are summarized in the 2 shaded columns of Table 4. The participant ranked scenario D, which promoted family and patient self management, as the most likely to improve outcomes for patients with Crohn’s disease. Scenario C, which implemented all 5 concept changes, was ranked as second. He ranked scenario M, which decreased
use and duration of steroids, and scenario N, which implemented planned care, as least likely to improve outcomes. The participant reported that no scenarios were very feasible (rating of 1 or 2). Scenarios H and K-O were all rated as being the least feasible.

The effect of each change concept on ranking is summarized in Table 5. These results are also shown graphically in the dot diagram in Figure 6. The change concept most likely to improve outcomes is decreasing steroid use and duration (RX) because this concept has the largest effect size to the left of zero. On average, adding decreasing use and duration of steroids to a scenario increased ranking by 3 points. On the other hand, optimizing nutritional assessment and management (Nutr) and planned care (Plan) are the change concepts with the largest effect size to the right of zero. Adding one of those two concepts to a clinical scenario decreased its ranking by 4.25. Therefore, in the view of this respondent, these two change concepts are not likely to improve outcomes.

The effect of interaction between two change concepts on ranking is shown in Figure 6. The pair of concepts that is furthest away from zero, and therefore has the largest effect size, is standardized diagnostic evaluation and planned care. This interaction is shown in Figure 7 by the two intersecting lines. The response plot shows that the effect of standardized diagnostic evaluation is dependent on planned care and vice versa. Therefore, adding standardized diagnostic evaluation to a scenario decreases ranking by 5.75 points if planned care is absent but only by 0.25 if planned care is present. Similarly, adding planned care to a scenario decreases ranking by 7.25 points if standardized
diagnostic evaluation is absent but only by 1.25 if standardized diagnostic evaluation is present.

Discussion

The goal of this study was to determine if conjoint analysis can be used to summarize current beliefs among pediatric gastroenterologists regarding the best way to change current CD management. Our results suggest that, according to one expert in the field, the change concept most likely to improve outcomes in pediatric CD patients is decreasing use and duration of steroids while the change concepts least likely to improve outcomes are planned care and optimizing nutritional assessment and management. The conjoint analysis shows that standardized diagnostic evaluation and planned care have the largest interaction effect.

Although no studies have used conjoint analysis to determine which attributes of disease management physicians believe are most important, many studies have used conjoint analysis to determine patient preferences for treatment. For example, using conjoint analysis, Johansson et al. determined that most asthma patients prefer using a combination inhaler for both acute asthma attacks and maintenance therapy. They also concluded that patients were willing to pay more for their preferred medications. Only one study, by Brown, Swinyard, and Ogle, used conjoint analysis to determine physician preferences. However, rather than surveying physicians on treatment
preferences for their patients, they surveyed physicians on the value of different attributes regarding potential job offers.

The conjoint method used in this analysis was a traditional full profile conjoint analysis. Stanek et al. used this method to study individual preferences for congestive heart failure treatment outcomes. Each study participant was given 16 different health state scenarios and were asked to rate them from 0 (least desirable) to 10 (most desirable). Each scenario was written as bulleted points rather than paragraph form. In this study, we chose not to write our scenarios as bulleted points because we were worried that participants would dissect each scenario as they ranked them rather than looking at the scenario as a whole. This could lead to an analysis with no interaction effects. On the other hand, the paragraph form may be so overwhelming for participants that they can no longer differentiate between them, making the results unreliable.

Based on our literature review and reviews on steroid use for CD, consensus exists in the literature about the importance of decreasing use and duration of steroids. Aminosalicylates are considered first-line treatment, but for patients who are steroid dependent, the thiopurine agents should be used to reduce steroid use. This consensus in the literature supports our result of decreasing steroid use as the change concept most likely to improve outcomes.

Guidelines for optimizing nutrition from our literature review clearly state the importance of nutrition screening for all children with IBD and the use of enteral or parenteral nutrition for children with growth retardation. Therefore, our result of optimizing nutritional assessment and management as a change
concept that is unlikely to improve outcomes is unexpected. This may be because the respondent felt that optimizing nutrition was not feasible and therefore would be ineffective. On the other hand, his past experiences may have shown him that optimizing nutrition does not improve outcomes.

Finally, our results also suggest that, in the view of one gastroenterologist, introducing planned care to CD management would not be likely to improve outcomes. Since the literature regarding this change concept is limited, this belief may be based on the physician’s own experiences with planned care. Planned care requires the interaction of professionals from different disciplines, which may affect feasibility. Therefore, our participant may have felt that planned care at most CD clinics would be minimal and play a small role in improving outcomes.

It is difficult to know if conjoint analysis can accurately summarize current beliefs among pediatric gastroenterologists for CD management because only one physician responded to our survey. The limited sample also makes it difficult to draw any conclusions from the results, because our study sample may not be representative of all the PIBD network members. To strengthen our results, we will need to increase our sample size by administering the survey to more PIBD network members. To improve our response rate, we may have to provide physicians an incentive because the survey can take an hour of their time. Or, rather than administer the survey online, it may be easier to administer in person because we could place each scenario on an index card and ask participants to rank the cards. With these potential changes in mind, we plan to administer this
survey to all of the PIBD Network members who will be participating in the improvement collaborative that will begin in the fall of 2006.

Conclusion

Variation in diagnostic evaluation and treatment therapies for pediatric CD exists and our systematic literature review shows limited consensus on the best way to manage pediatric CD. Therefore, we must rely on data gathered from experts in pediatric gastroenterology to identify the best way to manage CD.

Conjoint analysis, a tool used in quality improvement, has been used to measure patient preferences for treatment, but our results suggest it can be used to summarize current beliefs among physicians. However, the low response rate of this study requires repeating this study with a larger sample before it can be used reliably.

Acknowledgements

I thank Dr. Peter Margolis for his support and guidance in completing this project and in writing this paper. Dr. John Bucavalas helped complete my literature review and helped in the development of the survey. Dr. Richard Colletti also helped with the development of the survey and its administration to members of the PIBD Network. Finally, I thank Dr. Russ Harris, Dr. Margaret Gourlay, and Dr. Desmond Runyan for their guidance throughout the writing process.
Figure 1. Flow Diagram of Systematic Review

- Searching Ovid, PubMed, and Clearinghouse guidelines, found 73 potential articles
- 9 articles assessed as relevant
- 7 abstracts were relevant to guidelines for pediatric IBD
- Searching references of relevant articles and talking to experts, found 4 relevant articles
- 4 articles met inclusion criteria
- Total of 5 articles were accepted and critically appraised
- 2 abstracts did not meet outcome criteria
- 3 articles did not meet outcome criteria
- 2 abstracts and 1 article did not meet outcome criteria

Inclusion Criteria
- Published in English
- Published before March 2006
- Outcome included guidelines or recommendations for pediatric CD
### Table 1. Evidence Grading Scale

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<th>Score</th>
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</thead>
<tbody>
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<td>Poor</td>
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<tr>
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<tr>
<td>Good</td>
<td>&gt; 14</td>
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### Table 2. Evidence Table

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<th>ESPGHAN$^3$</th>
<th>Escher et al$^7$</th>
<th>Sands et al$^{29}$</th>
<th>Scott et al$^{30}$</th>
<th>ASPEN$^{26, 27}$</th>
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*Maximum score of 25
<table>
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<th>Change Implemented</th>
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<tr>
<td><strong>Standardize</strong></td>
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</tr>
<tr>
<td><strong>Diagnostic</strong></td>
<td>You use a standardized diagnostic evaluation to stratify patients by disease severity and type.</td>
</tr>
<tr>
<td><strong>Evaluation</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Optimize</strong></td>
<td>You assess nutritional status at every visit and classify the patients’ nutritional status as at risk, in nutritional failure, or acceptable and then treat accordingly.</td>
</tr>
<tr>
<td><strong>Nutritional</strong></td>
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<tr>
<td><strong>Assessment and Management</strong></td>
<td>Each of your patients is assigned a care team which meets each week to review goals and plan interventions for the patients scheduled during the upcoming week.</td>
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<tr>
<td><strong>Planned care</strong></td>
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<tr>
<td><strong>Promote Patient &amp; Family Self-Management</strong></td>
<td>You promote patient and family self management by meeting with the patients, their families, and other care providers to set goals in areas such as school attendance and disease management and then develop interventions to reach each goal.</td>
</tr>
<tr>
<td><strong>Decrease Use and Duration of Steroids</strong></td>
<td>Patients that you classify as having moderate to severe disease enter an evidence-based protocol to reduce steroid use through the safe and effective use of mercaptopurine and other steroid sparing agents.</td>
</tr>
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</table>
Table 4. Matrix Form of 16 Scenarios (non-shaded) and Participant Results (shaded)

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Standardize diagnostic evaluation</th>
<th>Decrease use &amp; duration of steroids</th>
<th>Optimize nutritional assessment &amp; management</th>
<th>Planned care</th>
<th>Promote family &amp; patient self management</th>
<th>Ranking* (n=1)</th>
<th>Feasibility* (n=1)</th>
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<td>+</td>
<td></td>
<td>12</td>
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</table>

*Ranking is on a scale of 1 to 16 where 1 is most likely to improve outcomes and 16 is least likely to improve outcomes.

^Feasibility is on a scale of 1-5 where 1 is most feasible and 5 is least feasible.
Figure 2. Dot Diagram Results: First Pilot Study (n=17)

RX = Decrease use and duration of steroids, Nutr = Optimize Nutritional Assessment and Management, Self = Promote patient & family self-management, Plan = Planned Care, DX = Standardize diagnostic evaluation, x = interaction (such that DXxNutr refers to the interaction of Standardize diagnostic evaluation and Optimize Nutritional Assessment and Management, etc.)
Figure 3. Response Plot for Effect of Self and RX Interaction: First Pilot Study* (n=17)

*Self = Promote patient & family self-management, RX = Decrease use and duration of steroids, (+) means the change concept is implemented while (-) means it is not implemented
Figure 4. Dot Diagram Results: Second Pilot Study (n=2)

RX = Decrease use and duration of steroids, Nutr = Optimize Nutritional Assessment and Management, Self = Promote patient & family self-management, Plan = Planned Care, DX = Standardize diagnostic evaluation, x = interaction (such that DXxNutr refers to the interaction of Standardize diagnostic evaluation and Optimize Nutritional Assessment and Management, etc.)
Figure 5. Response Plot for Effect of Self and RX Interaction:
Second Pilot Study* (n=2)

*Self = Promote patient & family self-management, RX = Decrease use and duration of steroids, (+) means the change concept is implemented while (-) means the it is not implemented.

<table>
<thead>
<tr>
<th>Change Concept</th>
<th>Effect on Ranking</th>
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<tr>
<td>Standardize Diagnostic Evaluation</td>
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</tr>
<tr>
<td>Optimize Nutritional Assessment and Management</td>
<td>4.25</td>
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<tr>
<td>Planned Care</td>
<td>4.25</td>
</tr>
<tr>
<td>Promote Patient &amp; Family Self-Management</td>
<td>-0.25</td>
</tr>
<tr>
<td>Decrease Use and Duration of Steroids</td>
<td>-3.00</td>
</tr>
</tbody>
</table>

*A negative effect means that ranking is increased and a positive effect means that ranking is decreased. A higher ranking is more likely to improve outcomes and a lower ranking is less likely to improve outcomes.
Figure 6. Dot Diagram Results (n=1)

RX = Decrease use and duration of steroids, Nutr = Optimize Nutritional Assessment and Management, Self = Promote patient & family self-management, Plan = Planned Care, DX = Standardize diagnostic evaluation, \( x \) = interaction (such that DXxNutr refers to the interaction of Standardize diagnostic evaluation and Optimize Nutritional Assessment and Management, etc.)
Figure 7. Response Plot for Effect of Plan and DX Interaction*(n=1)

*DX = Standardize diagnostic evaluation, Plan = Planned Care, (+) means the change concept is implemented while (-) means the it is not implemented.
Appendix A. Steps for Phase 0 of the Idealized Design Process\textsuperscript{16}

Step 1: Select a topic
Step 2: Obtain funding
Step 3: Select a team
Step 4: Develop a charter – describe goals by answering the following 3 questions\textsuperscript{11}
  • What are we trying to accomplish?
  • How will we know that a change is an improvement?
  • What changes can we make that will result in improvement?
Step 5: Capture what you know – review failures in current system and conduct a literature review
Step 6: Select a high quality organization – select a clinic with good outcomes for their patients
Step 7: Observe the clinic – determine the setting, how patients are behaving, interview groups, review available documents
Step 8: Synthesize – brainstorm ideas using diagrams, mind mapping, post-its
Step 9*: Screen – determine if ideas are desirable, different, feasible, and better than current practice; use conjoint analysis to narrow down the ideas
Step 10: Expert meeting – experts review ideas and provide new insights

*we chose to make the expert meeting part of step 9 and the conjoint analysis as part of step 10
Appendix B. Definitions of Change Concepts

**Standardize Diagnostic Evaluation.** Standardize diagnostic evaluation and stratify patients by disease severity and type. Disease severity is determined by evaluating signs and symptoms using a structured assessment tool (e.g., a checklist). Disease type is determined using radiographic, endoscopic, and pathologic findings and specific staging criteria (e.g., Vienna criteria).

**Optimize Nutritional Assessment and Management.** Stratify and manage patients according to their risk for nutritional or growth failure using BMI percentiles and height for age percentile. Patients with height z-scores less than 1 below the mid-parental height z-score or patients in the 10th-25th BMI percentile are categorized as “at risk” and are evaluated for nutritional failure. Patients with height z-scores less than 2 below the mid-parental height z-score or patients in the <10th BMI percentile are categorized as having nutritional failure and are evaluated and treated.

**Planned Care.** A care team (e.g., nurse coordinator or advanced practice nurse, dietician, and MD) is assigned to each patient and meets each week to review patients scheduled for the upcoming week. The review encompasses determination of disease activity, assessment of nutritional status, assessment of functional activity, and a review of the medication list. After identifying areas to focus on, interventions are planned to address each focus area.

---

1 Diagnostic studies include complete blood count, serum albumin, ESR, C-reactive protein, liver profile, and stool collection for pathogens.
**Promote Patient & Family Self-Management.** To promote patient and family self management, patients, their families, and care providers set goals in areas such as school attendance, extracurricular activities, disease control, emergency action plan, medical management, and adherence to medical management and then develop interventions to reach each goal. Health care providers also use educational tools to teach patients how to care for their own disease.

**Decrease Use and Duration of Steroids.** Patients classified as having moderate to severe disease enter an evidence-based protocol to reduce steroid use through the safe and effective use of mercaptopurine or other steroid sparing agents. For example, patients who start treatment with mercaptopurine are treated, monitored and assessed in a standard fashion. Deviations from the protocol are identified and the reason for each deviation recorded.
Scenario A
You use a standardized diagnostic evaluation to stratify patients by disease severity and type. Patients that you classify as having moderate to severe disease enter an evidence-based protocol to reduce steroid use through the safe and effective use of mercaptopurine and other steroid sparing agents. You review the patient’s medical record at each visit. For most of your patients, you identify, evaluate, and manage nutritional or growth failure. You promote patient and family self-management by meeting with the patients, their families, and other care providers to set goals in areas such as school attendance and disease management and then develop interventions to reach each goal.

Scenario B
Each of your patients is assigned a care team which meets each week to review goals and plan interventions for the patients scheduled during the upcoming week. You develop a diagnostic evaluation plan for new patients according to the patient’s presentation. You provide patients individualized treatment based on your analysis of their disease severity. You assess nutritional status at every visit and classify the patients’ nutritional status as at risk, in nutritional failure, or acceptable and then treat accordingly. You promote patient and family self-management by meeting with the patients, their families, and other care providers to set goals in areas such as school attendance and disease management and then develop interventions to reach each goal.

Scenario C
You use a standardized diagnostic evaluation to stratify patients by disease severity and type. Patients that you classify as having moderate to severe disease enter an evidence-based protocol to reduce steroid use through the safe and effective use of mercaptopurine and other steroid sparing agents. You assess nutritional status at every visit and classify the patients’ nutritional status as at risk, in nutritional failure, or acceptable and then treat accordingly. Each of your patients is assigned a care team which meets each week to review goals and plan interventions for the patients scheduled during the upcoming week. You promote patient and family self-management by meeting with the patients, their families, and other care providers to set goals in areas such as school attendance and disease management and then develop interventions to reach each goal.

Scenario D
You develop a diagnostic evaluation plan for new patients according to the patient’s presentation. For most of your patients, you identify, evaluate, and manage nutritional or growth failure. You provide patients individualized treatment based on your analysis of their disease severity. You review the patient’s medical record at each visit. You promote patient and family self-management by meeting with the patients, their families, and other care providers
to set goals in areas such as school attendance and disease management and then develop interventions to reach each goal.

Scenario E
You review the patient’s medical record at each visit. You use a standardized diagnostic evaluation to stratify patients by disease severity and type. Patients that you classify as having moderate to severe disease enter an evidence-based protocol to reduce steroid use through the safe and effective use of mercaptopurine and other steroid sparing agents. You assess nutritional status at every visit and classify the patients’ nutritional status as at risk, in nutritional failure, or acceptable and then treat accordingly. You continue to educate patients and their families as you do now.

Scenario F
Each of your patients is assigned a care team which meets each week to review goals and plan interventions for the patients scheduled during the upcoming week. You continue to educate patients and their families as you do now. You develop a diagnostic evaluation plan for new patients according to the patient’s presentation. Patients that you classify as having moderate to severe disease enter an evidence-based protocol to reduce steroid use through the safe and effective use of mercaptopurine and other steroid sparing agents. You assess nutritional status at every visit and classify the patients’ nutritional status as at risk, in nutritional failure, or acceptable and then treat accordingly.

Scenario G
You review the patient’s medical record at each visit. You use a standardized diagnostic evaluation to stratify patients by disease severity and type. You provide patients individualized treatment based on your analysis of their disease severity. You promote patient and family self management by meeting with the patients, their families, and other care providers to set goals in areas such as school attendance and disease management and then develop interventions to reach each goal. You assess nutritional status at every visit and classify the patients’ nutritional status as at risk, in nutritional failure, or acceptable and then treat accordingly.

Scenario H
You provide patients individualized treatment based on your analysis of their disease severity. For most of your patients, you identify, evaluate and manage nutritional or growth failure. You review the patient’s medical record at each visit. You continue to educate patients and their families as you do now. You use a standardized diagnostic evaluation to stratify patients by disease severity and type.

Scenario I
You promote patient and family self management by meeting with the patients, their families, and other care providers to set goals in areas such as school attendance and disease management and then develop interventions to reach each
goal. Each of your patients is assigned a care team which meets each week to review goals and plan interventions for the patients scheduled during the upcoming week. You use a standardized diagnostic evaluation to stratify patients by disease severity and type. For most of your patients, you identify, evaluate and manage nutritional or growth failure. You provide patients individualized treatment based on your analysis of their disease severity.

**Scenario J**
You review the patient’s medical record at each visit. You assess nutritional status at every visit and classify the patients’ nutritional status as at risk, in nutritional failure, or acceptable and then treat accordingly. You develop a diagnostic evaluation plan for new patients according to the patient’s presentation. Patients that you classify as having moderate to severe disease enter an evidence-based protocol to reduce steroid use through the safe and effective use of mercaptopurine and other steroid sparing agents. You promote patient and family self management by meeting with the patients, their families, and other care providers to set goals in areas such as school attendance and disease management and then develop interventions to reach each goal.

**Scenario K**
You continue to educate patients and their families as you do now. Each of your patients is assigned a care team which meets each week to review goals and plan interventions for the patients scheduled during the upcoming week. You use a standardized diagnostic evaluation to stratify patients by disease severity and type. Patients that you classify as having moderate to severe disease enter an evidence-based protocol to reduce steroid use through the safe and effective use of mercaptopurine and other steroid sparing agents. For most of your patients, you identify, evaluate and manage nutritional or growth failure.

**Scenario L**
You use a standardized diagnostic evaluation to stratify patients by disease severity and type. You provide patients individualized treatment based on your analysis of their disease severity. You continue to educate patients and their families as you do now. Each of your patients is assigned a care team which meets each week to review goals and plan interventions for the patients scheduled during the upcoming week. You assess nutritional status at every visit and classify the patients’ nutritional status as at risk, in nutritional failure, or acceptable and then treat accordingly.

**Scenario M**
You develop a diagnostic evaluation plan for new patients according to the patient’s presentation. You review the patient’s medical record at each visit. For most of your patients, you identify, evaluate and manage nutritional or growth failure. Patients that you classify as having moderate to severe disease enter an evidence-based protocol to reduce steroid use through the safe and effective use
of mercaptopurine and other steroid sparing agents. You continue to educate patients and their families as you do now.

**Scenario N**
You develop a diagnostic evaluation plan for new patients according to the patient’s presentation. Each of your patients is assigned a care team which meets each week to review goals and plan interventions for the patients scheduled during the upcoming week. For most of your patients, you identify, evaluate and manage nutritional or growth failure. You provide patients individualized treatment based on your analysis of their disease severity. You continue to educate patients and their families as you do now.

**Scenario O**
You review the patient’s medical record at each visit. You continue to educate patients and their families as you do now. You develop a diagnostic evaluation plan for new patients according to the patient’s presentation. You assess nutritional status at every visit and classify the patients’ nutritional status as at risk, in nutritional failure, or acceptable and then treat accordingly. You provide patients individualized treatment based on your analysis of their disease severity.

**Scenario P**
You promote patient and family self management by meeting with the patients, their families, and other care providers to set goals in areas such as school attendance and disease management and then develop interventions to reach each goal. You develop a diagnostic evaluation plan for new patients according to the patient’s presentation. Patients that you classify as having moderate to severe disease enter an evidence-based protocol to reduce steroid use through the safe and effective use of mercaptopurine and other steroid sparing agents. For most of your patients, you identify, evaluate and manage nutritional or growth failure. Each of your patients is assigned a care team which meets each week to review goals and plan interventions for the patients scheduled during the upcoming week.
References


