

# Results From a Patient Experience Study in Pediatric Gastrointestinal Endoscopy

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## Abstract

**Objective:** Gastrointestinal endoscopy in children has become a standard diagnostic and therapeutic modality. The aim of our study was to characterize the most memorable elements of the patient experience from the parent's and patient's perspective and determine ways to improve the overall quality of their experience. **Methods:** Using a structured questionnaire, we conducted 47 phone interviews with families who had recently undergone gastrointestinal endoscopic procedures. **Results:** Our study showed clear communication and mutual agreement on care decisions contributed to positive experiences. Inadequate communication of information regarding alternatives to the procedure and risk of complications during the informed consent discussion contributed to negative patient experiences. Standardization of postprocedure follow-up and timely communication of pathology findings also had potential for improvement. **Conclusion:** Our study revealed 2 areas for quality improvement interventions: The need to ensure that alternatives and complications are thoroughly discussed and the need for standardization of postprocedure follow-up.

## Keywords

patient experience, pediatric endoscopy, quality improvement, patient centered

## Background

The use of flexible gastrointestinal endoscopy in children was first described 13 years after Basil Hirshowitz invented the instrument in 1957 (1-3). Since then its use has grown enormously. The American Society for Gastrointestinal Endoscopy and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition have proposed guidelines on indications, preparation, equipment, procedure, and discharge (4). Adherence to these guidelines achieves excellent performance on the technical aspects of the procedure and clinical care; however, they may fall short in ensuring a high-quality patient experience. In today's customer-driven economy, it is important to ensure services provided are patient centered, with a result of improved patient experience and loyalty to the health care organization.

Our literature review revealed that in comparison with adult gastrointestinal endoscopy, quality improvement (QI) efforts in pediatric endoscopy are less frequently explored (5-8). A positive endoscopy experience increases the probability that patient will continue to follow-up with the same provider, be adherent with suggested management, and be a source of positive recommendation (9).

We aimed to obtain preliminary baseline data regarding patient experience in pediatric endoscopy and define elements that might contribute to a future QI project. Our study can be

described as “pre-QI” with qualitative characteristics. Due to the fact that our patient population of interest is under the care of a parent or guardian who not only shares the experience but can also provide greater verbal feedback, we interviewed parents and their children. Based on our literature review and individual experiences with endoscopy, we formed initial areas of interest that could negatively influence patient experience. We utilized an a priori approach that involved looking for answers to dichotomous and open-ended questions outlined in Appendix A. These questions looked at the following:

### Preprocedure:

- In order to determine how successful we were in communicating with our families, we examined parent understanding of the procedure and indication.
- Whether informed consent was obtained.

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- Whether Spanish-speaking patients encountered any language barriers.
- Whether the family encountered challenges in preparing for the procedure such as preappointment formalities (labs, referrals, and insurance) that posed a threat of overwhelming them.

#### Postprocedure:

- What new information, if any, did the parent gain about their child's illness after the procedure?
- Whether the outcome impacted the child and family in a meaningful way.

## Methods

St Christopher's Hospital for Children is a tertiary care academic medical center and is the primary pediatric teaching hospital for Drexel University College of Medicine. All the gastrointestinal endoscopy procedures were performed by 6 attending faculty gastroenterologists who had seen the patients prior to the procedure either at the hospital or at one of the satellite locations. Those patients who had been scheduled for a procedure were identified from electronic medical records (EMRs). The interviewer (D.A.J.) called the family between weeks 2 and 3 after the completion of the procedure to conduct phone interviews. Parents and their children (when older than 10 years) were interviewed using a structured questionnaire (Appendix A) that contained closed dichotomous and open-ended questions. The results of the questionnaires were read by 3 of the authors, D.A.J., H.P., and L.F., independently. This was then followed by discussion and development of common themes found among the responses. Interviews were conducted until thematic saturation was reached. Due to the fact that this study was done as a QI initiative, it was deemed by the Drexel Office of Research as not requiring institutional review board approval.

## Results

A total of 47 families were interviewed. Gender, age, type of procedure (esophago-gastro-duodenoscopy, colonoscopy, or both), and abdominal pain as most common indication for procedure are shown in Table 1. When parents were asked the reason they thought the procedure was recommended, 3 parents (6.4%) expressed a reason not listed as an indication in the EMR. In order to examine the content and quality of communication among the parent, child, and staff, we asked specific questions, the results of which have been compiled in Table 2. Of the 47 families interviewed, 2 parents required the use of a Spanish interpreter to participate in the interview. Responses were analyzed to provide insight into the components of a positive or negative experience. Appendix B contains examples of both positive and negative comments by patients and parents.

Overall, based on the high number of positive-specific comments during the interviews, respondents in our study

**Table 1.** Patient Demographics.<sup>a</sup>

Gender	19 Females/28 males
Age	Range: 20 months-19 years; median: 12 years
Type of procedure	29 esophago-gastro-duodenoscopy, 2 colonoscopy, 16 esophago-gastro-duodenoscopy and colonoscopy
Most common indication	Abdominal pain (n = 22)

<sup>a</sup>Total = 47.

were generally satisfied with the current way medical information was communicated to them. Parents in our study knew and agreed with the indication for the procedure and felt adequately informed about how the procedure would be done. In our study, families with positive experiences tended to be those where there was clear communication, mutual agreement on care decisions and a feeling of emotional support.

Upon examining our results in light of the questions we set out to answer, our study revealed the need for improvement in several areas based on the number of times the theme appeared (Table 2):

- We noted it was not uncommon for patients to either not understand or remember alternatives to the procedure. This was noted even after an informed consent discussion had taken place in the clinic prior to the procedure being performed.
- Patients were not always given an information leaflet about endoscopy.
- Patients did not at times remember being informed about potential complications during the informed consent discussion.
- Timely communication of pathology results and standardization of post-procedure follow-up could be improved further.

## Discussion

Patient-centered care is 1 of the 6 domains of quality for the US health care system proposed by the Institute of Medicine (IOM) (10). It is defined by the IOM as "health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care" (11 p 41).

A previous study examining patient satisfaction in adult gastrointestinal endoscopy revealed that satisfaction is correlated with the following factors: perceived technical skill of the endoscopist, absence of pain during the procedure, information provided before and after the procedure, wait time before and on the day of the visit, and the physical environment (6). A recent study of patient satisfaction in pediatric endoscopy showed patient understanding of medication intake prior to endoscopy was insufficient and patients

**Table 2.** Patient Responses.<sup>a</sup>

Item	No. of responses, (%)
Respondents who were not/did not remember being offered alternatives to the procedure	33 (70.2)
Respondents who said they were not provided with an information leaflet	7 (14.9)
Respondents who did not remember being informed about potential complications	5 (10.6)
Respondents who already had a follow-up visit or call at the time of the phone interview	19 (40.4)
Of these 19, the number that recollect being informed of the pathology results	18 (94.7)
Respondents who remembered that a doctor came out after the procedure and spoke to them about the findings	45 (95.7)
Remembered being informed how the procedure would be done	46 (97.9)
Respondents who felt that that they encountered difficulty in completing preprocedure investigations	0 (0)
Of the 18 patients that underwent a colonoscopy, number that recalled being informed on how to carry out bowel prep.	18 (100)

<sup>a</sup>Total = 47.

would have appreciated a more detailed description of the type of sedation (8). Our study is unique in that we set out to understand the entire patient experience from the patient and family perspective, beyond the patient satisfaction scores previous surveys have traditionally measured.

This study yielded several important findings, the execution of which can lead to an improved patient experience. Firstly, there is a need to discuss alternatives to the procedure and possibility of complications during the informed consent discussion. Additional information such as an educational leaflet should also be given to patients and families. Secondly, there is a need to develop standardization of postprocedure follow-up providing an opportunity to discuss pathology results and further treatment. This postprocedure follow-up serves to complete the loop of communication between the provider and the families.

### *True Informed Consent*

The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) is a nationally administered survey by the Centers for Medicare and Medicaid Services (CMS) to evaluate patient experiences and their demographic characteristics. Three of the six domains (communication with physicians, communication with nurses, communication about medications, quality of nursing services, adequacy of planning for discharge, and pain management) pertain to communication (12). Attending a preprocedure office visit scheduled with the intention of providing details of the procedure and vocalize queries has been associated with higher patient satisfaction (13). Therefore, in order for a family to utilize the benefits of such a visit and to ensure that true informed consent is obtained, the discussion must be held at an educational level and language which matches that of the family.

Based on our results regarding discussion of alternatives to the procedure and possibility of complications, we implemented interventions. Our practice organized an educational session for endoscopists to review the elements of an informed consent including the discussion on alternatives and complications. Utilizing a translator has also been an

important intervention in the setting of even a minor language barrier.

### *Communication of Pathology Results and Clarity on Postprocedure Instructions*

At the time of the phone interview, 19 (40.4%) of 47 families had a follow-up visit or call after the procedure. Of the 19, 18 (94.7%) remember having a discussion about the pathology results. However, it was noticed that not having the pathology results in hand did not appear to be a prominent source of concern among families. This could be because in most cases, the endoscopist had come out following the procedure and discussed the gross anatomy findings.

Based on responses to the question “What was told to you regarding how you would receive biopsy results?” (Appendix A), what appeared important to some parents was the lack of standardization regarding postprocedure follow-up. The recurring complaint which caused “staying up all night” or “missing school days” and lack of knowledge on how to deal with their child’s complaint until the next visit appeared to be a prominent concern. Timely communication of results is an important factor that determines patient satisfaction (14-16). It is our recommendation that postprocedure follow-up be standardized. At this visit, results of the procedures (including biopsy results) and collaboration on further management must be addressed, both to the parent and to the referring physician. An additional issue requiring deeper study is to determine what would be the optimal method to convey this information. It was found in another study that even when patients were provided with a computer-generated written report in addition to a verbal report, postprocedure recommendations could only be identified by the patient 72% of the time and the results 75% of the time (17).

As a result of the data from this study, we have modified our practice to now ensure that a phone call from our office is made to the family after the procedure to convey the biopsy results. If the biopsies are normal, a registered nurse makes the call. If the biopsies are abnormal, the endoscopist will make the phone call. This ensures that biopsy results are communicated to all families. At the time of this phone call,

the follow-up appointment is also confirmed with the family to ensure there will be an opportunity to discuss the findings in more detail and decide on next steps.

Limitations of our study include that all our data were collected from endoscopic procedures performed at a single center. Another limitation is that the feedback was not analyzed by the severity of the condition (eg, colonoscopy for polyposis surveillance versus an esophago-gastro-duodenoscopy to determine the cause of abdominal pain) or for sociodemographic data of respondents such as level of education and socioeconomic status.

Additional recommendations for general improvement in the failures of patient experience identified here include placing the patient perspective as a top priority when designing endoscopy unit work flows. We suspect the issues identified by our study are commonly encountered, and endoscopy units may find it beneficial to incorporate patient experience and satisfaction as part of their management strategies.

In conclusion, we present a descriptive study of a QI tool to help gastrointestinal endoscopy units evaluate where they might direct QI efforts. We believe this process of identifying improvement goals will be of broad interest for endoscopy programs, as they develop their QI initiatives with PDSA cycles and aim to improve patient experience.

## Appendix A

### Patient Experience Feedback Form

#### Background Information

Answered by: Parent / Patient

Age bracket: 10-20 / 21-30/ 31-40/ 41- 50/ 51-60/ > 61

Procedure: Endoscopy / Colonoscopy / Both

Reason for procedure:

#### Pre-Procedure

- Have you visited gastroenterologists at any other hospital? YES / NO.
- Which of the following do you remember the staff informing you about?
  1. How the procedure would be done? YES / NO
  2. Any alternatives to the procedure? YES / NO
  3. Complications to look out for after the procedure? YES / NO
  4. If your child takes any medication regularly, changes to medication to be taken the day before/day of the procedure? YES / NO
  5. How to prepare for the colonoscopy the day before the procedure? YES / NO (Only answer this question if your child had a colonoscopy.)
- Were you provided with an information leaflet? YES / NO.
- Did you read it entirely? YES / NO
- Did you have difficulty completing all the pre-procedure investigations (bloodwork, X-ray, anesthesia assessment, stool studies, insurance approval): YES/ NO

#### Post-Procedure

- On the day of the procedure, after it was done, what did the doctor explain about the findings?
- What was told to you regarding how you would receive biopsy results?
- Did you have a follow up visit / call? YES/ NO.
- At the follow up visit/call were you given the findings of the pathology report? YES / NO
- In your opinion did you gain any useful information regarding your child's condition after the endoscopy? YES / NO. If No please tell us why.
- On a scale of 1 to 10 please rate your satisfaction with the way your doctor communicates information to you.

To be answered by child if available (if older than 10years) or else parent:

1. Did you feel like you had a choice in the matter? YES / NO
2. Did you feel the doctor spent explained the procedure and results well? YES / NO
3. Did you find your doctor to be friendly? YES / NO

## Appendix B

### Patient Comments

These are two excerpts from patients who made positive remarks about their experience:

#### E12

- Have you visited G.I. doctors at any other hospital before? "I have been to G.I. doctors at 3 other hospitals but was unsatisfied with any of them because my son was inadequately diagnosed. His diagnosis of celiac disease and treatment plans were finalized at this hospital."
- Reason for the procedure: "My son has celiac disease and eosinophilic esophagitis."
- What did the doctor explain about the results of the procedure? "I was told that the counts had reduced dramatically and there was still some inflammation."
- Did you have a follow up visit or call? "Yes, I had a follow up call and was informed about the biopsy results within 2 weeks of the procedure."
- In your opinion did you gain any useful information regarding your child's condition after the procedure? "Yes."

#### E20

- Have you visited G.I. doctors at any other hospital before? "Yes."

- Reason for the procedure: “My daughter had her first esophago-gastro-duodenoscopy 7 years ago when she was diagnosed with celiac disease. This was a follow up esophago-gastro-duodenoscopy to examine the lining of gastrointestinal tract and determine possibility of coming off a gluten free diet.”

What did the doctor explain about the results of the procedure? “She told us that everything looked normal.”

- Did you have a follow up visit or call? “My follow up visit with the G.I. doctor is after 6 months. No-one has called regarding biopsy results.”
- In your opinion did you gain any useful information regarding your child’s condition after the procedure? “Yes, because it gave the final word that my daughter cannot be taken off a gluten free diet.”

Below is an excerpt from a family who voiced unhappiness with their experience:

#### B15

- Have you visited G.I. doctors at any other hospital before? “No.”
- Reason for the procedure: “My son has been having severe abdominal pain. We were offered to do the procedure 11 months prior but decided against it and did an X-Ray instead then. That’s why we’re getting the procedure done now.”
- What did the doctor explain about the results of the procedure? “He told us that the gross anatomy was good but we needed to wait for biopsy results.”
- Did you have a follow up visit or call? “No, my follow up appointment is 1.5 months after procedure.”
- In your opinion did you gain any useful information regarding your child’s condition after the procedure? “No. I only know that the gross anatomy is fine.”
- Additional comments: “I am satisfied with the way the doctor has informed me about results of previous studies but I am currently upset because there has been no communication about the pathology results of the endoscopy and colonoscopy. We visit one of the satellite offices and due to a scheduling error at the hospital’s end our follow up visit is one and a half months away which to me is unacceptable. My son is still in considerable pain.”

We found additional areas that contributed to an unpleasant experience:

- Perception of receiving inadequate information (B14): “I am extremely upset because I was not informed the procedure would involve putting my daughter to sleep. I was told it would be like twilight, in and out. But I only found out my daughter was put under when the nurse told me after the procedure that she had come back with a breathing tube.”

- Perceived delay in treatment (E23): “I am extremely unhappy right now. My son has had abdominal pain since 3 months, it took them a whole month to even do his first procedure (gastric emptying). I had to call to find out those results from the doctor. When I came in for our next appointment, the doctor was not in. We saw a nurse practitioner and because of that my next appointment for the doctor was cancelled. It has been 3 months since our first visit and my son is still in pain and has received no relief from medication.”
- Language barrier (B13): “My native language is Spanish, but I can speak and understand English. It is difficult for me to understand what is being said without an interpreter though.”

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