Utilizing Patient Engagement to Develop Integrated Mental Health Care for Pediatric Gastroenterology – Phase I of the DECADES Study

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ABSTRACT

Objectives: To determine patient and parent attitudes toward depression, anxiety, and mental health screening during gastroenterology (GI) visits, and to determine patient and parent preferences for communication of results and referral to mental health providers after a positive screen. Methods: Patient engagement methods were utilized to assess patient and parent preferences. Families participated in individual interviews and group activity sessions to provide feedback on the process for providing mental health screening and consultation in the pediatric GI clinic. Results: Overall, patients and their parents found integrated mental health care to be acceptable in the subspecialty setting. Patients’ primary concerns were for the privacy and confidentiality of their screening results. Both patients and their parents emphasized the importance of mental health services not interfering with the GI visit and collaboration between the GI physician, psychologist, and primary care provider. Conclusions: Patients and their families are open to integrated mental health care in the pediatric subspecialty clinic. The next phase of the DECADES Study will translate patient and parent preferences into an integrated mental health care system and test its efficacy in the pediatric GI office.

KEYWORDS: Qualitative research, patient-reported outcomes, depression, anxiety
INTRODUCTION

The DECADES (Detecting and Evaluating Childhood Anxiety and Depression Effectively in Subspecialties) Study seeks to develop a model for integrated mental health care that is acceptable to pediatric gastroenterology patients and their families and to compare this model of care with standard care. The first phase of this study sought to develop an integrated mental health care model that is acceptable to both gastroenterology patients and their parents by exploring their attitudes and preferences.

Depression and anxiety are two of the most common disorders in childhood and adolescence,[1, 2] but they remain unrecognized or untreated.[3, 4] Rates of depression and anxiety are significantly higher in children with chronic illnesses,[5] including gastrointestinal disorders,[6, 7] than in the general population. Furthermore, children with depression or anxiety are far more likely to have somatic complaints and have greater utilization of subspecialty care, especially in gastroenterology.[8, 9] Efforts to recognize and treat mental health problems in children with chronic medical illness, such as gastrointestinal disorders, have been shown to improve adherence to therapy, as well as other clinical outcomes.[10] More importantly, improving these mental health concerns may improve the outcomes patients care about most.

Validated tools exist to screen for anxiety and depression in children, including the Screen for Childhood Anxiety Related Emotional Disorders (SCARED)[11] and the Patient Health Questionnaire (PHQ-4).[12] Despite the established importance of depression and anxiety in the gastrointestinal health of children, few data-driven studies exist describing the identification and management of anxiety and depression by pediatric gastroenterologists and how families or patients view the subspecialty office as the setting to detect or care for mental illness.

Patient engagement is a process by which patients, families, and health professionals work in partnership to improve health care,[13] and it is a process for developing patient-centered care. When patients are engaged in the development of new models of care, it improves recruitment and retention to randomized clinical trials, and the clinical care is more meaningful to patients and their families.[14]

The current study describes the development of an integrated mental health care model for pediatric gastroenterology. We sought to develop this model of care by implementing innovative patient-centered design methods and engaging patients and their parents in the design process. The goals of the current study are to determine: 1) patient and parent attitudes toward depression, anxiety, and mental health screening during gastroenterology visits and 2) their preferences for communication of results and referral to mental health providers after a positive screen.

METHODS

The study activities included: 1) individual interviews in which patients and their parent(s) were interviewed in the pediatric gastroenterology clinic following a clinic visit, and 2) group sessions in which multiple families were interviewed together (Figure 1). The current manuscript will describe the results of the group interview sessions. This study was approved by the Indiana University Institutional Review Board. All patients and family members who participated signed informed consent/assent documents prior to participation.
Patients who were seeking care in a Pediatric Gastroenterology Clinic and their parents were recruited for the study. Inclusion criteria were: 1) age 5-18 years, 2) a parent/guardian who agreed to participate, 3) no diagnosed cognitive disabilities, and 4) a patient in the pediatric gastroenterology clinic. Recruitment was conducted in the pediatric gastroenterology outpatient clinic at a large Midwestern children's hospital. The PI or study coordinator recruited all eligible patients. Permission to approach the patient was obtained from the gastroenterologist of record. Both new and established patients were enrolled.

**Group Sessions**

Two group sessions were conducted with multiple families. Sessions were facilitated by design research specialists using human-centered design research methods. Sessions lasted approximately 90 minutes and were audio recorded and transcribed for analysis. All families were compensated for travel to sessions and given a $30 gift card.

Group sessions used generative design research activities to engage the patients and their parents in co-designing the integrated mental health process.[15-17] Sessions began with warm-up activities to encourage participation and collaboration. [18] Projective methods of generative research were employed to encourage
participants to express their thoughts and feelings, whereas constructive methods of generative research were used for concept development.[15]

**Group Session Activities**

**Question on the Board.** The goal of this activity[18] was to establish participants' baseline knowledge of anxiety and depression and understand how they express these concepts in their own words, informing how to present a screening tool to patients and their families. Participants were asked to answer the following questions on separate notecards: “What does depression mean to you?” and “What does anxiety mean to you?” Notecards were collected by study staff, and responses were not shared with the group.

**Card Sorting.** The purpose of the Card Sorting activity[19] was to identify concerns with the screener to inform messaging about the screener. For this activity, families were divided into two groups (parents and patients) in separate rooms. Both groups were presented with the same stack of cards. Each card listed an item from the SCARED-5[11] or the PHQ-4.[12] Parents were asked to divide cards into two piles: 1) “I would be concerned if my child said ‘yes,’” and 2) “I would not be concerned if my child said ‘yes.’” Patients were also asked to divide cards into two piles: 1) “I would have a hard time answering honestly” and 2) “I would not have a hard time answering honestly.” Next, parents and patients were asked to imagine that they/their child answered all cards in pile #1 affirmatively, and they were asked to write what they would be concerned about happening next and how they would want the results communicated to them. Then, the facilitator encouraged further discussion and elaboration.

**Sales Pitch.** The purpose of the Sales Pitch was to use projective methods[15] to inform the most acceptable sender, message, and environment for the mental health screener. Both patient and parent participants were asked to convince the person sitting next to them to take the anxiety and depression screeners. Then, they were asked to convince the person to be honest while taking the screener. After completing this exercise, the facilitator encouraged participants to discuss who they would like to explain the screener to them and where they would like to answer screening questions. They also discussed what steps patients and their parents expected would occur if the patient’s responses yielded a positive screen, as well as who would communicate results of a positive screen.

**The Struggle is Real.** This projective technique was a cartoon completion test[20] used to define what “feeling better” means to patients and their families with regards to anxiety, depression, and gastrointestinal symptoms. Patients and parents sat at separate tables for this activity. Patients were presented with several recognizable memes and were asked to fill in the blanks and react to prompts, such as, “My face when...” or “That feeling when....” Parents were presented with three different cartoon drawings with blank speech balloons. The first cartoon displayed a frowning child and neutral adult, the second showed a frowning child and happy adult, and the third showed a happy child and a happy adult. Parents were asked to fill in the speech balloons to describe a situation related to having and managing gastrointestinal disorders. After completing the activity, the facilitator encouraged participants to share their responses amongst the group and facilitated discussion.
**Backwards Experience Map.** The Backwards Experience Map activity was intended to explore patients' preferred experience from the time they submit the screening questions to symptom improvement a year later.[21] Patients and parents completed this activity separately. There was a large sheet of paper on the wall with seven equidistant points connected by an “s” shaped curve. The beginning point was identified as well as and the last three points (i.e., “leaving,” “three months later,” and “one year later”). Participants were asked to identify steps toward getting “better,” and fill in the appropriate points on the map. By identifying points that allow participants to get from point A to B, patterns begin to emerge. These patterns begin to uncover themes that establish patient preferences for the treatment experience, patient-centered outcomes, and what “better” means to them.

**Even Better.** This activity used constructive methods[15] to define patient and parent preferences for the best possible sequence of events. Patients and parents completed this activity separately. Expanding upon the results of the Backwards Experience Map, participants mapped out their ideal integrated mental health clinic flow process. The facilitator initiated discussion by asking participants to determine what would be “even better” than the ideas that were generated during the Backwards Experience Map.

**Analyses**

The results of all group session activities were analyzed and coded by the design research specialists who conducted the sessions. They synthesized data from pictures and written documentation (e.g., note cards, maps), and they reviewed the audio recordings of the sessions. Data were organized into themes based on Ackoff’s theory[22], which uses a grounded theory approach to distinguish between three levels of sense-making (data, information, and knowledge).

**RESULTS**

**Participants**

Eleven families participated in the group sessions (Table 1). Five families participated in the first group, and six families participated in the second group. One family was present for both group sessions.

| Table 1. Group Session Participant Demographic Characteristics |
|-------------------|-------------------|
|                   | Session 1          | Session 2          |
|                   | N (%) M (SD), Range | N (%) M (SD), Range |
| **Patient**       |                   |                   |
| Gender (Female)   | 4 (80.0)          | 5 (83.3)          |
| Age (years)       | 15.8 (2.7), 11-17 | 13.8 (3.3), 9-17  |
| Race              |                   |                   |
| Caucasian         | 5 (100.0)         | 5 (83.3)          |
| African American  | (100.0)           | 1 (16.7)          |
| Asian             | 0 (0.0)           | 0 (0.0)           |
|                   | 0 (0.0)           | 0 (0.0)           |
Table 2. Participant Definitions of Depression and Anxiety

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<tr>
<th>Patient Definitions of Depression</th>
<th>Parent Definitions of Depression</th>
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**Depression and Anxiety**

Table 2 displays participants’ responses to the Question on the Board activity. With regard to depression, they described emotional feelings of sadness, negative thoughts (e.g., worthlessness), and behaviors consistent with depression (e.g., social isolation, withdrawal). Participants described symptoms of various anxiety subtypes (i.e., generalized anxiety, social anxiety) as well as physiological symptoms of anxiety (i.e., tachycardia, sweating, nausea).
“Feeling worthless, being alone.”

“Living day to day feeling sad and not being able to function in the real world as you would like.”

“Sadness.”

“You’re 2 different people, the person on your good day and the person on your bad days.”

“Being sad.”

“Feelings of despair. Feeling like nothing goes right.”

“An illness of the mind.”

“Inability to shake ‘the blues,’ feeling there’s something wrong with you that the rest of the world doesn’t ‘get’—that you don’t fit in.”

“A debilitating mental abnormality as defined by the majority of psychologists & with my experience I would agree.”

“A feeling of being lonely, wanting to be by yourself, wanting to be left alone”

“Going to a very dark place in your life. Always feeling sad, not wanting to go anywhere or do anything but sleep all day.”

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<tr>
<th>Patient Definitions of Anxiety</th>
<th>Parent Definitions of Anxiety</th>
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<tr>
<td>“Strong feelings of fear that cause someone to lose normal rational behavior in extreme cases. Nervous or scared.”</td>
<td>“Where you don’t want to be in a room with a bunch of people.”</td>
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<tr>
<td>“Shaking”</td>
<td>“Tachycardia.”</td>
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<tr>
<td>“You worry about everything, even the smallest details that don’t matter.”</td>
<td>“Also a debilitating mental abnormality, but I think of it more as worrying more often than you need.”</td>
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<td>“Struggling to go into a large crowd.”</td>
<td>“Worrying, to the point that the stress caused by worry can sometimes become debilitating. A tight feeling in the pit of your stomach that just won’t go away.”</td>
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<tr>
<td>“Having the feeling in the pit of your stomach that makes you feel nauseous. Fast heartbeat.”</td>
<td>“…”</td>
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<tr>
<td>“Feelings to get through an event where you can’t breathe, have sweats, feelings of being overwhelmed.”</td>
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**Mental Health Screening and Consultation in the Gastroenterology Clinic**

It was important to patients and their parents that patients still receive the GI care they intended to receive. Many participants stated that they could be traveling quite a distance for their appointment, and they stressed the importance of keeping their regularly scheduled appointment. One patient explained, “You should still have the GI appointment because that’s what you were scheduled for and you still need that service.” They agreed that if the patient screened positive for depression or anxiety, they would like to discuss it with their doctor and consult with a psychologist, but it was important to them that this discussion did not interfere with their GI appointment.

**Patient Comfort with Mental Health Screening**
Patients indicated that their level of comfort with completing mental health screening was related to how the screener was presented. In turn, their comfort would impact how honestly they would answer the questions. If patients felt a sense of control, they would be more likely to respond honestly. For example, patients indicated that if their parents were worried, or if the screener was presented unexpectedly with no explanation, they would be more anxious about completing the screener. As a result, patients felt that they may rush through the screening questions or select the most desirable responses. Patients were clear that they would like to be prepared, and they requested to know 1) how many questions are on the screener, 2) how long it would take them to complete, and 3) what would happen after taking the screener.

Privacy
There was disagreement between parents and patients regarding the privacy of patients’ screening results. When asked about whether parents should receive the results of the screener at the same time as their children, many parents acknowledged that their children would probably want privacy. However, because it is a health issue, parents wanted to be involved and aware of results. Most parents agreed that they had a right to their child's protected health information and, therefore, should be given screening results. On the other hand, they acknowledged that their children may be less likely to answer questions honestly if they knew their parents would see their results.

Parent 1: “Some of the questions might be questionable. They may not want the parent to see. It’s their privacy.”
Parent 2: “Right, but kids don’t have that yet.”

Most patients did not want their parents to be aware of their screening results, unless there was a serious concern. They described being more comfortable discussing these issues with their doctor than with their parents. This was also observed during group sessions. When the parents and patients were together for discussion, patients generally did not express their opinions, but when they were separated from their parents, patients contributed their opinions and actively engaged in discussion. However, there were a few patients who noted that they would feel more comfortable discussing screening results with a parent in the room. One patient explained, “I just feel more comfortable with people I know around.”

In both sessions, patients expressed that sharing screening results with their parents may make their parents anxious, and they did not want to make them worry. One patient said, “I wouldn’t want her to have to deal with something unless it was like big or something.... If I hadn’t told her about that, I wouldn’t necessarily want her to know.” They acknowledged that not being transparent with their parents about screening results may also cause parents to be distressed. Patients agreed that parental worry was a major concern for them. Overall, they expressed that they wanted a choice about whether or not their parent was in the room when discussing screening results.

Communicating Results of Mental Health Screening
Patients agreed that they would not expect for their screening results to suggest that they have anxiety or depression, and taking a screener might cause some distress for them. Having conversations with both their GI doctor and a psychologist would ease their worry about the screener. Most patients wanted their doctor(s) to talk to them right
after taking the screener, without their parents. All patients stated that they would like some kind of result and plan immediately after taking the screener. While all patients said they would want some sort of feedback that day, only one said that they would like to get a diagnosis from the screener. Most patients wanted to talk with their GI doctor and a psychologist at the same time right after taking the screener.

The Best Clinic Experience

When asked what the order of events should be from the moment they completed the screener, patients and parents had little problem creating a process flow that was agreeable to the other participants within their own group, but they had difficulty synthesizing a single agreed upon flow. Please see Table 3 for the steps of the desired clinic flow for patients and their parents. Steps are numbered chronologically and “even better” steps are listed next to the initially desired step.

DISCUSSION AND CONCLUSIONS

We conducted a qualitative study of patient and parent preferences regarding integrated mental health care in the GI office. Our results suggest that this screening process is highly acceptable to patients and their families, with the caveat that confidentiality remains intact, message delivery be customized to the patient or family member, and mental health services do not interfere with their GI visit.

As such, we propose the following recommendations for integrating mental health care into a pediatric GI subspecialty clinic:
1. Create a survey or worksheet for the parents to fill out while the patient is taking the screener to both educate and provide a parental distraction.
2. Provide a handout that describes depression and anxiety and how it relates to GI symptoms.
3. Use informational graphics to educate patients on the relationship between GI symptoms and mental health (Figure 2).
4. Develop an introduction to mental health screening that includes how many questions will be included in the screener, how long it will take, and what will happen after patients complete the screener.

5. Use the following language to frame the screener:
   a. Regarding the relationship between mental health and physical health: “FACT: When your GI system is messed up, it can mess with your brain too, causing anxiety or depression. BONUS FACT: When you have anxiety or depression, it can mess with your GI system, causing all kinds of problems.”
   b. Regarding the brain-gut connection: “Your GI system and your brain -- like everything else in your body -- are connected. When one is irritated, often so is the other.”
   c. Regarding privacy: “The answers you give are CONFIDENTIAL. That means they can only be viewed by you and your doctor, unless YOU choose to share it.”

6. Help patients develop a plan for care that addresses both their mental health concerns and their GI symptoms.

7. Talk to the patient separately from the parent, and ask patients if they would like their parents to be involved in the discussion.
8. Have the patient meet with the GI physician and the psychologist at the same time initially. For example, the physician might say, “This is (psychologist). She’s going to talk to you about the results of that screener you took. We'll work together to make a plan for treatment of your depression or anxiety and how they might affect your GI issue.”

There are several limitations to this study. First, due to the relatively small sample size and few male participants, it is difficult to ascertain broad generalizability of these findings. However, we attempted to recruit patients of various ages, gastrointestinal complaints, and insurance types to increase generalizability to our larger clinic population. Second, the design methods used are novel in health-related research, but they have been well-established in service and product design. Third, results may be limited because adolescents were less likely to contribute to the patient-parent group discussions than their parents. However, patients engaged very well in discussion when they met as a separate adolescent group.

The next step in the DECADES project is to conduct a randomized comparative effectiveness trial. Patients in the gastroenterology clinic will complete depression and anxiety screening, in accordance with the results and recommendations of this first phase of the study. Those who screen positive will be presented with their results and randomized to either standard care or consultation with a pediatric psychologist on the same day as the visit.

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