Patient Engagement Strategies for Mental Health Diagnosis and Treatment in Pediatric Subspecialties (The DECADES Study)

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Detecting and Evaluating Childhood Anxiety and Depression Effectively in Subspecialties
DECADES

• Utilizes 4 cores set up within IUSM to improve comparative effectiveness research
  – Mentorship core (Carroll)
  – Informatics core (Downs)
  – Patient engagement core (Wiehe)
  – Implementation sciences core (Watson)
DECADES

• **Aim 1**: Determine family and patient attitudes towards tools to screen for mental illness in a pediatric subspecialty office utilizing structured interviews.
  
  – **Sub Aim 1a**: Determine patient and family attitudes toward anxiety and depression screening in a subspecialty office.
  
  – **Sub Aim 1b**: Determine outcomes of importance to patients and families related to anxiety and depression in a pediatric subspecialty office.
DECADES

• **Aim 2:** Develop an integrated approach that accounts for family and patient preferences as determined in Aim 1, to deliver anxiety and depression screening instruments to new and established patients in a pediatric gastroenterology clinic.
Aim 3: Perform a comparative effectiveness trial comparing screening in a pediatric gastroenterological clinic with notification of the physician to screening in a pediatric gastroenterological clinic with the addition of a psychologist, with respect to the patient-centered outcomes identified in Aim 1.
① Patient interviews (40 dyads)
② Patient advisory groups (2 sessions)
③ Recommendations from the Patient Engagement Core
④ Tablet application development
⑤ Implementation Core assessment
⑥ Randomized trial (2 years – 100-200 subjects)
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Patient interviews

- One on one interviews
- 30 minutes each
- Stacy Keller (previously a GI PNP) performed most of them
- Wide variety of responses
- Subjecting to qualitative analysis using NVivo to find themes (manuscript 2016 Q4)
Did you know that people who have GI problems are almost twice as likely to also have anxiety or depression?
About 50% of people who have GI issues also have issues with anxiety or depression.
Your GI system and your brain—like everything else in your body—are connected.

About 50% of people who experience anxiety and depression also have GI issues.
Your GI doctor was wondering how you felt about the following...
Remember this information goes straight to your medical record and can only be viewed by you and your doctor, unless YOU choose to share it.
Your answers to these questions are confidential. Nobody can access them except you and your doctor. Not even your parents.
Answer these questions as best you can. If you don’t understand one, or feel like you made the wrong choice, your GI doctor will be glad to talk about them with you.
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2. **Patient advisory groups (2 sessions)**
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Patient advisory groups

• Morning sessions, about 3-4 hours on a Saturday
• 10-12 families
• Group sessions
• Breakout sessions with parents vs. children
• Multiple activity types
  – Games
  – Experience maps
QUESTION ON THE BOARD

For this activity, which was included in Session 1, participants were asked to answer two questions that were written on the board. The facilitator introduced the questions on the board and as participants were settling, they recorded their answers on notecards. The questions were “What does depression mean to you,” and “What does anxiety mean to you.” The goal of this activity was to explore participant attitudes toward mental health and begin to inform the message. This activity begins to let us know who could be appropriate to give patients the screener and how the screener should be framed.
SALES PITCH

In this exercise from Session 1, participants were asked to convince the person sitting next to them to take a quiz for anxiety and depression. After this, they were asked to convince the person to be honest while taking the screener. They drilled down who, where, and what their expected next steps would be. This activity begins to identify the sender, message, and environment in which the screener should be given.
BACKWARDS EXPERIENCE MAP

This activity—which was included in Session 2—began to define the patients’ experience from the time they clicked send on the screener to feeling better a year later. We defined the beginning and end points, which were “Clicking Send” and “One year later” with points in the middle, like 3 months later. Participants were asked to identify points in time that will help them get to “better,” and fill in the appropriate points on the map. By identifying points that allow participants to get from point A to point B, patterns begin to emerge. These patterns begin to uncover themes that establish patient centered outcomes.
EVEN BETTER

Expanding upon the “what’s better” points established in the Backwards Experience Map, participants map out their ideal process after screening positive. The facilitator initiated discussion around these touchpoints, asking participants to determine what would be even better than the very best thing that could happen. This activity defines what could be the best possible sequence of events after a positive screen.
**Figure 1. The results of the “even better” activity**
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Parent’s Desired Flow
1 Simultaneous catering and info available in waiting room

It should be said, the parents were eating catered food when answering these questions. Information that connected depression/anxiety and GI, or normalized depression/anxiety was specifically requested.
2 First doctor gives results
   The results of the screener should be given by a human, not a tablet.

2 Parent and child receive results at the same time (even better)
   It was mentioned that in some cases (where the child is less than 9) the parents might even receive the information before the child and “break the news” to them.
3 Reading and brochures available

When it came to educational material, the parents had a “more is better” philosophy.
4 Receive referrals (even better)
Even better than seeing a Riley Psychologist would be a referral for one close to home.

4 Receive coping strategies (even better)
Even better than leaving with just a referral would be leaving with some literature on coping strategies, since it might take some time before their next appointment.
5 Receive next steps and everyone on the same page

Parents didn’t want to leave the clinic without knowing that they, their child’s GI doc and the psychologist all agreed on a care plan.

5 Child actively involved in plan (even better)

It would be even better if their child agreed with the plan as well.
Everyone has understanding of the specific problem affecting the child.

Parents hoped that some time out from the clinic visit, the visits to the psychologist and GI clinic would help give a clear picture of their child’s condition and thus help the treatment be more effective.
Patient’s Desired Flow
1 Feedback

Immediate results from the screener is preferred, perhaps with an animation or celebratory picture (one participant requested an animated gif of a cake with fireworks).
2 Discussion of results

The participants wanted assurance that they would be able to talk to the doctor if they thought they had answered a question incorrectly or misunderstood a question.
3 GI appointment

They didn’t want their GI appointment to be taken over by the psychologist. They were there primarily for their stomach pain, the anxiety/depression test is an important but secondary function of the visit.
4 Choice of timing and parental involvement

Some participants wanted their parents with them when the results were discussed (after the immediate feedback from the device) others never wanted their parents to know. An easy compromise was to ask if they wanted their parents in the room during the initial conversation.

4 Choice of therapist (even better)

Even better than a choice in how their information was discussed, they wanted a choice in all aspects of their health care—including who treats them.
5 Reassurance

Participants wanted to leave the clinic with an understanding that this was a normal and treatable condition, and also have...

6 A plan

Participants, like their parents wanted an agreed upon plan that they had a voice in making.
7 Improvement with GI issues

The participant’s number one hope for an outcome sometime out from the clinic visit was to feel better. (Their “even better” for this was to be cured).
8 Self-management

In lieu of a cure, they wanted to be able manage their illness with less visits to the clinic, GI or Mental Health.
Patient Engagement Core Recommendations
1. Create a survey or worksheet for the parents to fill out while the patient is taking the screener, the primary purpose of which would be to distract the parents, though secondary purposes could be educating the parent on anxiety, common parental triggers for kids with depression and anxiety, etc.

2. Have a handout of some sort that clearly and succinctly describes depression and anxiety and how it relates to GI issues freely available in the clinic.

3. Use informational graphics, like the one that got 9 votes in Fig. 3 on the screener.

4. Use a “cover page” to introduce how many questions will be included in the screener, appx. how long it will take, etc.
5. Use the following language to frame the screener:

- **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.

- Your GI system and your brain—like everything else in your body—are connected. When one is irritated, often so is the other.

- 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 form a plan for care that addresses both their anxiety/depression and their gastrointestinal disorder.

7. Talk to the child separately from the parent, perhaps in the same way it’s done for a physical—call the patient in first for a few minutes before inviting the parents to come back.

8. Have the patient meet with the GI and the psychologist at the same time initially. For example, “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 screener results and how they might affect your GI issue.”
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Implementation Core

• Two students from MPH classes (one M.D. Heme/Onc fellow and one Ph.D.)
• Will use qualitative methods, as part of a graduate course, to help determine best implementation of PEC recommendations using tablets
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Randomized comparative effectiveness trial

• Over 2 years
• 1-1.5 days per week
• Goal of 100+ patients, but hope to get more
• Positive screens randomized to either:
  – Usual care, with GI MD being informed of screen results
  – Automated shunting of patient to psychologist as part of visit when a positive screen occurs