Collaborating to Create Empathic Patient Engagement Tools

How Effective Communication Tools Reduce Anxiety & Improve Outcomes

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Disclosures

Geri Baumblatt: Employee: Emmi Solutions

Corey Siegel

Consultant/Advisory Board
   Abbvie, BiolineRX, Given Imaging, Janssen, Salix, Millenium, Prometheus, Takeda, UCB

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Intellectual property
   Dartmouth-Hitchcock Medical Center and Cedars-Sinai Medical Center have a patent pending for a “System and Method of Communicating Predicted Medical Outcomes”, filed 3/34/10. Dr. Corey Siegel and Dr. Lori Siegel are inventors.
Library of 260+ Emmi® programs
INTERACTIVE PROGRAMS

Interactive:
Ask Questions. Clinician sees them pre-visit

Intuitive navigation:
Simple VCR like controls

Visual learning:
Preferred by all & critical for understanding

Plain language:
Universal Precaution & validated with patient testing

Here's what a torn ACL can look like. It can tear all the way through.

Narrated:
A conversational and empathic voice
These blocks of bone (vertebrae) are stacked to give your spine its "S" shape.
HOW DOES IT WORK?

1. ORDER
   - EMMI MANAGER
   - EMR
   - BATCH FILE
   - PATIENT PORTAL

2. NOTIFY
   - EMAIL
   - PHONE
   - PRINTOUT
   - TEXT MESSAGE (2013)

3. ENGAGE
   - DESKTOP
   - TABLET
   - SMARTPHONE
   - PHONE
   - BEDSIDE ENTERTAINMENT SYSTEM

4. TRACK
   - EMMI MANAGER
   - EMR
   - SECURE FTP

Healthcare Professional  Patient  Healthcare Professional
Engagement

When people start programs, they usually complete them.

<table>
<thead>
<tr>
<th>Age</th>
<th>Engagement</th>
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<tbody>
<tr>
<td>0-17</td>
<td>81%</td>
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<tr>
<td>18-34</td>
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<tr>
<td>35-49</td>
<td>86%</td>
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<td>50-64</td>
<td>87%</td>
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<tr>
<td>65-79</td>
<td>87%</td>
</tr>
<tr>
<td>80+</td>
<td>85%</td>
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What about anxiety?

C'mon now Jim

It's time for your colonoscopy
Get real information from real people
Seem psychic

- Anticipate questions
- Address questions, fears & worries up front
- Proactively bring up embarrassing issues
QUESTIONS WEIGH ON THE MIND

- Pain
- Scars
- Sex
- Driving
If I have any hemorrhoids, will they hurt during the colonoscopy?
“Makes me feel like the few questions I have left won’t seem as out of place or ‘stupid’ to nurses and doctors since some were addressed already in this program.”

Hysterectomy patient
A polyp is a growth (extra tissue) that grows out of the wall of the colon.
I was impressed and greatly relieved to hear things explained in a way I could understand. I have a lot less anxiety now about getting a colonoscopy.

— Stanford patient
Set expectations
UNDERSTANDING WHY

✤ We don’t blindly follow instructions

✤ Satisfies curiosity and remove unknowns

✤ More likely to follow directions

✤ People make up their own reasons

In your colon, red can look like blood and make it hard for the doctor to tell what's what.
So no need to rush into a decision overnight. Give yourself some time to think about what's really important to you.
DO THESE STRATEGIES HELP?
**Summary**
Because poor patient compliance leads to cancellations for scheduled colonoscopies, University of Chicago Medicine used Emmi programs to combat these problems. Patients were prescribed Emmi programs and colonoscopy attendance was measured.

**Results**
- Improved scheduled procedure attendance
- Patients who had viewed an Emmi program were more than 30% more likely to attend their procedure than non-Emmi patients (89% vs. 68%)

**30% increase in procedure attendance rates**

<table>
<thead>
<tr>
<th></th>
<th>Non Emmi Viewers</th>
<th>Emmi Viewers</th>
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<tbody>
<tr>
<td>0%</td>
<td>68%</td>
<td>89%</td>
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<tr>
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</tr>
<tr>
<td>50%</td>
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<tr>
<td>75%</td>
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<tr>
<td>100%</td>
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</table>

2007, N=333, Confidence Level = 99.5%
Patient Comments on Anxiety

Interesting and very informative. I now have time to understand it w/o being nervous like on the day of the procedure.
— Anesthesia, St. John Medical Center

Extremely helpful and relieved most of the anxiety I feel toward my son having surgery (tubes and adenoids). I appreciate the simple animations and opportunities to take notes.
— Myringotomy Parent, McLane Children’s

It simplified the process in terms that anyone can understand it. It offered the most common scenarios. It gave great suggestions and advice. Thank you for offering it! It helped put me at ease.
— Cholecystectomy, SHO Hendricks Regional
Patient Comments on Anxiety

Easy to understand, clear and concise. Lots of organized information and helps lessen anxiety.
—Total Hip Replacement, Danbury Hospital

This program is quite helpful. It certainly clears up general questions prior to surgery that otherwise might be pondered with anxiety and uncertainty. —Anesthesia, Beaumont

I felt very informed to know some things I had no idea about. Now I'm not so anxious about the procedures and know what to ask. —Anesthesia, Southern Regional Health System
Colonoscopy Patient Comments

Made everything less scary and I loved the little funny notes throughout the presentation! — Cleveland Clinic

I am very nervous about this procedure, and this video has allowed me to not be quite as stressed about it.” — IU Health Arnett

Helped reduce my anxiety knowing more about the colonoscopy and what to expect. — Northshore
Objectives

» To describe a randomized trial using a web-based multi-media program about colonoscopy

» To describe a novel method to conduct a needs assessment using moment-to-moment affect trace technology

» To review the development of a personalized Crohn’s disease shared decision making program
Randomized controlled trial demonstrates a web-based multimedia program used prior to first-time colonoscopy decreased patient anxiety, sedation requirement and procedure time while increasing knowledge.

Siddhartha Parker, MD, MA, Jonathan Zipursky, MD, Helen Ma, Corey A. Siegel, MD, MS
Background

» Patients arrive for colonoscopy with significant anxiety about the procedure itself, and possible findings.

» We hypothesized that improved pre-procedural education would decrease this anxiety, and perhaps have an influence on sedation requirements and procedure time.

» A web-based program could be an ideal format to efficiently distribute an educational tool to patients.
**Objective and Methods**

**Objective:** To explore the impact of an interactive web-based multimedia patient engagement program on patient anxiety, perception and knowledge about colonoscopy in addition to procedure outcomes.

**Methods:**
- Randomized controlled trial, single site at Dartmouth-Hitchcock
- Intervention → a web-based multimedia patient engagement program (*Colonoscopy*, Emmi Solutions)
- Control group → standard pre-procedure colonoscopy packet
Results – Decreased Anxiety

State Trait Anxiety Inventory Score Prior to Colonoscopy

- Control: 40.4
- Intervention: 35.4

p = 0.03

Patient Perception of the Effect of the Intervention on Anxiety

- Increased Anxiety: 4%
- Decreased Anxiety: 58%
- No Effect: 38%

Effect of the Intervention on Patient Knowledge About Colonoscopy

- Control: 74%
- Intervention: 82%

p < 0.001
Results – procedure related

Average Procedure Time

Control: 29.0 minutes
Intervention: 24.8 minutes
p = 0.02

Average Total Midazolam Given

Control: 4.5 mg
Intervention: 3.7 mg
p < 0.005

Average Total Fentanyl Given

Control: 186 mcg
Intervention: 166 mcg
p = 0.06
Conclusions

» A web-based multimedia patient engagement program watched prior to colonoscopy significantly decreased patient anxiety, sedation medication requirements and procedure time while increasing knowledge.

» This easy intervention could not only help patients understand and feel more comfortable about colonoscopy, but increase efficiency and decrease cost by saving time and using lower doses of sedative medications.
APPLYING THESE STRATEGIES TO DEVELOP SHARED DECISION MAKING TOOLS TO DECREASE ANXIETY & INCREASE ENGAGEMENT FOR CROHN’S DISEASE
CD - Distinguishing Features

- Granuloma
- Focal lesions
- Asymmetric involvement
- Strictures
- Fistulization
- Endoscopic features
  - Skip lesions
  - Small bowel involvement
- Rectal sparing
- Perineal disease
- 20-30% without gross bleeding
Standard Treatment Algorithm for Inflammatory Bowel Disease

- **Surgery**
- **Biologic Therapy**
  - AZA/6-MP
  - Methotrexate
  - Systemic steroids
- **Antibiotics**
- **Budesonide**
- **5-Aminosalicylates**

Stoma

J-pouch

Ileostomy

*Illustration of ileostomy and ileoanal anastomosis.*
Typical Course of a Crohn’s Patient
But our patients have to deal with this...

- Serious Infection
- Cancer
- Tuberculosis

FDA Black Box Warning
Steps in Developing a Shared Decision Making Program

1. Needs assessment of patients and providers
2. Decision Aid creation and pilot testing
3. An individualized risk prediction model
A needs assessment to understand how IBD patients and gastroenterologists want to be involved in shared decision making

“Turbo Focus Groups” to create quantitative results from qualitative data
Technology Similar to Debate Reactions...
Moment-to-Moment Affect Trace

» Upswings in the line graph mean increased agreement with what is being said.

» Downswings in the line graph as disagreement regardless of whether the line goes below 5.

» Increases or decreases in the ALL trace (average) of 1, 2 or 3 points indicates a significant change in the level of agreement or disagreement with what is being said.
IBD Patient Turbo Focus Group

I've seen a few doctors that I feel like are a bit arrogant, and they talk to you like you're an idiot, and at times I won't listen to advice that I've been given.

I think maybe if I had more trust in my current doctor then I wouldn't be so skeptical of his suggestions.

I don't trust them. I want to know what they're up to and what they're thinking, and I want to talk to another doctor if I don't think I'm getting enough information from them.

I had a wonderful doctor who was all about a health, restoration, and prosperity. Because of that, I trust his opinion and his treatment choices, and if it's not broke, don't fix it.

Creating a Web-Based Decision Aid

» “Process Map”

» Emmi Solutions (Chicago, IL)

» Content and script development

» Scientific review

» Patient focus groups

» International Patient Decision Aid Standards
Risks
We typically use clinical trial results to guide our management of patients. But only a small proportion (31%) of the patients we see in the office would qualify for a trial!

We are treating individual patients, not a group of clinical trial subjects.

A validated web-based patient communication tool to display individualized Crohn’s disease predicted outcomes based on clinical, serologic and genetic variables


What is System Dynamics Analysis?

System dynamics analysis (SDA) is a methodology that addresses the inherent dynamic complexity of interactions between variables.

Advantages of SDA over traditional statistical methods are:

- Provides real-time individualized predictions of outcomes
- Simple input “control panel”
- Graphically conveys the outcomes over time

Complex Clinical Data → Patient Friendly Results

A model to predict individualized risk of Crohn’s disease complications

- 695 adult patients with Crohn’s disease
- Outcome = time to complication of Crohn’s disease

<table>
<thead>
<tr>
<th>Variable</th>
<th>Hazard Ratio, 95% CI</th>
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<tbody>
<tr>
<td>Small bowel disease</td>
<td>2.12, CI 1.05-4.29</td>
</tr>
<tr>
<td>Left colonic disease</td>
<td>0.73, CI 0.49-1.09</td>
</tr>
<tr>
<td>Perianal disease</td>
<td>4.12, CI 1.01-16.88</td>
</tr>
<tr>
<td>LogASCA</td>
<td>1.35, CI 1.16-1.58</td>
</tr>
<tr>
<td>LogCbir1</td>
<td>1.29, CI 1.07-1.55</td>
</tr>
<tr>
<td>LogANCA</td>
<td>0.77, CI 0.62-0.95</td>
</tr>
<tr>
<td>NOD 2 frameshift mutation</td>
<td>2.13, CI 1.33-3.40</td>
</tr>
<tr>
<td>Perianal*logASCA</td>
<td>0.63, CI 0.42-0.94</td>
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</tbody>
</table>

Model concordance
Calibration
Harrell’s C = 0.73

Adult Validation
Harrell’s C = 0.74

Pediatric Validation
Harrell’s C = 0.74

Now we need to translate this for patients, parents and providers using System Dynamics Modeling
Can we put this all together and make it more user friendly?
Corey Siegel's predicted risk of a complication from Crohn's disease

Based on the specific characteristics of your Crohn's disease, the graph below shows your risk of developing complications such as fistulas and blockages, which often lead to surgery.

Click below for more information about...

Your Crohn's Disease

Your Treatment Options
Program Creation

Web-Based Crohn’s Decision Aid

A very small number of people who take these medications may get lymph node cancer (non-Hodgkin’s lymphoma).

Individual Risk Prediction Tool

Personalized Shared Decision Making Program
Cluster RCT studying the Crohn’s SDM Program

- Adult patients who are being offered immune suppressive therapies for treatment
- 15 sites (8 academic, 7 community)
- Randomized by practice
- 270 subjects (18 per site)
- Two-year follow-up
- Outcomes include:
  - Choice of therapy
  - Time to initiation of therapy
  - Persistence with therapy
  - Decision quality
  - Disease outcomes and cost
Patients undergoing colonoscopy had a decrease in anxiety, procedure time and use of sedating medications after viewing a multi-media educational program.

Patients with Crohn’s disease have significant concerns regarding their disease and medications.

We have developed a personalized shared decision making program to help patients with Crohn’s disease make better informed decisions.

We hope to see that better decisions lead to better (and cheaper) disease outcomes.