Medical student with inflammatory bowel disease helps pediatricians understand the power of their words

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Catalina Berenblum Tobi, a 4th-year medical student at the UNC School of

Medicine. Credit: Catalina Berenblum Tobi

Catalina Berenblum Tobi had her first colonoscopy when she was just 10 years old. For more than a year she had been suffering from severe abdominal pain and diarrhea for which there was no apparent cause. While terrified and confused, Berenblum Tobi was ready for an answer. The diagnostic test confirmed she had Crohn's disease, an autoimmune condition that would require lifelong management.

Berenblum Tobi encountered a variety of social challenges in middle school due to her diagnosis. Her parents were reluctant to start her on a biologic treatment, so she was put on the specific carbohydrate diet (SCD) instead, which prohibited her from consuming refined sugars, processed foods, and starchy carbohydrates. When she had flare-ups, she transitioned to exclusive enteral nutrition (EEN), a highly restrictive treatment that involves only drinking formula and water for 8–12 weeks.

Instead of waiting in the cafeteria line, Berenblum Tobi drank her formula. She didn't dine out with friends. She often missed big holiday dinners. Her middle school friends grew more curious as time went on, leaving Berenblum Tobi no choice but to describe her condition. But she couldn't find the words.

"I would tell them that I had Crohn's, and then they would just look at me kind of confused," said Berenblum Tobi. "It was difficult at that age to figure out your own language to describe your disease and express how it is affecting you mentally and physically."

Now a fourth-year medical student at the UNC School of Medicine, Berenblum Tobi realizes how much word choice—especially those used when communicating diagnoses and explaining treatment plans—can

affect children's perceptions of their own health.

The beginning of a three-year research endeavor

During her first year of medical school, Berenblum Tobi noticed there was little attention to routine communication with young patients in the curriculum. Rather, most communication training was dedicated to "delivering bad news" or having difficult conversations about end-of-life care.

Berenblum Tobi then took full advantage of her new opportunity at a nationally ranked research university. While juggling intensive coursework, she decided to conduct a study of how physicians explain inflammatory bowel disease (IBD) to children. (IBD is an umbrella category that includes Crohn's disease and ulcerative colitis.) The project would prove to be a three-year-long endeavor.

Berenblum Tobi reached out to Mara Buchbinder, Ph.D., a professor of social medicine in the UNC School of Medicine who wrote her Ph.D. dissertation, and a subsequent book, on how clinicians explain chronic pain to children and adolescents.

Explanatory models are the ways in which people perceive and respond to their illness. The models, which are shaped by worldviews, education, and beliefs, frequently take the shape of allegories or metaphors that physicians use when making initial diagnoses or prescribing treatments. These, in turn, affects patients' own perceptions of illness and healing.

Although Buchbinder's research now focuses on physicians' stress and well-being, they were a perfect match intellectually. Buchbinder excitedly agreed to mentor Berenblum Tobi. Their connection grew even stronger when Buchbinder revealed that she, too, was diagnosed with Crohn's disease at a young age.

"I've had this disease for most of my life, and it's part of what inspired me to get a Ph.D. in medical anthropology. But explanatory models of IBD were not something that I had a lot of reflexivity about, as I was going through my own illness," said Buchbinder. "When Catalina approached me, I was so excited because there is a big gap in training clinicians to be a little bit more deliberative about the language they use with pediatric patients."

Common explanatory models for IBD

For her study, Berenblum Tobi interviewed pediatric gastroenterologists from across the United States to identify what explanatory models they are using with their young patients. In the summer following her first year of medical school, and under Buchbinder's mentorship, she conducted 20 hour-long interviews to explore how doctors communicate a diagnosis of pediatric IBD, how they explain disease etiology and treatments, how they assess a patient's understanding over the course of months and years, communication with caregivers, communication challenges, and more.

Berenblum Tobi and Buchbinder identified two prevalent explanatory models in pediatric IBD: the defense and protection model and the switch model. The defense and protection model characterizes the immune system as an "army" that is tasked with keeping the patient safe by fighting off infections or "invaders," but becomes "confused" and "attacks" the body instead. In the switch model, the faulty immune system is described as a switch that is left in the "on" position and cannot be turned back "off" without the use of medication.

Their results were published in *Qualitative Health Research*, a journal that aims to enhance health care and further qualitative research in health care settings.

The results didn't come as a big surprise to Berenblum Tobi and Buchbinder because the same battle metaphors and militaristic language are used by medical school professors to teach their students about the inner workings of the immune system. They were surprised that few respondents had concerns about the metaphors being aggressive, and even those that did often still used them.

Speaking from her own experience, Berenblum Tobi adds that this specific metaphor may also be contributing to further confusion about IBD and may dissuade children from taking care of their bodies or wanting to understand more about their condition.

"Children are taught that the body is 'good' because the body is fighting something 'bad', something that is not that person," said Berenblum Tobi. "These kids watch Disney movies. They know there's a villain and a hero. But when the body is fighting itself, it's like, 'Who's the good guy, who's the bad guy? Which one am I?'"

Moving forward, one word at a time

With the explanatory models now identified, Berenblum Tobi is interested in exploring how the models provided by physicians might impact children. She also wants to determine what models the patients themselves are using and whether they can be linked to patient outcomes such as medication adherence and negative impacts on mental health.

"If kids don't understand how their disease works, they might not understand why they're taking their medicines," said Berenblum Tobi. "They're going to stop taking them when they feel better. If a child has a negative self-image or negative self-perception because of their disease, then they might develop anxiety or depression."

Future research implications for Berenblum Tobi include working with

pediatric psychologists on joint studies, providing pediatric residents with additional communication training, and developing a standardized communication approach that doctors can use when diagnosing their patients.

Naturally, this kind of qualitative research can extend beyond IBD to include other autoimmune diseases like lupus, multiple sclerosis, and type 1 diabetes. The autoimmune space, in general, applies a lot of metaphors to explain the complexities of the conditions, but there remains much to be studied about what the explanatory models are being used for and how they're being used.

"Communication mediates all clinical education and clinical understanding," said Buchbinder. "It's so central to everything that physicians do. Looking at explanatory models of pediatric illnesses, like IBD, really brings home how much a qualitative perspective can really tease out mechanisms, which can help physicians reflect a little bit on their communication practice."

Berenblum Tobi is now focused on her next steps to become a pediatrician: Residency. No matter what institution she commits to, she will continue to advocate for patients with IBD and innovate ways to help give them something she struggled with as a child: A voice.

More information: Catalina Berenblum Tobi et al, Physicians' Explanatory Models of Pediatric Inflammatory Bowel Disease: A Qualitative Interview Study, *Qualitative Health Research* (2023). DOI: 10.1177/10497323231218159

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