

Katie: The Physician's Perspective of a Young Woman's Illness Experience

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The nature of my practice has been to care for patients with difficult-to-diagnose and -manage gastrointestinal (GI) problems (1), now called disorders of gut-brain interaction (2), and overlap disorders like inflammatory bowel disease-irritable bowel syndrome (IBD-IBS). I apply communication skills to achieve patient-centered care (3) and use neuromodulators (4) and behavioral treatments to manage the more severe symptoms that do not respond to usual GI medications. This approach, which relies on the biopsychosocial model (5), has been my “raison d'être” within academic gastroenterology. It has led to referrals from gastroenterologists and medical centers throughout the country.

THE REFERRAL

I met Katie by referral from an online service that helps match patients to doctors most qualified to handle their problems. The person who contacted me said, “this one is right up your alley”. I pondered what that meant. At first it seems like a compliment, but after hearing that statement over many years, I see an additional meaning: “I can't help her”, or even “I won't help her”. When confronted with patients having pain and distress, there is diagnostic uncertainty, and the patient fervently requests help; with a history of not having been helped before, one can feel overwhelmed and frustrated (6). To me this scenario, not uncommon, is challenging. So I accepted the referral.

THE FIRST VISIT

Katie, 29 years old, came to the office with her mother. She was thin but not malnourished, and seemed anxious, possessing a frenetic quality to her speech, as if she had to say so much in a short amount of time. She rapidly told me her story, interjecting her views that this symptom was caused by gluten, and that symptom by dairy, and that this dietitian said this, but that holistic person said the opposite. She seemed confused, even frantic trying to handle all the information offered by family, friends, and so many

different practitioners, not to mention her own efforts to make sense of it all through the internet.

THE MEDICAL HISTORY

Her history of stomach aches went back to early childhood and got worse in college where it was associated with more severe mid to lower abdominal pain, bloating, and diarrhea after an infectious gastroenteritis. She also developed early satiety and fullness in the upper gut after consuming small amounts of food. At age 22 she was admitted to the hospital and was diagnosed with diabetic ketoacidosis. This experience led to a marked deterioration in her health. Although the diabetes got under good control quickly, her perception, attitude, and behaviors around the illness experience went into a downhill spiral.

Katie became hypervigilant to food, restricting gluten, lactose, processed, and even hot and cold foods. She reasoned that her GI condition was so bad because her diabetes led to poor digestion of the food and hence the symptoms. She began to check her blood sugar up to 10 times a day. Her distress became worse a year later when a gastroenterologist diagnosed her with gastroparesis, though the study only showed about 20% greater than normal retention at 2 h. Being given this diagnosis had a profound psychological effect: “I'm only 22 years old and now I have a complication of diabetes?” She didn't clinically have gastroparesis with abnormal food retention; what she had was postprandial distress syndrome (PDS), the subtype of functional dyspepsia (FD) where there is incomplete relaxation of the gastric fundus leading to early satiety and fullness even with small amounts of food (7). In addition, she had IBS-D with postprandial lower abdominal pain and discomfort leading to diarrhea (8). But in her mind, she wasn't eating right because her diabetes was creating havoc on her GI tract. She was reluctant to discuss these symptoms, blaming herself for not achieving good control, and she continued to obsessively restrict food, eventually losing 30 lbs. So she went to family physicians, dietitians, gastroenterologists, psychiatrists, homeopaths, and naturopaths without benefit.

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EFFECTS OF THE ILLNESS

The impact of her illness was profound. She received a master's degree in early childhood development, but hadn't worked for years, and for financial reasons she lived with her parents. She reported being anxious, depressed, and frustrated, with occasional panic episodes and she displayed catastrophic thinking: "when will this end, I can't go on like this anymore, can't someone help me?". She stopped driving, going to restaurants, or socializing with friends. She reported feeling scared most of the time, thought about her symptoms all the time, and wouldn't leave the house out of fear that the symptoms would worsen. She reported no control over her illness or even her life, and felt abused by the health-care system for the way she was treated. She thought she was going crazy.

MEDICAL EVALUATION

A year earlier she had iron deficiency anemia, presumed nutritional in nature that responded to iron supplementation. Her A1c stayed in good control, always below 7, and the complete blood count and complete metabolic panel were otherwise normal. An esophagogastroduodenoscopy and colonoscopy with biopsies were normal with no celiac disease or microscopic colitis. She was taking insulin and was prescribed escitalopram from her psychiatrist for anxiety and depression. Her body mass index was 19. The physical examination was normal except for increased abdominal sounds and left lower quadrant tenderness overlying the sigmoid colon.

ASSESSMENT

We spent 45 min going over her diagnoses and explaining the physiology of her gut and why she was experiencing her symptoms. Stating the diagnosis of IBS and FD and what their physiological effects were had a profoundly positive effect on her. I explained that the diabetes is not causing her symptoms, and that her gut cannot really discern what she eats, so there is no need to be finicky about the foods. Rather, she has visceral hypersensitivity of the gut where even minimal distension from any food would cause pain, bloating, and fullness, much like having the volume turned up on the nerves in her gut. I also explained the brain-gut axis: no other organ is as closely connected and "hardwired" to the brain as the gut, and the brain sends down signals to modulate pain and gut function. However, when she is anxious or frustrated, the brain loses some of its capability to regulate gut sensation, and the pain and symptoms get worse; this is central hypersensitivity. We needed to work together to help downregulate the brain and gut hypersensitivity.

THE PLAN

I applied a patient-centered approach to her care, as first proposed by the Institute of Medicine 15 years ago (9). I clarified her understanding of our discussion until we were both satisfied. Then I sought to collaborate in the care by encouraging her to actively

participate in the decisions. For example, I offered the potential benefit and risk of different medications and allowed her to make the choice, and suggested we can work together to implement them. We set up mutually agreed-upon goals and expectations for outcome: I asked if she would be satisfied with 25% improvement in 3 months and she thought this to be reasonable. Throughout, I provided positive regard for her capability to get through this process, and was empathic. I monitored her verbal and nonverbal responses to be sure she was satisfied and that all her questions and concerns were met. Finally, I made it clear that whatever the outcome, I would work with her until she gets to where she wants to be in her recovery.

After that came the specifics of her treatment. For the IBS, we agreed to a 2-week course of an oral nonabsorbable antibiotic. We also started buspirone both for its anti-anxiety effect and to improve proximal fundus relaxation to help her PDS (10). She was also referred to a psychology colleague for CBT treatment. CBT was explained as a way for her learn to diminish the maladaptive thinking and ruminative thoughts about food and diet and to help her regain control over her illness and reduce its impact on her.

THE AFTERMATH

One month later, the bloating and diarrhea were reduced, but she still felt a great deal of anxiety particularly around meals. She was also reporting more sleep difficulties and still had moderate pain. I added duloxetine for the pain, and quetiapine for the anxiety and sleep disturbance and to augment the pain benefit (1,11). I discontinued the escitalopram. Over the next several months with the medication and the CBT she improved. By 6 months, the pain was virtually absent, she no longer had postprandial bloating, she regained her weight, began living on her own and socializing, and after years took on a new job. She volunteered how much control she now felt over her illness and her life, and went back to eating normally: "I didn't eat gluten or dairy or processed or sugary foods for nearly four years...now I can't stop eating them".

FINAL COMMENTS

Many have said: "It's not what you do but how you do it that counts". I believe what made the difference here was not just the medical treatment but the biopsychosocial aspects of the data gathering that incorporated an understanding of the illness from the patient's psychosocial world, and a humanistic, patient-centered approach that was linked with trust, respect, and mutual engagement in the plan of care. This was a collaborative effort that led to a shared sense of satisfaction and a positive outcome. This approach can be learned (3), and even assessed in terms of patient satisfaction (12). To see Katie's response, please read her column and view this video: <https://www.youtube.com/watch?v=hFra7Uj0z0>.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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