From Pretending to Truly Being OK: A Journey From Illness to Health With Postinfection Irritable Bowel Syndrome: The Patient's Perspective

Pain is something we all experience. Growing up the oldest in a conservative, protestant, middle class family you had to tolerate pain and learn to deal with it. Getting sick was not an excuse for sympathy or a day off from school. It was almost a badge of honor because you were tough, not weak like others. Maybe that's why, at the age of 13, when it finally came out that I was sexually abused for 4 years by my cousin, I held back communicating my deepest thoughts and feelings about the experience. Rather, I felt the need to express to my mother that I was okay, even though I wasn't. I was a "good girl," but was dying on the inside, and I still had to show I was okay.

So, I stuffed down the emotional pain and moved on to college. I married a great guy, had 2 kids, and with great passion I started a career in health and social justice nonprofits. Although I could help vulnerable, oppressed, and ill people in similar situations, I could not reverse the trauma in my own life. I also managed through more than a dozen surgeries, the care of my son with congenital health issues, and saw family members through attempted suicides, cancer diagnosis, and death. Through it all, I had to be OK.

Ten years ago it all changed. While raising my family and working a full-time, stressful job, I developed food poisoning from a chicken salad sandwich: the fever, abdominal pain, vomiting, and diarrhea were so severe, I almost blacked out. Then the diarrhea turned to blood and I could not leave the toilet. I felt I was dying, barely able to talk and shaking on the cold tiled bathroom floor. In the emergency room, a CT scan showed my colon was so swollen and inflamed that they transferred me via ambulance to a larger hospital. I spent 3 days receiving antibiotics, IV fluids, and pain meds. The diagnosis was unclear: the hospitalist said *Escherichia coli* gastroenteritis, but the gastroenterologist said possible ulcerative colitis. A colonoscopy was recommended, but it couldn't be completed until I was better.

One month later, the pain and bloating with diarrhea continued so I went to a GI specialist hoping he could help. Sadly, that was not my experience (Figure 1).

Dr.: Hi, I'm Dr. Blah Blah. (limp fish handshake) So, why are you here? (Looking at my chart and avoiding eye contact.)

Me: (Sitting in a gown, cold from waiting 30 minutes in the examination room.) Hi, Doctor. Well, I was in the hospital for a bad case of *E coli*. They recommended I follow-up with you to have a colonoscopy for a diagnosis and treatment. I still have pain and loose stools; I didn't know if that is normal or not.

Dr.: (looking at the computer) Uh-huh, okay. (Silence.) Well, you're too young for colon cancer so it's probably nothing serious. I'll do one if you want. (Turns to me.) Try some probiotics for the pain, and Kaopectate for loose stools. I will have the nurse set up the colonoscopy.

I couldn't believe it. "Really?" I thought. "You'll do a colonoscopy if I want one? Who WANTS a colonoscopy?! Shouldn't you make that call?" "Did you read my hospital record to see about possible colitis?" But I just sat there startled and wondered why I was in a gown if he didn't even do a physical exam.

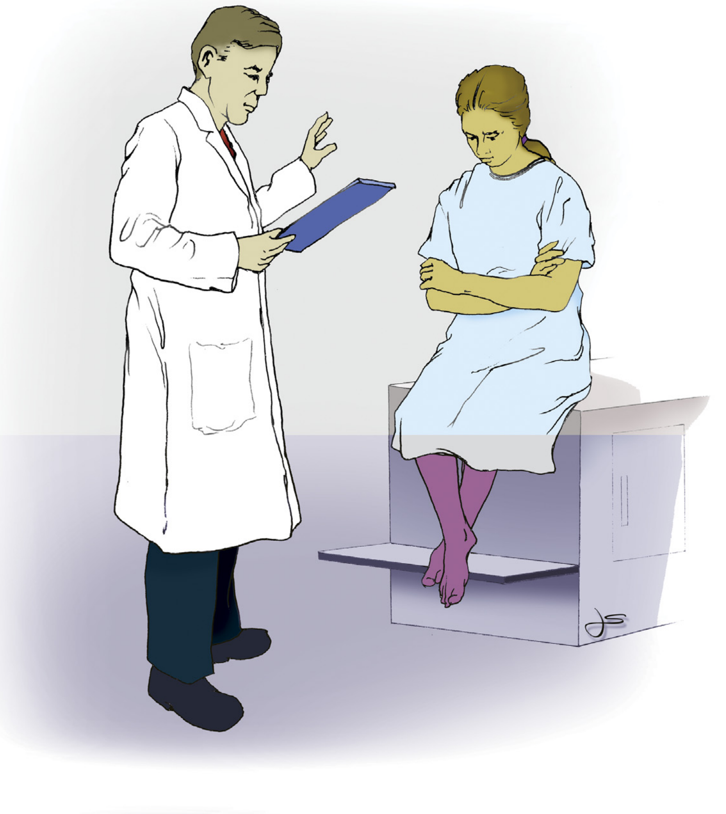

Figure 1. There is a lack of engagement as was demonstrated at the beginning of Johannah's story. The doctor is avoiding eye contact while looking at the medical record, and is turned away from the patient. He waves his hand in a way that dismisses the patient. The patient in turn is looking down with slumped shoulders and with crossed arms and legs displaying passivity and nonacceptance.

Me: Uh, okay, so, that's it?

Dr.: (Already closing the door on his way out.)

I had the colonoscopy but I was dreading the follow-up appointment because our last encounter had gone so poorly. Nevertheless, I wanted to get to the bottom of this once and for all.

Dr.: (Talking as he entered the room, head down reading my chart and sitting on his rolling doctor stool.) So, everything looked fine. I took out 2 small polyps. There was very mild inflammation but nothing like UC or Crohn's and certainly no cancer. (Looks up.) So, good news all around.

Me: Well, that's good. So why am I still having pain and loose bowels? Will that resolve on its own? Is it left over from the infection?

Dr.: (Looking at the computer and typing.) Probably. Don't worry about it. Stress causes this too, especially in women. You'll be fine. I won't need to see you again unless something changes. Just follow-up with your primary care doc if needed. (Gets up and heads to the door.) Take care.

I couldn't believe that he dismissed my questions so quickly. His words stung like a slap on the face. He didn't need to see me when I still felt so bad with these symptoms!? He had no interest in or understanding of what was happening and what it meant to me. He was really saying, "It's not that serious to me, so I don't want to spend any more time dealing with you." I was angry, hurt and frustrated. As a young girl, I was taught not to question authority and even as a grown, educated woman, I still resort to this thinking. Clearly, if a specialist did not think my symptoms were an issue, then maybe they really weren't. Maybe I was being a baby. My family's words echoed: "Suck it up, you're fine, stop making a big deal about it." So I thought, "Okay, I'll just deal with it."

Over the next several years, I continued with the abdominal pain and diarrhea, but it intensified and became almost constant, depending on time of day and what I had eaten. I thought it was worse when I ate dairy or meat, so I eliminated them and lots of other foods from my diet: broccoli, asparagus, dairy, beef, and pork. I tried heating pads, sleeping with a pillow under my rib cage, Gas-Ex pills, Imodium, and upwards of 12 probiotic pills a day.

The effects on my family were profound. I had to cancel on friends and family. I wasn't well, and didn't know if I could get to a bathroom quickly enough. I missed family soccer, football games, and concerts. Weekends were spent with me in bed and my husband and kids playing games or watching movies. My marriage was affected; who wants to be intimate when dealing with constant pain, restricted diets, and unpredictable bowel habits? So, I relented and saw three other doctors, who after reviewing my chart told me that I should eat more yogurt (but I gave up dairy), drink more water (why didn't I think of that?!), and try yoga (Is there a bathroom nearby?). Maybe I should hike or swim to reduce stress (if it were just that easy).

I had given up hope that a gastroenterologist was going to help me, so I saw an internist. This was my worst interaction.

Dr.: "Could you be exaggerating the pain a bit? From what I see in your chart, there is no structural cause for your symptoms. If it were as bad as you say, how can you hold a job or raise a family? Women can get hysterical and exaggerate pain, especially at certain times of the month. Maybe it's not as bad as you say?"

Stunned, pinching my arm to keep from crying and embarrassing myself, I felt the need to justify myself and my symptoms. My inner voice screamed: "Why are you letting someone speak to you like this, make you feel insignificant and unworthy, and even call you a liar?" Yet the little girl in me needed to prove to him that I was okay despite my symptoms, to prove the legitimacy of my pain and its effect on my life. I told him I worked every day, even though I was hurting with a heating pad at my desk, how I cared for my family even when repeatedly going to the bathroom, and how I served on 8 different nonprofit committees and boards in town while eating Imodium like candy.

I began my master's degree program and worked full time. My pain was now wide-spread also affecting my hands and feet as well. I was constantly tired and developed fogginess and forgetfulness. The doctors said I had fibromyalgia and gave me gabapentin for the pain and for sleep. Is fibromyalgia a real diagnosis? Did it come from the chicken salad sandwich and relate at all to the GI pain and symptoms? How could my health have declined so badly? Did I do something to cause this? I felt at the end of my rope, hopeless and lost.

Over time I missed more work. I even left an awards dinner early, where I was being honored as a top Professional Under 40. Going home, I sat in the car with tears in my eyes, frustrated and tired at the course my health had taken all these years.

I wanted to scream: I AM IN PAIN. WHY CAN'T SOMEONE HELP ME! I felt the diagnosis of fibromyalgia, the probiotics, yogurt, water, and yoga were all hodge-podge recommendations given as a last resort. I couldn't bear to hear that I had "mystery" symptoms or that I was "exaggerating." I believed my doctors would say, "We don't know what else to tell you and don't see any legitimate reason for your symptoms, so this is the best we can do. We don't want to really understand how this is affecting your life. So, please, stop coming; figure it out on your own." My medical chart must have said: "She is exaggerating the pain and diarrhea, and probably won't accept that this is stress. Smile, nod, and send her on her way with a new probiotic to try."

So, I stopped seeing doctors and tried to cope and adapt my life to this "new normal." I got my MEd with honors, poured into my work, and did the best I could to manage these symptoms. Then my husband got a job transfer across the country and my life changed. I started a new job and heard there was a GI specialist who might be able to help me. I was skeptical, but after stumbling back to the table from the bathroom for the third time while out for dinner, my husband convinced me to see him.

Dr.: (Looking directly at me with a smile) Hello, I am Dr. Blah Blah. Thanks for coming in? How are you and how can I help?

Okay, right away, I thought, “Why is he looking at me instead of the computer?!”

Me: Uh, well, I have some stomach issues and thought maybe you could help.

Dr.: Okay, glad to try to help. (Smile.) Tell me about your symptoms.

This dialogue went on for about an hour (Figure 2). With his encouragement, I discussed my symptoms, my feelings about them, and their effect on my family as well. He asked follow-up questions, expressed concern and support for my feelings and the impact my symptoms had on my personal life. I was excited. I thought to myself, “Why had I never experienced this dialogue with a doctor before?”

Suddenly, a glimmer of hope began in my soul. Even if he couldn’t completely help me, I knew he cared and was going to try. I felt validated and supported, and was overwhelmed. When he told me that postinfection irritable bowel syndrome (IBS) caused my symptoms and that they could be treated, I was relieved. Through his explanations and diagrams I learned that post infection IBS can occur when there is a gastrointestinal infection associated with stress. Strangely, this was exciting to hear, because it was so validating. I also learned how my earlier experiences triggered my helplessness with new challenges like this illness. Then we talked through treatment options. He explained why he would like to use an antibiotic for the IBS and an antidepressant to treat the brain’s poor regulation of the pain. Then he asked how I felt about the plan and we discussed the risks and benefits. I agreed willingly, because I was now part of the process of my care. Although recovery could take time, he assured me that he was in it for the long term and I knew he wouldn’t abandon me. They say that, when one is heard, they feel valued and loved. This was certainly the case for me, especially after so many years of being ignored and dismissed.

Today, my GI pains are resolved. I eat normally without restriction. I rarely have nausea or bloating, and my widespread pain and fatigue are a memory. How did this happen? Was it the pills or a placebo effect? Was it the doctor or just the passage of time? Or was it me?

Here’s what I now know: The patient–doctor relationship is complex and challenging. Chronic illness and pain can make you feel like you are spiraling out of control, especially when you falsely assume there isn’t

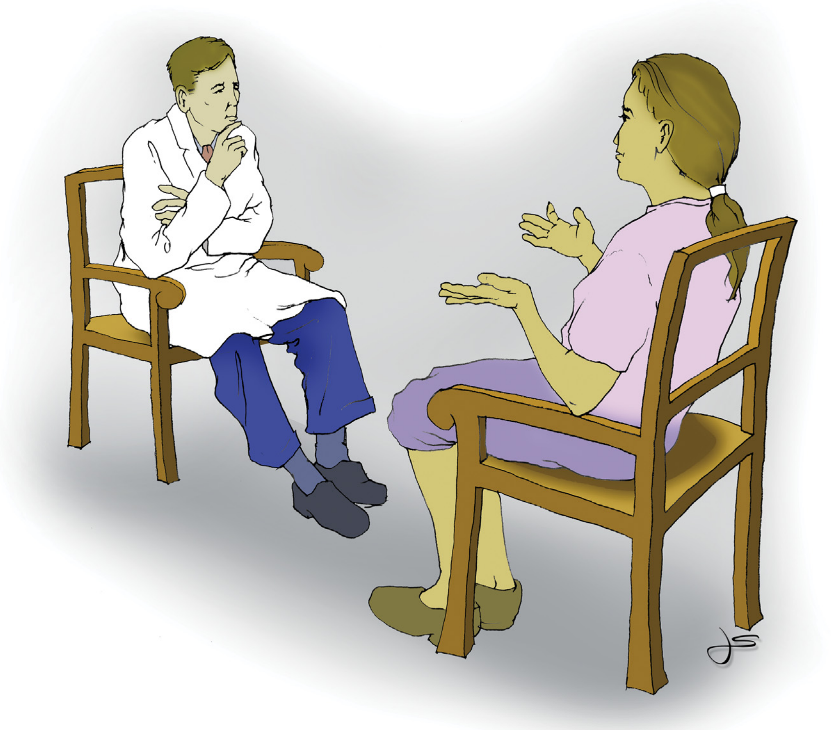

Figure 2. As occurred later in Johannah’s story, the doctor is facing the patient and making good eye contact. The finger on his chin indicates both receptive thinking and active engagement. To the patient, this communicates interest and acceptance by the doctor of what she is saying. The reinforces the patient to say more as she looks back at him with an open posture and active gesturing.

Table 1. Summary for Patients and Physicians

Patients Should Know	Doctors Should Know
You and your health are worth fighting for, no matter what.	Patients need to feel that you care about them as a person and not feel judged.
You can demand to be treated with dignity and respect.	Patients need to feel respected to share personal details that will assist you in their care.
You have a right to share your personal thoughts and feelings about your care	Patients need to feel that their doctor will be receptive to their thoughts and feelings
You have a right to ask questions and receive visual aids to understand your diagnosis and treatment.	Patients need to understand the diagnosis and treatment plan to participate and feel like they have a say in the process.
You have a right to be heard.	Patients are not impressed with ego and prestige; they want you to be humane and to care about the impact of the illness on their life.
You have the right to engage with your doctor as a partner	Patients are okay with “I don’t know” as long as you continue to work with them, or guide them to someone who will.
You can refuse treatment or seek another opinion if your needs are not being met.	Patients need to know that you are not going to abandon them.

any “real” cause for it and seemingly no way to treat it. Patients see a doctor hoping to regain control through treatment, but know they may not have a “quick fix.” What patients want is honest dialogue, to be heard and understood and not dismissed. They don’t mind if a doctor says they aren’t sure what’s going on, as long as they are committed to finding out, and won’t abandon them. My care changed when I was able to honestly share my symptoms, thoughts, and feelings with my doctor and know that he would listen and try to help; that made me feel validated and empowered. Even on days when I don’t feel 100%, I know that together, my doctor and I will come up with a plan to address my symptoms. Knowing that he wants my input and lets me know I can trust him makes me compliant with the treatments that we decide on together. Also, when a patient truly trusts their doctor, they feel safe to share other personal aspects of their health and experiences that might relate to their current condition and open more doors to further treatment options (Table 1).

My interaction with my doctor helped me to find my voice and to advocate for myself. Now I expect the same in the future, no matter what doctor I see. I also learned through this ordeal my role in the negative interactions with doctors. The difficulties with the doctors reverberated and amplified the feelings of helplessness, poor control, and anger that came from my childhood traumas. So, although I ferociously fought for my children, family, and friends, when the doctors came at me I shrank. No one should be given the power to take my health, my light, or my truth. I now feel a new sense of empowerment, as a patient and as a woman. For the first time, I can say, yes, I am okay. Really, truly, okay.

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