

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



Johannah's remarkable story reflects a transition from illness to health, and from helplessness to self-efficacy. It began with postinfection irritable bowel syndrome, the product of an acute infection along with stress-mediated central nervous system dysregulation: a gut-brain disorder.^{1,2} Because the impact on Johannah was so profound, we must consider what contributed to her physical and emotional decline and then what led to recovery. The lessons learned can help patients, clinicians, and our very health care process.

Why was Johannah treated so differently when having acute dysentery and bloody diarrhea, compared with the ensuing decade of chronic severe pain, diarrhea, and life impairment (considered "functional")? In our society, there is a greater perceived legitimacy when symptoms are structurally based versus when studies are negative, and psychological stigma is imposed.³ Second, doctors may feel pressured to focus their time on "sicker" patients, or to prioritize relative value units toward procedures rather than providing face-to-face care.⁴ Finally, at a deeper level, doctors not familiar with the pathophysiology and treatment of gut-brain disorders may feel unknowledgeable, ineffective, or inadequate to treat them, so these disorders are then thought not to fall within their responsibility. Then, when confronted with such patients, they may exhibit overt or covert behaviors perceived by patients as dismissive or derogatory.

What about Johannah's contribution to this process? She grew up in the

1970s and 1980s where family culture and societal factors^{5,6} encouraged stoicism and gender role socialization⁷: girls were not to be assertive and were to submit to (male in particular) authority without question. The trauma experience further limited her sense of control to handle unwanted situations like illness, increased vulnerability, and also decreased trust⁸; in addition, it worsened her pain and illness severity.^{8,9} She knew she was not being treated properly by her physicians, and although personally and professionally she could advocate for others, paradoxically these elements kept her from advocating for herself. In resignation she gave up on the medical system. Thus, the biopsychosocial features interacting between patient and the health care system produced the perfect storm: a downhill vicious cycle of illness, suffering, and dissatisfaction.

How did this cycle reverse? Visits with her new doctor set the stage. She felt listened to, concerns and expectations were validated, a specific diagnosis was made, and an explanation of the treatments to follow were negotiated. A collaborative process ensued that lifted her emotional distress, and increased her trust, self-efficacy and sense of control. In her own words: "My care changed when I was able to honestly share my symptoms, thoughts and feelings with my doctor and know that he was going to listen and try to help; that made me feel validated and empowered." No more will Johannah feel helpless when seeing doctors; rather, she will encourage them to engage in the way she expects and that will be good for both.

What can be done to prevent this in the future? Much can be resolved by improving the medical curriculum to cover the modern science on the disorders of gut-brain interaction (formerly functional GI disorders).¹⁰ We also need to develop programs to teach communication skills¹¹ and collaborative patient-centered care.¹² Knowledge is power, and the

acquisition of these skills can change clinician attitudes from being disinterested and dismissive, to engaging and satisfied in the care.

To hear and see Johannah's story go to: <http://bit.ly/2wAT96l>


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