



# Patient Journey: *Clostridioides difficile* Infection in the Context of Aggressive Inflammatory Bowel Disease

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Crohn's patient advocate of South Asian descent from New York, United States, describes her lived experience with several bouts of *Clostridioides difficile* infection (CDI) while navigating multiple challenges with inflammatory bowel disease (IBD).

I was diagnosed with inflammatory bowel disease (IBD), specifically ulcerative colitis (UC), via colonoscopy in January 2006 at the age of 22. I had a mild case of inflammation mainly in my rectum and sigmoid colon, diagnosed mainly because my father had passed from Crohn's colitis turned colorectal cancer at a young age.

Once I was considered in remission in October 2007, I traveled to Mexico from New York to celebrate my 24th birthday. During my travels, I ate mostly fruits and salads, in an attempt to not aggravate my condition. And I unfortunately picked up what is proverbially known as "Montezuma's revenge," a type of traveler's diarrhea that is transmitted in Mexico to which native Mexicans may be immune but tourists, like myself, are not.

Returning home, my gastroenterologist prescribed a quinolone antibiotic named levofloxacin based on my symptoms not resolving after a week. I never really felt like myself again after that and within the next month, my condition flared badly. Come January 2008, I was going watery, foul-smelling diarrhea 30 to 40 times per day and was unable to return to work. I remember being hospitalized soon thereafter and being treated for both a severe flare-up and an infectious disease called *Clostridioides difficile* infection (CDI).

I was told that CDI is a very contagious infection that could be caught in the community. I was also told that antibiotics like levofloxacin can wipe out the gut flora creating spores that can proliferate in the intestines known as CDI. I was later

told that a diagnosis of IBD can be associated with higher risk of CDI.<sup>1</sup>

I was initially treated with metronidazole but what I was left with was a very severe flare-up of colonic and rectal disease courtesy of my IBD. Over the next several months, it became clear that nothing would curb this flare-up. We advanced my medications from 5-aminosalicylic acid to prednisone to mercaptopurine to infliximab.

It was colectomy surgery in July 2008 that finally gave me relief, but it was a major decision and a tug-of-war ensued between my family and my physician regarding having my colon removed and an ostomy placed. Concerns around marriageability surfaced so I tried Ayurveda and other alternative therapies prior to colectomy and I worsened significantly. I suffered many complications postcolectomy as I was very malnourished dropping from 61 to 38 kg. Due to a fluid collection after surgery, I had been placed on intravenous Zosyn (piperacillin/tazobactam) via a peripherally inserted central catheter line for 2 months.

Within a few weeks of completing the Zosyn, I had CDI again, this time in my small intestine with an ileostomy, which I was told was very rare.<sup>2</sup> Given the number of times I had to empty my bag, I became severely dehydrated and was hospitalized again in October 2008. This time I was spending my 25th birthday in the hospital with hazard signs around me instead of celebrating.

It was very challenging to get the CDI under control the second time. The infectious disease specialist had to add vancomycin by mouth to the metronidazole I was already taking. The CDI did eventually settle after a few weeks, but I remained terrified knowing that CDI could return at any moment even in the small bowel.<sup>2</sup>

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In February 2009, I went on to have proctectomy surgery and a j-pouch created along with the ileostomy reversed. My doctors and I had decided to avoid antibiotics given my CDI history. However, even before my takedown surgery to make the j-pouch fully functional, I began to experience inflammation of the j-pouch, known as pouchitis, leading to many of the symptoms I had with IBD prior to my colectomy.

This put my doctors and me in a dilemma, as I clearly needed the antibiotics. For the next few years, I was mostly on antibiotics due to chronic refractory pouchitis alongside fistula and abscess development in the perianal region. Given the perianal fistulizing disease component plus granulomas beyond the j-pouch, my diagnosis was then changed to Crohn's disease from UC. To prevent CDI, metronidazole was added to ciprofloxacin to prevent CDI. This combination worked for a few years, but in 2013, I was put on heavy doses of prednisone again with the development of erythema nodosum.<sup>3</sup> We started the conversation around putting me on biologics again and before we could do that, CDI reared its ugly head again and that too in my j-pouch. This time I thought it was food poisoning but that watery consistency and distinct foul smell made me quickly realize what was happening.<sup>3</sup> I was again hospitalized in November 2013 and the tests kept returning negative for CDI so I was transferred to a more sophisticated hospital where they said I was definitely positive for CDI.

This third time with CDI was the most challenging. My j-pouch felt tired and weak and I was suffering from significant rectal burning and rashes. My gastroenterologist and I discussed fecal microbiota transplant (FMT), but he was concerned about how effective it would be in a j-pouch patient.<sup>4</sup> I had to be treated several times with metronidazole and vancomycin. Even after I tested negative for CDI, I continued to have a postinfectious diarrhea and was diagnosed with IBS-D (diarrhea-prone irritable bowel syndrome). I was prescribed the following in hopes of curbing the diarrhea: (1) making an enema out of VSL-3 DS powder and inserting into the j-pouch once a day, (2) taking a couple packets of EnteraGam (bovine colostrum powder) orally everyday, and (3) taking 2 pills of *Saccharomyces boulardii* daily. My physician said *S. boulardii* can bind to the CDI toxin, which could prevent recurrence and may help with the profuse diarrhea.<sup>5</sup>

Fortunately that cocktail worked like a charm in slowing down the bowel movements in early 2014. However, my IBD worsened after my third bout of CDI. Within weeks, I developed hidradenitis suppurativa around my groin, which ultimately ushered in multiple new rectovaginal fistulae and the excision of my j-pouch in late 2014.

Today, I remain CDI-free with a permanent ileostomy for the last the past 8 years but I follow many preventative measures. I always eat hot foods and take warm drinks especially while traveling to prevent traveler's diarrhea. I also take probiotics and/or drink kefir regularly. Whenever I do need antibiotics, I follow it with a short course of *S. boulardii*.<sup>5</sup>

Nowadays, there is a lot of hope for CDI patients. With the advent of new medications, including fidaxomicin and bezlotoxumab for instance, outcomes have improved.<sup>6,7</sup> Addition-

ally, FMT has emerged as a mainstay for CDI.<sup>4</sup> While I hope to never contract CDI again, it is important for us as patients to know our options and advocate for the best therapies possible in our care.

The truth is that many IBD patients globally are struggling with CDI and/or other gastrointestinal infections/mimics in addition to debilitating symptoms of IBD.<sup>8</sup> As patients, we do not anticipate such infections on top of an IBD diagnosis. Knowledge could help with prevention and also with treatment and management. My hope is that gastroenterologists can conduct more patient education to help patients and their families understand how difficult it may be to diagnose and manage infectious comorbidities and what signs and symptoms to keep an eye on for timely management.

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Not applicable.

#### Author Contributions

T.A.O. wrote and revised the manuscript.

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#### Conflict of Interest

None declared.

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