

Sample Project #3 - Living with Chronic Illness

The Condition: Crohn's Disease

Crohn's disease is a disease that affects the gastrointestinal (GI) tract, often resulting in chronic inflammation, mainly in the small intestine (Mario, Mario, & Peach, 2010). As an inflammatory bowel disease, Crohn's can affect any part of the digestive tract, from mouth to anus. The cause of this disease is currently unknown; however, it can run in families, leading researchers to believe that it is caused by a genetic defect (U.S. Department of Health, n.d.). In order for a doctor to make a positive diagnosis of Crohn's disease, they must perform many tests and exams. The most common preliminary test for Crohn's is a simple blood test, which tests the blood for signs of inflammation in the body. More extensive tests are conducted to diagnose this disease, such as endoscopies, biopsies, colonoscopies, and small intestine imaging (Arnett & Bennett, 2015). It is usually necessary for more than one test to be conducted in order to give an accurate diagnosis because Crohn's shares many symptoms with other bowel diseases. People diagnosed with Crohn's often suffer from extreme abdominal pain, frequent diarrhea, frequent bowel movements, rectal bleeding, fatigue, loss of appetite, and many other complications (Arnett & Bennett, 2015). Crohn's disease affects men and women equally and is usually diagnosed early in life, around ages 15-35 (Arnett & Bennett, 2015). Living with Crohn's is an unpredictable lifelong struggle, as the severity of the disease comes and goes, worsening over time (Mario, Mario, & Peach, 2010).

There are a few different ways to treat Crohn's disease, including medication, change in diet, and surgery when the previous two can no longer control the disease and its symptoms. Medications to treat the disease attempt to suppress abnormal inflammation, decrease flare ups, and lessen symptoms that accompany flare ups (Arnett & Bennett, 2015). Many people living

with Crohn's must change their diet and pay increased attention to what they eat. Some foods cause worsened symptoms, such as foods with high fiber, dairy, and foods that are spicy (Arnett & Bennett, 2015). More often than not, surgery is needed to treat Crohn's disease. About 70% of people with the disease require surgery at some point in their lives (Arnett & Bennett, 2015). Surgery often includes removing the section of inflamed small intestine that causes trouble for the patient, however, this does not stop the pain completely. For most people, surgery is not a one-time treatment, as the disease causes recurrent issues. Unfortunately, treatments for Crohn's can only provide temporary relief.

Though Crohn's is a physical illness, it can cause psychological pain for the people that live with it. Like many other illnesses, dealing with a lifelong diagnosis can cause extensive stress, anxiety, and depression (Arnett & Bennett, 2015). Emotional and physical stress potentially play a role in flare ups and severity of symptoms, while chronic stress has been shown to increase intestinal inflammation (Mario, Mario, & Peach, 2010). Many people also deal with the fear of having flare ups, gas, or pain when they are in public spaces, making peace of mind almost unattainable. Due to the fear, anxiety, and depression paired with the disease, traveling and going out can be quite difficult. Living with the chronic pain of Crohn's goes beyond physical hardships and also affects people mentally and emotionally.

Interview

Question: How did you find out that you had Crohn's disease and how old were you when you found out?

Answer: "I was fifteen years old. My dad took me to the ER [emergency room] because I was in extreme pain. The doctors thought that I had appendicitis, so they removed my appendix, but it turned out that it wasn't the source of the pain. After it was removed I

was still in pain so we went back to the doctor and they ran some blood tests. That's when they finally figured out that I had Crohn's."

Question: How did you feel when you were diagnosed?

Answer: "I was young...I didn't really think much about it. When you're young, you don't really understand the magnitude of things or how they are going to affect your life long term."

Question: Have you been hospitalized for your condition?

Answer: "Yes, at least 5 times. The longest time was when I was young, I was in the ICU [intensive care unit] for about two weeks then stayed in the hospital for about six weeks after that. I've had at least 4 surgeries: appendix removal, intestine removal, my intestines burst so I had to have surgery for that, and another for intestine removal after a flare up. I think I've had 31 centimeters of my intestines removed altogether."

Question: Does it affect you on a daily basis and what do you do to manage it?

Answer: "Yes. I try to maintain my stress and avoid foods like dairy, anything spicy, nuts, and vegetables because they are high in fiber."

Question: What is the hardest part of dealing with Crohn's?

Answer: "It's not a physical deformity so most people don't understand how much it affects me."

Question: Has anything good come out of having this condition?

Answer: "(Laughs) Is that a real question? Being sick is not a good thing, if you think having a high pain tolerance [because of the constant pain] is a good thing...that's just bullshit."

Question: Has it gotten easier or harder to deal with it over time?

Answer: "It comes and goes. When it's unexpected you always have to be prepared."

Question: Any advice for someone who has just been diagnosed with Crohn's?

Answer: "Start smoking weed. You might think I'm joking but I'm not. People don't realize how much it helps people that are sick, it helps with everything: nausea, stress, sleep, hunger, worrying about whether or not there's a restroom when you go out in public, worrying about what you'll eat when you go out."

Reflection

I have had a good understanding of Crohn's all my life, as someone I know struggles with it. As a kid, I did not understand the severity of the disease because, as they said in the interview, it is not a physical deformity. I have talked to them about their condition before, but never in such an objective and structured way. It was very informative to hear what it is like to live with the illness and the stress that it causes them on a daily basis. Reading about the illness does not truly give you a sense of the stress a person feels when they have to live with it every day of their life. To me, this process was a bit difficult because, of course, I do not like the thought of this person being in so much pain all the time. On the other hand, it was an opportunity to hear about their illness from the time they were diagnosed, to now, an in-depth conversation that we have not had before.

If I was diagnosed with Crohn's disease I would have a lot of mixed emotions. I would probably be scared at first, knowing that I would have to live with it for the rest of my life. Then, I would be stressed because I know that there are many complications paired with that diagnosis. Though I would be anxious and scared, I would also know that everything was going to be alright. If my friend can do all that they do while still dealing with their own stress and Crohn's, I

think that I would be able to make the best out of the situation. It would also be helpful to have someone close to me who knows exactly what I would be going through. Being diagnosed with Crohn's would be life changing news, but not life ending. I have struggled with severe stomach pain and other symptoms linked with Crohn's disease myself, and have taken many tests and undergone procedures to reach a diagnosis. Though I have not received a diagnosis yet, I have gained a lot of knowledge through my many doctor visits.

References

Arnett, P. R., & Bennett, N. D. (2015). Crohn's disease information. *Journal of Chronic Illnesses*, 47, 447-459. doi:10.1002/7hridnsp83

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Mario, M., Mario, L., & Peach., P. (2010). Life with Crohn's disease. *Pediatric and Adult Illnesses*, 3, 125-138. doi:10.1003/2jd93.3d