

## **Memory, identity, and disability**

*The formation of identity is a process that occurs across a person's entire life but has specific significance in adolescents. It "involves constructing an understanding of who one is and how one came to be that person" ("Identity Development" 1094). A large part of identity formation involves meaning making of past experiences, which is making sense of large, unanticipated occurrences. Being able to make sense of oneself in the past is an important part of this process, so what happens when a person can't remember these important past events ("Identity Development")? After traumatic events, some individuals are unable to remember these events, and if they are able to remember them, their recollections often stray from what actually happened (Eisen et al.).*

*I feel like I am unable to recall a lot of what happened when I was very ill and have doubts about some of the things I think I do remember. I cannot place many events in time and struggle almost ten years later to piece events together. How have I formed my identity as a chronically ill/disabled person if I can't even remember the things I am basing that identity on?*

I did not feel well in sixth grade but I don't remember it. I look small and sick in family pictures in the summer of 2009 but I do not know if I had any Crohn's symptoms at that point. My family and I go to Disneyland over Thanksgiving in 2009 and my mom says it was bad, but I don't remember anything besides Disneyland and spending time with my family.

I remember the first time I experienced a Crohn's symptom, but I do not know when it was. I was wearing my favorite outfit, waiting to go to church with my family on a Sunday morning. I didn't think much about it, but I remember telling my mom after I changed my clothes and going to church.

I am very sick. I am exhausted. My symptoms wake me up at night. I miss days of school. I see my pediatrician and then am referred to a gastroenterologist. I have to go to Duke Children's Hospital to see him which makes me feel like this is a very big deal. I get tested for Celiac's and probably some other things but I can't tell you what they were.

*I know broadly what my symptoms were, but I do not remember the details. One of my fears is relapsing and my health going back down to that point, but I can't fully grasp what that would actually mean. How have I based one of my biggest worries that I will live with for the rest of my life on something I can't answer basic questions about?*

My doctor puts me on prednisone. This happens a lot, but I don't know when. It makes me hungry all of the time.

My GI puts me on a pill that makes me nauseous. I don't know what it was, but it was small and round and yellow and just opening the bottle made me feel sick. I have to walk around outside my classroom every day at school because the fresh air makes me feel better. I tell my doctor this but he thinks I just have a stomach bug and he increases my dose to try and help my Crohn's symptoms. I wake up that night in the middle of the night and throw up all over my bed. I wake up my mom and she puts me to sleep in the spare room. My doctor takes me off the yellow pill. I do not know if I had been diagnosed with Crohn's disease yet at this point.

I have my first colonoscopy on December 19<sup>th</sup> of 2009. I am in seventh grade. I have to miss my science exam. The preparation clear liquid diet is absolutely miserable and it makes me sick so

my mom has to call the nurse. I don't remember anything about going to the hospital or getting ready for the procedure or coming home from the procedure, but I know I found out I had Crohn's disease that day.

*I can remember almost nothing about the day that gave me life-changing news. Not remembering the moment I found out I had Crohn's paired with the fact that I was diagnosed so young makes me feel like I have been sick for my entire life. I don't remember what it is like to not worry about my health, which is also due to the fact that I unknowingly took my health for granted as a kid.*

I go back to the hospital later to talk to the doctor with my parents about what this means. I drove there with my dad and he asked me how I felt about my diagnosis. I don't remember what I said.

I start getting intravenous infusions of Remicade, but I do not know when. A woman sits with me and shows me how an infusion works and the nurse tells me what an allergic reaction will feel like and tells me to get her if I have a dry cough. I don't mind them so much because I get to leave school to sit with my mom and watch movies.

*I only remember her telling me this because it ended up being extremely important information. I wonder about all of the things I have forgotten because they weren't meaningful enough at the time.*

My Crohn's symptoms start to go away because the Remicade works. I don't miss as much school and can play soccer.

At my fifth or sixth Remicade infusion (I don't remember which), my mom goes down to the hospital gift shop to get me a snack as I watch Cloudy with a Chance of Meatballs. While she is gone, I start to have a dry cough and tell myself it's nothing. Soon, I am unable to breathe, and I don't know what to do. I stand up to try to walk to get the nurse and the cleaning lady stops me and asks me if I'm okay and I shake my head. The nurses come and help me back to my chair. One of them says "Oh I've never seen anyone get that flushed before." I look down and my legs are bright red like I have a really bad sunburn. The nurses add an antihistamine to my infusion and the reaction goes down. The cleaning lady goes down to find my mom and gets her out of the elevator and she comes back with a Rice Krispie treat covered in purple, pink, and yellow icing shaped like an Easter egg. Or maybe she got me that another time, I don't remember. I am moved to a hospital bed in a private room and finish getting the rest of the infusion and watching Cloudy With a Chance of Meatballs. They have to slow the infusion down to prevent another reaction and my mom has to leave so my dad comes.

*I felt like I remembered everything about this reaction, I know what shoes I was wearing and the movie I was watching. But I don't remember the face of the cleaning lady who helped me or the nurses who came to help me or even how many nurses there were or how long the infusion took. This memory looks gray around the edges when I think about it, like I wasn't really there, or it happened a lifetime ago.*

The next day at school I have a small pain in my knee. I think I must have tweaked it and I go to my soccer coach's classroom to tell him that I don't think I'll be able to play. It gets worse as the day goes on, and by the time we get off the bus to the soccer field, I tell him I can't walk across

the field to sit on the bench and sit on the bleachers for the game, my knee getting more and more painful. At the end of the game, it is so painful that I cannot walk, and my dad and a dad of a girl on the opposing team carry me to the car. I'm in so much pain that I stay in my soccer uniform for days, it is too painful to move enough to change. My parents call my doctor the next day and he asks them to touch my knee for tenderness. My dad barely touches my knee and I cry out so loudly that my doctor can hear it on the phone.

I am on crutches on and off for around a week, kids at my school are confused as to why I'm using them. I do not get another Remicade infusion and switch to Humira, a biweekly injection.

I see a rheumatologist and find out I have rheumatoid arthritis. My joints never get as bad as the knee was but I have had joint pain ever since.

I have to get the first dose of Humira as four injections in the hospital and I go with both of my parents. I get two injections at a time, my dad doing one on one leg and a nurse on the other. Humira is known for being painful and I lay on the table and yell out and cry in pain. The pens make a loud cracking sound when they are injecting and it scares me. It is the only time I have ever seen my dad cry.

My dad does my injections until I go to college and then a nurse does them and then I decide that I can do them myself.

The Humira works and I am mostly symptom free and have never been as sick as I was in 2009.

In 2015, I feel fine until I look down and see enough bright red blood in the toilet that the water is opaque. I panic and get my mom and call my doctor, who goes to the hospital just to see me. We don't know what is wrong and decide to have my third colonoscopy (I do not remember when my second one was). That night, I go to theater rehearsal and start to get out of my car and walk into school with my friends and break down crying. I tell them through sobs that there is so much blood and they can't tell me why. Lucy gets into the passenger seat and sits with me and Ollie stands on the driver's side, hugging me as I cry into my steering wheel. I am very lucky. I bleed for two more days.

I don't really remember the colonoscopy prep or procedure, but I know the results were pretty normal and never really understood what happened. I sometimes bleed in the years after but never as badly.

I go to college and don't know how to talk about Crohn's with my new friends or be without my family and my doctor. I am terrified.

I remember being so tired I almost fall asleep sitting up at the dinner table every night the summer after my first year of college. My iron is low and I get an iron infusion the day before I go back to school.

I remember having to get colonoscopy number four over winter break my sophomore year to check for cancer since my risk is increased. The results are normal.

I am exhausted my senior year of college. I get two iron infusions and they help. I get my fifth colonoscopy to check again for cancer, as I will have to every two years for the rest of my life. I see a rheumatologist for the first time since middle school to see if my joint pain can be helped.

*I often think about the things I remember because my memories feel gray and fuzzy and like they will fade away if I don't think about them enough. Sometimes, I feel like I wasn't*

*even there when I think back on them, even though they make up a big part of me now. I wonder if I'll ever forget them. How will I identify as a chronically ill person or a person with a disability if I can't remember what got me that identity label in the first place?*

*“In conclusion, engaging in identity development processes that facilitate seeking and developing an integrated and coherent understanding of self across multiple domains, across time, and within one's cultural context is a critically important developmental project with relevance across the lifespan” (“Identity Development” 1097). “Across time” is the kicker for me here. What if I can't fully engage in this “critically important developmental project” that is crucial throughout life because I can't piece things together across time? Because I can't or don't want to remember what I'm so scared of becoming again? How will my identity as a disabled person shift as my memories change and fade, and as new ones are made?*



## **Healthy and unhealthy disability**

The distinction between healthy and unhealthy disability is important when thinking about the medical and social models of disability. The medical model of disability treats disability as a problem that needs to be solved by medical professionals (Albrecht). In contrast, the social model of disability does not view disability as a problem and instead views the design of society and environments for non-disabled people as the factor that needs to be changed, not people with disabilities (Albrecht). Supporters of the social model of disability often reject the idea that they need to be cured of their disability because it is a source of suffering in their lives. The distinction between these two models is blurred when considering the idea of unhealthy versus healthy disability. Healthy disability is disability that is stable over time and does not involve medical needs, while unhealthy disability is not stable and often involves a chronic illness that requires medical care (Wendell). The distinction between these two types of disability is often blurry, as health and ability are intertwined and can change constantly.

Because I have multiple chronic illnesses, I am unhealthy disabled. In my brief experience in disability studies, I have struggled with the social model of disability in relation to my own experience. Of course, I understand where supporters of the social model stand in their desire for societal changes in the environment and their lack of desire for a cure for their disability. I can't speak for other people with chronic illnesses, but my disability is a health problem for me and changes in my environment wouldn't make the difference. My disabilities have caused me immense amounts of physical pain and emotional suffering, and I feel like I do identify with parts of the medical model of disability. People with healthy disabilities tend to try to separate themselves from the idea that their disabilities are illnesses, which is an important distinction, but it also has the potential to divide the large and diverse group of people with

disabilities. I am not sure if it is possible to integrate these perspectives, but I do think it is important that people are aware that experiences of disability are vast and contradictory and that sometimes it causes pain but other times it does not, and sometimes society needs to change but others the person with the disability wishes that their disability would change. Thinking about the similarities and differences between healthy and unhealthy disability is an important part of this process, as it adds an important level of understanding to the experiences of people with disabilities. On a personal level, learning about this distinction helped me feel more at home with identifying as disabled, as I had been stepping back from that after reading critiques of the medical model and narratives about not wanting a cure and not relating to those ideas. Although the label of unhealthy doesn't sit completely right with me, as unhealthy things, like a diet or a lifestyle, tend to be seen as negative choices that a person makes, this idea makes me feel better equipped to identify as having a disability. The word sick works better for me, it is fitting to my experience and it is easy to understand.

In this self-portrait, I am portraying myself as an unhealthy disabled person and a sick person. In the picture, I am waking up from anesthesia after a colonoscopy and eating a cracker. When I think about myself as a chronically ill person, I think about myself in a variety of ways. I think about myself hungry after a clear liquid diet and in a hospital gown, getting an iron infusion, crying in my high school parking lot, injecting myself with Humira, along with a huge array of other things. I am unhealthy disabled because every day, every stomach or joint pain makes me wonder if I am going to have a flare and get very sick again, because doctors and nurses are a hugely important part of my life, because I depend on medication to keep me alive and well. Moving forward, I am excited to think more deeply about healthy and unhealthy disability and divisions between people with disabilities and struggles that may occur for people

for whom the line between these two ideas is blurred. What does it mean for someone to be healthy or unhealthy? How does being healthy or unhealthy change someone's goals and needs?



## **Disability pride and shame**

Disability pride is the idea that disability “should be positive and affirming, a source of distinct value, unique perspectives, and group solidarity” (Bogart et al. 156). Pride fits into the social model of disability and moves away from the medical model that views disability as a negative trait that needs to be fixed by medicine. Some research has shown that disability pride is a way that some people with disabilities protect their self-worth from negative stigmas about their disability (Bogart et al.). Because disability is not widely accepted and because of the medical model’s idea that disability is a problem in need of a solution, shame is also a common emotion for people with disabilities (Chandler). Part of the definition of disability pride is “a public expression of our belief that our disability and identity are normal, healthy and right for us and is a validation of our experience” (Chandler 77). The word healthy is key here when considering people with unhealthy disabilities/chronic illnesses. I do not consider my Crohn’s disease as healthy or right for me, and I struggle with feeling pride about my illness.

I more commonly feel shame because of the nature of my Crohn’s symptoms. I am open about having Crohn’s with other people, but I cannot talk about my specific symptoms, even with other people with Crohn’s. People with family members who have Crohn’s try to make jokes with me about it, as I’m sure their family members do with them, but it makes me feel even more ashamed. I was made fun of when I first got sick by some people in my class and told myself that I wouldn’t talk about it again and have pretty much stuck to that until I get extremely close with someone. Shame is rooted in a social context and what others think about you (Chandler). Because of the nature of my disease, this shame extends to when I am alone. I think about how other people would view this and how it makes me disgusting and undesirable. Over

time, I've opened up little by little and my shame has gone down, but I can see it rearing its ugly head again when I have a flare up.

Because I would prefer not to be sick and hide my symptoms from others, I don't think disability pride is accessible for me right now. This raises a new question for me: how do sick people feel pride if they want to be cured? How can I get the positive benefits of disability pride in relation to my self-esteem if my entire experience with illness is coated in shame? This self-portrait is a reflection of my effort to embrace pride in who I am because of my illness. My shirt adds a little bit of humor, but not the kind I am uncomfortable with. Five and a half months of my Humira injections are above my head. I might not experience pride in a way that views Crohn's as healthy and right for me, but I am proud in other ways. I am proud in how hard I have fought to get to where I am today. I am proud of myself for injecting myself with an extremely painful shot every other week. I am proud of my ability to participate fully in my own care and make decisions for myself. While people with chronic illnesses, especially those with stigmatized symptoms, may not experience disability pride in the same ways that people with healthy disabilities do, they can experience a type of pride that non-disabled people cannot know. This type of pride may be intertwined with shame, but in my personal experience, that makes this sense of pride in myself and my experiences even more important to me.



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