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THE EXPERIENCE OF AN INVISIBLE ILLNESS: HOW LEVEL S OF VISIBLE ILLNESS DETERMINE SOCIAL INTERACTION

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THE EXPERIENCE OF AN INVISIBLE ILLNESS: HOW LEVELS OF VISIBLE ILLNESS
DETERMINE SOCIAL INTERACTION

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A capstone project submitted for Graduation with University Honors

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Abstract

As we navigate our own lives, it is easy to forget that the people around us have their own activities, their own responsibilities, and their own problems. For some, their problems may be more obvious than others. A casted leg, wheelchair use, and having no hair may all be indicators of the deterioration of someone's health. When the condition is visible, people may be more inclined to empathize with and understand their capabilities and challenges, which may require outside assistance. However, problems that are not as obvious may yield different reactions. When seeing a person without hair, many may assume that the person is undergoing treatment and requires extra assistance. However, if that same person were to wear a wig, they may not receive the same empathy even though they are just as sick. This observation, that how people are treated by others differs based on how "sick" they look, was explored through interviews with people varying in health conditions. I considered a range of conditions from cancer to chronic pain and depression. The focus of this research is centered around the stories, experiences, and treatment of those that have underlying medical challenges and how these experiences affect their way of confronting their illness. A total of 10 participants were interviewed, and qualitative analyses were used to identify relevant themes. This project sought to promote exploration, reflection, and a better understanding of how our interactions may deeply affect others' mental health and coping.

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Introduction

Many of us have experienced or know someone who has experienced some kind of medical diagnosis, whether that be a sprained wrist and the flu or even diabetes and cancer. Along with these diagnoses, conditions present themselves differently across different people. Some conditions may be more visible, such as wheelchair use or loss of hair, and these indicators allow us to make an assumption that the person may require extra assistance or even just empathy for their condition. However, there are also many conditions that are not as visible, such as chronic pain, colitis, and many others that lack obvious physical symptoms. As a result, reaching the same levels of empathy and understanding may not be achieved as often. This lack of empathy may lead those sufferers to feel invalidated, which could result in difficulty coping with their diagnosis and impact their mental and physical health.

However, those with a more visible condition also experience discomfort from various social interactions. When someone looks sick and you can see them as such, it can be very difficult to determine how to interact with them without making them uncomfortable. Unfortunately, what may come from a place of sincerity may actually come off as pity. It can be difficult dealing with a disease or illness, but when others offer support the way that is preferred, it can make a significant difference in the way someone confronts and copes with an illness. This capstone project explored these issues through qualitative interviews with people suffering from various health conditions.

Socially Constructed Perspectives on Illness

Research over the last several decades has shifted focus toward the social construction of illness and how it impacts coping and confronting a health concern. Before, illness confrontation

was thought to only include the biological implications of the medical condition: getting a diagnosis, receiving treatment, then recovery. It was only recently that research has focused on how socialization, lifestyle, and interpersonal relationships contribute to the construction of illness. Illness can be seen as multidimensional, having influences from biomedical, cultural, and experiential dimensions that contribute to the social meaning of being sick. The way that individuals view these dimensions can influence stigma and how it relates to sickness (Conrad & Barker, 2010).

Stigmatized Illness and Social Isolation

Past research has examined the challenges faced by individuals with a stigmatized illness and how it can affect self-esteem, relationships, and coping with illness. Oftentimes, people who have not had a serious medical condition have certain stereotypes in mind as to what a sick person looks and acts like. Men who had been recently diagnosed with prostate cancer reported how they perceived stigma related to the disease and how it led to self-blame, social isolation, and unmet needs. Self-blame and social isolation can often lead patients to experience emotional distress and anxiety on top of the already mentally taxing diagnosis and treatment of cancer (Ettridge et al., 2017). Similar feelings, themes, and results were also found to be relevant to patients with lung cancer and breast cancer as well, allowing researchers to cross-examine age, gender, and illness as it relates to illness and social perception (Else-Quest et al., 2009).

A recent study conducted by Mathew et al. (2021) reported that more than half of the participants in their study ($n = 740$) reported negative associations with cancer and cancer patients. 26% of participants also believed the myth that cancer is transmissible, 45% agreed that patients are responsible for their own condition, and 40% agreed that people should still have to work while battling cancer. The findings of this study highlight the widespread prevalence of

harmful associations and stereotypes among the general population, which can impact an individual's ability to cope with their illness (Mathew et al., 2021).

People with illnesses that have less visible symptoms, such as chronic pain, often have greater difficulty with others believing their symptoms. Physicians have reported skepticism about conditions that lack objective measurable symptoms, which only adds to the difficulty people have in reaching out for help, support, and treatment (Åsbring & Närvänen, 2003). The invisibility of illnesses creates a challenge both for the person who has been diagnosed with the illness and the people in their lives. Experiences associated with the invisibility of their illness often leave them feeling frustrated and isolated with the lack of belief in their pain and little to no support to assist with coping. Common themes associated with stigmatized illnesses include disbelief, lack of understanding, and avoidance. Due to fears of being judged or appearing weak, many people who are experiencing a flare-up in pain tend to avoid interaction with others in general, so as to not acknowledge the lack of belief or understanding (Armentor, 2016).

Past research has provided limited empirical evidence addressing the stigma associated with the visibility of an illness and how it can affect coping and wellness. This study focused on the experiences and situations that resulted from having an illness that varies in visibility. Unlike most research, this study will also consider a wide range of medical conditions that range in age, visibility, and type of condition.

Unforeseen Consequences of the Visibility of My Illness: My Journey through Social Stigma and Personal Growth

Similar to the cases mentioned above, I have also had to experience a life-changing medical diagnosis. When I was ten years old, I started developing daily headaches. The headaches were relatively mild, but consistent and quite annoying. After going to urgent care

several times, doctors wrote off my symptoms as being migraines. I continued my life, going to school, playing sports, and trying to complete daily tasks all while reminding myself that these headaches were no big deal. Another month passed with my headaches becoming a normal daily occurrence when my left eye started crossing. Not only could I not see correctly, but it also intensified the headaches. Another trip to urgent care landed us at the ophthalmologist who then immediately discovered that there was swelling in my optic nerve. I was then sent to the emergency room where they had ordered a CT to see the swelling and anything else going on in my brain. At this point, I was really glad that *something* was happening, but at the same time, I was uncomfortable from being in the ER for so long, anxious from all the machines I was being put in, and just exhausted from a long day of testing and unanswered questions.

Come morning, I was transferred to the intensive care unit and told that they had found intracranial lesions, midline shift, and frontal lobe swelling in my brain. Being told there was actually something wrong was a mix of worry and relief. I was glad that they had found something and that maybe there could be some sort of plan that could finally rid me of my headaches. I was also relieved that now everyone knew that I wasn't lying about my headaches to get out of school, which some urgent care doctors had presumed. However, my relief was short-lived when they told us that they didn't know why this was happening. Several days, tests, and scans later, they finally discovered the foundation of all my troubles over the previous months.

“You have cancer.”

If only words could express the moment I heard those words. Unreal. Impossible. This couldn't possibly be right. I was only ten, I had only known about cancer because my grandpa had it. But he was old. And only old people get cancer, right? I didn't know what all this mess

could be, but the last thing on my mind was the possibility that I had cancer. But there I was, on day five in the ICU being told that I had cancer. I remember that day well, too. It was my dad's birthday. It was also the Superbowl; the Giants and the Patriots were playing. I could only process what was in front of me at that point, but I knew that everything was going to change.

It wasn't long before I was whisked off into surgery, where they biopsied the mass and placed a port in my chest that would make accessing my bloodstream easier. The next few days were filled with more tests, scans, and medications than I could even keep track of. Eventually, I was transported to the pediatrics unit, when the magnitude of the situation started to sink in. When I was told that I would be losing my hair, I finally broke down—because of course, my biggest concern at ten years old was the fact that I would soon be bald. Everything else seemed manageable up to that point, but losing all my hair? I could only imagine how other people would see me. Sick. Ugly. I could not comprehend how it was even possible that I could end up in this situation.

Around the time I began my first round of chemotherapy, my extended family started trickling into my room. At first, I was relieved to have some sense of familiarity, to just be around others and enjoy their company for the time being in such a scary situation. But I was emotionally unprepared for their very human reaction and I cannot express how heart-wrenching it was to see my grandparents cry. Seeing them sad, seeing my entire family cry, really got to me. I shut down. I didn't cry anymore, I tried to put on a smile and reassure everyone that I was okay, but I just didn't want to see them cry anymore.

I was finally able to go home after the mentally and physically exhausting two weeks I had spent in the hospital, soon after I finished my first round of chemotherapy. My younger brother and sister had made me a welcome home banner; I still regret not expressing how

grateful and appreciative I was. But I was tired. I was overwhelmed, angry, sad, and confused by how drastically life had changed. The next few weeks were just about adjusting and getting comfortable with all the new changes. It didn't take long before my hair started falling out. My long, brunette hair that I had spent so much time growing out. Watching my hair clog the shower drain was a devastating reminder of how real the situation was and one that I could not escape. It only took a few more showers before I reluctantly just shaved what was left of the hair on my head.

I only had a few days at home before I was back in the hospital. More check-ups, scans, tests, and what seemed like anything and everything between rounds of chemo. The first month when I was somewhat home, I developed a new concern that I wasn't paying much attention to: school. I was anxious that I would be left behind, that my education and my friends would continue on without me. Given my situation, the school had social workers come in and explain my situation to my class. I think about that often, how a group of fifth graders would react to hearing such news about a classmate. I can't imagine the questions, concerns, and overall confusion that would be generated by hearing such a scary word associated with a friend, classmate, and fellow carefree child.

Fortunately, another fifth-grade teacher volunteered to come by my house a few times a week to teach and provide me with assignments. Honestly, anything that prevented me from thinking was welcomed. She was so amazing, kind, and patient with me. There were several times further into my treatments when I didn't have the energy to get off the couch, so she would just sit on the floor beside me and help me do the activities I could for the day. I needed that. I needed that engagement and that mental push every once in a while. It can be incredibly easy to

spiral down into a dark and foreboding mental abyss, a place I had found myself getting close to several times.

Starting my second round of chemotherapy defined what the rest of my rounds would look like. After about a month of adapting to my new lifestyle, I had accepted that it was just something that I had to do and get used to. However, I thought I was more prepared than I actually was. I could no longer be left alone in my hospital room at all. One of my parents had to be there at all times or I would be overcome with anxiety and panic. One time, my parents had gone out to dinner and the doctor ended up needing a chest X-ray. The scan was simple and pain-free, but I found it incredibly difficult to cope with alone. After that, I could hardly handle my parents leaving to use the restroom for a few minutes. At the same time, I was disengaged from any interaction with them, or really anybody. My days in the hospital were spent laying in bed and watching the news until it would repeat, then maybe I could find a cooking channel that hadn't already been shown that week. They didn't really have much of a selection on the old TVs. I know the pediatrics unit had a game room, but I don't know what it looks like because I was never interested in leaving my bed.

The rest of my time at the hospital and at home were much the same. My treatments in the hospital were not the best of times, but they were bearable for the most part (although my treatments have unfortunately ruined mac and cheese for me to this day and I miss it greatly.). After my inpatient treatment, I would go home, sleep, then come back again the next day for outpatient treatment. These treatments were done in the pediatric clinics, a unit that had two big toy rooms with big recliner-looking seats in them. I was glad the treatment would only be a couple of hours, but they also ended up being the most brutal hours of my whole experience. Every time I would go in for these treatments, it would be as if I was hit by a literal freight train.

My entire body, my muscles, but especially my bones would hurt. I would get so nauseous and lightheaded that I thought it couldn't possibly get worse. Managing the pain was exhausting and would deplete any energy I had. If I was lucky enough, there were times I could sleep because of how drained I was.

Throughout this whole situation, my body and mind changed drastically. I was bald, I had gained weight from being on steroids, I was pale, and I was forced to grow up too fast. I didn't leave the house much during my treatments, but when I did it was maybe just a trip around Target—although it was always a grueling walk if I could even manage finishing a lap around the department store. It was also difficult trying to get out of my head during my occasional trip out in public. I despised wearing wigs, so the most comfortable option for me was just wearing a hat. But it was still obvious that I was sick. I knew I looked sick and that others perceived me as such. Most of the time, if someone did interact with me due to my condition, it wasn't even directed towards me; they would just speak to my mom about me as though I wasn't there. It was almost as if they didn't want to mention my sickness to me, like I wouldn't be aware of it otherwise.

Mentally, I felt like I was on some distant island far away from anyone else. I was surrounded by so many friends and family, and yet I could not help but feel utterly alone, like no one else really knew what I was going through. I did my best just to get through the days and limit the emotional toll this was taking on everyone else. Unfortunately, I have since realized that I was in a deep depression, although at the time I didn't even know what depression was. My only goal at this time was to just make it through the day, with the least amount of thinking about my condition as possible. I'm grateful to my friends, family, and teacher for all the support they gave me during this time.

Several months and rounds of chemotherapy later, I was finally declared in remission. What should have been a time for celebration was still rained out by my depression. I had no interest in interacting with others in regard to this achievement, no interest in making a big deal of my whole ordeal, and I'm still so sad that I didn't want to ring the bell to signal the end of my fight. But at the time, I was just ready to go home and return to my life before it was interrupted.

I was able to get back to school relatively quickly with the help of my oncologist. I was beyond ready to get back into the class, see my friends, and pretend that nothing ever happened. And for the most part, that's exactly what happened. My friends and the classmates around me didn't treat me any differently from the time I left, and it's something that I can greatly appreciate now. I craved a sense of normalcy, and I was so glad that my classmates provided me with such. There were times I felt so relieved that they weren't afraid to throw the ball at me during dodgeball (my favorite activity before getting sick), talked as if nothing changed but still caught me up with everything I missed, and didn't expect any less of me as a person. However, I could only wish the adults would treat me the same. It only took half a game of dodgeball before the school nurse determined that I couldn't participate in PE anymore (even though my doctor approved it), I was sat at a desk by myself in the front of the classroom, and my field trip spot was given away to another student because they "didn't think I could handle it." Just more reminders that I was still sick, looked sick, and had to be treated like I was sick.

I was more aware than ever of what I could and couldn't do, what I may need help with, and how I could ask for support or accommodations. However, many adults took it upon themselves to determine what I was and wasn't capable of. This really made me question my own abilities and further pushed me away from feeling normal. I so badly wanted to forget that I was sick, and I really wish they just would have let me. If only people would talk to me, ask me

what I felt like I could do, and treat me like everyone else in my grade. I think the only ones who understood were some of my teachers, who had experienced cancer as well. My band teacher was one of them. He was kind and compassionate but still expected me to complete the work that I could handle. I needed that, to just be treated like I was capable of basic activities and responsibilities. It's unfortunate that it takes having a debilitating disease to understand that you should treat people as people.

Getting through middle school was fine for the most part. By the time I hit the middle of seventh grade, most of my hair had grown back to a little above my shoulder, and it became less obvious that I had been sick. I still had regular doctor's appointments, tests, and scans, but it was nice that outside of the hospital I could go out and meet new people, and I wouldn't be defined by my illness. I got back into sports, made a lot of new friends, and finally felt normal heading into high school.

My cancer became more of my past, and I was able to forget on a daily basis the trauma of that whole situation. I tried out for the soccer team during my freshman year of high school and was able to play for the junior varsity team. Up to this point, I had been physically active for a year or so and did not have any issues with my physical health. However, one day while conditioning I was pushing myself through a grueling set of cardio exercises when it felt like my throat closed and it was like breathing through a straw. I panicked and got my coach's attention when all I could do was cry because I couldn't breathe. I sat down and waited for what felt like hours before the muscles in my throat started to loosen again and I could breathe.

This set off a round of different tests in the hospital. Asthma was ruled out after the medication didn't work for me, and after that they really couldn't determine why I was having such a sudden and intense reaction to cardio except that it was likely a result of the

chemotherapy. I was told to take it easy and to not push myself if I felt like it was getting more difficult to breathe. It was already difficult trying to get back to the level of play that everyone else had achieved in my absence, but to again have to be constantly worried about my health was exhausting.

I thought I was going to be met again with pity from others, but I was surprised to find that there was a lack of belief in the severity of my symptoms. Some of my teammates were girls that I knew back when I was first diagnosed, so it was disorienting when they completely dismissed this new health complication. “You can try harder,” “you’ll never be good if you don’t practice,” “you just don’t want to run with us,” and many more passive-aggressive comments filled me with doubt and made it more difficult to cope with my present health challenges. Maybe I was just being dramatic. I can probably push myself more. I don’t feel good. Maybe I should just quit.

For the second time in my young life, I felt defined by my physical characteristics. I often wonder, if I shaved my head again would they have believed me? If I look too sick then I am not capable of anything. If I look too healthy then I don’t have any excuses. Just the appearance of my good health created unrealistic expectations, which left me feeling like I had to justify my limitations. I loved playing soccer and I was really trying my best. Alas, doubt was deeply ingrained in my performance, all confidence that I had was gone, and I was overcome with anxiety. So, I quit.

Since high school, I have grown greatly as an individual and have spent a lot of time reflecting on the different interactions I have had with others at different points in my life. The stark contrast between how people treated me when I looked too sick and not sick enough is why

I had such a difficult time coping with my health. Since then, it has taken a lot of time to build the confidence I have now to know and accept my capabilities and limitations.

This research aims to bring attention to these types of interactions, as a multitude of others can relate to some of the relevant themes of my story. Dealing with any kind of illness or condition can already be mentally taxing, so it's important to be mindful of the way you interact with someone and how these interactions can greatly affect one's coping with their condition. Confronting and interacting with someone with an illness can be quite complex, as there are many factors to consider such as type of illness, personal coping preferences, age, and many more. This research project was undertaken with the hope that reading the following stories and experiences can create more insight and perspective into how people with an illness want to be treated and how we can dismantle the stigma surrounding what it means to be sick.

Overview and Hypothesis

The goal of this research is to promote exploration, reflection, and understanding of how various medical conditions with different levels of visibility can often influence social interactions. Participants were asked questions regarding their condition in different scenarios and prompted to share stories, experiences, and situations that will bring more insight and perspective into what it means to be diagnosed with a medical condition. Qualitative analysis was performed to determine relevant themes and similar experiences that may prompt an overview of how people with medical conditions varying in visibility are treated.

The ultimate goal of this study is spreading advocacy and awareness for what it is like to have a diagnosed medical condition and how social interactions influence coping. It was anticipated that the participants in this study would have experienced a decline in relationships after being diagnosed with a medical condition on the basis that others around them may

unintentionally cause distress through social interactions. Although it may be unintentional, it was expected that many participants would sense feelings of pity, doubt, and lack of urgency or seriousness, which may influence how they view close relationships. It is also anticipated that participants with an invisible illness will have had negative experiences in healthcare settings due to the stigma of invisible illness.

Method

Participants

A total of 10 adult participants (5 female and 5 male) were recruited to participate in this research through networking and social connections. Participants ranged in age from 18-53 years old ($M = 32.4$ years old). Participants had a variety of diagnosed medical conditions. All participants come from similar social classes and varied locations within the United States. Three participants were White, three were Hispanic, two were African American, and two were Middle Eastern.

Measures

This research explored the relationship between visible and invisible symptoms from diagnosed medical conditions and how they can influence social interactions. There was no requirement for how long each participant had the diagnosis; time with illness ranged from 1 year to 27 years ($M = 11$ years with condition). The interview consisted of 50 questions that were divided into 4 subcategories: demographic, daily experience with the condition, experience while socializing, and how they would prefer social interactions to go. Qualitative analysis was performed to determine relevant themes and similar experiences among the participants. Data were examined through a biopsychosocial lens in order to determine the different aspects that

factor into coping with an illness and how social interactions can perpetuate stigma associated with the visibility of an illness.

The 10 participants that took part in this study have different types of medical conditions that fit into one of the following categories: physical, mental, and substance abuse. Seven of the participants had various physical conditions, including severe ulcerative pan colitis, systemic lupus erythematosus, alopecia universalis, Osgood-Schlatter disease, leukemia, and Lyme disease, and one participant had various chronic pain conditions such as Rheumatoid arthritis and fibromyalgia. Two participants had only mental disorders, which included depression and anxiety and post-traumatic stress disorder (PTSD). Finally, one participant had a substance abuse disorder, namely alcoholism.

Procedure

Each participant was invited to participate in the study via email through social networking and connections. Participants were asked to volunteer to participate in the study and if the participant agreed, a separate email provided further details on scheduling the interview. Once the interview was scheduled, participants were provided with a Zoom link and a randomized password to ensure a private interview. Each participant was provided with a different password.

Once in the interview, participants read over the consent form and had to verbally consent to the experimenter to proceed with the interview. Participants had the option to have their cameras on or off and change their screen name if they felt more comfortable doing so. The interview consisted of 50 questions (Appendix A) that included demographic questions, questions about daily experience with diagnosed conditions, questions about how diagnosed conditions influenced social interaction, and how they would prefer these interactions would go.

Participants were encouraged to share personal stories, experiences, and situations, but could answer each question as directly as they would like. They could also opt to skip any questions or end the interview at any time without penalty. The interview varied slightly between participants, for example if a participant answered a later question as part of an earlier response or if a particular question was not relevant to the medical diagnosis. Interview times varied by the length of responses given but were generally between 30 minutes and 1 hour long ($M = 41.4$ minutes).

After the interview concluded, the recording was uploaded to a private Zoom cloud that would only be accessed by the experimenter. Each recording was manually transcribed so that individual analysis could be performed. After the conclusion of the research, all recordings and personal data were destroyed.

Results

The first set of questions addressed what it's like to be diagnosed with a medical condition and how one navigates daily life. Participants reported that it took a range of a few days to a few years to be diagnosed from the onset of their symptoms. Although most answers were ambiguous, most participants had an average of a few months from the start of their symptoms to their diagnosis. When asked questions pertaining to the social aspect of the beginning of their symptoms, three participants reported that they did not feel that others believed their symptoms while two more reported that only immediate family believed their symptoms and friends did not. Six reported feeling looked down upon for having their symptoms. When finally diagnosed with their condition, participants reported feeling confused, scared, and shocked by the outcome. When asked about the changes in relationships after their diagnosis, nine participants reported a decline in relationships with friends and family.

These results provide insight into what it means to be sick, how one copes with their condition, and how social interactions can negatively influence one's perspective on themselves. All of the ten participants reported some story, experience, or situation that caused them a great deal of discomfort or grief. The following stories will allow insight in greater detail into the thoughts, feelings, and emotions that come with being diagnosed with a medical condition and how social support is a difficult but important aspect of navigating this newfound illness.

Beyond the Diagnosis: A Look into our Participants' Experiences

The next several sections serve to give voice to participants and their experiences with their condition and diagnosis. Although the results give the definitive answers for each question asked in the interview, this section will provide a more detailed account of each person's unique experiences and the stories that come with them. Each participant selected a pseudonym to protect their identity; no real names were used in this study. It is important to be mindful that each participant in this study is a person who deserves to be viewed and treated with respect and empathy rather than a data point.

Amanda

Amanda is a middle-aged mom who started experiencing blood in her stool, pain and inflammation in her joints, bruising, fatigue, weight loss, and severe diarrhea. Before her symptoms, she would regularly exercise, socialize, and go out often. When the symptoms began, "I didn't think much of it. I just thought it was food poisoning or drinking too much alcohol." Soon, her symptoms began to worsen, which led to several trips to the hospital that would reveal that she was suffering from ulcerative pancolitis.

Ulcerative colitis is a chronic inflammatory disease that can occur at any age. This disease causes an abnormal reaction from the immune system that leads to inflammation and

sores (ulcers) along the lining of the large intestine, colon, and rectum. The cause of this disease is unknown, but some doctors have speculated that it may have been caused by a separate infection or virus to which the immune system had an abnormal response. Ulcerative colitis has several symptoms including joint pain, eye irritation, osteoporosis, and pain in the rectum. This disease can be diagnosed through blood tests, stool samples, colonoscopy, or a computerized tomography (CT) scan.

Unfortunately, there is no cure for ulcerative colitis, but medication can help reduce symptoms. In severe cases, someone suffering from this disease is likely to be hospitalized for pain management and to prevent dehydration from excessive diarrhea. 10 to 40 percent of patients with ulcerative colitis will eventually need to undergo a proctocolectomy, which is a procedure that removes the rectum and part or all of the colon. Most patients will also have to undergo an ileostomy, a procedure that attaches the remaining intestines to a stoma, a small opening made in the abdomen. A pouch is attached to the stoma and collects stool, which effectively eliminates the burden of pain and bloody stool (Bethesda, 2011).

As for Amanda, her symptoms quickly became severe as she found herself needing to use the restroom for bloody bowel movements more than 20 times a day and often with sudden urgency. These symptoms created a sense of isolation and anxiety, as she struggled to maintain a normal social life: “I stopped hanging out with friends and family. Friends stopped inviting me out and the lack of motivation puts a damper on my day-to-day activities.” Amanda went from having people and friends over every weekend to rarely leaving the house due to the pain and intense anxiety of constantly needing a restroom. “The frequency is unpredictable, I have to get up every 5-10 minutes to use the bathroom and sometimes I don’t make it. This makes going out in public very difficult.”

Trying to balance her health with her social life became increasingly difficult as the severity of her disease worsened. “I can’t really say if my friends were honestly supportive. Now I feel like so much time has gone by that they have given up and don’t really care anymore.” Several times she mentioned the lack of concern, consideration, and empathy she received from friends and extended family. On top of the lack of support from friends, it was also sometimes difficult to approach healthcare staff with her disease. At another point early into her disease, one doctor had asked if the bleeding was actually in her stool and if she wasn’t just on her period. “Sometimes I feel like the doctors dismiss my pain. When you tell people that you’re in pain they should believe you instead of treating you like you’re trying to take advantage of the system.” She soon also began to struggle with her mental health, as her life revolved around a toilet and access to the nearest restroom. “It’s a lonely disease. You feel alienated from everybody and everything. You have no joy with anything anymore and you’re in a constant state of worry.” The intensity of her disease was already overwhelming, and the emotional toll on her social life made it difficult to cope with her illness.

In situations like these, the topic of social support can be multifaceted and can be challenging to understand and address. As for Amanda, she wishes that others would just be more considerate and patient with her. Although she appreciates it when friends and family check up on her and her condition, it can become overwhelming when they check in every single day. Even though they had good intentions, a constant check-in can also just be a constant reminder that you’re sick.

Scarlett

Scarlett was a teenager when her family had just immigrated to the United States, and shortly thereafter she suffered a sudden pulmonary embolism when she fainted during PE in

school. After treatment for this sudden health emergency, she approached her doctors to find out what could have caused it. “A lot of doctors were hesitant to waste resources on investigating my pulmonary embolism and my doctor ended up telling me that it was because I was obese.”

Leading up to her diagnosis and as her symptoms progressed, she stated that her peers in high school were often insensitive to health concerns “Someone literally told me that I was breathing too loud. That still sticks with me to this day, that I’m that intolerable to you that just my breath causes you irritation.” She found out later that the pulmonary embolism was actually related to systemic lupus erythematosus after she had presented symptoms of swollen ankles, which indicated a problem with her body’s osmosis.

Systemic lupus erythematosus (SLE) is an autoimmune disease that can affect many parts of the body including the joints, kidneys, lungs, blood vessels, heart, brain, and skin. The immune system in a lupus patient produces antibodies that fight against the body’s healthy tissues and cells. People diagnosed with lupus report a variety of symptoms, but some common symptoms include extreme fatigue, swollen joints, kidney problems, and skin rashes. SLE is characterized as a form of disease that can affect many parts of the body compared to other forms. Research has suggested that genetics can play a role in the development of the disease, but there is no single factor that directly leads to the development of the disease. Diagnosing SLE can be a very complex and long process, as many factors need to be pieced together in order to diagnose correctly. Physical exams and blood tests can aid in the diagnosis of SLE, as it can often be mistaken for different conditions.

The primary goal in treating lupus is to manage flares, a period of intense illness, although there is still currently no cure. Several kinds of medications and treatments have been shown to be effective at treating flares, but each patient experiences different levels of

effectiveness with each medication, so it is important to be aligned with the proper medical personnel to best treat an individual's flares. Being diagnosed with SLE can lead to health complications further down the line, so it's important to take proper preventative care to extend quality of life (Bethesda, 2013).

After her diagnosis with SLE, her team of doctors' primary concern was trying to protect her kidneys from further damage and stress. She was told that she needed to limit salt intake, which can be challenging, especially since she was also placed on steroids that can increase appetite. Although it was difficult, "My family was very supportive [of my diet] and even cut out foods to support me and make me feel not as left out." However, outside of the household she reported that she often felt that people were condescending towards her when they would ask insensitive questions about her current condition. "I would get asked pretty much once a month if my ankles were so swollen because I was pregnant." She was already aware of the sudden fluctuation that her body was going through, and the insensitive questions and comments were making it more difficult to cope with her disease. She was also aware that some questions, especially from her close friends, likely came from a place of concern, but, "there's a proper way that you can show concern so that you don't hurt that person's feelings."

When she started college, she felt that it was easier for people to accept her due to the fat loss in and around her face. However, since her condition became less noticeable, others often attributed her fatigue walking long distances to her need to go to the gym. "They were from within my friend group so I guess they thought it was okay to say things like that but I would never say that to someone." The comments that she received from people at various points in her journey would often take a toll on her mental health, and she felt a strong desire to adjust her medication in hopes of "fixing" the physical symptoms so the comments would stop.

Fortunately, she felt that her mental health improved when she found a support group with like-minded individuals. “The people understood what I was going through, we were all struggling but it would help just to talk about it. It really gives you a sense of solidarity that you’re not alone.”

One thing that Scarlett would like the general public to be mindful of with SLE is the treatments. She is aware that her physical appearance has changed over the years of treatment but when you point it out, even inadvertently, it can really affect coping. “You don’t need to remind me, I know that I gained weight. I know that I have mood swings but it’s all out of my control. I wish people would remember that when they were interacting with me.” She would like to be checked on, but only if it comes from a genuine place. “This one kid in high school would always ask if I was hungry out of spite. He would pretend to check up on me but it was actually taunting.” It should go without saying that you should treat every person with respect and compassion, especially if they are actively going through health complications.

Cherry

Cherry was an active young girl who loved to dance and participate in other activities when she started to develop pain and swelling in her hands, joints, fingers, and feet. At the same time, she also started to experience stiffness in the morning in her hands, hips, back, and feet. Being only around 9 years old at the time, doctors concluded that her symptoms were due to growing pains and were normal. “I think the doctors were like, ‘You’re like 9. Of course it’s going to hurt, you’re growing and you’re an athlete.’” Trusting that the doctors were correct, her family told her that it was something that she would have to deal with and that everyone also goes through the same thing.

As the symptoms began to intensify, she once again looked to the doctors for answers about her ongoing body pains and other health complications. Eventually, she was diagnosed with rheumatoid arthritis (RA) and other chronic pain conditions such as fibromyalgia and temporomandibular joint (TMJ) at different points in her life. Even after diagnosis, she found that it was difficult to engage with healthcare staff at clinics, “they kind of shrugged it off, “Oh you can’t have RA because you’re young, thin, and fit. Thin young fit people do not have RA. Being dismissed was really common.” A common problem that people found when being diagnosed with RA is the lack of belief due to invisible symptoms.

Rheumatoid arthritis is an autoimmune disease that can cause symptoms such as joint pain, stiffness, and swelling, which can lead to joint damage and loss of function. Although the cause of RA has not been determined, many factors are thought to contribute to the development of the disease including genetics, environmental factors, such as smoking, and cellular abnormalities. For 70% of patients, the onset of RA is slow, while for 10% of patients, it is acute. Laboratory imaging such as x-rays, ultrasounds, and magnetic resonance imaging (MRI), are used to aid in diagnosing RA by determining the presence of autoantibodies rheumatoid factor and anti-cyclic citrullinated peptide.

Although every patient is different, the primary goals for treatment include reducing pain and stiffness and slowing disease progression. There are several medications that can aid in controlling pain and stiffness in patients, but most still have numerous side effects that can make management difficult. However, it is important for a newly diagnosed RA patient to begin treatment right away to slow the progression of the disease (Weisman 2011).

When Cherry was told about her condition, it was a mix of shock and fear. “What’s going to happen when I’m 50? I was really concerned about the future.” To decrease the symptoms of

RA, doctors suggested that she try an anti-inflammatory diet, but after nine months she felt no difference in pain. As her symptoms continued to progress and worsen, she found that her social life also began to change as her pain started to become more unpredictable. “I can’t make a promise that I can go out for coffee next week because I might not be feeling well. My social life has become a lot more limited.” Chronic pain can be a debilitating factor that can affect all aspects of daily life as well as lead to brain fog and memory loss. Cherry found it difficult to keep up with educational experiences due to these factors and had to accept that some days her body “was just not having it.”

Cherry prefers to not openly discuss her condition with others unless they need to know for work or school activities. Although she feels comfortable sharing some details of her diagnosis, she feels that it is not always relevant and some people just don’t need to know. However, something that she wishes the general public would know about her condition is that although you may not be able to see her symptoms, it doesn’t mean that it’s not there. “Just because it looks like I’m functioning on the outside doesn’t mean that I’m functioning on the inside, just because I’m in class and participating doesn’t mean that I’m not fighting the pain.” She also asks that people ask questions if they are unsure and to be patient and kind.

Luis

When Luis was born, it only took a few months before his parents realized that he was quickly losing all his hair. By the time he was one year old, he had complete hair loss and has had complete hair loss since. Doctors were quick to diagnose him with alopecia universalis, an autoimmune disease that only attacks hair follicles. Alopecia universalis is the most severe form of alopecia that results in complete hair loss, and treatments have not been particularly effective.

Most patients choose to wear a wig and not seek extreme treatment since the condition does not cause any physical pain (Khan 2018).

As for Luis, it was still a long journey to accept his lack of hair, especially when he was younger and in school. “Just growing up with it knowing that you will always be viewed differently just because of one thing that you have over everyone else.” He reported that he had difficulty with his social life at a young age due to this small difference between him and everyone else. “I look sick even though I’m completely healthy. When I was younger people used to think that since I looked sick that it was contagious so they veered to not interact with me.” This impacted his mental health for a while until he eventually accepted and embraced his lack of hair.

As an adult, Luis has found that most people tend to not acknowledge the difference in his appearance, which he greatly appreciates. However, he would prefer that people just ask if they’re not sure rather than making assumptions. “There is some passion in people when they don’t know. They think something is wrong and treat you as if you’re sick and tip-toe around you. Then when they find out it’s like, oh it’s really not that serious.” He does ask that people don’t stare, as some people have done to him in the past, and to talk to him instead. He can understand that it may seem like a sensitive discussion that others may want to try to avoid, but by doing so it can really invalidate how people with the condition feel. “People are trying to get better and they want to be treated as if they weren’t sick. We just all need to be a little bit more understanding.”

Overall, Luis has come a long way and has accepted and embraced his condition despite the comments and treatment he has received over the years. The social implications of any condition can be difficult to navigate, but one that is especially visible can make it a complex

process. Supportive friends and family as well as confidence in oneself can greatly contribute to coping and the ability to increase life quality. “I view myself as unique. Knowing the facts about my condition, I have the rarest kind. So I like to think that when other people are interacting with me they’re interacting with someone who is rare.”

Luke

Luke was an energetic and active young boy who grew to love the sport of hockey and spent numerous hours practicing and playing the game. However, sometime in middle school, he noticed that he started developing sharp pain in his knees that made playing very difficult. His parents and doctors told him that he was just growing and that pain was normal, especially since he was already really tall. Soon, the pain became unbearable and he had to quit being active in order to find what was causing the insufferable amount of agony he was feeling. Several x-rays later, the doctors discovered that he was suffering from Osgood-Schlatter disease.

Osgood-Schlatter disease, or osteochondrosis of the tibial tubercle, is a fragmentation of the tibial tubercle cartilage that becomes ossified sometime during a period of rapid growth such as puberty. Repeated friction and tension, likely occurring during sports activities, is likely the underlying cause of Osgood-Schlatter disease, especially when one is participating in more problematic sports such as soccer, basketball, and volleyball. Treatments for this disease include icing, massage, and stretching, but the best way to prevent pain is by limiting exercise and physical activity. Some research has suggested that one can prevent the onset of the disease by limiting progressive overload during the pivotal stage of growth. Once you develop the disease, there is a chance that it could get better over time, but for others, it may never go away (Itoh et al., 2018).

“Being a little kid, I didn’t really understand what it meant when I was diagnosed. I just knew that I had pain in my knees. When they told me I had to stop playing all my favorite sports it really took a toll.” Luke did not realize how much his lifestyle was going to be forced to change after his diagnosis in order to reduce the pain. He was devastated that he had to quit sports, and he also didn’t realize how much it would impact his social life as many of his friends were also his teammates. “I couldn’t go out and hang with my hockey or soccer friends at the time because I couldn’t play. I couldn’t run and I couldn’t skate.” It was a difficult disease to navigate for Luke, one he didn’t completely understand himself, much less anyone else around him. Because of this, he often felt dismissed regarding his pain and belittled for his inability to participate in physical activities. “It’s a very different pain and no one was really supportive because they just didn’t understand it. With PE in school they were like, yeah, you have to finish the mile regardless of how bad your legs hurt. I would literally be limping to the finish line.”

After a year of being diagnosed and not playing any sports, Luke decided that he wanted to try to get back into it. However, if he wanted to play again, he would have to prove to his dad that he could handle it. “It was like 10 at night and he made me get ready and brought me to the park with a whistle and three cones. He made me sprint between each of these cones and when he blew the whistle he made me throw myself to the ground in the wet grass. and I did that for an hour and I remember I had a hard time walking after. It made me want to quit everything after that day. To experience that day and to have him yelling at me and to go through all of that was one of the worst experiences I have ever had. He made me truly doubt if I was ever having pain or just making up or if I thought it wasn't real or whatever. After that day my mental health took a huge decline.” Alas, Luke did not play for another two years after that night.

Unfortunately, even well into high school, Luke did not notice a change in pain in his knees even though it was expected that the pain would subside after he was done growing. Missing the sport he loved more than ever, he decided that he wanted to try again to get back into hockey despite the amount of pain it would cause. Most of the time, he would push himself as far as he could during a game so that he could meet others' expectations of him, but oftentimes he would be in a great amount of pain during and after a game. Today, he is a young adult who still has the disease, but he still enjoys playing hockey recreationally, although has had to negotiate and accept his limitations and how hard he pushes himself, regardless of how other people may view him.

Alonzo

The following story contains graphic details about war and the effects it can have on a person.

Alonzo is a father, a husband, and a friend but also a veteran who has served multiple tours of duty during wartime. During his time in the military, Alonzo had spent the time, dedication, and work to make rank, which he thought was what he wanted when he was younger. However, the brutalities of war can be detrimental to anyone and everyone. "You tryna get home and you tryna get them home. And I've had instances where I've called a PID which is positive identification. I made the call, they let loose, then it's a 14-year-old boy. But I can't tell you how old he is, I can only tell you that he has a weapon. All I can tell you is that he is armed and that's how I made my call. For me, the hardest thing is a person that was out there was trying to plug up his wounds, plug up his wounds with her female personal hygiene products, and things like that. She was at her prom the year before that. She was at the prom. But I call for it, 'Hey, you

have PID? Do you have a positive identification?,' 'yeah man, sorry, they had a weapon.' That was that. So you dream about that stuff. That's where the anxiety comes from."

Originally, Alonzo had planned on staying in the military for 30 years until he had an encounter with a suicide bomber. "I got a combat action badge from the army listed but a suicide bomber had got me and after that, I thought I'm done when I get back to the US." However, reintegrating into civilian society after spending so much time in the military was another challenge he was not expecting. "It was hard to reintegrate back into society when I came back from war. I was yelling at my kids. [Mom] was like, '[Alonzo], those are not your soldiers, those are not your troops, and you have to take a step back.' Not being able to sleep. Not playing cards anymore, not playing dominoes anymore, not going to sporting events anymore. Not doing any of that kind of stuff." Soon after coming back, Alonzo was diagnosed with anxiety, depression, and post-traumatic stress disorder (PTSD).

PTSD is a reactive mental disorder that is typically expressed during environmental or interpersonal interactions. PTSD can occur through any experience with a traumatic situation, which varies from person to person, such as witnessing a death, sexual assault or abuse, a car accident, etc. The pathological exaggeration of the disorder is thought to be an adaptive human response in order to be aware, prepared, or avoid similar threats. Most symptoms related to PTSD include intense feelings of anxiety and a sense of danger, anger, and uncontrollable fear. Responses vary based on individuals and situations, but most cases can be treated to some extent with medications, therapies, and interventions that can provide assistance with trauma response. Cognitive behavior therapy is the most common type of intervention that may be effective to some level in managing PTSD due to the comorbidity the disorder has with anxiety and depression, which need to be observed and treated as well (Stein & Blanco, 2011).

Alonzo had been experiencing symptoms such as crying often, constantly being agitated, and wanting to “tear anything and everything apart.” However, he was fortunate to have a supportive wife, who was also a veteran, but had difficulty socializing with his other family and friends. “My social life is guarded, really guarded. You realize what you love but you have to stay out of the way. I’ve seen some uncompassionate people with this “get over it” attitude, but until you’ve been through what I’ve been through you don’t know. I feel like I’m always ready to snap.” He stopped hanging out with others and started to pay more attention to himself while he was dealing with the effects of this disorder. Fortunately, he was able to get accommodations in his workplace that allow him to work alone, a feature that has aided in his comfort and reintegration into society.

Alonzo still struggles with his PTSD and although he reported that some support groups with others with PTSD have helped, he views himself as “fractured, broken, tired. Just one day I want to get some peace again.” The brutalities of war are indescribable, but he wants the general public to know that “war is not funny, war is not fun, war changes you, war does a lot to your family, immediate and non-immediate. Death changes you, all of that changes you, it affects your sleep, how you handle your business, it affects you being on guard, it affects you watching every move.” He also asks that others don’t ask questions about war but rather the disorder itself. Trauma can be a sensitive topic, so it’s important to be mindful of how an individual might react to discussing such topics and to approach the conversation with empathy and respect.

Kate

Kate was a typical undergraduate student when she noticed that she was feeling extremely tired and would fatigue easily. She had waited a few days to try to see if her symptoms would improve, but would soon find it difficult to complete daily tasks, so she went to the

hospital. Several tests later, the doctor diagnosed her with leukemia. “It was really scary, obviously. I also didn’t know much about it at all. So my first question was kind of like how long do I have to live? What’s an oncologist?”

Leukemia is a type of cancer that is caused by abnormal lymphoid or hematopoietic cells in the lymphoid system. There are several subtypes of leukemia based on the origin, genetic information, and molecular features of the malignant cells. The cause of this cancer is still unknown, but some speculate that a small number of cases are due to genetic predisposition while most seem to be based on random chance. The cancer forms when the blood cells in the bone marrow produce and divide uncontrollably, leading to abnormal white blood cells. These white blood cells, known as leukemia cells, interfere with the production of healthy cells and can cause symptoms such as fatigue, bleeding, and infections. Treatment for leukemia depends on the type and stage of cancer, but the most common treatments are chemotherapy and radiation (Vecchione & Tedesco, 2012).

Her immediate family during this time was really there for her and provided the support that she needed. She also made the decision to keep her current diagnosis private, only telling her immediate family and a few select friends. When going out in public and back to school, it was not obvious that she had been sick and she preferred to keep it that way. However, in the midst of treatment and medications, she found that it was difficult being able to keep up with her daily habits. “A lot of the time I get tired so I can’t always do what I want to do. It’s just harder to study or focus because there is such a thing as chemo brain or you have to deal with medication side effects.”

This also played a factor in her return to school and dealing with professors and other faculty who were unaware of her condition. “It was really hard to interact with my professors

because a lot of the time, especially after covid they would have a hard time believing me or you know just brush it off. I was really surprised by the lack of understanding and compassion I received a lot of the time. I was more surprised when they were kind. So that was really hard.” She was trying to maintain her responsibilities as a student, but when she needed to go back to the doctor for a test, scan, or anything that was important, she only asked that professors and teaching assistants be more accommodating by allowing her to make up an assignment instead of fighting her. “I had to spend so much time trying to protect my privacy and trying to protect my grades and work.”

Navigating a cancer diagnosis can be an incredibly difficult ordeal, and trying to maintain outside responsibilities only add to the amount of stress and energy it takes to get by. Kate didn’t ask for a lot during this time from others, but she wishes that people would support her by “just being more understanding. Just basic kindness and I just think that if everyone thought if that were to be my family, my dad, my mom, my sister, my brother, my child in that situation, would I be treating them the same way? What can I do to make their experience better? If that’s how they treated me, I would be happy with that.” You may not always be aware of what others are going through and what health complications they may be facing, but being kind, understanding, and compassionate can go a long way toward making someone feel validated, heard, and supported.

Carlos

Carlos is a middle-aged adult who always loved to have family and friends over to watch sporting events, birthday parties, other celebrations, and to just hang out. Most of his party antics stemmed from when he was a teenager in high school, always with friends and always drinking alcohol. As they all grew up, connections changed and new connections formed, but the common

variable no matter the situation was alcohol. Soon, Carlos found that he had not just grown dependent on alcohol, but he was addicted to it. The line between weekend party behaviors and taking care of responsibilities during the week started to blur, and he had grown increasingly reliant on alcohol regardless of time and situation. Carlos had developed alcoholism.

Addiction is defined as compulsive consumption with an underlying basis of chemical dependency. Most addictive behaviors start with impulsivity that then develops into compulsivity, which may result in synapse destruction and impaired brain function. Alcohol addiction consists of two indicators: tolerance and withdrawal effects. As one develops an increased tolerance to a drug or alcohol, the ability to stop becomes much more difficult as withdrawal symptoms can include body pain, chills, vomiting, nausea, and in the worst-case scenario, seizures and death. Drug addiction can develop through two different paths: a genetic predisposition to develop addiction and by consuming too much of the substance too often. Alcohol dependence and alcoholism are separated by different sets of criteria according to the DSM-V, but some common points consist of the inability to complete responsibilities, drinking interfering with relationships, and drinking leading to destructive or abusive behavior (Obembe, 2012).

As his behavior started becoming more destructive, his immediate family started approaching his condition with more concern and worry. Although Carlos could accept that his behavior and drinking had turned into an addiction, it was difficult to find the support he needed. “All my friends and family were heavy drinkers too. So I fit in with them and they fit in with me. They always knew that wherever I go with them there's going to be alcohol involved.” What started with drinking every weekend started to spill into the week and affect his professional career. Carlos knew he had a problem and was trying to find resources and support to help with

his addiction. Unfortunately, drinking for 30+ years is a lot of damage to undo and a journey that would not be easy. First, he identified that some of his friends were bad influences, but even after approaching them with his desire to stop drinking, they encouraged him to drink anyway. “They support me. Or they just avoid me. The other day, my brother came down and he's got to have alcohol with his meal. Then encouraged me to drink with him. So, not a whole lot of support. I hear less from my friends. I really don't have any more friends or people I would call friends. They're all just acquaintances now and some of them my family doesn't care for them.”

Carlos did not anticipate that his journey to sobriety would be a lonely one, one where only his immediate family supported him because the rest of his friends and family were unwilling to give up alcohol when he was around. Even without the influence of his friends, Carlos found himself relapsing often, as the grip alcohol had on him was difficult to loosen. “Alcohol is the biggest drug abused in America. It's not something that you can just quit overnight, it's really difficult to stop. Especially since [alcohol] is always out there on signs, on TV, in movies, just always out there and trying to make it look like it's what everyone needs and desires.”

Carlos still struggles on his path to sobriety and often feels embarrassed, guilty, and disappointed for the decisions he's made that resulted in his addiction. The stigma surrounding alcoholism can be especially difficult to deal with, as many people often assume that alcoholism results from a lack of willpower, personal weakness, and irresponsible and dangerous activities. We must recognize that alcoholism is a disease that can affect anyone, and like anyone diagnosed with any other disease, it's important to treat them with kindness, dignity, and respect in order to better support them on their path to recovery.

Lily

Lily was a young adult who was always active and loved to go to the gym and hang out with her partner and friends. She had gone on a hike with some friends when she started to develop a rash a few days later. Thinking nothing of it, she assumed that she was just having allergies or irritation from the hike and that it would go away on its own. After the symptoms didn't change, she finally went to the doctor, who prescribed her some topical cream to treat the rash and ordered blood tests. After the rash had gone away, Lily resumed her life and forgot about the whole ordeal until about two months later.

Soon, she started to experience brain fog and found it difficult to concentrate like she used to. However, she dismissed these concerns as physical health was not taken as seriously. “[My family] were just like, ‘Oh, it’s nothing, just wait until it goes away and stop overreacting.’ Since I was raised like that I never really addressed my health.” However, soon her symptoms began to progress into muscle pain and achy joints that started to affect her workouts, one of her most enjoyable activities. As she grew increasingly concerned about her health, she looked into her voicemail where she found an urgent call from a nurse. After calling back, a doctor told her that she had contracted Lyme disease, likely from her hike.

Lyme disease is a tick-borne illness that is caused by the bacterium *Borrelia burgdorferi* species complex, a pathogenic spirochaete that requires a blood-feeding arthropod to transmit to a vertebrate host. Symptoms typically include headache, fatigue, fever, and a skin rash, known as erythema migrans. If left untreated, Lyme disease can progress to other parts of the body and cause joint and muscle pain and various neurological issues. Treatments can include antibiotics and, if found early enough, treatment can lead to a full recovery (Karami, 2012).

Lily was treated for Lyme disease with antibiotics and thought that would be the end of the pain she was experiencing. Unfortunately, a few months later the symptoms came back and

really started hitting her hard. “They tested my blood again to see if there were any more bacteria and there weren't, so [my doctor] was like, oh you're cured. So I went about my day and months later the symptoms really kicked in. There's this thing called post-Lyme disease syndrome and you start experiencing the lingering effects of the damage it already caused. When I went back to address that pain and to see what I could do because that was when the pain was really high and new. So I went and she was like, ‘Oh no it's all in your head.’ She literally said, no it's all in your head, you're cured, you're fine.” After this experience, Lily found that it was difficult to trust healthcare providers and did not want to go back to have her pain dismissed.

After a few more months of the same symptoms, Lily tried changing doctors to see if she could get a different response. Most doctors that she saw would validate her pain and experience with her disease, but they all were unsure about what to do about it, “He believed my pain, but he just didn't know. So I had to go to someone else and it would happen again. They would be like, I'm not an expert, I can't help you. There are communities of people with Lyme disease and they experience the same thing. My most recent doctor said that too. I told her my pain and my experience and she believed me and she said, yeah that's unfortunate, Lyme disease is really understudied.” However, with the new validation for her pain, Lily received more support from her family and friends, which helped her accept and better come to terms with her limitations.

Today, she has noticed a difference in her thinking and how she views herself in regard to her condition. “I'm so much more compassionate, kinder, and patient with myself. I'm more accepting of it now and I can accommodate new things now. Especially now that I'm trying to work out again, I can be kinder to myself when I'm in pain. I used to feel more angry with myself even though it wasn't my fault.”

Terry

Terry was a pretty average high schooler who was always hanging out with friends, going to Friday night football games, and getting ready to graduate. He considered himself an extroverted person, getting along with everyone and always going out on the weekends to engage in whatever antics his friends wanted to do. He had also just recently made the decision to enlist in the military and would be leaving the summer he graduated. He made this decision to make his family proud, to have the chance to travel, and to escape some of the troubles of his home life.

He made that decision towards the beginning of the year when his home life was not ideal, and the thought of getting away for a little bit sounded intriguing. However, his home life began to improve and he was no longer sure he really wanted to leave in the first place. "I found myself starting to notice once I enlisted in the army, it just kind of clicked, something in my brain. It was there in my head, messing with me." As the school year continued, he found that he started to have difficulty concentrating, had little to no motivation or interests, and constantly felt like he was spiraling. It soon became clear that he was struggling with depression and anxiety.

Depression is a mood disorder that is characterized by low mood such as loss of interest, depressed states, and loss of enjoyment in activities. Classifications of depression have different criteria depending on severity and time. Unlike the occasional unhappiness or sadness, clinical depression, which ranges from mild to severe, is diagnosed based on the severity of symptoms, duration of symptoms, and the inability to function normally. Risk factors that are associated with the disorder include genetics, psychological, social, socioeconomic, and lifestyle. There are two different routes that can effectively treat depression, pharmacotherapy and psychological therapy (Haddad, 2017).

Terry found that he had depressed feelings over the course of several months, which greatly impacted his social life and academic performance. Fortunately, Terry really felt that he could be open and honest about these feelings with close friends and family. “There were people I could rely on, they would hear me out. What actually really helped me a lot was being able to talk to others that were in the same shoes as me. So for example, right around the same time I enlisted, my best friend who was enlisted in the Navy was going through the same kind of lifestyle change mentally. I feel like whenever we communicate with each other, we just both get each other. We know what we are each going through.”

Terry soon was deployed and had little time to think about his life back at home while he was going through boot camp. Several months later, he finally received news on where he was going to be stationed. He had silently hoped that it would be at a base close to home but was shocked to find out he was going to be living in Germany. A mix of excitement and worry was all he could focus on, but as the feelings started to subside in his new home, he started to struggle again with his depression. “I always look back into the past when I didn't really notice these symptoms. I was always outgoing and worry-free. Now, day to day, it's just like I'm always trying to figure out how to ground myself. I'm still trying to understand depression and anxiety.”

Terry found comfort with others in his troop knowing that he wasn't alone with these thoughts and feelings, but it has still been difficult doing daily tasks and responsibilities. “It's pretty demanding, especially being a lower rank. You're very hard working when you're a lower rank. You just get thrown around, just do this job, do this detail, do that job. To cope with my depression, I spend a lot of time by myself. Other people in the army cope in other ways. It is very known in the army and military in general that a lot of soldiers drink, I guess it just helps them cope with whatever they have gone through and just work. There are a lot of days where it's

just so tiring, it's terrible. It really affects everyone here. I would say that depression is very prevalent here. It plays a big factor in your work and life in general.” It’s important to recognize that depression is a serious issue that can affect the lives of many. The military offers resources that can help when one feels this way, and it’s important to be aware and observant of those around you who may be struggling with depression.

Discussion

In this study, participants were able to share their experiences, stories, and situations they faced in regards to their health condition and how social interactions affect their coping. Although each participant had unique encounters with their friends, family, and healthcare professionals, many reported similarities and common themes. This study looked at a range of different health conditions that includes physical conditions, mental disorders, and substance abuse disorders.

Although social support varied from person to person, a common theme that arose among participants with physical health conditions was that they felt that others did not initially believe their symptoms were serious or felt that they were looked down upon for these symptoms. This reaction can be related to the stigma surrounding physical health-if you don’t look sick then you aren’t sick. Due to others not believing their pain, participants often had difficulty confronting their illness and downplayed their own experiences. As we have seen in some of the stories above, not taking health complications seriously can have potentially devastating consequences. Although social support is needed during a time of health adversities, it's important to be in tune with your body and your pain. You know yourself and your body better than anyone else, so it’s important to listen to it, even if it does happen to be a false alarm.

However, sometimes, even when you do take caution and visit the doctor, you can still be met with doubt and dismissal. As seen in several stories above, many participants had a difficult time approaching healthcare professionals with their health concerns. Even when some professionals acknowledged the condition, participants often felt like they downplayed the severity of their pain and discomfort. Many felt that healthcare professionals did not want to waste resources, investigate, or give proper care and attention when needed most. Invisible illnesses affect a multitude of people, and it can be disheartening to be turned down by the people who are supposed to treat and take care of you. Moving forward, it is encouraged that we as a society learn how to trust others when they say they are in pain. We cannot dictate what is too little pain for someone else but rather validate how they feel and provide support, empathy, and understanding towards their experiences.

More often than not, people have negative feelings about asking for social support, help, or accommodations. It is thought that people with health conditions may feel weak, powerless, and like a burden when asking for needed support. Although these feelings applied to participants with various levels of visible illnesses, those especially with less visible illnesses felt that others did not believe their pain, which made asking for support more difficult. On the other side of the scale, those with more visible illnesses felt compassion and empathy from others, but at the same time felt belittled and treated like they were unable to do anything for themselves. In situations like these, it would be more effective to ask the other person what they felt they were capable of and to assist them when they ask for it. The person with the health condition is able to determine what their capabilities and limitations are, and it's best to be supportive when they ask for it.

In regards to social support, sometimes it can be difficult to know how to approach someone with a health complication. For the most part, the most effective way to know how to properly support someone the way that they want and need is to ask them. Some participants wanted others to check up on them more often, some wanted others to check up on them less. Some participants preferred that people not ask directly about their condition so as to not remind them of the pain that they are experiencing. All participants wanted to be treated with the same approach as you would any other person who was not sick, with kindness, consideration, and empathy. It is understood that others may have the best intentions when trying to help or support someone during a medical diagnosis, but it's important to be mindful of how you approach them so as to not accidentally cause pain or discomfort.

Aside from support, it can also be difficult to really understand what another person is going through, especially if you are not familiar with the condition that they have. All participants encouraged asking questions in a thoughtful and sincere manner. No participant minded questions about their condition, but as a side note for Alonzo, he encourages questions about PTSD itself, but not questions about war or his time in the military. This is an instance where it's important to be thoughtful and aware of others and how certain conversations may be too sensitive to raise. A good way to approach this in conversation if you're not sure is with the question, "Hey, would you mind if I ask questions about..." and depending on the other person's answer, it will allow you to make a better judgment on what is appropriate to talk about.

Coping with any health complication can be an isolating experience, and it is necessary to reach out for support, whether it be from friends, family, or health care professionals. Many physical health conditions are comorbid with mental disorders such as anxiety and depression, so

it's important to be aware and take necessary steps, such as seeing a primary care doctor or therapist, when noticing these symptoms.

Limitations

Since the focus of this study was the personal experiences of those with a diagnosed medical condition, there was a small sample, as more participants would have led to less in-depth analysis and a less in-depth understanding of individual experiences. Since all participants were recruited from networking and social connections, it was also difficult to find participants outside of connections with invisible illnesses. Future research in this area could benefit from having a larger sample size as well as more of a balance of participants with mental disorders and substance abuse disorders compared to physical conditions.

Since this research utilized qualitative analysis, it may be beneficial to use scales, questionnaires, and other forms of assessment to quantify experiences in meaningful ways. The data was analyzed subjectively, which may include unintentional bias towards specific findings and themes. Using other measures such as scales and forms would produce quantitative data that can be analyzed objectively.

Conclusion

In this study, participants with various medical conditions were interviewed and provided unique stories and experiences that have similar and relevant themes. Results provide insight into what it means to be sick, how one copes with their condition, and how social interactions can negatively influence one's perspective on themselves. All of the 10 participants reported some story, experience, or situation that caused them a great deal of discomfort or grief. The stories revealed the thoughts, feelings, and emotions that come with being diagnosed with a medical

condition and how social support is a difficult but important aspect in navigating newfound illness.

As we move forward, it is hoped that these stories provided insight, awareness, and compassion for others you may interact with in the future and that you may have a better understanding in approaching and supporting them. Listen to others, be there for them, and allow them to express their emotions, feelings, and thoughts that assists them in coping.

References

- Armentor, J. L. (2016). Living with a contested, stigmatized illness. *Qualitative Health Research*, 27(4), 462–473. <https://doi.org/10.1177/1049732315620160>
- Åsbring, P., & Närvänen, A.-L. (2003). Ideal versus reality: Physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia. *Social Science & Medicine*, 57(4), 711–720. [https://doi.org/10.1016/s0277-9536\(02\)00420-3](https://doi.org/10.1016/s0277-9536(02)00420-3)
- Bethesda, MD. (2013). *Systemic Lupus Erythematosus*. National Institute of Arthritis and Musculoskeletal and Skin Diseases, National Institutes of Health
- Bethesda, MD. (2011). *Ulcerative Colitis*. National Digestive Diseases Information Clearinghouse, Department of Health & Human Services, NIH, National Institute of Diabetes and Digestive and Kidney Diseases
- Conrad, P., & Barker, K. K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behavior*, 51(1). <https://doi.org/10.1177/0022146510383495>
- Else-Quest, N. M., LoConte, N. K., Schiller, J. H., & Hyde, J. S. (2009). Perceived stigma, self-blame, and adjustment among lung, breast and prostate cancer patients. *Psychology & Health*, 24(8), 949–964. <https://doi.org/10.1080/08870440802074664>
- Ettridge, K. A., Bowden, J. A., Chambers, S. K., Smith, D. P., Murphy, M., Evans, S. M., Roder, D., & Miller, C. L. (2017). “prostate cancer is far more hidden...”: Perceptions of stigma, social isolation and help-seeking among men with prostate cancer. *European Journal of Cancer Care*, 27(2). <https://doi.org/10.1111/ecc.12790>
- Haddad, M. (2017). *Fast facts: Depression*. Abingdon, England: Health Press

- Itoh, G., Ishii, H., Kato, H., Nagano, Y., Hayashi, H., & Funasaki, H. (2018). Risk assessment of the onset of Osgood–schlatter disease using kinetic analysis of various motions in sports. *PLOS ONE*, *13*(1). <https://doi.org/10.1371/journal.pone.0190503>
- Karami, Ali. (2012). *Lyme Disease*. IntechOpen
- Khan Mohammad Beigi, P. (2018). *Alopecia Totalis/Universalis*. In: Alopecia Areata. Springer, Cham. https://doi.org/10.1007/978-3-319-72134-7_3
- Mathew, R. M., Shambhavi, ., & Sibi, S. M. (2021). Effect of teaching intervention on cancer facts to reduce cancer social stigma in rural adults-a pilot study. *Journal of Clinical and Diagnostic Research*. <https://doi.org/10.7860/jcdr/2021/50918.15615>
- Obembe, S. (2012). *Practical skills and clinical management of alcoholism and drug addiction*. Elsevier Science Publishing Co.
- Stein, D. J., Friedman, M. J., & Blanco, C. (2011). *Post-traumatic stress disorder*. Wiley-Blackwell.
- Vecchione, S., & Tedesco, L. (2012). *Acute lymphoblastic leukemia: Etiology, pathogenesis, and treatments*. Nova Science Publishers.
- Weisman, Micheal H. (2011). *Rheumatoid Arthritis*. New York: Oxford University Press

Appendix A

Demographic information

What is your name?

What is your date of birth?

What is your race?

What gender do you identify with?

Do you identify with a religion?

What is your highest degree or level of education you have completed?

What medical condition(s) have you been diagnosed with?

When were these medical conditions diagnosed?

Experience-Based Questions

What symptoms led to your diagnosis?

How were you treated by family/friends/peers while you were first experiencing your symptoms?

Did you feel that others believed your symptoms?

Did you feel that others looked down on you for symptoms?

How long did it take for you to be diagnosed?

What was the experience like when you were first told about your condition(s)?

What lifestyle changes did you make after you were diagnosed?

How would you describe your experience with your condition?

How did your social life change after being diagnosed?

How did your diagnosis impact your mental health?

How supportive did you perceive other people to be?

How did relationships with others change from before to after your diagnosis?

Do you experience different treatment from others before and after your diagnosis?

Do you feel like the same person as before your diagnosis?

How did your condition affect your experience with school or work?

Were people accommodating to your condition in school or work settings?

Have you had any negative experiences with hospital or healthcare staff?

Do you often feel like hospital/ healthcare workers truly understand your pain and/or discomfort?

Do others often make you question your own abilities?

Do others often make you question your own experiences with your illness and pain?

Do you often feel uncomfortable discussing your condition with others?

Do others make you uncomfortable with their support?

What kind of support or accommodations would you like to receive from others?

How do you wish others interacted with you based on your condition?

Do you often feel like you have to push yourself, which may come at the expense of your comfort and health, in order to feel in line with others' expectations?

Do you often feel like others dismiss your pain?

Do you often feel like you have to “prove yourself” when others doubt your condition/pain?

Do you feel that others doubt your pain if you’re not showing any obvious signs of your condition?

Do you often doubt your own capabilities?

What do you believe the stigma surrounding invisible illness is?

What changes about the healthcare system would you make to address invisible illnesses?

What do you wish people would know about your condition?

How do you wish people would act when they find out about your condition?

Do you feel like the accommodations you ask for are fair? Do you believe that you may be asking for too little in comparison to what would actually make you comfortable?

How does asking for support make you feel?

Do you feel less of yourself when asking for help, support, or accommodations?

What is your experience with meeting new people? Are they aware of your condition? How do they act once they are aware?

How would you describe your experience in group settings?

Do you feel like you “fit in”?

How do you view yourself in regards to your condition?

Do you want others to check up on you?

Do you mind if others ask questions about your condition?