Unmasking the Unseen

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Abstract

Objective

Invisible diseases, such as Crohn’s disease, arthritis, celiac disease (CD), and diabetes, often go unnoticed by many, leading to widespread misconception. Increased awareness can pave the way for improved treatment, particularly for diseases that frequently remain untreated.

Methods

Participants in the USA from ages 22-77 with a diagnosed invisible disease completed a 24-question survey gathering demographic data and personal insights into their experiences which were analyzed utilizing Excel software. All participants consented.

Results

The narratives offered by participants in this study provided a glimpse into the lived experiences of people dealing with invisible diseases. Their personal views reveal a mosaic of resilience and adaptation, shedding light on the numerous challenges of managing diseases including Crohn's disease, arthritis, CD, and diabetes. Each narrative emphasizes the profoundly personal aspect of treatment, as well as the complex interplay between medical interventions and everyday life. From the meticulous dosage of prescriptions to the emotional toll of navigating social interactions, participants' experiences create an obvious representation of the complications that come with the disease. After the study was completed, it was clear that these often undetected diseases play a heavy role in the quality of the patient’s daily lives. It was shown that 64% of all participants voted 5 or higher for the question stating: “How often do you experience symptoms of your invisible disease? (1: Never, 10: Always)” as portrayed in Appendix 1.

Discussion

The intricate views of responses from participants provide crucial insights into the complex realm of invisible diseases. Their stories not only shed light on the difficulties associated with treating chronic disorders but also highlight the necessity of comprehensive approaches to treatment. By looking into the complexities of lived experiences, this study lays the framework for increasing awareness and understanding of invisible illnesses among healthcare communities and society as a whole. Furthermore, the stories recounted by participants demonstrate the resilience and determination of individuals. As we continue to explore and analyze the data collected, these narratives will continue to act as guiding beacons, revealing paths toward increased care and advocacy for individuals living with invisible diseases.

Author Summary:

In this study, we explored the real-life experiences of people living with invisible diseases such as Crohn’s disease, arthritis, celiac disease, and diabetes. Through surveys with participants aged 22-77, from the United States as well as France, we gained valuable insights into how these Invisible Diseases affect their daily lives. After the study was completed, it was clear that these often undetected diseases play a heavy role in the quality of the patient’s daily lives. We found that many participants struggle with symptoms that impact their work,

relationships, and mental health. The challenges they face range from managing complex treatment regimens to dealing with the emotional toll of having a condition that others cannot see. Our findings highlight the importance of understanding and acknowledging the hidden struggles associated with these invisible diseases.

Introduction: *Invisible diseases, unseen but not unfelt*

From the outside, a person may be perceived as normal, when in actuality, there is a huge realm of health challenges below the surface. An invisible disease is an umbrella term for a medical condition that cannot be seen just by looking at someone, such as Crohn's disease, Arthritis, Celiac Disease (CD), and Diabetes (Fabian, 2018). They may be physical, cognitive, and/or mental, and are defined by their non-contagious nature, risk factors, an extensive latent period, a prolonged temporal course, functional impairment or disability, and incurability (Piovani, et al. 2022); thus, living with chronic illness is a complex and multidimensional process(Ambrosio, et al. 2015). Additionally, invisible illnesses are becoming more and more prevalent throughout today's society (Campbell, 2023). According to the CDC, invisible illnesses affect around 10% of the 61 million Americans who deal with a physical or mental ailment that limits their movements or senses (Salamon, 2023). These diseases are profoundly affecting the daily lives of many individuals. Yet, despite their prevalence, invisible diseases are often stigmatized and misunderstood, and the etiology of invisible illnesses is understudied. This study aims to raise awareness on invisible diseases and provide insight from real individuals about their experiences and treatment through surveys revealing individuals' coping strategies and mental health. Furthermore, participants were asked to rate their management satisfaction, symptom severity, and impact on mental health to quantify the effect of invisible diseases on a patient's overall quality of life.

Background

Crohn's disease

Crohn's disease is a type of inflammatory bowel disease (IBD) that causes inflammation and tissue destruction anywhere along the gastrointestinal tract, from the mouth to the anus. This disease, among many invisible diseases, is chronic, lasting a long period of time without a complete cure. In Crohn's disease, the immune system is thought to be triggered by some foreign pathogen in the gastrointestinal tract. The symptoms of this disease include diarrhea and bloody stool, malabsorption, abdominal pain, and weight loss. The diagnosis typically involves a combination of clinical presentation with medical history and physical examination, labs and imaging tests, and endoscopic procedures to assess the extent of inflammation. The treatment of patients with Crohn's disease depends on disease severity, patient risk stratification, patient preference, and clinical factors, including age. Crohn's disease treatment includes anti-inflammatory medications, immune system suppressants, and biological treatments. Other medications often prescribed for treatment also consist of steroids, monoclonal antibody therapies, immunomodulators, and surgery (Cushing, 2021). Nutritional treatment with specialized diets is often recommended as well to help patients maintain their health and surgery is occasionally required to remove diseased parts of the digestive tract.

Arthritis

Arthritis is characterized by joint inflammation, encompassing several types including Ankylosing Spondylitis (arthritis of the spine), Gout (typically arthritis of the big toe), Juvenile Arthritis (arthritis in children), Osteoarthritis (arthritis commonly from overuse of the fingers, knees, and hips), Psoriatic Arthritis (arthritis alongside skin inflammation from psoriasis usually in fingertips and spine), and Reactive Arthritis (transient arthritis caused by an infection in the body). Symptoms of arthritis can include pain, stiffness, redness, heat, and swelling in the joints. Individuals may also experience fever, weight loss, rashes, and more. Anti-inflammatory medications (NSAIDs), disease-modifying antirheumatic drugs (DMARDs) like methotrexate or sulfasalazine, and biological response modifiers like adalimumab or etanercept are all used to treat arthritis. Physical therapy can further enhance treatment and surgery is sometimes required to replace badly damaged joints.(Wang, 2022)

Celiac disease (CD)

CD is an autoimmune condition where exposure to gluten causes an immune reaction leading to subsequent inflammation in the small bowel. Autoantibodies are created in response to gluten and target the epithelial cells to cause inflammation in these areas and develops in early childhood and can sometimes be hereditary (Celiac Disease Foundation, n.d.). Most people who have celiac disease do not even know they have it. Some symptoms include diarrhea, fatigue, weight loss, anemia, mouth ulcers, dermatitis herpetiformis, and more. CD is diagnosed through blood tests which look for antibody markers such as Anti-tissue transglutaminase antibody (tTGA) and Endomysial antibody (EMA). tTGA is the preferred single test for the detection or screening of CD at any age (Farina et al. 2021). Immunoglobulin A (IgA) EMA is a test for CD that has a specificity of almost 100%, making it the most specific test for CD, although it is not as sensitive as the tTG-IgA test. The diagnosis can also be confirmed with a biopsy. Celiac disease necessitates the entire avoidance of gluten-containing foods including wheat, barley, and rye from the diet. Nutritional supplements may be recommended, and medication may be administered to treat symptoms.

Diabetes

Diabetes is characterized by high blood glucose levels which are grouped by type 1 and type 2 diabetes. Under normal circumstances, carbohydrates break down into glucose which is carried to various parts of the body to give cells the energy necessary to function, and healthy beta cells produce insulin which binds to its receptors on target cells and induces glucose intake. However, in diabetes, this process is disrupted. For instance, in type 1 diabetes, the immune system mistakenly attacks the beta cells in the pancreas which normally make insulin and this results in a lack of pancreatic insulin production and high blood sugar levels (Basu, 2017). In type 2 diabetes, cells become resistant to insulin and are unable to uptake glucose leading to a similar outcome. The diagnosis involves blood tests to measure fasting blood glucose levels, oral glucose tolerance tests, and glycated hemoglobin (HbA1c) tests to assess long-term blood sugar control. Diabetes medication includes insulin therapy for type 1 diabetes and oral medications such as metformin, sulfonylureas, and Dipeptidyl peptidase-4 inhibibitor (DPP-4) inhibitors for type 2 diabetes to help control blood sugar levels. Diabetic patients must also maintain a healthy diet, limiting carbohydrate intake and engaging in regular exercise with consistent blood sugar monitoring. Medication requirements can be altered accordingly based on blood glucose and HbA1c levels.

These five invisible diseases are just a few of the vast array of invisible diseases to exemplify the extent an invisible disease can affect a person’s life. This subset of participants were asked the same questions in a qualitative study to understand more about their experiences. In other studies, the experiments focused mainly on the physical aspect, however, this study incorporates both the mental and physical aspects of living with an invisible disease. This can serve as an asset to understanding more about patient experiences to further advocate for this patient population.

Methods: qualitative cross-sectional study

Participant criteria

This study used qualitative techniques to examine in-depth individual interviews. The sample included adults with ages from 22-77 years old who live in the United States and have a diagnosed invisible disease which include either Crohn's, Arthritis, Diabetes, or CD. Participants had to be over the age of 18 in order to participate in this study. Participants were referred to the study by physicians or found through social media and community engagement. The participants in the study all spoke English or French. Those who spoke French fully understood English as well and had a native speaker in the study translate in order to ensure full integrity. This study assumes that these conditions were well-controlled in the population that responded to the survey.

Interviewing participants with invisible diseases

This study was a qualitative cross-sectional study performed through participant interviews and questionnaires collected via Microsoft Forms. The pdf of the questionnaire is in Appendix Part I and individuals' responses are in Appendix Part II. Interviews were conducted through a questionnaire form which lasted from 20-25 minutes or a Facetime call which lasted around the same amount of time. The calls were recorded via voice memos and transcribed onto the Microsoft Form. Participants were given a QR code which led them to a questionnaire document through Microsoft Forms. They were asked a total of 25 qualitative and quantitative questions. Participants were asked to rate on a scale of 1-10 how satisfied they were with their medication, how severe were the symptoms and how it impacted both their mental and physical health, and were asked to write about how their invisible disease affects their day-to-day life. All 15 participants consented to participating.

Analysis of questionnaire results

This study utilized Excel to compare categorical variables, such as age, sex, race, etc as well as to collect descriptional statistics and make corresponding graphs.

Results:

Demographics of participants

There were 15 participants in this study who all fully completed the study. Participants were between 22-77 years old. 15 (100%) of participants spoke English, 3 (20%) of participants spoke French, and all lived in the United States and 3 (20%) of participants spoke French as well. 15 (100%) of participants had a diagnosed invisible disease.

Table 1. Patient Demographics. Acronyms: CD: Celiac Disease; RA: Rheumatoid Disease

Sample characteristics	**Participants (N=15)**
Age (Mean years old)	44.6
Sex	
Female (%)	77%
Male (%)	33%
Language	
French (%)	20%
English (%)	80%
Race	
Black (%)	8%
White (%)	92%
Invisible Disease	
CD (%)	15%
RA (%)	23%
Crohn’s (%)	31%
Diabetes (%)	31%

Quality of life affected by invisible diseases

1. **Quality of Life Affected by Invisible Diseases: Work**

In the examined cohort, it was universally observed that their invisible illness affects their daily life in many ways. Some experience trouble due to pain, others due to the inability to complete simple tasks, and others the necessity of adhering to a daily medication regimen. These difficulties have led some to not be able to effectively work. Individuals with diabetes, for example, emphasized the importance of regular insulin shots and dietary changes, which impacted their productivity and energy levels throughout the day. Similarly, patients suffering from Crohn's disease highlighted the difficulty of balancing work commitments while experiencing debilitating symptoms such as stomach discomfort and exhaustion. Furthermore, many participants feel conflicted about disclosing their invisible illness in employment settings since they do not want to be seen as less capable than others due to their invisible disease. Since their disease is not visible outwardly, people may not understand what they are going through.

> *"It obviously affects my daily life as I have medicine that I have to take daily and shots of insulin every evening. My diet has changed as I must avoid certain food and all types of sweets. I also must check my blood sugar level 3 times a day."*
> *-Participant 10, 62 years old, Diabetes*
>
> *"Unfortunately, managing my chronic pain and fatigue can be challenging… I find that staying active helps me manage the pain and avoid dwelling on it. While I still feel it, focusing on activities keeps it from significantly impacting my daily life."*
> *-Participant 3, 42 years old, Diabetes*
>
> *"Sometimes it's complicated to keep trying to take care of my 4 children properly or to turn in a job on time because of my illnesses, I try to tell myself that it's not a big deal even if it affects me. I'm lucky enough to be my own boss, which suits me a lot for the work side!"*
> *-Participant 12, 36 years old, Crohn's*

2. **Quality of Life Affected by Invisible Diseases: Relationships**

The impact of invisible illnesses went beyond individual experiences and into interpersonal connections, with individuals negotiating diverse dynamics within their relationships. While some people received constant support from family members, others faced misconceptions, stereotypes, and social isolation due to the invisibility of their conditions. People tend to doubt the reality of things that they cannot see, so these symptoms or their severity are often called into question(Aimone, 2019). For example, one participant thanked their husband for their understanding and assistance in managing their diabetes, emphasizing the importance of familial support networks. Others bemoaned the loss of friendships and the necessity to remove themselves from others who did not understand the difficulties created by their illnesses. Friends can become frustrated with the need to cancel plans to manage symptoms, with some people going as far as blaming the person with the illness because they mistakenly assume that they have control over a physical or mental symptom(Sowińska, Tudela, 2023).

> *"My family is aware of it but no one ever sees me taking my treatment, except my wife who is a great support."*
> *-Participant 10, 62 years old, Diabetes*
>
> *"I limit my triggers, I have lost a lot of friends who do not understand my health, my life, my journey and I have gained so many friends who are true friends who understand. I always say on my zooms having a chronic illness is a blessing in disguise with friendships and knowing who the true people in your life are. Once you get rid of the bad friends, you have more energy to give to the good people. My zooms you are surrounded by people who get it and you don't feel indifferent nor isolated."*
> *-Participant 6, 27 years old, Crohn's*

3. Quality of Life Affected by Invisible Diseases: Symptoms

In the examined cohort, the severity of symptoms ranged from mild discomfort to severe pain and were as low as one and as high as ten. For example, individuals with Crohn's disease described symptoms such as vomiting, loss of appetite, diarrhea, weight loss, and abdominal pain, while those with diabetes mentioned thirst, increased urination, and increased appetite as common symptoms. Most of the chronic diseases, by restricting the individual's ability to live, can lead to the worsened general health of patients, limited performance, and increased healthcare costs (Samiei Siboni, Fatemeh et al. 2019).

> *"I was diagnosed 3 months after I started having the first symptoms (vomiting, loss of appetite, diarrhea, weight loss, abdominal pain...). It was like a never-ending gastroenteritis. As I said above, everyone has different symptoms, which is why Crohn's disease can sometimes be difficult to detect. I had to have a colonoscopy so the doctors could see the inflammation in my colon and intestines. I was 16 years old."*
> *-Participant 9, 27 years old, Crohn's*
>
> *"My blood cells don't respond to the hormone insulin properly. The main symptoms that I feel are thirst, increased urination, and increased appetite. I need to constantly check my blood sugar level."*
> *-Participant 10, 62 years old, Diabetes*
>
> *"Joints / stomach and joint pain / attacks often / fatigue/depression sometimes related / I don't assimilate iron and vitamin b12 well so big lack of energy"*
> *-Participant 12, 36 years old, Crohn's*

4. Quality of Life Affected by Invisible Diseases: Mental health

In addition to physical symptoms, participants also experienced mental difficulties in coping with these illnesses. As seen in graph 2 below, many people included in the sample group faced mental health issues due to their invisible diseases. People with chronic illnesses, such as Crohn's disease, Arthritis, CD, and Diabetes, are also more likely to experience mental health issues, such as depressive symptoms(Li, Hongjin et al. 2018) Chronic illnesses can affect physical, cognitive, social, and emotional development. A patient who is diagnosed with diabetes, for example, will be instructed to visit several specialists each year, including an endocrinologist, ophthalmologist, and podiatrist. But rarely are patients referred to a mental health specialist as part of their treatment plan[14]. Around 37 million Americans have diabetes, and they are 2 to 3 times more likely to develop depression than people without diabetes; however, only 25%–50% of diabetics with depression get diagnosed and treated(Fernandez, 2021).

> *"I called a psychologist several times. The first time after 2 years of illness but I stopped quickly because she didn't help me properly and didn't understand my pathology at all and then another person 12 years later who helped me a lot for more than two years. My therapy mostly helps others with the same disease through social media."*
> *-Participant 12, 36 years old, Crohn's*
>
> *"I host weekly international zooms where people all over the world who have chronic illnesses join, they all vent and I help them navigate life through chronic illness. I am extremely blessed and grateful that my mom is my best friend, caretaker and the sweetest angel who helps implement what I preach on others and is always right by my side through everything."*
> *-Participant 6, 27 years old, Crohn's*
>
> *"I've made Crohn's disease part of my life. I assume I'll have it for life, so I have no choice but to live with it. If I need reassurance or advice, I turn to the healthcare professionals who treat me for Crohn's disease."*
> *-Participant 9, 27 years old, Crohn's*

5. Treatment

In the realm of invisible diseases, treatment involves more than just taking medication; it also entails building one's own resilience. Treatment tends to be firmly established in participants' daily lives based on the experiences they share. They discuss routine duties, including taking prescriptions, testing blood sugar levels, and dealing with dietary limitations. Beyond the practical aspects, treatment considers how people function emotionally and socially. It has to do with overcoming preconceptions, getting support from close ones, and occasionally losing friendships in the process. Treatment is more than simply a habit; it demonstrates their strength and resolve in confronting their invisible disease.

> *"Daily medicine, daily insulin shots, and blood level checking. One has to be serious about following the doctor's recommendations. Sport activities help also mentally and physically."*
> *-Participant 10, 62 years old, Diabetes*

> *"Treatment by infusion every two months in hospital (Remicade injection) And blood test"*
> *-Participant 9, 27 years old, Crohn's*
>
> *"Medicine, injections, protection for hands knees and shoulders. For me, i like to take massages, take baths, go swimming and watching my weight."*
> *-Participant 5, 76 years old, Arthritis*

Discussion:

The analysis of the collected data from this qualitative cross-sectional study explored individuals with invisible diseases' lived experiences. In-depth interviews and questionnaire responses revealed that invisible diseases impact individuals daily life and work, relationships and social interactions, mental health considerations, and treatment and management. shedding light on the multifaceted impact of these illnesses on various aspects of individuals' lives. The analysis of the collected data further demonstrated that invisible diseases heavily impact individuals' daily life, such as in work and relationships, due to challenges with symptoms, mental health, and management of their invisible disease. Furthermore, the findings highlight the significance of taking a comprehensive approach to managing invisible diseases, addressing not just physical symptoms but also the mental.

Strengths of the study

The strengths of this study include in-depth qualitative data, a diverse participant pool, and a focus on both the mental and physical aspects. In this study, both qualitative and quantitative methodologies were used to provide a full understanding of the participants' experiences. In-depth interviews enabled a nuanced examination of individual narratives, whereas quantitative data provided measurable insights into symptom severity and treatment satisfaction. Furthermore, the study consisted of a diverse group of participants with various invisible diseases, providing a broad view of the issues faced by people with varied illnesses. This allows for more awareness of different types of invisible diseases.

Limitations of the study

The limitations of this study include the study's sample size, self-reported data, and geographical limitations. This study's sample size was 15 participants and this can limit the generalizability of the findings. Additionally, the reliance of self-reported data can introduce biases due to inaccuracies in recalling experiences. Finally, all participants were either from the United States or France which may not fully represent the experiences of individuals with invisible diseases in other regions or countries.

Conclusion:

This study establishes a framework for future research and sheds light on the multifaceted impact of invisible diseases on individuals' lives. Through identifying similar experiences and obstacles faced, this study emphasizes the need for increased awareness and support for individuals living with invisible diseases. Future research should further explore demographic factors influencing individuals' quality of life, such as socioeconomic status, access to healthcare, and cultural factors.

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Ethical Considerations

Conflict of Interest:

The lead researcher of this study did not have financial or personal relationships that could influence the work.