Invisible Illness And Identity Are Deeply Connected

The number of people with disabilities is on the rise, yet not all illnesses are visible. The absence of reliable medical testing and a lack of funding for medical research has long meant that people with invisible illnesses are left out. This means that people in pain are left without support and often, without proper diagnoses. People with invisible illnesses also experience other difficulties when it comes to managing their illnesses. These include stigma, lack of popular understanding, blame, relationship issues, anxiety, depression, and loneliness. Despite these challenges, it is important to remember that we are talking about real people. So, how do invisible illness and identity connect?

A strong sense of self is of paramount importance to navigating society and the medical realm. There is an urgent need to address the global economic implications of invisible illnesses if we truly want to achieve the Sustainability Development Goals (SDGs).

demystifying Invisible Illness and Identity

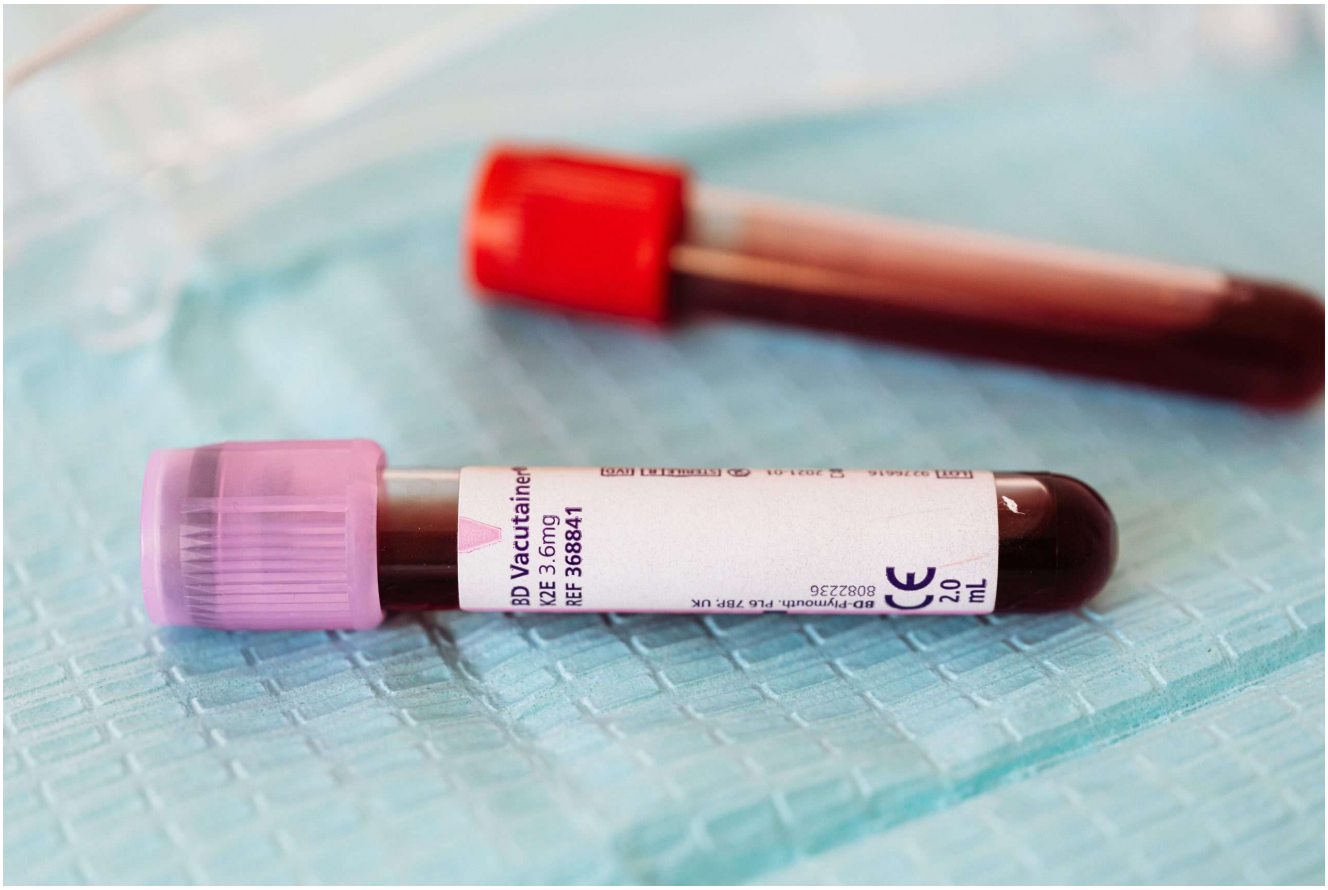
Invisible Illness

Billions of individuals globally suffer from invisible illnesses: physical, mental or neurological conditions that have symptoms that are not visible externally, but that limit human functionality, or challenge a person's movements, senses, or way of life in a negative capacity. People with invisible illnesses are still fully fledged humans that live full lives, despite the challenges, so it is important to raise awareness about the unique beauties and difficulties of their lives.

Invisible illnesses can be hard to diagnose with simple medical tests, and there are extensive challenges that come with diagnoses- results can be vague and subjective. People who suffer from invisible illnesses bear the extra burden of people in their life who don't believe that they are ill because they don't 'look sick'. Regardless of these burdens, people with invisible illnesses develop interesting perspectives on their own humanity and health, and have a valuable perspective that is worth sharing and listening to.

"The term 'invisible illness' refers to any medical condition that is not outwardly visible to others, even healthcare professionals. Invisible illnesses encompass a broad range of conditions, including heart disease, diabetes, dementia, psychiatric illness, autoimmune disorders, and even cancer."

– Social Work Today



People who suffer from invisible illnesses bear the extra burden of people in their life who don't believe that they are ill).
Source: Pexels.com

Illness And Identity

A person diagnosed with an invisible illness endures the significant chronic physical distress of the disease. As well as this, they also often have an identity crisis and feel detached from themselves. It can be challenging to adapt to a new normal.

An individual's sense of self {is} defined by (a) a set of physical, psychological, and interpersonal characteristics that is not wholly shared with any other person and (b) a range of affiliations (e.g., ethnicity) and social roles. Identity

> *involves a sense of continuity, or the feeling that one is the same person today that one was yesterday or last year (despite physical or other changes). Such a sense is derived from one's body sensations; one's body image; and the feeling that one's memories, goals, values, expectations, and beliefs belong to the self.*
>
> *– APA Dictionary of Psychology*

Transitioning Into a New Identity

Any chronic illness can have an overpowering effect on every domain of our life, and redefine our sense of self. We may have to re-evaluate our goals, career options, activities that we can undertake, and even simple daily choices. This new normal may shut a few avenues, and you may feel a deep sense of loss of your identity. This grieving phase is normal, and eventually the new reality will open new opportunities for you.

> *"Researchers have conceptualized four different illness identity states: rejection, engulfment, acceptance, and enrichment. Each of these states have ramifications for our mental and physical well-being."*
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> *– Psychology Today Blog*

Rejection

This refusal phase can encompass dismissing or ignoring the existence of the illness or minimizing its effects. This often has the effect of preventing us from seeking medical help or adhering to a treatment regime. This can further aggravate the disease, and profoundly impact our quality of life. When we see a progression of the illness, additional health care costs and indirect economic impacts will become inevitable.

Engulfment

This is the phase where the disease is overwhelming. People in this state disregard other domains of their life such as relationships and hobbies. Naturally, they feel elevated anxiety and depression in this period.

Acceptance

Grieving is an essential part of moving towards true acceptance of the illness as part of one's identity. The disease is not ignored, but is also not overpowering. Anxiety and depression also subside.

Enrichment

This stage revolves around realising positive changes as a result of the illness. People begin to appreciate the little joys in life, experience a renewed perspective, gain clarity on their values, gain resilience, and experience enhanced well-being. This stage may also include career changes that lead to new paths like advocacy work, or new friendships made with deeper understanding of others and the self. Expressing yourself through art or journaling can also be part of enjoying one's new life.

While invisible illness shifts self identity through the above stages, cultural identity also has its implications, which is explored in the next section.

invisible illness And cultural identity

While adapting one's self identity to a disease is demanding, the matter of one's cultural identity can add even more to a sense of being blocked. Needing to understand one's illness within the context of one's cultural identity can exacerbate the burden of the disease for marginalised groups in society. Systemic biases often prevail in the health care systems of the world. As well as this, negative societal attitudes towards age, gender, race, sexual orientation, and immigration status among other factors are more pronounced towards people with invisible illnesses. A person with an invisible condition faces extra barriers in accessing healthcare if they are from a minority group.

Gender bias in medicine and science

The interplay between invisible illness and gender identity is disturbing. Invisible illnesses affect females disproportionately more than males. This is especially true for conditions like chronic fatigue syndrome (CFS), Lyme's disease, lupus, fibromyalgia, and Crohn's disease. The Autoimmune Association has reported that a striking 80% of patients with autoimmune diseases in the US are women.

A study published in September of 2021 in The Journal of Pain found that the presence of gender bias posed elevated challenges for women in this regard. The pain endured by women was downplayed compared to men by the observers in this study. As a result, the observers recommended more psychotherapy for females, while increasing doses of pain medications for males.

Similar results were noted in this BIPOC long-COVID study, where women of colour around the world shared their experience with long COVID illness. About 63% of them reported to have been not believed by their doctors. More shockingly, 19.6% of the 27 females who visited the hospital seeking medical attention were drug tested for narcotics.

Systemic gender bias unfortunately prevails in medicine and science.
Source: Pexels.com

how invisible illnesses wreak havoc

Physical and economic impacts

Health professionals have a habit of misdiagnosing, disregarding or dismissing the symptoms of patients with hidden illnesses. This prevents those suffering them from accessing necessary and adequate medical support as any other patient with a visible ailment would. This results in the affected parties living with the burden of the disease for long periods without any medical intervention. In some instances this lasts a lifetime. Effects of a lack of medical attention obviously hinder productivity, creating housebound individuals who rely on others for their daily needs.

Mental and Social impacts

Clinicians often react irrationally when patients present, owing to a lack of visible evidence of their illnesses. Doctors may express apathy, frustration, etc. They may also accuse the patients of being hard to handle, dishonest, or label their diagnosis as psychosomatic. This can take a toll on a patient's mental well-being. When people feel misunderstood, lonely, and helpless, despite their thorough knowledge of their condition, crisis is inevitable. It would seem that stigma is caused by numerous factors – knowledge of the diagnosis, moral judgments, and incorrect knowledge held about the disease.

Those suffering from invisible conditions feel pressured to prove their symptoms. They feel the need to show that their symptoms are legitimate, against all misconceptions. Others may easily downplay the pain based on outer appearances, which can be depressing and stressful. If one does not have a strong sense of self, these situations damage one's self-esteem and self-worth.


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Those suffering from these invisible conditions have to prove their symptoms to society against misconceptions.
Source: Pexels.com

strategies to increase awareness about invisible illness and identity

Self-belief and self awareness

- Invisible illness sufferers should trust themselves, and be their own advocates. They must not ignore their symptoms simply because a medical professional disregards them, as it can be life-threatening. Developing a strong sense of self and self-efficacy is key to believing in how they feel, and to confidently seek treatment to overcome it.
- Sufferers can keep track of their symptoms, and specifics, such as the location of pain or fatigue, the time period, and the situation surrounding its occurrence. Additionally collating all the lab results and imaging studies can be quite useful when putting all the information together to identify the exact diagnosis. Self awareness is important.

Research and self education

- Reading research materials published by leading universities and bodies that are relevant to their condition is of great assistance to sufferers in understanding their unique needs better. It will also equip people to educate and explain their experiences clearly to others. This helps relieve their stress, and strengthens their relationships due to openness and honesty. It helps sufferers to reveal their authentic identity to the world, while embracing the illness.
- A focused approach can help medial professionals give close and thoughtful attention to symptoms. Family history often helps to identify an increased risk of potential disorders. Likewise, conditions the patient has already eliminated through their own research, and tests they may have already done also help the treating clinician. It is therefore imperative for sufferers to research and familiarise themselves with the right medical terms.

- Patients may consult other medical professionals if a doctor dismisses their symptoms. This ties back to having complete self awareness and a healthy sense of self.

Engagement with a support group

- Sufferers of invisible illness could engage with others within their neighbourhood with similar conditions, and seek suggestions about supportive medical practitioners. The internet can be a powerful tool to support this process, if used wisely and only after verifying the authenticity of information. These sorts of social interactions also empower people with invisible illness, and increase their hopefulness. Further, it boosts a sense of belonging and self-esteem.

If you have an invisible illness then seek suggestions from supportive medical practitioners.
Source: Pexels.com

Invisible Illness As A Global Priority

Economic burden Vs. Funding

Early detection of invisible illnesses can delay and control the progression of these diseases. This further minimises direct medical costs by avoiding high cost episodes, and creates better adherence to the treatment option. Conversely, misdiagnosis can waste health care funds unnecessarily. Besides, early treatment reduces loss of working days due to illness, and job productivity. These are major indirect costs. According to a study in 2019, the annual indirect savings for a Multiple Sclerosis patient with proper treatment was nearly $6377, in the USA.

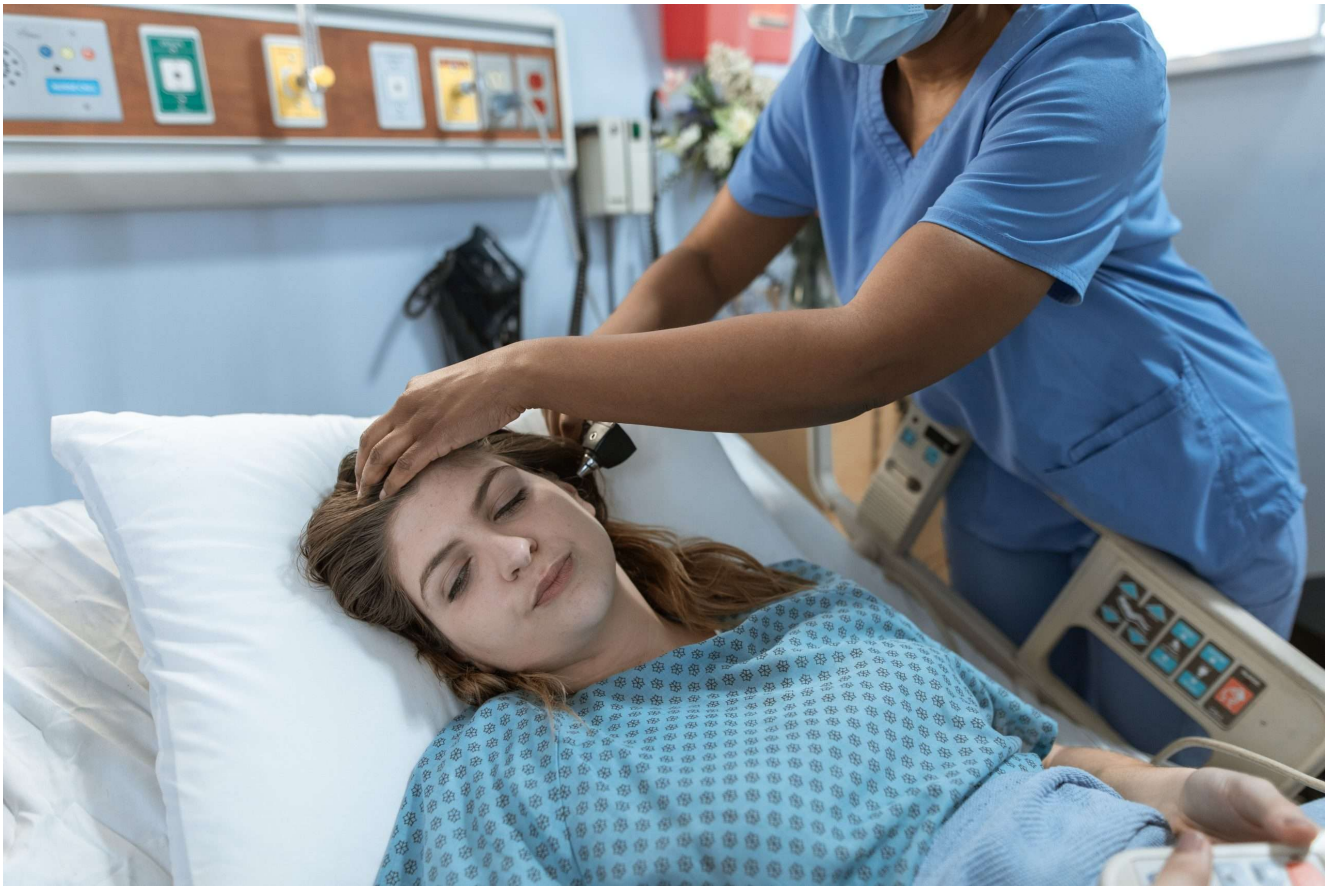
Interestingly, there were 1.5 million CFS cases with $36–51 billion in financial implications in the USA, before COVID. However in 2022, post-COVID, these figures have jumped dramatically to five and nine million patients with $149 to $362 billion in medical expenditure and income loss. This economic impact does not include disability grants, social assistance, and earnings lost by caretakers. To offset the economic burden of invisible illness, funding needs to rise to about 40 times its current allocation.

Access to employment

People with mental health disorders are keen to work. However, their unemployment rate is double the rate of those without any such disorders. Concurrently, income levels also show drastic discrimination for those with invisible illnesses. Much education is needed to enhance understanding, training, and empowerment for actors in the employment sector to integrate an inclusive labour force.

Employers should support employees with invisible illness to return to work at the earliest time after an ill period, through positive relationship management. Communicating, providing information, and rendering accommodations can curb the inequities, harassment, and struggles that they face. The workplace must assist and treat these talented workers fairly. The economic benefits of doing so

will be far-reaching. These types of actions and measure will help alleviate unawareness and non-disclosure, which make the opportunity to measure and monitor findings concerning invisible illness difficult. Real data and information is invaluable for designing appropriate government policies, and budgets for supporting people with invisible illness.



Many issues contribute to the stigmatisation of invisible illnesses.
Source: Pexels.com

why Is it essential that we focus on this issue?

Invisible illnesses are often misunderstood and underdiagnosed, leading to lasting harm. In the USA, 96% of people living with severe disability were living with an invisible illness Despite knowledge about these conditions including studies on the adversity they create in patients' lives, conditions such as autoimmune diseases are on the rise. Therefore, speaking up about these issues is critical. Building a supportive circle that can feel and understand the pain of patients can alleviate their physical and psychological distress. Information sharing, and advocating necessary accommodations can foster positive change.

We also must draw more attention and funds towards much needed scientific research. Notably, long COVID has managed to attract more medical research and financial resources compared to other hidden conditions. Research is vital as these disorders present symptoms that can mimic other conditions, and thus are hard to recognise. Furthermore, evidence based approaches will aid the medical community to spot and medicate early. According to the Autoimmune Association, it takes four physicians and 4.5 years to diagnose a person with an autoimmune disease in the USA. Evidence based approaches will also abolish the stigma against sufferers of invisible illness.

Impact on achieving the Sustainability Development Goals (SDGs)

Funding and medical research to understand invisible illnesses can shed light on early diagnosis and disease progression. The medical community needs to change its approach and attitude towards patients with invisible illness (Scoles & Nicodemo, 2022). Medical intervention can control/delay the crippling effect of illness on one's functionality as well as financial independence. This will promote the SDGs that relate to poverty, hunger, good health and employment.

The goals of destigmatising invisible illness and promoting an inclusive society and labour force warrants education and training to spread awareness. Removing systemic barriers including gender bias and other inequalities is key to eliminating discrimination. Accommodating persons with invisible illnesses through innovation and smart technologies will improve disclosure that can aid in policy formulations and fund allocations (Abualghaib, Groce, Simeu, Carew, & Mont, 2019). The potential economic contributions of people living with invisible illness through their participation in the workforce are immense. Since the number of people with invisible illnesses is rising and they can offer diverse skill sets and perspectives. This will help to attain the SDGs that relate to decent work, economic growth, gender equality, reduced inequalities, justice, innovation, etc (Abualghaib, Groce, Simeu, Carew, & Mont, 2019).

THRIVE Framework

THRIVE Project invests interest in issues fundamental to the integrity of our society. Apart from sustainability, this also means examining issues related to the

judicial process and human rights. Safeguarding human well-being in all domains is paramount to THRIVE's mission. Thrive strongly supports an inclusive society where everyone including persons with invisible illnesses can thrive with a strong sense of self.

To learn more about how The THRIVE Project is researching, educating and advocating for a future beyond sustainability, visit our website. You can follow our informative blog and podcast series and learn about our regular live webinars featuring expert guests in the field. Sign up for our newsletter for regular updates.