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Chronic illness and disability can lead to many more problems than simply those concerning health. People who have these conditions must also face the social ramifications of being different from others. These troubles manifest differently for each person, and how people will deal with them also vary. It is important to analyze the experiences of those who have chronic conditions through a sociological perspective so that we can better understand, and eventually address the deep-rooted inequality that each of these individuals are forced to face. There are many real consequences to the inequalities that will be described here– negative self-concepts, lack of professional opportunities, social isolation, stigmatization, educational barriers, an overall lowered quality of life, and many more. Considering about 133 million people suffer from some sort of chronic illness, the research being done here has clear practical importance in that it will set out to provide better support for each of these individuals.

Suffering the Silence works to share the stories of those who have chronic illnesses. By doing this, they hope to break down the stigma surrounding these illnesses, and ultimately bridge the inequality gap between those who have chronic illness and those who do not. We will continue this mission in our own work. Through this literature, we wish to share some troubles that many of these individuals face, and ultimately, how they cope with these troubles. In doing so, we will be better equipped to analyze the recordings provided by Cam, and ultimately promote sentiments of empathy and support among our audience.

Besides physical difficulties, dealing with a chronic illness can also present emotional and social problems, which can worsen inequities in health outcomes. In order to appreciate the nature of the issue and its consequences for inequality, we will first examine Kathy Charmaz's "Experiencing Stigma and Exclusion".

Charmaz uses a qualitative method of research which furthelives conducts critical, detailed interviews with those who live with chronic illnesses in their daily r highlights the various effects of social isolation and stigma on people's everyday lives. Through these interviews, Charmaz sheds light on the different ways that people who liareith chronicnesses and how they deal with society attitudes and beliefs; they very regularly are subjected to marginalization, discrimination, and identity loss. Charmaz's study emphasizes how important it is tonot only acknowledge the individualized experiences of people with chronic illnesses, but also the need for increasing our knowledge and comprehension of this topic to ultimately solve the disparities they encounter.

Beyond Charmaz's research, Gengler's "Emotions and Medical Decision-Making"study focuses on how these same individuals living with chronic illnesses make medical decisions based upon their emotions. Gengler aims to find out how patients' views, and decisions about readily available treatments can be influenced by emotions such as fear, anxiety, and hope through a socio-emotional perspective. The study helps us to understand the disparities that can come as a result of when patients' emotional needs and perspectives are ignored by healthcare professionals, by focusing on the complex interactions and dynamics between emotions, and social context in influencing medical decision-making.

The aforementioned readings enhance our comprehension of the complex characteristics of inequality within the framework of chronic illness. Based on ideas like stigma, identity, and socialization, the research shows how institutional practices, cultural norms, and cultural beliefs interact to maintain differences in health outcomes among people with chronic illnesses. For instance, stigmatization can exacerbate pre-existing disparities based on racial, ethnic, gender, and socioeconomic status, restrict access to healthcare, and lead to social exclusion and discrimination.

The literature also emphasizes how crucial it is to consider the intersectionality of identities and experiences in order to comprehend the disparities related to chronic illness. Several demographic trends, such as differences in the recognition and treatment of chronic illnesses between genders or racial/ethnic groups, impede efforts to attain health equity by exacerbating already-existing inequalities. To create targeted treatments and policies that meet the particular needs and difficulties experienced by disadvantaged and underserved populations living with chronic illness, organizations and politicians must know these causal variables and demographic tendencies.

The article "Disability and Attitudes Toward a Cire om a Sample of Disabled Activists" by Hahn, Harlan D, and Todd L Belt provides insights into the nature of inequality experienced by individuals living with chronic illnesses and disabilities, aligning closely with the mission of Suffering the Silence (STS). Through exploring the attitudes of disabled activists towards the prospect of a cure, the study examines the dynamics between identity formation and societal stigma. Disabled individuals, often marginalized and disenfranchised on a larger societal scale, navigate a landscape where their status and power are restricted. However, the research uncovers a poignant resistance among many disabled activists against the notion of a cure, revealing a profound sense of pride and community identity within the disability rights movement. Moreover, the study highlights the significance of early onset in shaping attitudes towards a cure, suggesting that prolonged exposure to failed medical interventions fosters skepticism and reinforces a positive self-construction around disability. The study closely aligns with the dramaturgical perspective of inequality, which suggests we agree upon a single definition of a situation we are in, and therefore the self is not a psychological entity, but that it is a predetermined essential character that is generated collaboratively in scenes of face-to-face interaction. Many of the subjects in Hahn et al.'s reject this notion, as they redefine what it means to be disabled and reject the stigma that is associated with the identity, fostering new communities that celebrate what so many stigmatize. Suffering the Silence's work largely aligns with this message, as their works aim to foster a community of empowerment and solidarity within the realm of chronic illness and disability activism. A huge part of their mission is to strengthen communities among disabled people, and the article affirms this idea, claiming that those who feel strong ties to their disabled communities are more likely to be happy with themselves and their identity.

Douglas C Baynton's "Disability and the Justification of Inequality in American History" helps to contextualize the origins and widespread cultural impact that the stigmatization and unequal treatment of those who deviate from the norm has had. Overall, Baynton argues that disability has been one of the most prevalent justifications for mistreating and stigmatizing groups in American history, whether the group in question is traditionally "disabled" as we would characterize it today. He provides historic examples such as women's suffrage, African American freedom, and the restriction of immigration in this country, all of which were justified by claiming that the groups at hand were "subnormal," or lacking certain essential qualities of citizenship in some way. He emphasizes our society's obsession with "normality," which is used as a weapon against those who conflict with the culturally-settled norm. This article highlights the scale of the issue, revealing the alarming extent to which our society has normalized the unequal treatment of those who deviate from the norm. This has profound implications for disabled folks in our society today, especially those who possess identities that have also been historically marginalized (women, people of color, immigrants).

As we have seen, individuals with chronic illness must deal with constant stigmatization regarding their identity. These stigmas are clearly harmful, but there seems to be ways to remain positive. The way individuals choose to cope with these stigmas, however, can play a huge role in their self-esteem. Michelle Nario-Redmond et al. examine this idea in their piece called "Redefining Disability, Re-imagining the Self: Disability Identification Predicts Self-esteem and Strategic Responses to Stigma". People can choose to cope with stigma in two ways: individually or collectively.

Individual coping strategies often focus on emphasizing one's own strengths, interests, and efficacy as an individual. People will try to structure their coping through external means, so that they can show they are capable of functioning similar to anyone else around them. Individualistic coping strategies often address the stigmas of their body as weak or "less than" someone who does not struggle with a chronic illness. The people who choose individualistic coping strategies will try to overcome or "escape their illness".

Conversely, some choose to embrace a more collectivist strategy in their coping, namely through group identification. Those who use this strategy will instead claim that their disability can serve as a life-enriching experience, view their disability as a positive cultural heritage and a defining characteristic for themselves. This allows them to embrace their disability, and all that comes with it, rather than being forced to act in a way that is in accordance with norms that naturally cannot apply to them. A collectivistic coping strategy lends itself to building community, and communities give a great deal of support to people that we have seen distinctly lacking in overall support. People in these communities highlight the list of positives that come with their disabilities. For example, many choose to highlight the problem-solving skills and unique insights that they have developed. Through this emphasis, they can focus on what makes them different, not in a stigmatized sort of way, but in a positive manner.

Overall, Nario-Redmond et al. found that the more strongly respondents endorsed their disability as a central aspect of their identity, the higher their self-esteem would be. This made sense through the lens of social identity theory, as those with a disability will define themself based on the perception of the group they identify with. So, if they frame their disability as a positive aspect of their identity, their self-esteem will naturally rise. Conversely, if someone considers their disability something that should be hidden and overcame, this can cause lower self-esteem as they feel discontent with something that is such a large part of their life.

Furthering the discussion on identity and self-perceptions, in "Perseverance of Self-Sentiments in Late-Life Dementia", Francis et al. examines how people with dementia adapt to their conditions by engaging in activities that reinforce their sense of self. The authors touch on how emotions, interactions, and support systems all shape the self-perceptions of individuals with dementia.

Some strategies that those with dementia used to maintain their self-identity are engaging in familiar activities, as these are things that are already established to make the individual happy prior to their dementia. This speaks to the idea that having a chronic illness does not mean one is barred from enjoying their life and the things they have always loved. Further, the authors highlight the importance of social interaction and support systems provided by family, friends, and caregivers. Comfort and reassurance can be provided by these groups, allowing the emotional benefits to transcend any cognitive decline. When these aspects are good, the person with dementia will feel validated in their emotions and experiences, thus maintaining a positive self identity.

These findings were expressed through the theoretical framework of affect control theory. The authors suggest that individuals with dementia would maintain better self-sentiments if they shifted their self-perceptions to be based in affective meanings rather than cognitive. Since cognitive decline goes hand-in-hand with dementia, finding self-satisfaction through emotional well-being makes it so self-esteem can persevere through the illness. Thus, similar to the findings expressed by Nario-Redmond et al., finding community and social support is integral for people suffering from chronic illness, as it provides them a way to reframe their identity perceptions in a positive way, rather than rooting their ideals in the negative associations that come with their illness.

Individuals with chronic illnesses are often seen as deviations from the norm. In her article “Invisible Illness and Inequality,” Jane D. McLeod points out the lack of awareness surrounding invisible disabilities, even in academia. In her analysis of previous literature, she states many researchers are hesitant to approach the sociology of mental health while considering some of the psychological aspects, such as personality. Additionally, much of the current research on stigma and disability does not present disabilities as a source of inequality. In the article, McLeod focuses on invisible mental disabilities as a dimension of inequality while also considering the psychological processes that create and perpetuate this inequality. The effects of invisible disabilities, particularly unequal access to resources, begin early in life, which then accumulate over the course of a lifetime. McLeod argues that this unequal distribution of resources for individuals with invisible disabilities is unique for four reasons. First of all, the definitions for what constitutes an invisible mental disability is much more debatable than the definitions might be for physical or visible disabilities. The second quality is that those that have individual disabilities are often seen as abnormal, which is not necessarily the case for other stigmatized statuses, such as gender or race. Third, invisible disabilities are socially disruptive. Finally, invisible disabilities are defined by cognitive, emotional, behavioral, and/or intellectual impairments. To address these differences and the gaps in the literature, McLeod analyzes disability and inequality as a result of social categorization, identity processes, and stigmatization. However, unlike other researchers, McLeod also incorporates stigmatization into her analysis.

Building off of this framework, Ekl and Brooks also investigate chronic conditions as a result of stigma in their article “Take the day off: Examining the sick role for chronic back pain by race and gender.” They do so by taking a closer look at the legitimization and helpseeking behavior regarding chronic back pain and the “sick role,” which is temporarily being relieved from typical social roles because of illness. Much like McLeod, Elk and Brooks acknowledge the subjective nature of chronic back pain diagnoses. Both the public and medical professionals often question the legitimacy of back pain as a reason to be considered for the sick role. They assert that, since healthcare has become much more commercialized, public perception has a great impact on how medical professionals view certain topics. Therefore, it is important to understand how the public views chronic back pain in order to fully understand the processes that either legitimize illnesses or perpetuate inequality. Looking beyond the broader effects of stigma, Ekl and Brooks bring in an element of intersectionality by examining the topic in the context of race and gender. They look into who legitimizes pain, whose pain is legitimized, who is suggesting different help-seeking behaviors, and for which individuals help-seeking behavior is endorsed. Gathering evidence from a Qualtrics panel, they find that the respondents’ identities are associated with how acceptable they think it is to miss work, while both the respondents' identities and the identities of those they judge in the panel are associated with help-seeking endorsements.

Spencer Cahill and Robin Eggleston craft a discussion on stigma and the ways in which socialization affects the development and management of stigmatized identities through their article “Managing Emotions in Public: The Case of Wheelchair Users”. By exploring how wheelchair users cope with their stigmatized identities in their day-to-day lives, they are able to develop a complex analysis on the experience of stigma within a social context and the various levels that interconnect to dictate how individuals choose to handle inequality or discrimination. In their findings, Cahill and Eggleston draw attention to an important coping mechanism that stigmatized individuals often use: situation definitions. Through the use of situational definitions, individuals can redefine stigma and view their identity under a different light. One example of this was the use of humor in order to ease the tension of interactions while simultaneously protecting their own emotions. By opening up their illness to lighthearted humor, the stigma is reduced, and it diminishes awkward encounters with others, something which helps these individuals feel more comfortable and less “othered”. Cahill and Eggleston demonstrate how stigma is subject to societal pressures and power distribution because just as stigmatized individuals can redefine the situation, the “normals", as Goffman calls them, can also redefine the situation because of their unequal power and status. By rejecting the self-deprecating humor of stigmatized individuals, the “normals” cause identity disconfirmation and instill feelings of guilt in the stigmatized individual for attempting to cope in a way that goes against the norm and expectation. Furthermore, the authors also describe another phenomenon where wheelchair users were viewed as a patient, and thus unable to advocate for themselves. Because of this belief, servers at restaurants for example would refer to their caretakers instead of them. The authors noted how this was a very dehumanizing practice and caused strong emotions in wheelchair users because it forced an identity on them that they didn't align with. Stigmatized individuals are often placed in these situations and their emotional reactions are regulated by their struggle to remain calm and not be a burden vs. advocating for themselves and having their identities respected at the expense of making others feel uncomfortable.

This leads into some concepts of identity theory described by Kathryn Lively and Carrie Smith in their chapter of the *Handbook of the Sociology of Health, Illness, and Healing:* "Identity and Illness". Lively and Smith discuss why stigmatized individuals face so much issue with identity confirmation and disconfirmation when interacting with others. During the socialization process, we are introduced to stereotypes and beliefs toward stigma which we often go on to reproduce. This is why stigmatized individuals often believe and take on the identities and roles put on them by society because they were taught to associate them with stigma early on. However, Smith and Lively describe how, relating to Cahill and Eggleston's situational definition, symbolic interactionism sometimes allows for individuals to adopt other roles which make their stigma less salient in their identity hierarchy. Roles we enact allow us to further confirm and adopt identities that we want to uphold in our presentation of self, and by adopting roles that go against preconceived notions of stigma, we are able to resist the stigmatized identity and feel more in line with the "normals". Therefore, we understand why there is constant inequality in social interaction due to dynamics of power and identity which affect who has the ability to define the situation and uphold their identity while protecting their emotions.

In the next stages of this project, we look forward to continuing on research to best understand the issue of inequality within the context of disabilities. Our research thus far has given us a firm grasp on many issues surrounding disabilities, including societal beliefs and attitudes, emotions, identity, legitimization, visibility, and, most pressingly, stigma. Based on this emphasis of stigma in findings thus far, combined with the psychological concentration in this class, we plan on extending our research on how individuals with disabilities internalize and respond to stigma. This information can potentially have very important implications for how we go about listening to and interpreting Cam’s voice memos as well as how we would most sensitively and appropriately format the podcast. We believe that addressing stigma in the podcast can help challenge misconceptions and promote empathy and understanding among listeners. By shedding light on the experiences of people with disabilities and the impact of stigma on their lives, in this case Cam's story, the podcast can contribute to broader conversations about equality, inclusivity, and social justice. As we have learned in class thus far, stigma is a far-reaching concept that affects many corners of people’s lives, including self-esteem, social networks, institutional success, and it has the potential to increase the risk of prolongation or reoccurrence of mental illnesses. We hope to bring a psychological sociological approach of stigma to our partner, Suffering the Silence, providing an in-depth understanding of its importance and implications. Reducing stigma is a central part of their mission, and we would love to provide academic insights that can aid in their success.

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Formal Report on Field Research for Suffering the Silence

Many people with chronic illness often feel overwhelmed and uncertain over what their life will be like. They tend to be seen as deviations from the norm, so they can feel ostracized and like they are unable to get help. Over the course of this term, we have researched the social psychological effects of chronic illness through several means: an extensive literature review, the blog posts provided on the Suffering the Silence website, and Cam's voicemails. Through this research, we have found a number of underlying themes, such as stigma and delegitimization surrounding chronic illness, the emotional effects that it has on individuals who have been diagnosed, and the desire to live a normal life while living with chronic illness. After looking through this variety of sources, we hope to produce a final deliverable (in the form of a podcast and/or a framework for future podcasts) that will allow those suffering from illnesses to see that they are not alone as well as increasing awareness so that the stigma decreases and they are able to get easier access to care.

Goals

After conducting our literature analysis and looking into the various accounts of other individuals on their differing experiences with illness and stigma, we were looking to devise a way to link Cam's experiences with those of other stigmatized individuals. To do so, we set out to find connections between the generated codes from the other STS group and the themes we found in the blog posts. One of the most prominent goals for this portion of our research was to filter and gather content to include in our final deliverable, the podcast. As we mentioned in the end of our literature review, our hope is to bring valuable social psychological insights to our partner, and we must do substantial research on both Cam's experience and others in order to do so. Doing this research gave us clarity on what we wanted to include in our podcast, as we spent a lot of time investigating several sources, both primary and secondary, in the process.

Methods

To achieve these goals, we first worked with existing individual stories that were posted by Suffering the Silence themselves. These blog posts provided unique accounts that provided direct representations of many of the issues identified by our literature review in action, such as the delegitimization of illness, intersectionality, cognitive reframing, and many others. To ensure methodological rigor, we elected to analyze all 13 blog posts on Suffering the Silence's website to ensure we represented the organization's publications, and individual's stories, as best as possible. These blog posts were written by a diverse array of people living with a variety of chronic illnesses, serving well as representation for many identities and experiences in our project. Since this issue inherently concerns people on an individual level, with each requiring their own unique and personalized care, we felt this was the best approach to avoid people "falling through the cracks". Obviously with 13 blog posts, we cannot ensure everyone will be represented, but working in the confines of what the partner provided, we felt this was the best approach. Following these blog posts, we grouped them thematically and matched them with the codebook provided by the other Suffering the Silence group. After we identified and compiled these themes, we were able to solidify our findings and what we hope to produce as a final product. Considering this, we plan to use our themes to inform how we will proceed with our final deliverable, producing a podcast episode (or framework for a podcast episode) that will encompass each theme we identified.

Findings

One of our biggest takeaways was the array of emotions that people with chronic illness can experience. These emotions can often present themselves in an up-and-down fashion, and have large impacts on the individual experiencing them. Lack of access to treatment methods can create stress and hinder mental health. A related challenge is the delegitimization of one's illness by medical professionals. Another recurring theme is a profound yearning to live as normal a life as possible and still engage in "normal people things." Despite the limitations imposed by their conditions, this desire to partake in everyday activities remains strong. We would love to include this in our podcast, perhaps at the end as a good, positive way to round out the episode. In order to try to maintain as "normal" of a life as possible, many people search for coping mechanisms that help ground them in their everyday battle with chronic illness. Even though the individuals struggling are often overwhelmed with uncertainty, they are able to find things that help make the pain just a little bit more manageable.

Conclusions

Based on our research on Cam and Suffering the Silence, we see how theories like identity theory and expectation states theory or concepts on inequalities based on social class impact individuals living with an illness. Those living with illness are in constant turmoil with their identities because they have to grapple with their own self perceptions and those of others as well as the input they are receiving which delves into affect control theory and the way we interpret interactions based on affective meanings. Access to resources are hindered by cultural and social capital because patients are either not well informed on how to treat their conditions or they aren't able to afford the proper care which shows the ways in which these structural inequalities perpetuate inequality and stigmatization. So far, our work assists Suffering the Silence with creating more diverse and personal narratives as well as showing other people with illnesses that they are not alone. By expanding our research through the literature review and drawing connections between Cam and other members of the organization’s community, we are able to structure a true to life representation of illness and stigma grounded in social psychological research.

Furthermore, based on Cam’s voicemail codings as well as what we have derived from our research from the Suffering the Silence blog entries, it is clear to see the emotional rollercoaster that living with chronic illness can be. These emotions can be incredibly sporadic and present themselves at any time throughout one’s journey. Additionally, we can see the implications of these emotional effects on individuals such as Cam. Throughout his journey these implications can be seen in various aspects such as his relationships and his quest to find validation in his experiences.

It is also clear that individuals with chronic illnesses, like Cam and Janet, strive to maintain normalcy and engage in activities they love despite significant health challenges. This desire highlights their resilience but also underscores the impact of societal status beliefs, which deem healthy individuals as more competent and worthy, leading to discrimination and lower expectations for those with chronic conditions. Stigma, particularly in how people view disruptiveness and aesthetic qualities, exacerbates this. Our research adds value by humanizing these experiences, providing evidence that can inform more inclusive policies and interventions. In our podcast, we hope to illustrate the real-world impact of theoretical concepts on inequality by showing Cam’s story.

Ultimately, society has a natural tendency to try to make everyone fit into the norms they have grown accustomed to. This means that those who inherently do not conform to those norms, such as those with chronic illness, will struggle to be seen and treated the way they need to be.

This makes it very important for healthcare professionals and support systems to be especially conscious when caring for individuals with chronic illness, so that they can ensure experiences of minimization like Cam’s and others’ do not continue to be the norm.

Outlines for Future Episodes:

Episode 2: Managing Daily Life with Chronic Illness

Topics of Conversation

1. Pacing: Managing Activity and Energy Levels While Continuing to Encounter Life Events

- Chronic illness requires daily management of emotions
- Balancing activity and rest to prevent exacerbation of symptoms
- Strategies for listening to one's body and adjusting plans
- Societal challenges and planning around responsibilities
- Pressures to feel happy or seek happiness as opposed to engaging with depressive feelings
- Discuss Cam's personal experiences with emotion management

2. Balancing Work, Education, and Chronic Illness

- Challenges of managing work or education with chronic illness.
- Personal stories of balancing responsibilities, from the STS community
- Tips for accommodations and self-advocacy in professional and academic settings
- Resources for support and flexibility
- Discussion on the need for inclusive policies for individuals with chronic illness

Episode 3: Mental and Emotional Well-being

Topics of Conversation

1. The Role of Mental Health in Chronic Illness Management

- Cam's personal accounts of mental health struggles and successes in his daily life
- Benefits of integrated mental health care alongside physical care
- Strategies for managing mental health alongside chronic illness and how the two interact
- Incorporate outside sources that discuss best practices for management

2. Building a Support System: Friends, Family, and Community

- Importance of a strong support system, how Cam uses his friends, family, and other communities to better support his journey
- Communicating needs and boundaries to loved ones to protect well being and how this looks in Cam's experience
- Tips for creating and finding support groups.

Episode 4: Intersectionality and Overcoming Stigma

Topics of Conversation

1. The Intersection of Chronic Illness and Identity

- How chronic illness intersects with race, gender, and other aspects of identity
- Cam’s personal stories highlighting diverse experiences
- Challenges faced by marginalized communities in accessing care
- Strategies for navigating intersectional identities
- Expert insights on addressing disparities in healthcare

2. Stigma and Misunderstanding: Breaking Down Barriers

- Exploration of the stigma surrounding chronic illness
- Personal stories of experiencing and overcoming stigma
- Impact of societal attitudes on mental and physical health
- Strategies for educating others and reducing stigma
- Advocacy for greater awareness and understanding

Episode 5: Innovative Care and the Future of the Healthcare System

Topics of Conversation

1. Innovations in Chronic Illness Care: What's on the Horizon?

- Latest advancements in chronic illness treatment and care and how accessible these are to patients like Cam
- Personal anecdotes from Cam on benefiting from new treatments or technologies and challenges that might arise
- Opinions from Cam and other members of the STS community on new directions/policies the healthcare system could take to better support individuals with chronic illness