Introduction

The prevalence of chronic illness and disability is widespread, exerting profound impacts on individuals and society as a whole. Statistics indicate that a staggering sixty percent of American adults have a chronic disease, while 40% have at least two (CDC 2021). In addition, approximately one billion people — about 15% of the global population — live with some form of disability (WHO 2021). These persistent health conditions can cause significant social and financial challenges. For example, the direct and indirect economic costs of chronic disease and disability have exceeded $3.7 trillion in the U.S. alone (Waters and Graf 2018). It is clear that chronic illnesses represent a large material cost for societies, and adequate solutions for these issues remain of incredible importance. But numbers and statistics are not the only ways we can conceptualize the costs of disability. Indeed, we must also acknowledge the countless stories of hardship, resilience, and perseverance among individuals living with disabilities. These real-life experiences, rich with struggle and triumph, merit close examination through a sociological analysis to better understand and address their broader societal implications.

Chronic conditions and disabilities are important to study from a sociological perspective because they are social phenomena shaped by cultural norms, institutions and structures, and broader systems of inequality. Various other academic disciplines have already sought to study disability within their respective domains. Medical sociologists, for example, examine how factors such as race, class, and gender impact the social construction of illness and disability, access to care, and health outcomes (Cockerham 2021). This field of research also explores the illness experience, including the social and emotional impacts of conditions that are invisible, contested, or stigmatized. However, while much is known about the epidemiology and health effects of chronic illness and disability, there still remain epistemological gaps in understanding the sociological dimensions of these issues.

Through a partnership with Suffering the Silence, an organization dedicated to breaking the stigma around chronic illness and disability through storytelling, we hope to gain deeper insight into the lived experiences and challenges faced by people with disabilities. Situated within the broader Upper Valley disability community, Suffering the Silence's work is grounded in the realities of stigma and discrimination, as well as the ongoing dialogue about disability rights and visibility. The organization leverages storytelling to illuminate the lived experiences of those with chronic illnesses and disabilities, which aligns with key themes identified in sociological and psychological research.

One of the most significant effects of storytelling is its capacity to foster community and affirm an individual's lived experiences. Accordingly, the importance of storytelling in shaping illness identity and social conceptions of disability should not be understated. Barker's examination of self-help literature on fibromyalgia syndrome (FMS) reveals that cultural narratives not only affirm the legitimacy of contested illnesses, but also help build a deep and profound sense of community among sufferers (Barker 2002). This approach to acknowledging disability proves effective as it works to mitigate effects of stigma, including domination, enforcement of social norms, and contamination, by destigmatizing and normalizing illness as a common part of the human experience (Link et al. 2014). In that sense, storytelling can serve as a blueprint for organizations to challenge hegemonic understandings of disability through empowering narratives. By documenting and sharing personal stories of struggle and resilience, Suffering the Silence is employing this approach by directly challenging the normalized, ableist assumptions about what individuals with disabilities can achieve.

Academic literature that explores the sociological understanding of illness and disability can provide invaluable insights into the challenges faced by the disability community. This literature review underscores the significance of integrating academic theory with social activism to enhance the well-being of marginalized individuals. Our research question is: What role does stigma, identity, and justice play in the lives of people with disabilities? This question is crucial for guiding the collaborative efforts between academic research and the initiatives led by Suffering the Silence, allowing us to promote a more inclusive society and culture through a better understanding of chronic illness and disability.

Identity and disability

Identity allows people to understand themselves in the context of a shared community, interest, or belief. One's disability identity, then, can refer to the self-beliefs that a person has towards their own disabilities and their ties to the disabled community (Dunn 2014). As such, disability identity emerges from the relevant understandings and personal experiences that are shared by individuals with disabilities. And unfortunately, one's disability identity (whether from a visible or invisible identity) plays a substantial and often negative role in determining friendships, romantic relationships, educational and professional outcomes, and social behavior and conduct (McLeod 2023). It should also be understood that disability identity can begin very early in the life course, and thus can have implications and repercussions for the entirety of one's life.

A crucial factor influencing the experience of illness in relation to identity is how people and societies construct and interpret disease. Barker's (2002) analyzes self-help literature pertaining to fibromyalgia syndrome, and reveals how these texts help sufferers combat stigma, assert the legitimacy of their condition, and build a collective illness identity focused on physiological causes, showing the importance of cultural narratives and community in coping with contested illnesses. Grue (2016) similarly conceptualizes disability as being a sociopolitical category rather than a medical condition, evidenced by legislation that has addressed the natural, social rights that disabled people are entitled to.

Additionally, the connection between disability and identity need not be negative; disability activism strives to redefine the meaning of being disabled, focusing on transforming perceptions from shame to pride (Grue 2016). Identity narratives can also permit individuals to reconcile the diverse facets of their being, facilitating a deeper understanding of their collective identity. These narratives illuminate social psychological concepts such as communal attachment, self-worth, and the personal meaning of disability. Lively and Smith (2010) examine how illness and personal identity interact with each other by using sociological and psychological theories such as symbolic interaction and identity theory. The authors found that diseases can disrupt and reshape personal identities in profound ways, and emphasize the vital role that social roles play in maintaining one’s identity in the face of illness (Lively and Smith 2010). The application of social psychological theories could further complement studies into these dynamics, creating better outcomes and interventions for individuals grappling with health-related identity changes.

Stigma and disability

Alongside identity struggles, people with disabilities frequently deal with stigma. In their 2007 paper, Fennell and Liberato identify three distinct forms of stigma that affect individuals with obsessive-compulsive disorder. The first, self-stigma, involves an internalized belief that one's disability is deviant, leading to feelings of shame or diminished self-worth. The second, experienced stigma, refers to the direct discrimination or negative reactions one may face as a result of their disorder. Lastly, anticipated stigma occurs when individuals conceal their illness due to the fear of negative consequences should their condition become known. These variations of stigma do not act in isolation, but rather coexist simultaneously. Moreover, stigma in all forms profoundly influences an individual's interactions with others and their engagement with societal institutions. This interaction forms a mutually reinforcing cycle, as experiences of stigma serve to strengthen its impact over time.

Hegemonic understandings of disability are also shaped by the influence of societal institutions and prevailing ideologies. Charmaz (2020) analyzes stigma from an institutional perspective in which stigma is exacerbated by neoliberalism. Neoliberalism, according to the author, places a focus on the importance of individual responsibility, which can often result in victim-blaming for people with disabilities who see their struggles as self-caused. It also shrinks the social safety net as individualism is given the primary focus in a neoliberal society (Charmaz 2020). This effect leads to little support for people with disabilities — both financially and socially — and can also result in experiences of exclusion of those with disabilities, whether that is by choice or by coercion. Lack of support and exclusion reinforce the pre-existing inequality of the disabled community's limited access to resources.

Additional stigma is attached to invisible disabilities. McLeod (2023) examines how invisible disabilities affect a person’s outcomes across the lifespan. She discusses four key social psychological processes — social categorization, identity, status, and stigmatization — and how they affect the experiences and outcomes of people with invisible disabilities. These processes are especially important for understanding why people with disabilities that have no outward appearance still face worse outcomes than their non-disabled counterparts. The author argues that invisible disabilities have characteristics that distinguish them from traditional dimensions of inequality, such as less clearly defined boundaries and nonnormative behaviors. These traits demonstrate that inequality and stigma largely emerges from the social interplay between individuals and their institutions, rather than one’s disability itself.

Furthermore, the persistence of ableism in modern society, despite the fact that the majority of the U.S. population suffers from a disability, reveals the extent to which people with disabilities are stigmatized (CDC 2021). Today, ableism exists as a pervasive form of prejudice that advantages able-bodied people while marginalizing those with disabilities. Dunn (2019) presents a comprehensive social psychology-focused approach, suggesting that situational constraints such as social attitudes or norms might play a larger role in perpetuating inequalities than the disabilities themselves. In that way, ableist attitudes can be understood as being one cause of disability stigma rather than a reaction or effect. Such a finding ultimately underscores the importance of recognizing the role that social factors play in the creation and continuation of stigma.

Justice and disability

Justice plays an important role in the lives of people with disabilities, as it can be used to explain the processes through which people with disabilities are discriminated against. Justice can be described as the congruence between expected and actualized outcomes, according to society's normative rules. However, these normative rules often benefit those with more power and status, which leads to the disadvantage of those without. There are various types of justice, but all necessitate the existence of more than one group, so that the treatment of the two may be evaluated and determined to be just or unjust. In our society, people with disabilities are considered to be in a separate social category from people without disabilities, and these separate groups form distinct identities that favor members within their group and therefore influence assessments of justice.

Within the framework of distributive justice, which can be understood as the fairness of the distribution of rewards, the normative rules vary between distributions based on equality, equity or needs. Most systems in our society are not equality based, which means that all receive an equal share, but equity based, which means that one's share depends on their contribution. Because people with disabilities are not valued within society and their contributions are perceived to be minimal, they receive little rewards compared to people without disabilities. Although people with disabilities might consider their contributions to be significant, people without disabilities often have more power and status and therefore distribute rewards according to their own discriminatory beliefs about the ability of disabled individuals.

Within the context of the medical field, the process of medical rationing is a prime example of the inequality that is perpetuated by distributive justice. Medical rationing is performed through the concepts of utilitarianism, egalitarianism and prioritarianism, all of which devalues those with disabilities and reinforces pre-existing inequalities between abled and disabled groups (Andrews et al. 2021). Utilitarianism determines rationing priority based on quality of life, but since abled people are the ones who decide how that is calculated, disabled people are ranked much lower for quality of life than abled people. Egalitarianism determines rationing priority by lottery, or first come first served, in an effort for equal opportunity. However, this results in resources going to those who do not need it, or gives an advantage to those who have the economic and social resources to ensure that they are first in line. Prioritarianism determines rationing priority based on those who have had 'less opportunity' in life, which advantages those who are younger and typically not disabled or chronically ill (Andrews et al. 2021).

Procedural justice and interactional justice similarly reinforce inequality in the lives of people with disabilities. Procedural justice can be described as the fairness of the way in which distributions or decisions are made. Actors with status, power and resources have more control over what gets legitimized, and are typically abled people. Therefore the distribution of resources either favor abled people, or do not take into account the specific needs that a disabled person might have (Engelman, Craig, and Iles 2022). Decisions such as the laws or practices of an organization may similarly exclude individuals with disabilities, which reinforces social and resource inequality between disabled and abled groups. Interactional justice can be described as the fairness of the treatment of individuals. One of the normative rules for evaluating interactional justice is standing, which refers to respect for an individual's rights and opinions. Disabled people are often not given respect, and this lack of respect furthers inequality, because abled people with power do not take into account the opinions of disabled people when making legislation or other impactful decisions that directly affect the lives of people with disabilities (Engelman et al. 2022).

Conclusion

Utilizing a framework based on the sociological and psychological theories presented above, we intend to listen to the voicemails and other media provided to us by Suffering the Silence to tell the story of Cam, the creator of these voicemail messages. We plan to address how Cam's story fits within the context of pre-existing academic research on disability and in what ways it might contradict other research or even add a new dimension. In particular, we hope to see how Cam’s experiences might offer more insight into the ways in which stigma, identity, justice, and inequality color the experiences of people with disabilities.

References

Andrews, E. E., K. B Ayers, K. S. Brown, D. S. Dunn, and C. R. Pilarksi. 2021. "No Body Is Expendable: Medical Rationing and Disability Justice During the COVID-19 Pandemic." *The American Psychologist* 76(3):451–461.

Barker, Kristin K. 2002. "Self-Help Literature and the Making of an Illness Identity: The Case of Fibromyalgia Syndrome (FMS)." *Social Problems* 49(3):279–300.

Centers for Disease Control and Prevention (CDC) 2021. "Chronic Diseases in America." National Center for Chronic Disease Prevention and Health Promotion. Retrieved April 19, 2024 (https://www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm).

Charmaz, Kathy. 2020. “Experiencing Stigma and Exclusion: The Influence of Neoliberal Perspectives, Practices, and Policies on Living with Chronic Illness and Disability.” *Power, Stigma, and Exclusion in Everyday Life* 43(1):21-45.

Cockerham, William C. 2021. *Medical Sociology*. 15th ed. New York: Routledge.

Dunn, Dana S. 2014. “Towards an Understanding of Disability Identity.” Pp. 93-106 in *The Social Psychology of Disability* edited by B. Caplan, T. Elliott, J. Farmer, R. Frank, B. Nierenberg, G. Prigatano, D. Rohe, and S. Wegener. Oxford, United Kingdom: Oxford University Press.

Dunn, Dana S. 2019. "Outsider Privileges Can Lead to Insider Disadvantages: Some Psychosocial Aspects of Ableism." *Journal of Social Issue*s 75(3):665–82.

Engelman, A., L. Craig, and A. Iles. 2022. "Global Disability Justice In Climate Disasters: Mobilizing People With Disabilities As Change Agents: Analysis describes disability justice in climate emergencies and disasters, mobilizing people with disabilities as change agents." *Health Affairs* 41(10):1496–1504.

Fennell, Dana and Ana S. Q. Liberato. 2007. "Learning to Live with OCD: Labeling, the Self, and Stigma." *Deviant Behavior* 28(4):305-331.

Grue, Jan. 2016. "The Social Meaning of Disability: A Reflection on Categorisation, Stigma and Identity." *Sociology of Health & Illness* 38(6):957-964. DOI: 10.1111/1467-9566.12417.

Lively, Kathryn. Carrie Smith. 2010. “Identity and Illness” Pp. 505-525 in *Handbook of the Sociology of Health, Illness, and Healing*, edited by B. A. Pescosolido, J. K. Martin, J. D. McLeod, SA. Rogers.

McLeod, Jane D. 2023. “Invisible Disabilities and Inequality.” *Social Psychology Quarterly* 86(1):1-24.

Waters, Hugh and Marlon Graf. 2018. "The Costs of Chronic Disease in the U.S." Milken Institute. Retrieved April 19, 2024 (https://milkeninstitute.org/report/costs-chronic-disease-us).

World Health Organization (WHO). 2021. "Disability and Health." Retrieved April 19, 2024 (https://www.who.int/news-room/fact-sheets/detail/disability-and-health).

Report for Suffering the Silence: Cam's Story

Neha Agarwal, Arianna Steadman, Jessica Sun Li, Andy Trinh, Nolan Yee

Department of Sociology, Dartmouth College

SOCY 065: Social Psychology of Inequality

Dr. Kimberly B. Rogers

May 17, 2024

Introduction

The goal of our field research was to analyze Cam's voicemails and identify themes to understand the various ways his illnesses impacted his life. We identified three basic premises underscoring the importance of this approach.

First, the voicemails would provide invaluable emotional context into the experience of being chronically ill. By analyzing the voice recordings, which inherently provide deeper insight into Cam's emotions, feelings, and attitudes during moments of distress, we uncovered nuanced experiences that a mere transcript, impersonal interview, or broad survey would not reveal. Second, this analysis would enable us to understand the validity of oftentimes abstract academic concepts in a practical context. We employed an inductive approach by first identifying themes throughout the voicemails and then conceptualizing the broader themes they reflected. This method fundamentally enhanced our understanding of living with chronic illness as it truly affects the individual, rather than trying to fit Cam's experience into existing literature.

Third, this analysis would support Suffering the Silence's goal of sharing real stories from those who are disabled or have chronic illnesses. Analyzing these voicemails provides Suffering the Silence with a clearer picture of the salient themes and topics that arise, helping them decide how to present Cam's story and determine the direction of the project. Furthermore, this approach creates a framework for recognizing similarities among disabilities and highlights the importance of focusing on what fundamentally binds people with disabilities together, regardless of their specific conditions. We hope that these underlying themes might help connect Cam's experiences with those of other individuals who are suffering, one of the most important outcomes of sharing personal narratives.

Methods

For our field research, we worked with existing voicemails from the years of 2020-2024 that were recorded by Cam and sent to Ari. These voicemails detailed Cam's experiences, and focused on his medical journey. The years 2020 and 2021 saw an abundance of messages with the COVID-19 pandemic and the inability for Cam and Ari to see each other in person, while 2023 and 2024 saw significantly fewer messages. All in all, there were approximately 71 voicemails. They ranged in time from 1-3 minutes, as the voicemail machine cuts off at the 3 minute mark. Prior to starting to listen to the voicemails, we came up with a couple of potential codes. However, the majority of our codes were inductive.

We came across many themes in Cam's messages, as he continually expressed the challenges he had with his illness and treatment, as well as the stigma that he faced. We defined the most notable themes based on a combination of deductive and inductive coding, and produced a theme table and codebook. We also transcribed parts of the voicemails that best fit the codes. When transcribing the voicemails, there were instructions about Cam regarding information that he is comfortable and uncomfortable with being presented and recorded. As a result, information such as names of doctors and hospitals have been omitted. Overall, these transcriptions will inform the creation of a podcast.

Conclusion

Our research into Cam’s voicemails has helped reveal the real-life challenges faced by people with chronic illnesses. By focusing on personal experiences, we have gained insights that broad surveys can not always provide. We have seen firsthand how chronic illness affects individuals’ social support, identity, and how they experience stigma.

We found that social support is crucial. It helps individuals manage the emotional and physical challenges of their illnesses. For example, Cam mentioned several instances where support from friends and medical professionals made a noticeable difference in his ability to manage daily challenges. On the flip side, the absence of support led to isolation and a significant impact on his mental health. Cam’s experiences also demonstrated the struggles with personal identity that come with chronic conditions. He often discussed how his condition forced him to redefine his roles and expectations, from career aspirations to day-to-day social interactions. This identity struggle is captured in his fluctuating sentiments of hope and frustration, which demonstrate the unpredictable nature of his symptoms. These stories have shown us how deeply an illness can affect someone’s sense of self and their expectations for the future.

Our analysis also identified a pervasive stigma associated with invisible illnesses. Cam’s experiences demonstrate how misconceptions and biases in healthcare and social settings not only exacerbate his struggles but often leave him and others feeling misunderstood and marginalized. He spoke about doctors who dismissed his symptoms or underestimated their severity, and social encounters where his illness was not taken seriously, all of which compound the emotional toll of his condition. Evidently, there is a clear need for more understanding and better support in both the healthcare system and society at large. This would help improve the lives of those with chronic conditions.

Concepts and theories from our course — including symbolic interactionism, social structure and personality (SSP), and expectation states theory — apply to the problem of inequality in our research. Cam's struggle with his identity and how his chronic illness influences his sense of self directly relates to symbolic interactionism. His identity is shaped through his interactions and the meanings he assigns to his illness. As he navigates the social world, his self-concept evolves based on how others perceive and react to his chronic condition. This process of identity negotiation is helpful in understanding the psychological impact of chronic illnesses. Additionally, the stigma Cam faces, as described in your findings, is a product of social interactions and the meanings attributed to his illness by others, including healthcare providers. Symbolic interactionism helps explain how stigma is constructed through these interactions and the significant role that societal perception plays in shaping Cam's experiences. Additionally, Social Structure and Personality (SSP) emphasize how larger social structures influence individual psychology and interactions. Cam's experiences demonstrate how the broader social and institutional frameworks, or the lack thereof, impact his access to and quality of medical care and support systems. The SSP framework would look at how specific structural elements, such as healthcare policies and societal attitudes toward chronic illness, affect Cam's daily experiences and psychological state. Furthermore, the concepts of status and power dynamics within group processes can be applied to understand how Cam and others with chronic illnesses are seen and treated in different social and medical settings. For instance, Expectation States Theory could be used to explore how societal expectations about chronic illness patients influence their interactions with healthcare providers and others, potentially leading to unequal treatment and access to resources.

Ultimately, our research provides Suffering the Silence with a look into the themes that matter most to people with chronic illnesses. By focusing on personal narratives, such as Cam's, we draw attention to aspects of chronic illness that are often overlooked or misunderstood in broader societal discussions and medical literature. This helps further the academic discourse on chronic illness by adding depth and specificity to theoretical concepts like stigma, identity negotiation, and the role of social support. Our analysis helps Suffer better articulate the complex experiences of those with chronic illnesses, allowing them to tell these stories more effectively and advocate for change. By documenting and analyzing the stigma and challenges associated with invisible illnesses, our research provides evidence that can be used to advocate for better policies, practices, and social attitudes. This supports Suffering the Silence’s mission to change the stigma associated with chronic suffering and promotes a more informed public discourse. Additionally, our research emphasizes the importance of community and social support for people with chronic illnesses. This aligns with Suffering the Silence’s programming goals, such as their retreats and storytelling nights, by validating the need for these events and helping to design them to be more responsive to the needs of participants. Ultimately, by connecting personal experiences to broader concepts, we contribute to a more empathetic understanding of chronic illness and support efforts to reduce stigma that can help Suffering the Silence in their goals.