

Capstone Project Proposal

Working Title:

The (dis)course of disclosure for individuals with an "invisible" condition/disability: An analysis and narrative recounting of the experiences of individuals with Multiple Sclerosis

Brief Summary:

The research that I am in the process of delivering as my senior capstone project has not merely been an assignment that I've thought about for the past two quarters, but rather something that has been in the making for almost five years. My inspiration – as most inspirations do – comes from a personal life experience that came to shape me as the person I am today and the passions I will carry on to tomorrow. As a UCLA freshman, I was diagnosed with Multiple Sclerosis. The experiences I have had since were certainly not what I had foreseen for my college years, yet they've challenged me both as a person and as a scholar. And so, I wanted to bring these two realms together, because I believe that our foundations of knowledge come first and foremost from the human experience. Thus, for my project, I'm exploring the experience of individuals with MS – an often invisible yet potentially debilitating condition - when it comes to considering disclosing about their condition to family, friends, significant others, employers, coworkers, etc. I want to dive into the stigma that piggybacks this disclosure dilemma and perceptions of the concept of disability, and additionally argue that the MS community's overall hesitation in disclosure is not only the product of a vicious cycle of stigma, but also lends to this cycle and a lack of awareness already in place in our culture at-large in regards to disabilities.

The intentions of my research project's impact and contributions to the field of Disability Studies are several-fold:

1. To bring awareness and a voice to the condition that is Multiple Sclerosis (MS), and what the chronicity of the condition entails for the population diagnosed with MS.
2. Highlight MS's place in disability culture. How have we as a society come to conceptualize disability? How is it looked at through a medical and social lens/construct? What are the implications of MS as a disability? I problematize the concept of disability, and hope to exploit that the negative connotations of the concept make many reluctant to understand the experiences of individuals identified (by self or society) as disabled or are averse to being labeled as such themselves.
3. After considering these questions, I want to display the unconventionality of MS, both as a stand-alone condition and as a disability. One of the most paradoxical components of MS as a disability is its "invisibility". How does this crucial component play into the social and psychological realities of those with the condition? The main reality is the option to disclose, that is, revealing their condition to others.
4. MS is a physiological condition, yet as revealed by past and present literature,

psychosocial difficulties are also heavily in play, particularly through the disclosure dilemma. I want to expose the harms of psychosocial difficulties for the individual's mental health. I hope that this will highlight a need to further intermarry the fields of disability studies, psychology, and sociology.

5. I hope that my project will also establish a platform of discourse about the disclosure dilemma for individuals with "invisible" disabilities. I hope to stress that disclosure, or lack thereof, plays a crucial role in the "invisibleness" of MS as a very real condition and potential disability.
6. I aim for my work to display that the only way to bring awareness to MS, as well as all other conditions and disabilities, is the action of disclosure, and for individuals to talk about their experiences. More so, society at large needs to instate a culture in which every individual can speak comfortably about his or her circumstances. This is not only for the betterment of the individual, but also for society as a whole.
7. Most importantly, I want to emphasize the importance of personal narratives and the human experience to the scholarship of the field of Disability Studies.