

Work in Progress: Accessibility of Identity: Piloting an Analytical Frame using the Medical and Sociocultural Models of Disability to Understand the Disability Identity Transitions of Engineering Undergraduates

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Abstract

This work-in-progress paper presents a pilot analysis exploring the experiences of engineering undergraduate students who are in the initial stages of disability identity formation using the medical and social/sociocultural models of disability as an analytical frame. In this work, we describe these initial stages of disability identity formation as ‘disability identity transition’; that is, the period of time in which students are being identified or have been recently identified as having a disability, either through self or formal diagnosis. Here, we present our initial findings on how students navigate the formation of disability identity as they adjust to a different version of themselves and discover different ways of navigating extant university support systems. Our results highlight three key themes related to engineering student disability identity transition as situated within the analytical frames of the medical and social/sociocultural models of disability: (1) the role of symptoms (medical model-based); (2) comparison between a non-disabled self and disabled self and others (medical model-based); and (3) shifts in expectations and navigational strategies (social/sociocultural model-based). When considered together, these analytical frames intersect at a recurring, iterative process of disability acceptance in which disability identity begins to become a more salient and integral component informing how a student understands themselves and navigates their engineering educational experience.

The results of this study will inform the implementation of a larger phenomenological study exploring the same topic with an overarching goal of developing better university support structures for students with disabilities, especially for those who have recently been or are currently in the process of being diagnosed with a disability. Simultaneously, we examine the alignments and tensions between the medical and sociocultural models of disability related to transition within engineering education culture. In doing so, we seek to contribute to research efforts focused on finding ways to lessen the dissonance that often occurs when students are simultaneously forming their engineering and disability identities.

Introduction

It is estimated that more than 10% of engineering undergraduate students identify as having a disability, with an additional 3% identifying as having a chronic illness [1]. At the same time, it is reported that approximately 50% of students who have disabilities in college acquire them or are diagnosed while in college [2], meaning that many postsecondary students enter college and experience a disability identity transition, either through experiencing new symptoms or by receiving a formal diagnosis, after enrolling in their respective programs. Research suggests that the professional identity development of students with disabilities, can be significantly impacted by the access barriers that accompany the physical, social, bureaucratic systems associated with higher education while they pursue science and engineering careers [3]. Such experiences can communicate messages of exclusion, reduce belonging, and create internalized contradictions as they attempt to form their identities as engineers [4], [5]. These contradictions further perpetuate an ongoing cycle of exclusion as students continue to experience access barriers that manifest as academic roadblocks and programmatic bottlenecks that have cumulative impacts on the identity

formation of undergraduate science and engineering students with disabilities, thus making both their engineering and disability identities harder to access and accept [3], [4].

Most of the current research on college students with disabilities has broadly focused on undergraduate students in higher education [6], [7], [8], [9]. While some studies have focused on STEM undergraduate students in general, little work has focused specifically on engineering [4], [5], [10]. For studies related to disability identity formation among college students, the focus is often placed on the congruencies and incongruencies between engineering and disability identities and cultures as experienced by students who have already acquired a disability (e.g., [5]), with little work examining the transition students experience as they acquire or are in the process of being diagnosed with a disability [6], [9], and specifically during their undergraduate education.

To initiate our research, we ask the following question: How do engineering undergraduate students experience disability transition while in college? We refer to ‘disability identity transition’ as the period of time in which students are being identified or have been recently identified as having a disability, either through self or formal diagnosis. This paper presents an initial analysis of secondary data collected through a series of three semi-structured interviews conducted between January 2019 and July 2020 with a single participant. Specifically, our research aim was to pilot an inductive analytical process informed by both medical and social/sociocultural perspectives of disability to gain an initial understanding of the impacts that disability transition has on engineering students’ undergraduate experiences and vice versa. The secondary data analyzed as part of this paper serves as a pilot case for a future phenomenological study focusing on disability transition. The participant with which these interviews were conducted fits the demographic of interest and goals for our future work [11]. The analysis presented in this paper is intended to begin understanding essence of disability identity development/transition during the undergraduate engineering experience. The ultimate goal of our work is to find ways to lessen the dissonance that often occurs when students are simultaneously forming their engineering and disability identities [5].

The results from this pilot work will be used to inform a larger phenomenological study exploring how students experience the formation of disability identity as they adjust to a different version of themselves and how they navigate and use extant university support systems. Such work provides insights into how institutions can better support students who are maneuvering the systems they are expected to use or why they choose not to use them in light of a newly acquired disability.

Guiding Frameworks: Medical and Social/Sociocultural Models of Disability

Because the topic of disability identity transition has not been extensively explored in engineering education research, our inquiry is guided by two frameworks: (1) the Medical Model of Disability, which focuses on physical symptoms and conditions; and (2) the Social/Sociocultural Model of Disability that focuses on interactions between people with one another and with established social systems and institutions. These models offer specific lenses from which disability can be defined, understood, and perceived. Together, these models provide insights into individual and collective understandings of disability across a wide range of people, disabilities, and contexts.

The medical model describes disability as an impairment that impacts the body or reduces standard function. Traditionally, we see the medical model in contexts that focus on biology and normality, with the goal being to restore a person's body or function to be as close to "normal" as possible [12]. This view of disability is especially salient when considering the problem-solving context of engineering. For example, in a 2020 study by McCall et. al., an engineering student described their disability as a problem to be solved while also saying that "most of what engineers do is solve problems." Because of the nature of engineering work, the medical model of disability, where disability can be seen as a problem to solve, is often the lens through which engineering culture views disability. While this view is useful for creating assistive technologies and other supports, it can leave students' disability identity at odds with their engineering identity as problem solvers. The social or sociocultural model of disability provides a different perspective. In this model, disability is described as one aspect of a person's identity that influences how they experience and interact with others and their environments. From this perspective, disability is conceptualized as a result of a "mismatch" between a person and their environment; the design and implementation of the environment create access barriers that, in turn, constitute disability. This perspective shifts the focus from disability as an individualized condition to disability as an outcome of systemic, environmental and social design by changing the environment, not the person [12].

Together, these models provide a useful and valuable approach to examining disability from both individualized and social views, which are critical for understanding how we can better support undergraduate students who experience disability identity transitions during their engineering programs. While the medical model focuses our attention on the biological and functional aspects of disability at an individual level, the social/sociocultural model focuses our attention toward the environmental, social, and cultural impacts of engineering education on the disability identity of students. To date, researchers have tended to choose one model to address the research questions being asked [1], [13]. However, in this research, we have specifically chosen to use multiple models to acknowledge that students are often experiencing the impact of these models simultaneously.

Researcher Positionality

Given the deeply personal nature of research on the experiences of people with disabilities, it is essential to acknowledge that the members of the authorship team identify as having or experiencing our own disabilities. The desire to pursue this research area directly relates to and is informed by our lived experiences as past engineering students and current engineering educators who have undergone disability identity transitions and continue to make sense of ourselves in our daily lives. The first author acquired her disability while she was an undergraduate engineering student and continues her disability identity transition as a graduate student in engineering education. The second author acquired her disability while she was a graduate student in a doctoral engineering education program and continues her disability identity transition as an engineering faculty member at an R1 university. Our experiences have profoundly impacted how we engage and relate to our participants [14].

Methods

For this study, we conducted a secondary data analysis [5] on a series of three interviews conducted with a research participant between January 2019 and July 2020 as part of a previously funded National Science Foundation project (EEC #1733636). This project focused on exploring the identity formation of undergraduate civil engineering students with disabilities [5], which aligns with the goals of the present study. The semi-structured interviews collected as part of this prior work were conducted by the second author and lasted approximately 90 minutes each. For more information about the prior study, including recruitment and data collection details, see [5], [15].

For the present study, we focused our analysis on a single participant from the prior data set, Bubba (pseudonym), who had been diagnosed with Lyme disease during his third year of his civil engineering program. Bubba had received his formal diagnosis just a few months before participating in the first interview [11]. Due to the newness of Bubba's diagnosis and onset of disability identity, his interviews served as a valuable pilot case for exploring the experiences of undergraduate engineering students in the initial stages of disability identity formation (i.e., disability identity transition) through the lenses of the medical and sociocultural models of disability.

Data Analysis

The transcript of Bubba's interviews was qualitatively analyzed in four rounds. First, an overall review of Bubba's transcript was conducted to become familiar with his data and story. Second, thematic analysis of the interviews based on the medical model of disability was completed, followed by a thematic analysis based on the sociocultural model of disability. Last, the themes identified using each disability model as an analytical lens were compared to generate a deeper understanding of what Bubba experienced as he navigated the initial stages of disability identity formation – transitioning from a non-disabled person to a disabled person – while in his undergraduate civil engineering program.

Results and Discussion

The Medical Model Perspective

When examining Bubba's experiences with disability transition from the perspective of the medical model, two salient themes present: (1) the role of symptoms, and (2) comparison between a non-disabled self and disabled self and others.

Medical Model Theme 1: The Role of Symptoms

The three interviews follow Bubba for one and half years, beginning with his very recent diagnosis of Lyme Disease to his first job after graduating with his undergraduate civil engineering degree. Throughout his interviews, the symptoms he experienced played a changing yet consistent role in his disability identity formation. His search for a diagnosis began when he started to experience symptoms, "I knew something was wrong, and obviously wasn't really sure what. WebMD only helps so much when your symptoms match up with 200 other diseases." His search eventually led to his diagnosis, a time that he described as a "relief". Bubba's feeling of relief is consistent with prior research suggesting that, upon receiving a diagnosis, students

experience an increased and empowering understanding of an aspect of themselves they previously lacked [7].

In gaining a deeper understanding of himself, Bubba also began to grapple with ideas of what it meant for him to be “normal.” He further explained that that, with a cure, “there was a way to go back to normal.” His idea of “normal” and “go[ing] back to” it are indicative of the influences of the medical model on how Bubba was making meaning of himself [12]. He also described that when he acts like everything is “normal,” his symptoms seem less prevalent in his daily life. Throughout the rest of his interviews, Bubba continued to discuss his symptoms and how they impacted his experiences as an engineering student, often reflecting back on how he performed and functioned in school prior to acquiring his disability, “I know I’m not functioning at a rate that I could be or the rate that most other people are.” These ideas of ‘normal’ and ‘function’ are those that are captured in the medical model, and Bubba revisits these ideas throughout his interviews as he completes his education and embarks on his career.

Medical Model Theme 2: Comparison between a Non-Disabled Self and Disabled Self and Others

Bubba’s comments also highlight an internalized process of comparison. For example, he compares his current functioning rate (as a person with Lyme disease) as less than his prior functioning rate (as a person without Lyme disease). At the same time, he also began to make comparisons between himself and others who he perceives as having disabilities. This idea became particularly salient when Bubba talked about identifying as disabled when applying for internships or jobs:

They have a list, usually, of things that qualify [as a disability], and for me, if I see in the list that there’s autoimmune diseases, then they’re all pretty much the same. As far as symptoms go, there’s some [disabilities] worse than others, obviously. So, I kind of compare [my disability] to one of those in the other boxes. For that reason, I usually feel that I can say “yes” and then explain further if needed. I still haven’t been asked about it once from a company.

Bubba continues to compare himself with others as he described his experience after arriving at a neurology appointment. After arriving in the lobby and looking around at other patients waiting to be seen, he noted that they were in noticeably worse condition than himself, with doctors even telling him that he looked “fine.” Such comparisons have been identified in prior research as people grapple with making meaning of their acquired identities. In a study examining the experiences of LGBTQ+ students with mental health disabilities in community colleges, Baranowski identified that students questioned their disability status by asking themselves, “am I disabled enough?” [16]. Because disability has been broadly conceptualized as physical impairments – and diagnosed by medical professionals – it is often interpreted through apparent severity (i.e., the extent to which others can observe disability impacts on function); the less disability is seen by others to limit function in a given context, the less likely a person will claim a disability identity.

For Bubba, descriptions of symptoms and comparisons tended to intersect at disclosure. Since Bubba’s disability is generally non-apparent, he can more-readily pass as non-disabled –

meaning that he can decide whether and when to disclose at different points in his education and when moving into his career. The decision typically came when the non-apparent nature of his disability was more limited, and disability started to become apparent.

The Social/Sociocultural Model Perspective

The most salient theme identified using the social/sociocultural lens focused on the ways disability prompted shifts in strategies used to navigate the sociocultural institutions and systems associated with engineering education and the expectations that accompany them.

Social/Sociocultural Model Theme 1: Shifts in Expectations and Navigational Strategies

Bubba's experiences also highlighted how his disability changed his perspective of and the strategies he used to navigate engineering education. Prescribed timelines, cohort structures, and progress evaluation techniques, such as mid-term exams and heavy workload, all constitute definitions of what it means to succeed in engineering. His experience of an engineering degree had once assumed these norms, his experiences of disability prompting him to reconsider expectations he had previously taken for granted and to re-evaluate how he navigated these norms. This change in expectation became evident in the way Bubba describes how his perspective on the engineering environment shifted:

What's funny is "falling behind" doesn't really exist. There's just that ideal four-year period that you're supposed to take your classes and graduate in... I don't know. When thinking about falling behind, I guess, it's just because you're with a group of people that are doing the same thing. They're set to finish on this date, so it's kind of what you have in your head as being ideal.

In this instance, Bubba realized that his idea of an engineering degree was built on assumptions and expectations from a non-disabled perspective. He explains how his idea of "falling behind" changed from an attempt to keep up with his peers to recognizing that it is not an actual program requirement. In this sense, Bubba's comments are somewhat empowering; once his outlook on himself and the world around him changed, he decided it was okay to change his educational plan. He also started to place less emphasis on certain aspects of his education like GPA, noting that "not really caring" was one of the better things he did for his education.

Bubba continued to identify how the structure of his civil engineering education impacted his outlook on problems and solutions as he transitioned into his career. He explained that while problem solving in engineering school was very structured (i.e., a clear problem with a single correct answer), the problems in the workplace are vague with multiple solutions that depend on several variables such as cost, materials and safety. The way that Bubba described industry's focus on cost and efficiency in a system seemed to mirror how he navigated his disability – having multiple solutions, each with different costs and benefits. Notably, changes in Bubba's understanding of engineering work coincided with those related to his perception of disability, indicating that shifts in disability identity and perspective can also prompt shifts in understanding the field of engineering and what it means to become part of it.

Intersections of the Medical and Social/Sociocultural Models of Disability

Bubba's interviews revealed a key point at which the medical and social/sociocultural models of disability began to intersect. This intersection, which we identified as acceptance, became evident when Bubba commented, "I can't really do a whole lot about it so I'm very accepting of it and just hope that everyone else is as accepting of it." The status of acceptance has been identified by Forber-Pratt and colleagues as the initial status of the Disability Identity Development (DID) Model [6]. They refer to acceptance as an initial stage because it is often accompanied by various levels of grief that are dependent on awareness and nature of the disability onset [6].

For Bubba, this process of accepting disability was not linear nor streamlined. While he acknowledged that he could not recall what "normal" used to mean to him prior to acquiring disability, he also noted that, as his symptoms came and went, his mental health decreased. Because his symptoms were unpredictable, both in how and the frequency/duration in which they presented, Bubba also described new experiences of anxiety and depression, which required his attention:

Kind of trying to figure out the patterns as to when I go into these stages of anxiety or depression, and then when I come out of them, and [identifying] what was going on at the time that I went back in [to that stage] versus when I came back [out of that stage]. So, I'm kind of trying to filter, I guess, thoughts and certain situations that, I guess, make me struggle mentally, and just trying to avoid those too, I guess. Just so I don't have to deal with it. But I'd say I'm somewhat figuring it out, just being very observant with my body and the environment. How I feel in certain situations.

Here, Bubba's comments provide a valuable example of the interconnected nature of the medical and social/sociocultural models and demonstrate how they can be present at the same time. They also underscore the complexity and nuance of disability, particularly when it prompts the development of new reflective strategies, such as being attuned to the physical and affective feelings that specific environments or situations evoke. The DID Model notes that this awareness, takes place when individuals are in the acceptance status, and is dependent on the surroundings.

Conclusion and Next Steps

This preliminary study starts to uncover the ways students experience disability transition within the context of undergraduate engineering education. Using the medical and social/sociocultural models of disability, we analyzed a series of three interviews conducted over the course of one and half years from Bubba, a civil engineering student who was experiencing disability transition. We found that these two models intersected through acceptance. Notably, Bubba was not recruited for the initial study due to disability transition. Rather, this characteristic emerged during his first interview, which brought about questions regarding the impacts of recent diagnoses on students' experiences. Our future work will continue to gain a better understanding of disability transition and its impacts on how students experience and navigate their engineering education. Specifically, we will continue to recruit more participants with a focus on undergraduate engineering students who are currently undergoing or have recently gone through disability transition. This will allow for a more focused collection of data, and analysis to better

understand disability transition and how engineering students in this transition can be better supported.

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