

Becoming a Doctor-Patient:
An exploration of lived experiences of disability in medical education.

Jessica Campanile
Elizabeth Carpenter-Song, Advisor
Dartmouth College
Department of Anthropology
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Chapter I – Introduction

Diversity in Medical Education

“When patients enter our hospitals, they want to see staff members and physicians that resemble them,” wrote Dr. Paul Rothman, Dean of the Medical Faculty at Johns Hopkins University (Rothman 2016). Racial and ethnic diversity initiatives have received most of the attention in medical education and the health professions, including multiple court cases regarding affirmative action policies, and research that suggests that medical students from underrepresented minority backgrounds are more likely to practice healthcare in underserved areas (Saha et al. 2008). In addition, by studying at a more racially and ethnically diverse medical school, white and non-white, non-underrepresented minority students are more passionate about healthcare equity and access issues and were more likely to rate themselves as “highly prepared to care for minority populations” (Saha et al. 2008).

Recent studies have also shown that beyond affecting a medical student’s career trajectory, self-concept, and awareness of health disparities, diversity in the medical education system can have a measurable impact on health outcomes. In cases where African-American men were treated by African-American physicians, they were 47% more likely to undergo a diabetes screening, 72% more likely to undergo a cholesterol screening, and 56% more likely to agree to a flu shot (Alsan et al. 2018). In this particular study, the “black doctor treatment effect” was estimated to create a possible 19% drop in the black-white male gap in cardiovascular mortality (Alsan et al. 2018). However, this effect is muted by the limited quantity of African-American physicians in relation to the African-American population in the United States. African-Americans make up 13% of the U.S. population, but only 4% of physicians (Alsan et al. 2018). Given the dramatic effect that race

concordance shows in this study, one can imagine the possible impact on people with disabilities, who currently make up only 2.7% of the physician workforce (Meeks & Herzer 2016), but 25% of the United States (Okoro et al. 2016). For physicians-in-training and patients alike, it is clear that increasing diversity in the health professions can benefit all involved.

The Relationship Between Disability and Anthropology

Upon first glance, the American Anthropological Association (AAA) seems to be committed to accessibility for people with disabilities in a manner that is more progressive and comprehensive than most higher education institutions. The Accessibility webpage states: “The American Anthropological Association is committed to ensuring it is accessible and goes beyond the Americans with Disabilities Act (ADA) requirements” (AAA 2019). Furthermore, there are ample webpages that explore accessibility and disability vocabulary, best practices, and meeting and conference accessibility measures for attendees and presenters alike (AAA 2019). As an association that strives to make meaning of and understand the wide variety of human experience and difference, it seems logical and necessary that the AAA would display this type of sociocultural sensitivity to people with disabilities.

Notwithstanding the progressive nature of the AAA’s site and practices, upon more investigation it becomes clear that these developments are all relatively recent. The Accessibility and Meetings Coordinator, who has personal experience as a member of the disability community, was hired into this newly created position in 2019 (AAA 2019). The Society for Medical Anthropology, a subset of the AAA, includes a Disability Research Interest Group (DRIG), which is over 30 years old. This group seems to be a hub of disability scholars and scholarship within the

AAA, with similarly progressive language and a strong subscription to the social model of disability.

However, increased scrutiny leads one to a blog post on a site called “Anthrodendum,” in which three scholars who are members of DRIG write at length about the inaccessibility of the AAA. They note the requirement that, beyond critical engagement with anthropological scholarship centered on disability, their function as an interest group has necessarily extended into making the AAA meetings accessible and equitable (Friedner et al. 2018). This process of disclosing a disability and educating others about accessibility practices in order to be able to function as a student, scholar, and human, is a phenomenon that will be explored in Chapter IV of this thesis. The post touches upon popular issues in the intersection between disability and academia: the fact that disability issues are rarely included in course content, disability studies programs are few and far between, especially at universities that consider themselves to be “elite,” and scholars with disabilities continuously face disability discrimination in the tenure process, issues with disclosure and accommodations as a faculty member, and unfair criticism of their work (Friedner et al. 2018).

The comments section of this blog post included a quote from Devva Kasnitz, a professor in the City University of New York’s Program on Disability Studies, which reads:

“There is still a premium on “Cowboy Anthropology.” I also think that anthro[pology] has lost status as a discipline in our, at best, neo-liberal times, just as we also see great demographic diversity changes among anthropologists. No one dares say there is a causative connection between loss of status and the feminizing, browning, [queering], and crippling of anthropologists, but do they think it? Do they feel but not express it?” (Friedner et al. 2018).

It seems that those who are different, who may have or still do fit into categories that are more often studied in anthropology rather than represented in the scholarly community, continue to feel alienated by this field, and specifically the leaders within it, despite increased diversity. In my anthropology coursework, I have felt the lack of disabled perspectives in conversations of diversity, health and illness, and ethics. As such, I feel a mixture of responsibility, excitement, and opportunity in pursuing rigorous research that is propelled by a student anthropologist with a disability, incorporates ethics protections that are conscious of accessibility needs, and focuses on and amplifies disabled voices and experiences.

There is considerable scholarly precedent for the exploration of lived experiences of disability and chronic illness. From medical anthropology to disability studies, individuals living these experiences are often the subject of biomedical practice and social science research. However, as noted above, they have only recently been included within the roles of researchers and practitioners. The disabled community has a frequently espoused motto, rooted in the Polish quest for democracy in 1505: “Nothing about us without us” (Charlton 1998). The issue is, some institutions, namely those of “elite” standing in the United States, live by this creed, though not in the way that people with disabilities would hope. Instead of this motto becoming a driving force for representation and accessibility in academic spaces, it has unfortunately proved emblematic of the value – or lack thereof – that much of American higher education places on disabled voices, perspectives, and knowledge. In short, there is nothing “about us,” which highlights the fact that most of these elite institutions are also “without us,” insofar as not housing disability studies programs, disability scholars, or even adequate accommodations and affinity-based resources for students with disabilities.

My positionality in this work will be explored deeply throughout the thesis. It will be specifically highlighted as it relates to the framing of this research (and thus the framing that many anthropological scholars with disabilities feel that they must address or adhere to), my investment and personal interest in the work, and my personal experiences at the intersection of disability and the healthcare system. I feel strongly that this public, academic disclosure of my disability and disabled experiences can act as “powerful disability praxis,” (Friedner et al. 2018) and that my proximity and intense knowledge of this subject can strengthen the purview of an undergraduate thesis and lay the groundwork for an academic line of inquiry to which I feel a deep level of personal commitment and hope to continue at the graduate level.

However, I have found – and will explore later in the thesis – that living in this triplicate world of academic, advocate, and applicant – as I was also in the midst of the application process to post-baccalaureate premedical programs at the time of this research – is an exercise in complexity, consistently navigating identities that at times, can conflict with or affect one another. In this work, the blurred line between positionality and autoethnography is explored insofar as how it manifests when a member of a marginalized community conducts research on that group. As I will expand upon in Chapter II, negotiating these triplicate identities is an inextricable aspect of this work, affecting everything from my writing to my ethnographic relationships to my sampling of participants.

The Relationship Between Disability and Healthcare

The medical model of disability, which is the way of thinking held by many who have little experience with disability, including governmental organizations and officials, focuses on disability as “an individual deficit” which is meant to be cured. Many who have firsthand

experience with disabilities prefer to subscribe to the social model, which states that an individual may experience an impairment, however it is society, and complex social and historical contexts that disable them (Shakespeare 2006). A member of the #DocsWithDisabilities Twitter community, a group of users on the social media site who identify as or advocate for the increased presence of doctors with disabilities, writes: “Disabilities are less about the person and more about the environment. It’s more that the environment is disabled because it’s not allowing that person to have the tools they need.” Instead of following the familiar social model, which would cast the environment as playing a disabling role towards the person experiencing disability, this Twitter user places the environment in the subaltern position that people with disabilities prefer to avoid – thus it is the ground who is disabled, and it is the ground who is at fault for the tasks that cannot be done.

Biomedicine is predicated on ideas of disability as undesirable and, in an ideal world, avoidable. In fact, there is a common biomedical and public health term called the Disability Adjusted Life Year (DALY), which pathologizes disability, and in doing so, deems years lived with a disability as worth less than those lived without (Rock 2000). Though created to help allocate resources in international development and global health initiatives, the DALY and its creator maintain that those living with a disability would choose to be “healthy” if they had the option, and that anyone who says otherwise is subject to false consciousness, much like the conundrum of the “happy slave” (Rock 2000). “That some slaves may have been happy,” the creator of the DALY said, “does not make slavery acceptable,” and thus, that some people with a disability view themselves as members of a cultural group rather than as sufferers of illness and impairment, does not mean that biomedicine should not solve their suffering (Rock 2000). In

saying this, Rock stipulates that part of the purpose of biomedicine is to alleviate the “suffering” of those with non-fatal health conditions – that is, to eliminate disability.

There is also considerable scholarly attention paid to the experiences of patients with disabilities. A 2012 report by the National Disability Rights Network entitled “Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights” detailed the tense relationship between the disability community and the healthcare system, noting the tendency for caregivers and medical professionals to make decisions for a patient with a disability that may not be otherwise made for an able-bodied, neurotypical patient (Carlson et al. 2012).

Data on doctors with disabilities is sparse, which is one of the reasons I was so passionate about pursuing this topic as a thesis project and generating additional data to bolster this conversation within the scholarship. Lambert et al. attributes the lack of data on physicians with disabilities to “the difficulty in clearly defining ‘disability’ on the one hand and a reluctance on the part of the students to own up to a non-obvious disability for fear of discrimination” (2014).

Less well-documented are the difficulties faced by people with disabilities attempting to enter the medical profession. Despite legislative progress demonstrated by the Americans with Disabilities Act and its amendments, many U.S. medical schools will not accept applicants with certain mobility or sensory disabilities (Ouelette 2012). These barriers are often codified in the Technical Standards at each medical school, a list of baseline qualifications for applicants that include the ability to “speak, to hear, and to observe patients in order to elicit information, describe changes in mood, activity, and posture, and perceive nonverbal communications” (Harvard Medical School). These technical standards also require fine motor skills, such as suturing simple wounds or conducting laboratory tests (Harvard Medical School). “In other words, deaf, blind, and

physically impaired undergraduates need not apply to these medical schools. They are not welcome. They are, by definition, unqualified” (Ouelette 2012).

Likely as a result of the filtration process by which Technical Standards disqualify individuals with disabilities, most physicians with disabilities acquired their condition after being admitted to medical school, and often after they had completed their residency. “Had they been similarly impaired as applicants, it is likely these doctors would have had a very difficult time getting admitted to medical school” (Ouelette 2012).

The process by which people with disabilities are excluded from medical education not only impacts those in the disability community, but also excludes individuals with these experiences from contributing to key conversations at the medical school level. This exclusion means that medical students are mainly seeing people with disabilities as their patients, not their peers (Ouelette 2012). Power dynamics may be heightened by this dichotomy and contribute to feelings of liminality within the experiences of physicians or aspiring physicians with disabilities.

Anthropological Significance

The purpose of this work is to leverage medical anthropology methodology to document structural as well as sociocultural barriers to an ability-representative physician workforce, and in documenting the lived realities of aspiring, current, and former medical students with disabilities, as well as the subjective beliefs of faculty and staff who interact with this population, possibly lead to increased awareness within the medical education system, and the review and revision of admission and curricular policies that unfairly disadvantage students with disabilities.

Medical anthropology is the ideal field through which to view this topic. As a discipline deeply attuned to the culture of biomedicine, and the production of disparities that this culture encourages, “the critical orientation of medical anthropology provides a firm foundation for homing in on the shortcomings and failures of American medicine” (Carpenter-Song 2011). This field of inquiry has a unique ability to identify and explore the “rifts, breakdowns, and slippages that occur within clinical encounters” (Carpenter-Song 2011). Medical anthropological literature focuses often on the culture of biomedicine, a culture that presses a healthcare provider to construct disease, to run tests and exams in order to replace subjective patient experiences with objective biological information, and thus to “discount the moral reality of suffering” in its patients (Kleinman 1997). Medical schools, now understanding the cold, distant gaze of biomedicine and its effects on patients, have embraced curricula of “cultural competency.” Medical anthropologists have criticized the idea that culture is a static fact base in which medical professionals can be trained, and instead understand that it is a fluid, dynamic process that influences how people understand and engage in their world, and namely in this case, receive and deliver healthcare (Baker & Beagan 2014).

The rigid structure present within biomedicine lends itself to hierarchical power dynamics, and in entering this system through medical education, students find themselves in the midst of “professional socialization” which primes them for the “hidden curriculum” so highly valued in medicine (Craig 2018). These hierarchies “simultaneously increase students’ and clinicians’ feeling of vulnerability while denying them places to express it comfortably” (Craig 2018). Medicine displays a strong need to “categorize and universalize human experiences of illness” (Craig 2018). In doing so, the discipline often creates a binary in which it is the doctors who care for the ill, and the ill who are cared for by the doctors – a dichotomy where one person cannot

straddle the two worlds and cannot be both a doctor and an ill individual. The “sick role” as described by Talcott Parsons contributes to this limiting delineation between those who are sick and those who care for them (Parsons 1951). Further discussion in Chapter IV will explore the limitations of this theoretical framework as well as others common in anthropological scholarship.

For people with disabilities, medicalization and competing ideals of wellness are enshrined in the current biomedical system of the United States, much like heterosexism is inherent and unavoidable for LGBTQ patients (Baker & Beagan 2014). Interactions and experiences in which these oppressive structures are emphasized, such as the existence of gender-specific restrooms, can contribute to decreased feelings of safety and trust between a patient and healthcare provider (Baker & Beagan 2014), which has been shown in some cases to decrease a patient’s likelihood to engage in preventative health services, and thus, result in a poorer health outcome (Alsan et al. 2018). Additional connections and opportunities for future intersectional research will be discussed regarding the related experiences of the disability community and the LGBTQ+ community in Chapter V.

This thesis leverages previous work done on other forms of diversity and marginalization in the biomedical ecosystem, paired with the lived realities and experiences of people with disabilities within this system, to highlight the opportunities and possible benefits of representative medicine and ability diversity of the physician workforce, as well as the barriers individuals with disabilities and chronic health conditions face when attempting to enter the medical profession. .

Thesis Overview

In the United States, public concept of disability fails to separate people who experience functional limitations as the result of illness or incident from the society that disables them. There

is no setting in which the disabling role of society becomes clearer than in clinical medicine. People with disabilities are continuously made to be objects of the healthcare system, with their disabilities viewed as comorbidities and leading to unequal and inadequate care, especially in preventative health service utilization (Fitzgerald & Hurst 2017). The most pressing issue is the lack of adequate representation of disability in the medical professions. In the United States, 1 in 4 people have a disability (Okoro et al. 2016), but only 2.7% of allopathic medical students receive accessibility services (Meeks & Herzer 2016). Representative medicine, the idea that our physician workforce should be representative of the diversity of patients that it serves, is not only a social justice and equity initiative, it is a life-saving one, as demonstrated in the aforementioned Alsan et al. study on the “black doctor treatment effect.” However, before the disability community can see the benefits of representative medicine, more individuals with disabilities and chronic health conditions would need to make it successfully through the medical education system and be put into a position of power within the healthcare system. This thesis herein strives to understand the lived realities of aspiring, current, and former medical students with disabilities, as well as the academic ecosystem they exist within. The work builds upon preliminary investigations in ANTH 18 and 85 during the Fall 2019 academic term. This thesis draws upon semi-structured interviews with students, faculty, and staff at undergraduate institutions and medical schools in the United States, the methodology of which will be expanded upon in Chapter II. Within the theoretical frameworks of rites of passage, liminality, and the social roles of the sick and the well, this thesis brings to light the extra mental work – the additional decisions and tensions – that this community must complete in their trajectories towards physicianhood.

Chapter II: Methodology

Research Setting

Initially, this research was set to take place primarily at Dartmouth College and Geisel School of Medicine given their proximity and accessibility to the researcher and faculty advisor. Both have considerable connections with relevant personnel and students at each school, which aided the recruitment process. In addition, this setting seemed fruitful for these conversations given the recent newsworthiness and intensity of advocacy efforts at the undergraduate and institutional levels.

I had plans to expand the reach of this research setting to undergraduate institutions and medical schools along the East Coast over the break between Dartmouth's winter and spring terms. However, the COVID-19 pandemic, which began to affect institutions of higher education in the United States during mid-March of 2020, while this research was still in the data collection phase, forced a change in research settings, as I moved back to my home in suburban New Jersey and attempted to continue conducting ethnographic interviews via Zoom, a videoconferencing technology. Though challenging to be displaced in the midst of this research and disappointing to miss out on the opportunity to travel down the East Coast and be on-site with my research participants, I took this as an opportunity to expand my sample. I increased my reach to experts and practicing physicians with disabilities at institutions that I would not have been able to travel to in-person, such as those on the West Coast or in the Midwest.

Participants and Recruitment

For this semi-structured interview series, I recruited aspiring, current, and former medical students with disabilities and chronic health conditions. I also included broader stakeholder groups that I believed would have meaningful information on these issues, including accessibility staff at undergraduate institutions and medical schools, faculty and staff at these institutions, and those who serve on admissions committees. Throughout the thesis, I use the word “participants” to refer to those who took part in my study who identify as having a disability or chronic health condition within the context of medical education, and I use the term “informants” for those such as administrators, accessibility staff, and faculty. Informants in this study were not selected as a result of their personal identity as an individual with a disability or chronic health condition, but rather because of their professional expertise and knowledge of the culture of accessibility in American higher education and biomedicine.

Participants were those who self-identified as having a disability or chronic health condition. I purposely utilized this broad, participant-led identification process to ensure that those who I was interviewing considered themselves to be a part of the community I was interested in exploring.

“I utilize the CDC and WHO definitions of disability, which state that “a disability is any condition of the body or mind that makes it more difficult for the person with the condition to do certain activities and interact with the world around them.” This definition is purposely broad, and within my study I also place specific emphasis on self-identity. That is, participants should be those who self-identify as having a disability.”

In addition, keeping the definition of “disability” within this study purposely broad allows me to explore a diverse range of participant experiences in terms of the visibility of their condition and their interactions with accessibility services.

I recruited mainly through purposive sampling. This involved asking participants who I had interviewed if they had additional contacts who I should speak with next, and either reaching out to those contacts on my own or having the interviewee introduce me to these new prospective participants. I also posted a brochure with the study information as approved by CPHS around high-traffic areas on Dartmouth’s undergraduate campus, such as dining halls and study spaces. In addition, I conducted outreach online, posting my study information in undergraduate group messages as well as on my professional Twitter profile, where I follow many accounts that focus on medicine and medical education. I also cold emailed experts in the field as identified by the presence of their research, experiences, or advocacy on the Internet.

Prospective participants filled out a Google Form and then were reached out to via email with more information about the study and an opportunity to sign up for a spot on my calendar that was convenient given their schedule. In the calendar sign-up process, particular attention was paid to accessibility, asking participants if they needed any accommodations or adjustments in order to participate comfortably in this interview. I had funding available should an ASL interpreter prove necessary for a study participant, or other accommodations with fiduciary needs. Special attention was also paid in the writing of my IRB protocol to ensure accessibility for all prospective participants.

For example, in the process of obtaining informed consent from participants, I included measures to be taken if an individual’s disability means that they cannot complete the consent process in the traditional manner (verbal or written consent).

“I will obtain verbal and written consent from my participants at the beginning of each interview, using the introductory script which reminds participants that participation in this project is voluntary and can be stopped at any time, summarizes the purposes of the research, and details the risks of participation. Verbal and/or written consent may be substituted for the other should a participant's disability preclude them from engaging in one of the acknowledgements of consent. Should someone be unable to process visual information, or physically unable to sign using a pen, I will verbalize the consent form to them, ask permission to record, turn on the audio recorder, and get documentation of verbal consent.”

In including anthropologists as well as participants with disabilities in the discipline, I feel strongly that accessibility must be codified and ingrained in every step of the research process to ensure equitable access to the exploration of lived experiences.

As Groger et al. notes, though the sampling conducted for this study resulted in participants currently in premedical and medical education as well as practicing physicians, there is much to be learned from the populations that did not participate in my study (1999). Notably, most of the participants in my study were individuals who did not have visible disabilities or chronic health conditions. All participants had a diagnosis process which they remembered, meaning that they had all lived some portion of their lives as non-disabled or healthy before being diagnosed with a condition or acquiring a disability. Additionally, most participants identified as female. The groups represented by my participants included premedical students, medical students, and practicing physicians, but notably, the smallest sample came from medical students and no residents or fellows were interviewed as a part of this study. Beyond the sampling bias demonstrated by the predominance of premedical students in the data and my status as an undergraduate student with connections to other undergraduates, this lack of physicians-in-training in my sample might

indicate a hesitation to discuss such sensitive topics during key moments in one's career for fear of one's professional status or reputation.

In addition to these possible sampling biases noted above, there is also the significant issue of my positionality as the ethnographer. Through this study, I have navigated my triplicate identities – that of an ethnographer, disability advocate, and applicant with a disability who one day hopes to become a physician. It is nearly impossible to separate myself from these identities and makes the interactions with my participants all the more interesting.

My positionality is much of what has prepared me to take on this work – a deep familiarity with disability issues, a personal knowledge of navigating accommodations in higher education, and my position as an individual with a disability contributed to the care and sensitivity present in designing this study. Though I feel a deep personal connection to this work, it is centered on participants who have graciously shared their lived experiences with me. I write in this work about these participants, many of whom were made more comfortable by the knowledge of my positionality, and our interactions, many of which I felt were enriched by these shared aspects of our identities. Not only is positionality essential for “better understanding (and rendering more transparent) our ways of coping with difficult field encounters and the moral stances we take in response to them,” it is also a substantial aspect of data analysis and ethnographic writing (Dilger et al. 2014). “That is, it is relevant to all stages of anthropological knowledge production” (Dilger et al. 2014). There is something to be gained from discussions of positionality and drawing upon experiential knowledge to inform ethnographic encounters, as perhaps most iconically referenced in Renato Rosaldo’s “Grief and a Headhunter’s Rage.”

I know that by invoking personal experience in this work I introduce a risk of “early dismissal” (Rosaldo 1989). Instead, I argue that my utilization of personal experience was critical

in recruiting my participants, establishing rapport with them, and generating ethnographic perspective on their lived experiences. Like Rosaldo, I use personal experience in this thesis as a “vehicle” for making the messy, nuanced, and at times difficult to discuss lived experiences of disability and chronic health conditions in medical education “more readily accessible to readers than certain more detached modes of composition” (Rosaldo 1989). The dual purpose of spotlighting positionality in this thesis comes from this understanding of intersubjectivity influenced by Rosaldo, as well as the knowledge of the challenging experiences of anthropologists with disabilities in the discipline.

An unexpected side effect of my triplicate identity and the relatively small disability community at Dartmouth College meant that prospective participants and informants at times approached the study with pre-existing knowledge about me and my advocacy work on our campus.

At the end of an interview with one of my first informants, who sits on the admissions committee at a medical school in the Northeastern United States and teaches at the institution, I asked, “Is there anything you thought I was going to ask you about today but didn’t?” I like to ask this question to try to gauge what informants and participants were expecting when they agreed to take part in my study.

“I was thinking we’d talk more about discrimination,” they replied.

This response made me take pause. Though engaging with this work inspired by activist anthropological methods and an avid activist myself, I didn’t approach these interactions with my informants specifically as a researcher investigating discrimination. Naively, I thought the utilization of the term “lived experience” might shield me from these worries. In hindsight, I wonder if my positionality weighed contributed to creating this informant’s expectations. As a

student with a disability, who advocates for the disability community, who is also hoping to go to medical school one day – all aspects of my identity that this informant was familiar with – was I, by virtue of my positionality, creating expectations that this was some sort of investigation or exposé of inaccessibility in medical education? I also noted the institutional context – this informant worked at an institution that had, within the last few years, been sued for noncompliance with the Americans with Disabilities Act and lost, leading to the drafting and implementation of considerable administrative policies to ensure compliance and non-discrimination on the basis of disability.

After this interview, I ensured that I stressed to future interviewees that this was simply an exploration of their experiences and that I was purely reaching out to them to learn from them. I assured them of the confidentiality measures I was taking and engaged in a dialogue about participation in the study to make certain that we were all aligned in our expectations.

During this interactive process of recruitment, one prospective participant, a premedical student, wrote to me in an email, requesting additional information about the study and asked if I had a “main argument” or “thesis” for the work. She qualified this by explaining that she knew my work from around campus. “I understand that you do a fair amount of advocacy for the disabled community, and, if my experiences will be used in such a way, I would like to know what they will be advocating for.”

Receiving this email, I was taken aback. I knew that my intersecting identities meant that this work would be challenging for me as I negotiate this shared space, and I had realized through my initial round of interviews that there was a certain collegiality with participants who realized that I was a researcher in as well as an inhabitant of this space. I had never anticipated that it might bias my sample – which I can now recognize as an implicit bias on my own behalf. This

prospective participant – to whom I replied with an explanation of the inductive process of anthropology as well as the hopeful goal of this program of research in the future, which is to shed light on these experiences in medical education and highlight best practices for accessibility and inclusion – never replied and never participated in the study. However, the interaction proved valuable in pushing me to think of who else I might be excluding in my work. I know that in making clear that participants in the study should identify as having a disability or chronic health concerns, I exclude those who may be struggling with their identity or less willing or comfortable to talk about these issues.

To combat this, I attempted to be radically inclusive in the design and execution of my ethnographic interviews. I offered multiple opportunities for participants to request accommodations, had a budget set aside should an individual require live captioning or an ASL interpreter, and was sure to book accessible locations for interviews conducted in-person with participants. All advertisements and recruitment materials were distributed in accessible, screen-readable formats. I was passionate about accessible human subjects research design from the start, especially after learning about the somewhat frayed relationship between the disability and anthropology communities – I was determined to find a way to codify accessibility in my work by writing it explicitly into my CPHS research protocol, discussing it at length with my advisor as well as participants who requested accommodations, and continually reflecting on how my work could be more accessible to the disability community.

This goal of ultimate anthropological accessibility became more important than ever in the switch to remote learning that happened in the wake of the onset of COVID-19 in the United States. As an individual with a disability, some of my symptoms can be triggered by excessive screentime, so additional measures had to be taken on the part of the ethnographer to ensure accessibility.

These included writing large portions of this thesis via the voice-to-text feature in Google Docs, which allowed me to speak aloud instead of type and look at a screen, as well as printing and coding many of the interview transcripts by hand to limit screentime. In a moment where all productivity seems to revolve around our screens, identifying ways to continue to stay engaged and productive with this anthropological inquiry in an accessible manner was a key component to the success of this thesis.

Procedures

This research approaches these multifaceted issues with particular attention to the ethnographer's positionality. The primary mode of inquiry is semi-structured interviewing, which were conducted with aspiring, current, and former medical students, as well as staff and faculty at undergraduate institutions and medical schools in the United States. Domains covered in these interviews included background and motivation for pursuing medicine (or an educational career in which they have interacted with people with disabilities), the participant's relationship with disability as an identity, perceived relationships between disability and the medical field, personal experiences (if any) with accessibility services and accommodations, and personal experiences and conceptualizations of power in the healthcare system and what can be done to address imbalances therein. These interviews were all audio-recorded (with plans in place to have them video-recorded in the case of an interviewee using ASL) and lasted approximately one hour each. In some cases, where interviewees were willing, I approached them again for a follow-up interview, touching on topics that weren't talked about in the initial interview, or bringing up themes that other data collection work brought to my attention to get interviewees' perspectives on them. This study was approved by the Dartmouth College Committee for the Protection of Human Subjects. All

participants gave informed consent to participate, and information about the study was communicated in the manner most accessible for participants.

Analysis and Interpretation

As noted by Padgett, proper data management is essential to a successful ethnographic project (2012). The rise of qualitative data analysis software, such as Dedoose, the software utilized to code and store data in this study, lent a “technological cachet to a methodology known for being low tech” (Padgett 2012). I would add that it added an additional accessibility barrier as well, as I know that, though I had the chance to utilize Dedoose as a part of this research, I also had to do much of my coding by hand given my accessibility needs. A deep dive into the Dedoose website and user guide shows no mention of disability-related accessibility – it talks about accessibility in terms of easy access to data via the internet, given that it is a web-based platform. From the information I could find, there is no speech-to-text or text-to-speech availability within Dedoose, no option to change the color contrast or text size on their interface, and no screenreader accessibility. If these industry-standard tools are inaccessible, how are anthropologists with disabilities expected to continue to contribute to the field? As anthropological methods reckon with modernity and technological advancement, concrete steps must be taken to ensure that anthropologists with disabilities can advance alongside their abled counterparts.

Though the combination of Dedoose and manually coding the interview transcripts, I utilized a thematic analysis approach to identify and trace patterns within the data (Braun & Clarke 2006). Some codes were driven by preset researcher-generated questions as well as the interview guide, and others arose inductively as I immersed myself in the ethnographic data. All participants and informants are referred to using pseudonyms. The balance between aggregating coded excerpts

from multiple interviews with the intimate portraits I draw of specific participants in Chapter III allowed me to move fluidly from the specific to the holistic in the context of this study. With these diverging methodologies, I take detailed snapshots of individuals at multiple points on the trajectory to physicianhood while speaking across participants to note the main themes arising from interviews with this population.

Chapter III: Portraits of Disability and Chronic Health Conditions in Medical Education

This chapter includes five portraits of participants in this study. They are each situated at a different point in their trajectory towards physicianhood. From Abigail, who is just starting her premedical journey, to MaryAnn, who has been practicing for years, the individualities of their experiences are underlined by common threads related to issues of disclosure, stigma, individualism, and the definition of success within the culture of biomedicine.

Abigail – Premedical underclassman student

“Like before all of this started, I was so, so sure that I wanted to be a doctor. Like I had no doubt in my mind, and I find myself wondering about it a little bit more now.”

Abigail is a current premedical student at a top-ranked university in the Northeastern United States. She entered college knowing that she wanted to eventually go to medical school and chose this institution over another she was accepted to because she was hoping to avoid a cutthroat environment. Abigail is about halfway finished with her premedical course requirements and is on track to finish them by her senior year. We spoke via Zoom from her home in the Northeastern United States.

For Abigail, it seemed like she always knew that she wanted to be a physician. “For as long as I can remember that’s like sort of been the thing that I want to do, when like adults asked me what I wanted to be when I grew up, I always said, ‘I want to be a doctor.’” She did a lot of extracurriculars related to these interests in high school – she shadowed and worked in a lab, such that, by the time she got to college, she had already had considerable exposure to the field. “I was pretty sure that that was the path that I wanted to take.”

"I wasn't diagnosed until three years ago, so it isn't something that I like grew up with, which I think is different than a lot of people." Just before Abigail began her college career, she was diagnosed with a chronic health condition. "[The past three years have] been a little bit of a transition for me from going from just like being a very high-functioning high school student to like all of a sudden having to deal with all this like medication management, and going to all these doctor's appointments."

These transformational experiences – that of moving away to college and becoming ill – were simultaneous yet challenging in different ways. "The transition to being a college student and the transition to being a person living with a chronic health condition really coincided for me [...] they were both really kind of growing up experiences for me, um, because I was on my own for the first time, and I was dealing with like all my health issues for the first time by myself." Figuring out how her body could best function in its new condition, miles away from home and familiar healthcare providers, was not an easy feat. "There definitely was a little bit of a learning curve [...] I think most people have the experience of like having their parents help them manage their health before they have to do it on their own." Unlike others who might have grown up with disabilities or chronic health conditions and been used to that type of family support, Abigail was on her own to figure out how to manage her condition.

Having a chronic health condition affected her college experience – though she is still on track academically, she spoke about its effects on her social and academic lives at college. "It definitely sort of forced me to be a little bit more of a like responsible college student than some of my peers [...] I just have to be a little bit more careful about the way that I do things." Being a "little bit more careful" means cancelling plans at the last minute, needing to go home before an event has finished, or being late to outings with friends.

“That’s the thing about invisible disabilities that like it’s not obvious to the people around you, so it’s easy for people to think that like, ‘Oh you’re just like being lazy, or you’re just [...] not working as hard as the people around you.’”

It’s not that Abigail’s not working hard – if anything, she’s working even harder to manage her health and schedule academics, extracurriculars, and social time around her condition. “I think I have to plan a lot more than other people do.”

The intentionality with which Abigail approaches her schedule also underscores her relationships with her faculty. “A lot of the classes on the pre-med track are super rigorous and expect you to be engaged with it all the time, every day, studying constantly, and that can be a little difficult when you just don’t really have the capacity to do that.” Explaining that to faculty can be challenging, especially given the confidential nature of student health information.

“[Interactions with professors are] always a little bit funny, because professors like want to know what you’re dealing with, but can’t ask. [...] They’re always like, ‘Oh, are you okay?’ And [laughs] you’re like, ‘Yeah, um, I’m okay.’ So this sort of like gentle prying where they like can’t ask outright what’s wrong with you, but like they want to know, is a little bit funny.”

Though interactions with professors can be awkward or downright difficult, Abigail makes an effort to let them know, “Hey, I just like ... I can’t study for this class in the way that a traditional student might.” This proactive, open approach is not common, or even required for students with disabilities – they can file documentation with an accessibility services department at their institution that helps to mitigate these personal conversations with faculty. “So like a lot of times, I try to go to the professor first on my own and ask what they’re willing to do. And then if they’re

not willing to make the accommodations that I need, that I can have, [...] I can contact [accessibility services].”

In this moment, I was taken aback. Most students prefer to have the institutional advocacy and backing of an accessibility services department to support them in their requests for accommodations, so I was curious, what was the difference in philosophy in Abigail’s case?

“[The accessibility services department at Abigail’s institution] has been great for me. [...] I try to use them as sort of like a second line of defense.” In this battle waged for accessibility, where Abigail’s honest, open ask for accommodations acts as one line of defense, while the legislation-backed, fully-staffed accessibility services department acts as another, I was surprised at the order in which she called them into war. “I think I’m just working towards like a future where I’m gonna be the person who has to advocate for myself, and I’m not gonna have like this institutional backing. [...] [Accessibility Services] is a good fallback to have, but I never wanted it to be like my first point of contact.” Abigail’s aversion to institution-backed accessibility services comes possibly at the behest of her desire to be like her peers. “I think there was a while where I was like ‘I just want to do this in the way that everyone else does it, and like I should just be able to suck it up and do that.’”

Abigail has just gotten a service dog, Hazel. A fluffy, yellow-colored dog that I’d guess is a Golden Retriever, Hazel interrupts our Zoom call numerous times because she has walked over Abigail’s headphone wire or begun chewing on an unknown object in the corner. Abigail got the dog two months ago, when she first came home from school at the beginning of the COVID-19 pandemic in the United States. “So I’ve never actually had her on campus.” When asked, she laughed nervously, “I am anticipating [having Hazel on campus] being a little bit challenging.”

“Especially in the science fields, there isn’t really any sort of [...] there are no real guidelines for like service dogs in laboratory environments, for example.” Beyond laboratory work, Abigail worries that this visible manifestation of her disability might mean that she is less likely to be given other coveted premedical opportunities that are integral to her medical school application. “I definitely worry about things outside of the classroom. Are people going to be less inclined to give shadowing opportunities to someone with a service animal? Are people going to be less inclined to hire me for internships because they’re not going to think that I [am] capable?”

Ethnographer: “How do you anticipate your identity as someone with a chronic health condition intersecting with your application process to medical school?”

Abigail: “It’s definitely something that I think about a lot. I don’t know if it’s something that I wanna disclose [...] as much as people say that they wanna ignore things like that and their decisions aren’t influenced by that, it’s pretty hard not to be.”

She worries, at some level, that she might be disadvantaged if she applies to medical school with a personal statement that discloses her disability. From others within the premedical community, faculty and students, she’s heard, that she might not have what it takes. “I’ve heard the line before that like if you’re disabled enough to need accommodations you probably shouldn’t be a doctor.” These creeping feelings of doubt come from external sources, but also from internal trains of thought that Abigail finds herself thinking. “If you are, I don’t know, sick enough or disabled enough to like need accommodations, does that mean that you don’t have the capacity to be a physician? Because in a life-or-death situation, no one’s going to give you extra time.”

She clarified for me that it’s not that she is worried about handling the work intellectually. “I’m not questioning my intelligence. I’m questioning whether like my body literally can function in that environment.” These feelings of doubt have led her to explore possible alternative career

options within the medical field, like physical therapy. However, it just didn't excite her as much as the prospect of medicine does. "I think I always circled back to the idea that like I'm never going to be happy doing that, because it's not what I want to be doing. [...] I know what I want, and I don't want to be limited by my health status, and at the same time like I'm worried that I just don't have the capability to do it."

At times like these, when Abigail is questioning herself or doubting her career path choice, I was curious to know where she found community – does she find it with other people with similar chronic health conditions?

"Yeah, I don't really know anyone else who's in the same boat. I have mixed feelings about the sort of like disability community or like the service dog handler community, those sorts of things, because there's so much of me that just wants to be like a normal person, and I'm just like, I don't need those like affinity spaces, because it's like, this is part of me, but it's not my entire identity. But at the same time, it probably could be a sort of helpful community to have."

This aversion to affinity-based organizations or any notion of community based upon her health status seems to mirror that of her relationship with accessibility services. She finds ways to separate herself from her illness, from her body, such that she can focus on the Abigail that exists outside of those realms. I wondered why.

"I think for a lot of people and myself included, there's just like some internalized stigma and shame around it. And as much as like I don't want that to exist and [...] at a conscious level, it doesn't, it definitely seeps into the way that I interact with other people. Like I never want to lead with [her identity as having a chronic health condition], because I don't want that to be like the way that people think about me." At this point, Abigail seems to stray away from externally

identifying as someone with a chronic health condition unless necessary to receive accommodations for her courses. Internally, she struggles with this, wanting to go back to the Abigail of three years ago, who wasn't worried about any of this and was on her way to becoming a doctor.

We spoke further about her aversion to public disclosure. "I think that's going to change for me when I have like such a visible piece of medical equipment in Hazel. [...] I'm not going to really have the choice anymore about whether or not people know that I have a disability. So that will be an interesting new challenge." Given this newly visible condition that, with a service dog by her side, she would be disclosing to everyone on her campus, I asked how she planned to navigate those conversations.

"With people that I don't really know, I'm going to go with the phrase like 'She's a medical alert dog and that's as specific as I'd like to be.' Most of my friends know pretty specifically what I'm dealing with. And I'm totally comfortable sharing that. I just feel like I don't really owe it to anyone especially people that I don't know. [...] I tend not to disclose specifics unless they're like really prying for it. And even then, I just kind of give like a general overview, like I don't tend to give like the name of my condition." This general response to universal disclosure seems to echo the conversations she has with her professors regarding her condition as well.

Though Hazel will be a huge benefit to Abigail's functional abilities at school, she still will spend time away from the service dog and work on managing her illness on her own at times. "I do still need to be able to function without [Hazel] so I'm making sure that I'm still spending time on my own and like still knowing how to manage my health without her is going to be big because there's going to be a point where like I can't bring her into an OR. No matter how well-trained she

is, she's not a sterile piece of medical equipment." Though the ADA might protect her right to bring Hazel to classrooms or dining halls, even this iconic legislation has its limits.

Though Abigail's medical condition brought with it a slew of challenges and transitions in her life, it also gave her increased exposure to medical professionals. "It's kind of like a weird little side benefit of seeing that many doctors. It's not anything I could like put on my med school applications, but just for myself, it has been like it's been interesting." She's been able to talk with them about their stories, and better understand, she believes, what it means to be a good doctor. "I think I just have a better idea of what it entails. It's one thing to like see a doctor for 45 minutes and then not see them again for 6 months, or a year, or something. It's another thing when you're seeing them every day and you're seeing the real hours that they're working or you're seeing them once a week [...] I just feel like I'm a little more in touch with like what it actually means to be a doctor." Her increased exposure has not only increased her understanding of what it's like to be a patient, but also what it's like to be a physician.

Ethnographer: "What makes a good doctor?"

Abigail: "Someone who believes their patients. Like I just can't tell you the number of times that I've had someone think that I'm lying, or making it up, or told me that it's just anxiety. [...] I think a good doctor is someone who listens to their patients, who believes them, and who makes a commitment to advocate for them. [...] Some of the best doctors have been the ones who said like 'I can't help you with this, let me send you to someone who can.'"

For a doctor to engage with empathy with their patients and know their limits as a healer – that's what a good doctor is to Abigail. This definition and its focus on empathy makes sense, given some of her experiences with healthcare professionals. "I remember really being like 'I

promise, I'm not lying, like this is really what's happening for me.”” The burden of proof was so high for Abigail, and as an individual with a chronic health condition that has no external indicators, it was paramount that her physicians believed her. “It's hard to have to justify that I know something's not right with my body, and you don't believe it.”

Abigail’s increased interactions with the healthcare system mean that she’s thought critically about what it means to be a patient, and the chronic patienthood that she and others with chronic conditions live within. “I mean, everyone’s gone to the doctor, but not everyone has been in a position where like their entire life is managing their health. [...] Patients are still patients after they leave the doctor’s office. If you’re not a person with a long-term medical condition, like you might, go to the doctor and then you leave, and you get to go back to like being a normal person. And that’s different when you’re someone like me, like you, it doesn’t stop when you leave that building.” She punctuated this point with a sip of her Gatorade, a certain amount of which, she’d told me, was critical to keeping her body in balance.

Given her reticence to identify as a part of a community, I was curious what prompted her to respond to my call for participants, specifically given that this study was based upon interviewing those who identify as having a chronic health condition or disability. “I think it’s something that I tend to avoid talking about. Which is a little weird, because it’s such a big part of my life.” She chalked up this avoidance to stigma and shame about being someone who requires accommodations to function on the same level as her peers. Implicit also was her desire to be like her peers, like everyone else.

“I think also like there’s always been a part of me that’s like, why can’t you just like suck it up and be a normal person? Which obviously is not something I can just do. But I think

sometimes I feel a little bit embarrassed about just not being able to like function at the baseline level that a lot of my peers can.”

This internalized stigma underlies every beat of our interview. The sentiment that Abigail should just “suck it up” and “deal with it” is challenged by the way her life has been greatly improved over the last two months with the addition of a service animal that helps her manage her health.

“I’m a person who has pretty high expectations for myself in general. And this one is just too high, like I can’t just override what’s happening in my body.”

Perhaps this visible manifestation of her disability is the connection that will open Abigail up to ideas of community or affinity. Obtaining her service animal seems like a large step forward in her acknowledgement that her condition is chronic, and that she will struggle to hide it from others, given its many effects on her academic and social lives.

Josh – Premedical upperclassman student

“I feel like I’m just held to a different standard. Like I’m held to a normal person’s, not normal, but like an able-bodied person’s standard, even if I’m not.”

Josh is a current upperclassman at a prestigious university in the Northeastern United States. We spoke via Zoom. Behind where he sat was a pennant with his university’s colors, and he swiveled back and forth in the desk chair when he was thinking between my questions. He is taking his last premedical prerequisite course this academic term (online as a result of the COVID-19 pandemic), and plans to take the MCAT and apply after another gap year.

Josh was always intrigued by medicine, but it was the fall of his senior year of high school when he decided, "this is what I'm going to do." He was admitted to this prestigious university and entered knowing that he would be following a premedical track. Just before he was leaving his hometown to move to college, he had a panic attack. "I had never had anything like that before and that kind of like cascaded into like this whole issue. [...] it was like two weeks before coming to [university], I was like frantically figuring out how do I get rid of this, you know, 'cause it just came outta nowhere."

Josh had never had this experience with his mental health before.

"When it first happened, I wasn't really sure what it was, um, cause I wasn't even familiar with what a panic attack was, you know.[...] The way I described it was like that feeling when you're [...] just like playing around on your chair and you're leaning back and it feels like you're about to fall back, you know, you get that feeling in your chest. But like that feeling being permanent, um, or like being called to the principal's office or something like that."

Josh saw a therapist and nurse practitioner, at which point, he was prescribed some medications. However, despite Josh' efforts, these experiences continued throughout his first year of undergraduate schooling. "Like all freshman year pretty much, it was like cycles of like getting better and then like it would go, get worse. [...] So just like all of freshman year that was, was a big issue." After making some lifestyle changes coupled with continued medication management, he saw some improvement in his symptoms.

Josh never interacted with the accessibility services department at his undergraduate institution. "Um, I didn't really feel like I needed to go through them, just 'cause I like, I could vouch for myself and my props. There wasn't really anything that I needed help on, I think."

By this point in our conversation, we were about a third of the way through the time allotted for our interview. It wasn't until this critical juncture, where I asked about Josh' identity and its intersections with his pursuit of medicine as a career, that the primary reason he had volunteered to participate in this study became clear.

Ethnographer: Do these experiences factor at all into your continued decision to pursue medicine?

Josh: "Um, not really because my actual like invisible illness wasn't like mental health, it was, that's something else. [...] I have this thing called [chronic health condition] and I think that's kind of part of, I think it's like related. It's interrelated to my mental health. [...] One of the big reasons that I started, I got this panic attack was because I realized I was getting kind of older and like you read all the stories [about people with Josh' condition dying young very suddenly and seemingly at random]. [...] I was like kind of scared about my own mortality and [...], that was one of like various factors that led me to have this panic attack 'cause I was just like, 'Holy shit. I'm kind of getting to that age where I should, I'm kind of like a demographic where it affects me now.'"

In most narratives of chronic health conditions, I don't see individuals who are grappling with their mortality – moreso, I see people grappling with the idea that this condition will affect them for the rest of their life. Josh, in this case, was struggling with his mortality to the extent that it manifested as adverse mental health events. His chronic physical health condition had extended its effects to his mental health as well. These adverse events caused some self-doubt for Josh. "[The panic attacks] definitely made me question my like mental strength I think." However, he continued to connect these experiences back to how they would prepare him to become a better physician.

"I feel like physical health and mental health are very like interrelated so I know, like in my mind I think there are a lot of people who are going through the same things that I am or like a lot of kids that I would wanna help later on, like as a doctor. [...] Aside from like the physical things, they're also going through these mental challenges and like, you know, having had gone through those mental challenges, it's just like another thing that would allow me to like be a better doctor."

Josh' focus on children and their experiences of illness continues to crop up in his narrative. As a child, he had found out that his mother and grandmother carried a genetic health condition – and so did he. "My grandma, my mom's mom, was in the hospital for something and [...] that's when my mom found out about [genetic condition] and then she didn't tell me. I only found out 'cause I was at a checkup in like seventh grade [...] The doctor asked about [genetic condition]. And so I was like, "What's that?" And I Googled it and that's how I kinda found out." His mother had never told him that he also carried this genetic condition that could become very serious very suddenly.

Josh: "My mom had already known that I had it, so it wasn't like a big deal to her, I guess. It was just like she had wanted me to not know about it until like much later.

Ethnographer: "And so how did you feel about finding out about it?"

Josh: "It was pretty like shitty. [...] You have like one shot at life and it's pretty terrible to not be able to do the things that you want to do, like that, like, you know, in my mind, every other person can do, you know. Um, so it was very like depressing."

What had it done to Josh' identity given that he had lived with this condition for so many years before diagnosis, and that his mother had known and withheld that information from him? Some of the traits that Josh' symptoms causes in him are some of the physical attributes that he identifies

most closely with as an individual. He expressed that he wouldn't want to feel like he only has these traits as a result of his chronic condition.

Josh' physician was adamant that, as a result of his condition, he shouldn't play sports. This assertion, given to Josh as a teenager, did not sit well with him. He found it very frustrating, specifically because his physician was placing limits on Josh that he himself had likely never faced. "It's definitely like a one thing to say it as a doctor and another to actually like live it, you know. Like for him, like as nice as he is, it's just like what he does, he has to just tell people, 'You can't, you can't play sports now.'" These interactions surrounding Josh' lifestyle changes that his condition necessitated is a large part of his current focus on and interest in clinical interactions between doctors and patients. Josh emphasized the importance of the ability to "recognize the implications of the disease the person has beyond just the cardiovascular side of it and then be able to [...] figure out how their life looks like as a result of all that." In his future practice, he hopes to delve into the implications of the disease on the physical and mental health of patients, informed by his personal experiences. "I know how much having this illness affects you mentally, so I wanna be there for people."

Nowadays, he doesn't talk about his condition with many people, and it's not visible just by looking at him. When he does talk about it, he names it only as a chronic condition – rarely as the specific genetic he has.

"For the most part I don't tell anyone. [...] I've only told like two or three of my friends about the entire like [genetic condition] itself. But 'cause I feel like it kind of has, like it's just kinda like a different stigma to it than having a [chronic health condition] [...] I feel like there is a stigma against people with like inherited diseases [...] I think 'cause it's like, then you can like pass it on and like, I feel like evolutionarily speaking we as human beings,

[laughs] don't wanna pass on like fatal diseases to our offspring. [...] I saw it like kind of as like an unattractive quality."

Josh felt like, even despite medical advancements in IVF and genetic screenings, the genetic aspect of his condition was the most stigmatized and unattractive quality, while he finds that just telling people that he has a chronic illness is easier, and even uses this communication strategy to explain to others why he might not play sports despite his athletic body stature.

Genetic diseases are frequent examples in biology courses when teaching students about genetics and reproduction. For Josh, this became a little more of a personal experience than it might have been for his peers. "When we were learning about things in genetics, I was like, 'Oh, like me. That's what happened to me.'"

Though Josh doesn't talk about his condition much with others now, that is a central part of his philosophy as a future physician. His specific interest lies in a pediatric specialty – the same one that he spent time in as a patient with his health condition.

"I feel like there's a way, there are ways to like help out the parents and be like, 'Hey, like your child might go through like this later on his life, you know, when all his friends are playing sports and he can't, these are some ways that you can help him go, get through that.' If it's like patients who are older, like say teenagers, [...] who are more aware of what this diagnosis means to them, then I would be like, 'Hey, but, you know, here are all the things I wish I had known when I was your age. These are the things I wish I'd started, you know, like hobbies so that I could take my mind off of things when like things get bad."

Josh' biggest motivator is being able to become a figure who can speak to pediatric patients and show them, "Hey, I like was able to go through this and then go to med school and you know, have this career, which means that you can too." He noted that he lacks role models who have

similar conditions to his. "I don't see any other like role models that have the same condition as I do, like having, I guess, the types of jobs that you associate people coming from [university that Josh attends] to have. [...] Like sure, there are a lot of adults who live like happy lives, who have my condition, [but] it was never like the really like demanding professions that I always saw myself taking, you know?" Part of this concern over lack of mentorship also related to the self-doubt that Josh was feeling. "I was always concerned about whether or not I would be able to, you know, become a doctor."

For people with Josh' condition, it is recommended that patients don't take high stress jobs, as that increases the risk of adverse health events, which can be fatal. Though the stress of the training and job is a part of Josh' worry, another aspect is the physical ability required of physicians, especially surgeons. "I was watching surgeries and whatnot and it was just like the coolest thing ever. And like, I feel like that's something I wanna do, but I don't know if it's something I could realistically do given that, you know, I get like back pain and I'm like 22 years old right now." The back pain Josh feels is more than just soreness from crouching over a computer screen, it's a symptom of his condition, and one that many people find quite debilitating.

Though Josh still has time before he has to write his medical school applications, he has been thinking about whether or not to disclose his chronic health condition in his personal essay. "That's something I wanna, um, I was gonna talk to [his pre-health advisor at his university] about. Well, I do think yes [...] it is like the main reason I wanna go into medicine." While he seems pretty certain about disclosing, he noted some trepidation. "I don't want it to be like a cliché."

"I wanna be like the role model or like the doctor that I like always wanted, but like never had, um, just because I've been like someone who's been in their shoes." Josh' desire to be a physician stems deeply from his interactions with his illness and his own healthcare team. He is

also focused wholly on patients and their experiences as a result of his identity and illness, rather than finding a cure for conditions like his. “I’m not interested in finding a cure or anything. I’m like much more interested in the clinical aspects of like helping someone with it, like live their best life once they find out, [and] actually interacting with patients.”

Sophia – Upcoming matriculant to medical school

“When I had a physician who focused on empowering me and educating me and giving me agency over my health, it made a huge difference.”

Sophia completed her premedical courses while studying the social sciences at a prestigious university in the Northeastern United States. Since graduating, she conducted research abroad for a year while applying to medical school, and will matriculate in the fall of 2020 to a top medical school. She enjoyed science in school, and had been going to physicians for her chronic health condition since the summer before she began high school.

“The medical world was very familiar to me and [...] I was always interested in and grateful for what my doctor had done for me.” By about a year or two after she was diagnosed with her chronic health condition, it was mostly managed through medication. Sophia was able to “live mostly a normal life through high school and to succeed, you know, academically to get into college and all of that.”

Though she was able to manage her condition relatively quickly with the help of her physician and parents, obtaining her diagnosis was not an easy process. When her symptoms began, she was really fatigued and ran out of energy very quickly. The first physician that she went to with her parents diagnosed her very early on in her clinical encounter. “[The physician] pretty

bluntly said to me, ‘This looks like it could be [condition], but we need to do further testing [...] You can go home and read about what [condition] is.’” Very little effort was made during or after the visit to this doctor to explain Sophia’s condition to her or her parents. “We were shocked, and we felt very unsupported and also that I received a diagnosis without any definitive information.”

Though her interaction with this physician was frustrating, Sophia’s symptoms continued to affect her life, and she had the necessary tests done – they came back negative. “We had been deeply upset trying to figure out what this condition could mean for me, and then we heard that I didn’t have it.” Understandably, Sophia and her parents sought out a second opinion from another physician to uncover what was possibly causing these symptoms. “I went to a physician in a very well-respected hospital that focuses on [condition] and had tests redone, and at that point I was diagnosed officially.”

Sophia found that her second physician, unlike the first, went above and beyond in patient encounters to ensure that she understood and felt that she had control over her condition. “I was drawn diagrams about where my condition was located, and explained the options that I had in terms of medication and given a lot of agency for a young person you know, with the help of my parents, over the direction of my healthcare.” This experience and this type of care, that is focused on empowering patients to take control of their health, forms the basis for Sophia’s interest in and passion for medicine.

Sophia began high school shortly after being diagnosed with her chronic health condition. She and her parents were proactive in ensuring that any accessibility needs that might arise would be met. “I set up a 504 plan and all my teachers were made aware of my health condition. Ultimately I didn’t need any extensions on assignments or special accommodations.” Sophia’s

accessibility plan was not utilized for any procedural or structural accommodations, but to inform her teachers about her health condition.

“I felt like my teachers needed to know what was going on with me, just because I wasn't necessarily paying attention fully in class or may have looked like I was not engaged when I was doing my best. So, in that context I wanted them to know. Then once I was managing my condition and my energy levels were back to normal, then I didn't speak to my teachers about it.” Insofar that Sophia's condition differentiated her from other students, she felt that teachers should know about it. After it was under control, it wasn't something that she felt the need to focus on. This persisted into her undergraduate experience. “Fortunately my [condition] has been really well-managed and I didn't have, there was no impact on my academics while I was in college [...]”

I never spoke to professors about my personal health issues. The only times that professors were made aware was when I asked them to write recommendation letters.”

In her application to medical school, Sophia mentions that she has a chronic health condition in the very first line of her personal statement. “The first sentence is about having [condition]. And then I quickly you know, move away from that, but the premise of my application is that I had [condition] and [...] my first experience with a doctor was [...] now I have the language to say it was not patient-centered. It was not focused on the understanding my condition.” After this initial disclosure of her chronic illness, Sophia moves on to talk about the research she has done, her experiences abroad, and her passion for serving marginalized populations.

Sophia was nervous about disclosing her chronic health condition in her personal statement. “I had never explicitly stated the name of my condition in any application essay.” In concert with the pre-health advising office at her undergraduate institution, she decided that she was going to include that information. “I asked the pre-health advisor what she thought about the

choice, and she said that the way that I was implying it in the essay was thoughtful.” Sophia had been worried that it might harm her chances in some way in the application process, but the advisor reassured her. “[The advisor said it was] not going to hurt me because I was explaining it as a foundation for my interest in medicine and then pivoting towards how that has influenced me.”

“[Sophia’s interest in medicine] truthfully was sparked by my diagnosis and my experience with healthcare and it’s certainly not the whole story, which is why I start there and then quickly pivot to how it’s informed or led me to my other interests. [...] so I think it was just the natural place to start and I wanted to be sure that it wasn’t my whole story.” Sophia didn’t want to focus her “whole story” on her personal experiences as a patient in the healthcare system, because the existence of her chronic health condition “doesn’t necessarily explain why I would be a good physician or why I’m prepared to be a physician.”

In her interviews during the medical school application process, “some people brought it up and some people didn’t [...] some people did ask me, I can’t remember the language exactly, but like, if it was hard to have [Sophia’s condition] or what my experience with [condition] looks like. [...] I think I gave maybe a two sentence answer saying that it sparked my interest in medicine and thankfully it’s been well-managed, and kind of left it at that.” Though Sophia had initiated her personal statement with this disclosure, she didn’t want her health condition to be a focal point of her interview – because being a person with a chronic health condition isn’t Sophia’s “whole story.” Much like her experience in high school, her health condition wasn’t central to her premedical experience because it hadn’t impacted her academics in any major way. “I think it was clear from my academic record that having [condition] hadn’t inhibited me from being successful in terms of any of my grades, or MCAT exam, or any of the experiences I’ve had.”

In terms of disclosing in her interviews at various medical schools, Sophia noted that she almost found these experiences more comfortable than disclosing with people outside of a medical setting. “All the friends I have from college and from earlier in my life who know me more fully as a person obviously know my story, which includes my health. I think in the medical setting, particularly in the interviewing setting, I got very comfortable talking about my personal health issues in a way that I never would have done with strangers.” Even in her personal statements, this global disclosure seemed uncharacteristic of someone who seemed to have been previously operating on a need-to-know basis with teachers and professors. “I feel much more comfortable [disclosing in a medical setting] because I think people have an understanding that [Sophia’s condition] is not just one thing. It’s not the severe image that many laypeople have in their mind. And so, I had much less of a hesitation to tell my interviewer or to write my application that I have [condition], because I think people with a medical background can see that there’s more depth to that and that it’s not going to inhibit what I’m capable of.” Even in these high-stakes interviews at medical schools, Sophia felt comforted, and felt that the medical knowledge of these interviewers might even benefit her, because they would have the empirical and experiential knowledge to understand that her condition can vary significantly in severity and impact on daily activities, and that it would not inhibit her from being a successful medical student and physician.

Outside of these scenarios, Sophia doesn’t make a notable effort to disclose to anyone that she is not particularly close with. “If I’m not feeling well and I have a good relationship with somebody, then I’ll tell them why I’m not feeling well, but if I’m fine and going about my daily activities without a problem then, I don’t usually feel the need to share.” Even her interactions with the accessibility services department at her undergraduate institution were limited. “I only interacted with them in terms of housing. I wanted my own space in the case that I had a flare or

wasn't feeling well, and I also wanted my own bathroom for the same reason. [...] Our interaction was largely just me justifying why those accommodations would help me, you know, carry out daily activities just like everybody else." In fact, Sophia never met in person with anyone from the accessibility services department. "I think everything was all documentation and paperwork."

Sophia, as someone who is matriculating to medical school in the fall, has already been in touch with the accessibility services department at her new institution. "So in the same vein that I interacted during undergrad with [accessibility services department] is my intention for medical school." She has already been in contact with a representative from the medical school's accessibility services department and completed paperwork for housing-related accommodations, which were accepted. Sophia didn't request any academic accommodations. "The [accessibility services] office made it explicit that if at any point throughout my time in medical school I need further accommodations or to discuss the services that are available, that they are available to me, but initially all I requested was housing accommodations."

Sophia's condition is chronic but can flare up and worsen at times, so can be quite unpredictable, though it has been really well-managed throughout her undergraduate career. I asked if she anticipated needing or requesting any additional accommodations during her time in medical school. "I think it largely depends on my health, and if I have a flare in my condition or not. My condition has been so stable for so many years that it seems unlikely to me to envision that change happening but it's also unpredictable. And so I'm grateful that the channel of communication is open."

Though she knew that she would be requesting accommodations at whatever medical school she attended, accessibility was not a consideration in building her school list. "I just assumed that all schools would have a disability office that would make housing accommodations

for me. And because the accommodations I request are not academic, I didn't feel that I needed to look into those services beforehand. Maybe I should have.”

In her undergraduate career, Sophia never disclosed to a professor unless it was necessary, such as when they read her personal statement while writing recommendations for her for medical school. In medical school, it seems as though Sophia has no plans for these relationships to shift. “I think so long as I'm performing academically like a typical student and feeling well, I don't feel the need to disclose my personal health information in the same way I wouldn't disclose my personal *any* information to a professor unless it was relevant to what we were talking about.” Given that in medical school, her experiences with the healthcare system might be relevant to course material, Sophia said that she might engage in this academic type of disclosure. “I don't imagine myself hiding the fact that I have more experience with that region of the body [implicated in her condition], and when we learn things that are relevant – and some things that I may already know from my experience – I probably will share that if I'm in a group of people that I'm comfortable with.” Outside of this topical disclosure when academically relevant, Sophia doesn't plan to disclose to her faculty. “I don't think that I would need to tell the professor unless I wasn't feeling well or felt like I wasn't contributing to the group and needed to make a change.”

Though she utilizes housing accommodations and has experience with a 504 plan and interfacing with disability services offices, Sophia doesn't consider herself disabled. “I would say that I have a chronic health condition, not a disability [...] chronic is just a word that feels like it fits with what my experience is.” Her condition is characterized by chronic symptoms. Insofar that her health condition plays into her identity, she acknowledges that it has been a force of change in her life, and has been a source of internal growth and learning. “I think it is definitely a part of my

identity in the sense that it's shaped my story and it's giving me a very different lens on what, on the importance of feeling well and health that many young people may not think about."

However, as seen in her interactions with peers and faculty, it is not a part of her external identity. "In terms of my outward identity, [...] my disability or my chronic illness is not visible so it's not outwardly part of my identity and it only really becomes part of my identity when I disclose that information to close people in my life." Nonetheless, Sophia's experiences as a patient within the healthcare system ignited and honed her interest in medicine. "I think it's definitely shaped who I am and what my priorities are and my value of health [...] Yeah it shapes my values in what I want to accomplish and how I want to help people."

Emily – Medical student

"I'm pretty good at playing the game, which often means keeping my disability in silence."

A current medical student at medical school in the Northeastern United States, Emily met me for an interview in a building on her campus. As we walked through the building's lobby towards the room we had booked for her interview on the third floor, there was an unspoken agreement that we would take the elevator. Students passed us, taking the stairs two at a time, while we waited for the elevator doors to open. We chatted on our way up about the weather, her upcoming exams, and where she was originally from.

Emily had always loved science and wanted to be a doctor for as long as she could remember. "I think growing up, I wanted to go to medical school. I don't think I knew what being a doctor really was, and other than like I was good at science [...] it seems like the natural way to

like combine my academic talents with like an interest in helping people." She studied biochemistry in college in preparation for her medical school aspirations.

A competitive athlete throughout high school, she'd undergone a surgery on her ankle that left her with numerous health issues, despite the fact that she was told that she could be back pursuing her sport after a ten day recovery period. "I was supposed to play [sport] in college, and then suddenly like I couldn't even put a shoe on my foot." Emily completed her first two years of college from her bed as a result of her chronic condition. Portions of her condition were able to be surgically corrected during her undergraduate career, which increased her physical ability. Her close encounters with the healthcare system and with a team of physicians made her realize, "Oh, there's more to being a doctor than just being good at science."

To Emily, a key aspect of being a good physician is that "you really partner with patients during their times of illness." She described her treatment as being highly informed by her future plans to pursue medicine. "I was really fortunate to have doctors who really took seriously that I wanted to be a physician, and they treated my condition aggressively [and] very quickly." Emily's disclosure of her professional aspirations to her medical team meant that they pursued treatment for her chronic condition that was "aggressive but not risky in a way that would compromise my ability to be a physician."

Though Emily's interest in medicine preceded the onset of her chronic health condition, she noted that her experiences as a patient shaped the type of physician she wanted to become as well as her experiences in medical school thus far.

"One of my friends who saw a patient with me, um, noticed that I asked the patient who was sitting in a chair [...] if they were able to get onto the physical exam table. And just like the small question of like, "Are you able to do this?" Not assuming like that it's easy

for them to move. [...] Being able to talk to patients in a way that makes them feel comfortable, that makes them feel heard [...] Humbly, I hope that I do that a bit better than my classmates who have not been through similar experiences."

Emily's entrance into medical school was one where disclosures were made strategically and at key points in her application cycle. She disclosed in her personal statement, writing about the way she conceptualized justice given her experiences. Her condition made her see that "my form of justice was fighting on behalf of people who like me, had a disability, [and] that maybe didn't have the support system both socially and medically that I had." She noted that if it wasn't for the support she received from her family, friends, and medical team, she wouldn't have been able to pursue medicine as a career.

In her interviews with various medical schools, she said, "my goal for the interview was not to talk about my chronic [health condition], but to talk about why I wanted to do the things I wanna do." Emily didn't want to allow the focus to stray to her personal health experiences, and kept her interview conversations professional and academic. Even when an interviewer began to press her on her prospective specialty interests, saying things she felt were incorrect given her experiences as a patient, Emily continued to shy away from bringing up her personal experiences with her health, despite having mentioned them in her personal statement. "So I had to talk about that without saying like, 'I've had [specialists] totally mess me up.'" Emily attributed her non-disclosure in the interview settings to a fear of judgement from the interviewer. She didn't want her interviewer to have any question as to if she could be successful at their medical school.

"Part of me feels like I have to justify that I'm well enough to be here, and that [...] by talking about my [condition], I didn't wanna cast any doubt in an interviewer's mind that I

was well enough to be here. And I think my accomplishments say that and I think it's probably like a personal fear that's probably unfounded to an extent."

For Emily, this trend of non-disclosure followed her to medical school. At her institution, she doesn't talk about her disability outside of her closest group of friends, the accessibility services office, and select administrators involved in arranging her accommodations. "I have like a very close group of friends [at the medical school] who, um, know what I've been through. And that has been an interesting adjustment for me, because the people who had been in my life prior to [medical school] have like been in the hospital with me, have seen me in really tough shape." The transition across the country to complete her schooling also meant that she left behind those who had seen her through the throes of her diagnosis and treatment journeys. "Here, even if I describe what I've been through, people haven't seen it and [...] I don't know, [they] don't see that side of me, because for the most part I am able to keep up with everybody here." Though Emily has been able to forge close and meaningful relationships with peers at the medical school, there's still a distance between those who know the experiences she has had as a patient and those who have only heard retellings of them. "So that's a little bit isolating, I think."

Emily's relationship with the accessibility services at her medical school began before her matriculation. She had heard from other students that some schools were better for medical students with disabilities than others, so she wanted to gauge how each institution she had been accepted to treated students with disabilities.

"So I waited until I'd been accepted, and then I contacted the accessibility services offices at each school, just to find out like what the vibe is, and get a sense of how they treated people with disabilities, whether they were proactive and engaged in with faculty, um, both during the pre-clinical years which they have more control over and then during clinical

years when you're sent out, and you could be working with whomever and they don't care that you have a disability [...] And so I wanted to get a sense of just what the culture was. Um, and I don't think I saw any red flags [at her current medical school]. There's one school that I saw red flags that just didn't seem like it was a supportive place."

Emily's proactive outreach was predicated on her knowledge of what medical education would entail, how her disability might affect her education, and what a "supportive environment" might look like – which required considerable research and effort on her part, beyond all of the other considerations such as location and curriculum that go into choosing a medical school.

Though she feels supported at her medical school, she feels that there is considerable stigma against people with disabilities in medical education. Emily hasn't been able to find meaningful community with other students with chronic health conditions and disabilities at her medical school. "I generally feel like I'm in a group of [...] very healthy, very strong people. Um, and so talking about the ways that I don't feel well doesn't feel good." Not only has she not been able to forge community with other students dealing with similar health concerns, she said she wouldn't even know where to begin to look for this type of peer affinity.

Ethnographer: "Have you been able to find community at [medical school] with other students who have disability or illness experiences?"

Emily: "No."

Ethnographer: "Do you have an idea of how you would go about doing that if you wanted to?"

Emily: "I don't think so, partly because there's a lot of stigma in medicine. Um, and so I don't know that people would be comfortable talking about any ongoing disability challenges."

Emily doesn't share much about her illness experience with others at the medical school. She only shares in the context of requesting or utilizing her accommodations, and though she says she feels "comfortable" doing so, "there's always a line." At times, she feels like she is "asking too much" when she utilizes her accommodations. "Like if I can't attend the day of class, um, and I have to let somebody know that, then I feel like it's inconvenient just because most medical students don't ever miss class." However, she noted that enacting her accommodations in medical school has been easier than her experience in her undergraduate education.

"The awesome thing about medical school is that instructors have no power. Um, so whereas in college, my doctors would make a list of things that they thought were necessary, and they provide that to the accessibility office. And then I'd have to go like share everything with each professor and they'd be like, "Well, I'm not gonna do this. I'm not gonna do that." Um, in med school, like when I need to miss a day, I email the attendance secretary and say, 'I'm not feeling well. I'm not gonna be there today.'"

While in her undergraduate experience it felt like professors could cherry-pick which accommodations they would adhere to and which were unreasonable from their perspective, Emily's interactions at the medical school have been mainly with the accessibility services office to set up her accommodations. She feels that her medical school instructors have much less power over her accommodations or need to know about her medical condition than her professors in her undergraduate education. "If I need a test to be moved on a day because I'm not feeling well, then

I email the dean, and she finds a time for me to make up the exam with a proctor. Um, I never engage with professors. They don't know anything about my situation unless I tell them."

Emily's process for obtaining her accommodations from the accessibility services office was a relatively straightforward one in her eyes. "I had my doctors write a letter saying what my medical situation was and what types of ongoing treatment I might need. And then like a list of suggested accommodations. When the accessibility office here received that, we met in person, and for them I think it was really like once they had some documentation that I had a diagnosed disability, they would really approve any accommodations that seemed like they might be necessary, because there wasn't a way for my physician to predict everything that might come up during medical school." This iterative process of continually reassessing the reasonable nature of accommodations as the needs may arise shows an acknowledgement on behalf of both Emily and the accessibility services office at her medical school that chronic conditions can fluctuate wildly and unexpectedly over a given period of time.

As she moves through medical school and approaches her clinical years, Emily is unsure of how her accommodations might function in this new environment. "I suspect at that point ensuring that I am taken care of will be probably my burden as opposed to the accessibility office. I think that I will have to say what I need to the attending. And if they are inappropriate in a way that doesn't fit with the ADA, then I will say something, but otherwise I'm guessing I'll have to just take whatever they give." She is preparing for an experience where she will become not only her own advocate, but the arbiter of whether or not an instructor is violating the Americans with Disabilities Act. In explaining her disability to her instructors, Emily doesn't necessarily plan to share the name of her condition, just that she has a disability that might make it difficult for her to move physically like her abled peers. She plans to assure her instructors that this difference in her

movement or position is “not ‘cause I’m not interested, it’s because I have a medical condition.” Emily doesn’t plan to consult with accessibility services during her clinical years if she can figure things out by herself. “Maybe I’d probably be more likely to talk to them like if something was going wrong, and I needed assistance. Um, but if, if it goes smoothly, then I probably will just deal with it on my own.”

Emily’s identity as someone who has a disability has ebbed and flowed in the years since her surgical complications. After her surgery, she essentially completed her first two years of college lying down in her bed, until one of her health concerns was resolved surgically. This additional surgery let her “start having fun again,” and in that small moment of recovery, Emily said it was vital to “shed” her identity as someone who was sick “a little bit,” because it was more important for her to focus on “being functional in my work,” not “feeling too emotionally attached to like finding solutions to this condition that I have that is poorly understood.” At the same time, Emily tried to utilize her experiences as a patient to design experiments in her research position that allowed her to model the symptoms she had experienced and understand more about her condition. “So I think there is a balance between like me as a disabled person with a condition that I was studying, and I don’t know. I tried to balance that identity. I think here [in medical school], I find that my experience as a person with a disability helps me to relate to patients.”

Though at this point, Emily notes that she “really embrace[s] my identity as somebody with a disability.” However, that’s not always the case. “I think I try to ignore it sometimes when like I’m exhausted and I wanna get into my bed, and my friends wanna go out and do stuff [...] People our age don’t understand what it’s like to have a disability.”

Despite the lack of community that Emily has found at her medical school, she strongly believes that her future as a physician can assist in breaking down barriers between healthcare

providers and her patients. “There are a lot of people in medicine who have never experienced hardship [...] there's this kind of barrier between the patient and the physician or trainee wherein med students or physicians think it's okay to make fun of somebody's situation – particularly if it's pain or like [they think that] they just want opioids or whatever. Like there are all kinds of stereotypes in every specialty about every type of patient.” Emily has demonstrated her role as someone who works to dispel these stereotypes and remind fellow healthcare providers that: “Even for the person who's seeking opioids – like say they have no medical condition and they're just a person who has a drug addiction – even that person deserves care.” Her experiences as a patient mean that she is knowledgeable about what it means to be a patient as well as a provider.

“It's always harder to be the patient than it is to be the medical student, or the physician. And I think that that's something that gets lost in all the hours that are spent studying and training. [...] Just always acknowledging that it's harder to be the patient, but if the patient is driving you [as a healthcare provider] crazy, it's because they're having a terrible time not because they wanna drive you crazy.”

Emily feels particularly strongly about the presentation of pain in her medical school curriculum. When students say things that are incorrect or might contribute to creating negative stereotypes about patients, she says they have not been corrected.

“And one student said you know, like, ‘Pain is a symptom not a disease,’ which is BS. When pain becomes chronic, pain becomes a disease. Um, and another student said that like, ‘How do you know how to deal with patients who come in when like they're screaming and crying, and saying their pain is at 12 out of 10. Like you don't have a way to prove that their pain is a 12 out of 10. So how do you like decide who to give the opioids to?’”

Emily doesn't necessarily subscribe to this idea that a physician must objectively prove how much pain or discomfort a patient might be in – they just have to treat them with the information that they have.

"And neither student was corrected like to say, 'Well actually, pain can be a disease. Sometimes it's a symptom, sometimes it's a disease,' and nobody corrected the student to say like, 'You don't need to prove that pain is present.' Like if you have a patient and, or say you have this like m- mass, uh, I don't know, like a pain meter and you were able to measure your patient's pain and it said zero out of 10, but they were telling you 12 out of 10. Like you have to treat that patient even if your meter says it's a zero. That's the job you've taken on."

Emily said she doesn't necessarily feel comfortable in large lectures speaking up and calling out a peer when they might contribute a statement that negatively stereotypes certain patients. In small groups, however, she has forged close enough relationships with others such that she can challenge them when she disagrees with their statements, but always in an "academic way."

Ethnographer: "Do you feel comfortable in those situations speaking up and telling [other medical students] that it's offensive?

Emily: "If we're in a small group, I do. There's one student in one of my small groups who says stuff like that and periodically like I will find an academic way of telling [them that they are] wrong."

However, the onus is on Emily to speak up. In her experience in medical school thus far, she has never had a person in a position of power correct a student for statements that she felt were incorrect regarding patient stereotypes.

Ethnographer: Have you ever had an experience where professor, or if a faculty member, or an administrator or someone, um, someone in a position and power told someone that they were wrong about something like that?

Emily: No.

Emily's position at the bottom of the totem pole in medical school at the moment means that she finds herself compromising, both on speaking up and correcting others when they might say things that she has additional insight on given her patient experience, as well as pushing herself beyond her limits physically. She said she knows that "nobody takes me seriously as a [...] medical student, and so I have to accept that and I have to let like ... I have to do things that are hard for me physically." Her goal is to "play the game as it is now so that once I'm a physician – and hopefully people take me seriously – then I can help to change the system."

Emily has entered "the game" with the knowledge that most of the other players have never experienced patienthood as intimately or for as long a period of time as she has. She finds herself compromising and working harder to continue to play a game that wasn't constructed with players like her in mind. "There are not many people with chronic [health conditions] who pursue medicine, because it tries to defeat you at every step. And so my goal for getting through this process was to change the game." Until Emily comes into a position of power in this system, she feels like her experience of medicine is unlikely to change. "I think medicine especially because it's so full of tradition both like of abled people and of men, they're not gonna change until they take you seriously."

MaryAnn – Practicing physician

“I don’t want anything that I do to be like, ‘Wow, you know, blind medical student graduates.’”

MaryAnn Doyle is a psychiatrist who practices at an academic medical center in the midwestern United States. She greets me with a smile and a vibrant virtual background of as we log onto the Zoom call. I found her on a popular social media network, where she used a hashtag and posted content relevant to physicians with disabilities, and even included one of these hashtags in her bio on the site.

MaryAnn was diagnosed at the age of 17 with a vision condition. “Looking back, I had symptoms probably my whole life that just went underrecognized.” She started wearing glasses at the age of four, and had always “had difficulty in school,” especially when it came to reading, whether in a book or on a board. “Teachers, my parents, like nobody really thought it was off. Like, I’m [laughs] not really sure what the thought was. Maybe I guess just that I needed glasses or something.” MaryAnn shrugged. “Nobody really addressed it.”

As a child, MaryAnn had trouble with sports, too. “Colors that are close in the color spectrum are really hard for me to differentiate.” At times, she wasn’t able to see the ball as it came flying towards her. “If you know, a softball was going through the sky and kind of was obliterated by a cloud, like I just lose it, right?”

Though these visual difficulties affected her education and extracurricular activities, her condition wasn’t caught until she was 16. She was in high school and she’d gone to her optometrist for a visit, perhaps to get her prescription updated. It was this clinician, whose primary purpose in her life had been to correct her vision with glasses, who realized that her vision “should actually be able to be corrected” but it “could never be corrected to 20/20.”

MaryAnn was sent to an ophthalmologist to get some testing done on her eyes, in an encounter she described as “very clinical.” The ophthalmologist performed the test and spent “very little time” with her. He presented the test’s findings in a “very scientific way.” “Like, I remember very clearly from that visit, him saying like, ‘Well here’s your macula and it has a beaten-bronze appearance.’ [laughs], and I was like ‘What does this mean, right? I have no idea.’” This “jargon-filled” encounter left MaryAnn wanting more. “Like at the time I’m like ‘I don’t even know what a macular is. I don’t know what beaten-bronze is.’”

At the end of the visit, nobody explained the consequences of her macula’s condition. “That’s how I was diagnosed,” she said. “And it was just wholly unsatisfying.”

Since it was so unsatisfying, MaryAnn didn’t take it very seriously. “It didn’t seem like that big of a deal to me, I guess.” Her diagnosis was just “this strange thing” and she continued to live as she had before. “Not necessarily that I was in denial. It was more that I didn’t, I couldn’t, conceptualize even what it was, and I didn’t have at the time a sense that it was gonna get worse.” Unaware of the consequences of this diagnosis or the prognosis of her condition, MaryAnn continued business-as-usual. “That was just how I lived, kind of, for a while.”

After high school, MaryAnn started college as a nursing major. “That lasted about, uh, a month [laughs].” She swapped to the pre-med track and completed that course of study as well as an English minor.

Ethnographer: “What was the impetus to go into [medicine or nursing]?”

MaryAnn: “I wish I had a really good answer for you. Um, I always envy people that like, you know, say like they knew since the age of five that they were gonna do this. I don’t have anything that profound. [...] Of course, you know, I wanted to help people and give back, but mostly I just found it really interesting.”

She liked the sciences, and in switching from nursing to pre-med, she'd already completed some of the prerequisites. "So that's a completely unsatisfying answer, I know, but that's just the truth [laughs]."

In her applications to medical school, MaryAnn chose to disclose her vision condition. This choice, however, wasn't a straightforward one. "I really, um toiled over [it]." She was caught up in ideas of right and wrong. "I felt like it was almost like an ethical dilemma." Her philosophy then, which she described as different from her current views on the situation, was "Well, I don't wanna not disclose because [...] I was worried about more like [...] if something happened to a patient and I hadn't disclosed, then I felt like I- I would have, like be legally accountable or something like that."

Her choice to disclose in this introductory essay to medical schools was not because she "wanted to set up like an air of transparency or [establish her claim to] accommodations"; it was more like a fear of what would happen if I didn't disclose." Looking back on her actions, MaryAnn would have done things differently. "I think I would have maybe not included it [in the personal statement] and gone through the interview process just like, with my cane and so then I wouldn't have to necessarily disclose anything. It would just be: that's what it is, right?" MaryAnn's cane, which she uses sporadically, is a visual signal to others of her disability – without it, MaryAnn can pass as an abled individual.

"And maybe," she said. "There's not a right answer to this, because on one hand you want to be viewed the same as everyone else, right? Like you don't want your disability necessarily to be front and center when you're applying, because you want to be seen for your accomplishments and be seen as good enough."

This drive to be seen as “good enough,” coupled with MaryAnn’s difficulty accepting her disability, manifested most potently through powerful denial – she’d made it through her first two years of medical school with worsening vision before she got into a car accident while driving. It was two weeks before her Step 1 exam. “Two weeks before my wedding, actually, too.” MaryAnn laughed. “I plan big life events very well.”

“It was a white car, it was a bright sunny day, I didn’t see it.”

This was the breaking point – the juncture at which MaryAnn had to “face the fact that it was getting worse and that it really was like affecting my life in a more concrete way.” She stopped driving, and for the first time, had to begin to disclose her condition. “How I had operated up until that point was just like playing it off. Like my vision wasn’t bad enough that people really could notice right away.” MaryAnn became an “expert” at passing as a sighted individual, “adapting and sort of pretending I could see things where I couldn’t.”

Throughout her time in medical school, she never disclosed much to the institution. “Except then finally I had to do my surgery rotation and I was like, “I have to disclose, like, you know, I can’t, I don’t feel comfortable with somebody on the table and me suturing, like this is a terrible idea.” When she finally told the clerkship director, “nobody did anything about it.” MaryAnn wasn’t offered any accommodations, the school just said, “Okay, you don’t have to, like you don’t have to do that. [...] You still have to take the test to show us that you can do it, but we won’t make you do it.”

“I thought it would be wiser for me to choose a specialty that wasn’t procedural, that I could potentially do even at the prospect of losing sight.” This consideration, coupled with a genuine interest in the field, led MaryAnn to her psychiatry residency in [city], which she had chosen because of the mass transit system. “I knew I wouldn’t have to drive, so I thought it would

kind of allow me to integrate in a more normal way.” Not only had her choice in specialty come at consideration of her disability, but even the location of her training depended on the ability to “integrate” with other trainees.

“So for the first three years of residency, again, like my vision was getting worse, but I still could play it off fairly well, though it was getting harder.” The reliance of physicians on electronic health records, stored on computers, posed an issue for her vision-based disability. “It was taking me longer to do things on the computer, ‘cause of the bright background.” Nevertheless, she persisted – continuing to “play off” her deteriorating vision and working around her disability.

Much like her medical school experience, it wasn’t until the very end – in this case, her fourth year of residency – that she approached her program director for assistance. “By this point, like I’m not driving, like I’m not seeing well, I think my current vision at that point was like 20/200. Like I was legally blind, but I wasn’t carrying a cane.” MaryAnn went to her program director, asking for a computer program that could change the display settings such that they’d be more accessible to her – “she was like shocked. She was like ‘I had no idea.’ And [laughs] I’m like, ‘Really?’ ‘Cause I wrote about it in my personal statement. And to me that was disclosure.’”

The program director said to her, “You know that you have the right to have accommodations, right?” MaryAnn knew accommodations existed, but she didn’t realize that her employer could or that they were obligated to provide them for her. “And I didn’t even know what to ask for, to be honest.” The residency program was able to get her a computer with the specialized software and “it was life changing.” Having this interaction with her program director and discussing her right to accommodations meant that, when she applied for her fellowship, she knew who to ask and what to ask for.

MaryAnn struggles with being “totally out there with [her] disability.” She says it’s difficult because of a lack of mentorship and representation in the field. “I’m in a couple of leadership positions and I don’t have any examples of people with disabilities that have, you know, even been in medicine and then also been in leadership positions.”

This power hierarchy is also something to which MaryAnn attributes her growing comfort with disclosure and more visible manifestations of her disability, such as her increased use of her cane.

“As a trainee in medical school, you’re constantly facing and making these like, split second decisions of like, ‘Do I disclose? Do I not? I don’t know.’ And it’s hard, right? Because medical school’s hard enough when you’re like just trying to learn the information. [...] Then when you’re doing it while also trying to kinda navigate these, like, really tough decisions, it just makes it even harder.”

However, she’s made progress in her level of comfort when it comes to disclosing her disability. “It’s been easier for me to disclose the farther in my career [that] I get.” As an attending physician now, MaryAnn now finds it easier to disclose to her trainees. “It isn’t that hard for me to disclose with learners [...] and I don’t know if it’s because I feel impassioned about trying to set an example and normalizing it, or if it’s because of the hierarchy thing?” She’s not as “afraid of the perception” in interactions with her learners – the “perception” of what, goes unsaid for a while. Disclosing to learners “is a lot easier than like going into like a board meeting or something with people I report to; that, that’s a lot harder for me. ‘Cause again, the perception thing is sort of what I fear. Like I don’t want to appear incompetent.”

MaryAnn has started using her cane more recently, but this wasn’t always the case. She’s had more physical injuries than she can count – “falling, or tripping and scraping my knees, and

running into poles” – and still, it’s taken a dramatic decline in her visual acuity to prompt her to begin to use her cane more often. Her husband used to ask, “How do you cross the street?” and she’d reply, “I just wait until I don’t hear the cars coming from the other side.”

Ethnographer: “What spurred those past decisions not to use a cane when doing things like crossing the street or walking outside?”

MaryAnn: “Denial, I think [...] being worried about what other people thought [...] it’s not necessarily like good reasons. But we’re all human, right?”

MaryAnn: “And I think also stubbornness, too. Like you know, we medical students and all, we’re just like cut differently, right? I kind of have this belief that if you work hard enough, you should be able to solve a problem, right? If you’re smart enough, you should be able to solve it, and so it’s been really frustrating to me that I haven’t like been able to solve this, right?”

This drive to solve problems and create systems to deal with her declining visual ability proved frustrating for MaryAnn. “At some point, my vision got bad, [...] even the systems I had in place weren’t working.” Her frustration mounted. In her mind, she should be able to fix this, to find a solution for the issues she was facing without needing to utilize her cane, the only visible symbol signifying her disability to those around her. “[I had] this idea that [...] I can outsmart this blindness.”

MaryAnn has found immense support in her current position – her current boss was one of the first people to make the effort and approach MaryAnn about what her needs might be. “At first I found [these interactions] kind of jarring, but it’s just been like, okay, well what do you need? Are you getting what you need? What can we do to make things easier for you? And I was like, ‘Wow.’ Like nobody had ever asked me that, right?” Her position is now one where she can

practice, take on leadership and educator roles, and feels “like my experience adds value to the department.”

In her relationships with patients, this openness dissipates. “I’ve never used the cane in front of a patient. Which is nuts.” MaryAnn mused that perhaps she would have acted differently had she been in a specialty besides psychiatry. “Psychiatry is just so different than other specialties.” The methodology she was trained under taught her to focus on the patient – “you never wanna make it about yourself, right?” She chooses not to use the cane in front of her patients, partially because she feels it might take away from the environment of honesty and transparency that she fosters in her practice. “I don’t want to necessarily make patients feel like they can’t be honest with me if they’re struggling, right? Like I don’t ever want them to feel like ‘Well I can’t say anything because you know [pause] *she* has problems.’”

Though she is confident in this choice given the way that her disclosure might affect therapeutic encounters, she also questions it. “Am I modeling a good example? [...] Like if I’m trying to tell them that they need to be them, their genuine selves and accept themselves [...] and then I’m not doing it, like isn’t that kind of hypocritical?” MaryAnn answers herself. “Yes.”

She thinks back, as she did with her medical school interview process, and decides that she would have done things differently. “At my current job that I’m at, I probably just should have started using a cane from the get-go.” At the beginning, it might have been hard, but then again, “once people get to know you, it just is what it is.”

Despite her secure position at her institution, MaryAnn exhibited considerable frustration with the lack of doctors with disabilities – she’s lacked mentors with disabilities her whole career. When I asked, when the first time was that she met a physician with a disability, she mentioned a conversation with a blind psychiatrist at another institution when she was searching for her first

job. “That’s really like the first time I remember really ever having a conversation with somebody that I really truly felt like knew what I was experiencing [...] But that’s really unfortunate now that I think about it.” She hadn’t met this mentor until she was starting her job as an attending. “Medical school, residency, no.”

There were these half-baked efforts, though, from peers who meant well, to connect her with people with disabilities in the medical field. “People would tell me stories like, ‘Oh yeah I had a friend who had cerebral palsy and went to medical school,’ or something and it was like, ‘Okay. [pause] That’s not very helpful.’” These attempts to connect her with the few other instances of disability in medical education that they had seen had peers equating MaryAnn’s experience with that of someone with a vastly different disability. “It kind of like made me actually feel like I belonged in this other category.”

“I hope none of this is deterring you from pursuing this profession,” MaryAnn laughed. “I would choose this career again, like believe it or not [...] any journey has its challenges, so absolutely I would do psychiatry 100 times over. I love my job [...] I just think that there is lots of room for things to be, you know, better and more supportive.”

Chapter IV: Disclosure

"I am definitely, um, a bit nervous about like, trying to figure out navigating when it's worth, um, disclosing to try and get accommodations, and when it's just like easier to not [...] medicine isn't always the most accepting place, and it's sometimes easier to just like conform, um, and not ask for any accommodations."

Katherine, matriculant to medical school

Rites of Passage and Their Limitations

In this section, I theorize the act of disclosing a non-apparent or non-visible disability as a rite of passage. The human experience, especially in an American cultural context, is rife with rites of passage. I have utilized this theoretical framework as a result of its deep roots in the discipline of anthropology as I explore the trajectory of becoming in the culture of biomedicine, a highly hierarchical environment defined by the movement between discrete social roles, and the experiences of identity that refuse to slot neatly into this structure. The rite of passage that comes most easily to mind, perhaps as a result of its significant disruption by the COVID-19 pandemic, is graduation from college or university. I employ this archetypal example to illustrate the “ideal type” of rite of passage before exploring the nuances and complications of identity and affiliated rites.

College graduation neatly fits into the tripartite structure of a rite of passage laid out by Van Gennep (1909) and expanded upon by Turner (1969). First comes the separation stage, where students are sent away from their homes to live and study for four years. They are surrounded

predominantly by others like them in age, mindset, and ambition, and this detachment from the rest of society separates them from their prior identity as children or teenagers, and places them in a completely different category. Individuals in this category have increased autonomy yet considerable oversight. Their identity as a student is quite different from that of their high school experience, and they are, at least at residential institutions like Dartmouth, predominantly living outside of their prior cultural context of home and family.

The liminal stage of graduation as a rite of passage comes at the moments after the final exams are taken and papers are turned in, yet before students hold their diplomas in their hands. Liminal entities, as defined by Turner, are those which lie “betwixt and between” social positions assigned by cultural conventions (1969). In the graduation example, these individuals have finished their college careers, effectively shedding their identity as a college student, but are not yet a college graduate. In this between state, one might use an identifier that signals the dual occupancy of these social positions, for example, “I’m a graduating senior.”

A key aspect of the liminal stage of rites of passage is communitas, a coming-together of individuals collectively undergoing a rite of passage in which they recognize and codify the “generalized social bond that has ceased to be and has simultaneously yet to be fragmented into a multiplicity of structural ties” (Turner 1969). Everyone dresses in their identical caps and gowns for a graduation ceremony, sits together, and then afterwards, go off with their respective family and friends to start new lives outside of their identity as an undergraduate student.

Reaggregation, the “consummation” of a rite of passage, leaves the ritual subjects in relatively stable states once more, though in different social roles than they began the rite of passage process from (Turner 1969). It places these subjects into a clearly defined social role that,

although new, fits neatly into the structure of a given community, such as this transition between college student and young professional.

Disclosure of a disability or chronic health condition, as I conceptualize this rite of passage, does not fit neatly into this tripartite structure, simply because it lacks what reaggregation requires: the complete shedding of the previous social role in favor of a new place in the societal structure. As disability is not a social role or structural type, and is instead an intractable identity and identifier, the ritual subject may not ever fully separate themselves from this entity as is required by the rite of passage structure as defined by van Gennep and Turner. In this chapter I acknowledge the connections to and limitations of the rite of passage theoretical framework in relation to experiences of disability in medical education. I posit that disclosure as a rite of passage functions not as a movement from one social role to the next, but as pedagogy and methods of seeking out *communitas* in the cutthroat world of biomedicine.

I focus on the intense experiences of separation seen in my participants, who acknowledge the fundamental mismatch between bodies and minds with disabilities and the culture of American biomedicine. It is perhaps the most potent form of separation when an individual cannot be their whole self in their interactions with others – such as when students with disabilities do not disclose this aspect of their identity for fear of discrimination or bias in the medical school admissions process. I linger on the seemingly unending experiences of liminality present in those who must simultaneously inhabit roles of physician and patient, and the chronic nature of this liminal identity, especially on those with non-apparent or non-visible disabilities. I theorize not a phase of reaggregation, as we might expect given the structure laid out by anthropologists past, but of constant negotiation and mental calculus moving forward in one's life. In contrast with the rite of passage theory focused on social roles, undergoing this rite does not drastically change or shift an

individual's life such that they now have no difficulties disclosing in other contexts. Instead, much like the subjective experiences of those living with and "recovering from" schizophrenia-related disorders, these constant negotiations of the self are "gradual and incremental," and "manifest in the mundane facets of everyday life" (Jenkins & Carpenter-Song 2006). Participants report weighing all of the possible repercussions and benefits of a disclosure before sharing their identity with someone, whether that be a peer, a parent, a supervisor, or a medical school admissions committee, and find that sharing with these diverse audiences leads to a variety of responses and possible consequences in their personal, academic, and professional lives.

For those with visible or apparent disabilities, this rite of passage might look quite different. At the time that the participants in this study applied and matriculated to medical school, none of them had a visible or apparent disability, which is why this conversation of disclosure focuses on the experiences of those with invisible conditions. There is an element of privilege that comes with invisible disabilities, because these members of the community can pass as being abled when necessary, but also an additional burden of navigating these continuous conversations of disclosure when someone with an apparent disability may not need to explain their accessibility needs. Katherine, a participant with an invisible disability, said that her condition is sometimes so invisible that she felt out of place taking part in this study at times during her interview.

"But I'm like really privileged in terms of like, it's really sometimes a choice for me whether I want to pass, and just like not have accommodations, or ask for them. [...] I think I'm really privileged of that because my disability is like invisible, and often not always something that I cannot bring up if I don't choose to. It's like, I'm going to have to figure out how I wanna navigate it.

I feel like the entire time I've been talking, like I feel like I do still kind of like, I'm just kind of coming to this at the end of like, I feel like I do sort of still feel a bit of like a disconnect of like I almost feel guilty being part of this [study]. It's like, I know that on the

spectrum of people who are having to navigate [disability and chronic health conditions] while applying to medical school, I am like so incredibly privileged of like that I have the privilege of like choosing whether or not I disclose, and like the privilege of like doing well on the MCAT even though I was denied for accommodations, and like, so I think that I still sometimes feel like, oh, like I don't even know if I should be included [in the disability community].”

Katherine, matriculant to medical school

The end of this excerpt from Katherine’s interview hits upon a key point – for those with invisible disabilities, disclosure is integral to identifying to others as having a disability and receiving the benefits of accommodation, affinity, and community with others who have disabilities or chronic health conditions. For those who can still achieve traditional metrics of success without accommodations (although it may be much more difficult than if they received their accommodations), it becomes a question of “Do I have the right to disclose? Do I have the right to be included in the disability community?” Disclosure serves many purposes, one of which is to forge community and interpersonal bonds with others who share this identity.

Disclosure as a rite of passage is incremental – someone with a disability cannot untell someone else their disclosure – yet nonlinear – the patterns of environments in or individuals to which people with disabilities disclose or do not disclose don’t always follow a logical direction. One participant disclosed to me, a complete stranger on the other side of the country, yet has not disclosed to her own family. In this section, I will dive into the mental calculus described as contributing to disclosure decisions, as well as what I hypothesize to be the heavy weight of *communitas* in the context of this ethnographic inquiry. The environments and interactions that prompt disclosure are numerous and nuanced. In this study, I explore disclosure on the local and

global levels, as well as how the rite of passage of disclosure is formed within the context of institutions, academic settings, and clinical practice.

Disclosure as Pedagogy

While there is a certain universal right to privacy ideally granted when it comes to health-related information, in order to access accommodations or assistive services, as one is legally entitled to, a person with a disability must approach an accessibility professional, human resources employee, event coordinator, etc. and disclose their condition to receive these services. In doing so, they must effectively educate these gatekeepers on their specific condition and/or accessibility need. Thus, accessibility gatekeepers receive specific instructions on which gates need to be opened, for how long, and why the opening of the gates are necessary. Without such education, these gates will remain closed as a baseline, normal state.

This theme of marginalizee pedagogy, the need for the marginalized community to speak up and educate their oppressors about the trials they face, echoes that of the Māori and Pacific Islander women in Alison Jones' 1999 paper, "The Limits of Cross-Cultural Dialogue: Pedagogy, desire, and absolution in the classroom." She speaks of, within a classroom of diverse students, the way in which the "colonizers" – white students – "grant hearings" to the "subalterns" – non-white students, specifically those of Māori and Pacific Islander descent – in order to incorporate these diverse perspectives into their education (Jones 1999). Insofar as doing this, the white students have essentially cast the non-white students in a pedagogical role, and what was meant to become a sort of dialogical pedagogy turns into a full-blown lesson on marginalization, taught by the marginalized group, which in turn, only serves to highlight this unequal power dynamic as they fulfill a role and trope created by their marginalizers (Jones 1999). We see this same type of

“marginalizee pedagogy” – that is, those being marginalized being pushed to educate their oppressors about the lived experiences of that perpetrated oppression – in the disability accommodations request process, in which students must detail much of their medical history and/or personal struggles to arbiters of accommodations and assistive services, as well as the everyday personal, professional, and sociocultural lives of people with disabilities, specifically invisible ones.

In the #DocsWithDisabilities community, there are a few striking examples of premedical and medical students reaching out for assistance in educating their medical schools on experiences of disability and the need for accessibility in the application process. Some ask for help with MCAT accommodations, or advice when their requests for accommodations have been rejected, whether or not they should disclose their disability in their medical school application, and still others ask for guidance on accommodations conversations with their medical school advisors.

One prospective medical school student wrote: “Have received advice on whether I should disclose my deafness in my med school app. If disclosure, how do you explain to med schools what it’s like to have a disability in a limited number of characters b4 interview invite?”

A current emergency medicine resident tweeted: “Help please! I'm an EM resident & need help with ADA accommodations. I had a MVC and now have hearing & vision problems. my hospital denied a lot of the accommodations my doctors requested. does anyone have experience with residency & ADA? #DocsWithDisabilities #AccessInMedEd”

Another prospective medical student posted: “Do you know anyone who's successfully obtained extended testing time on MCAT due to their deafness or other disabilities? I'm building my case, and I'd like to know others' positive experiences of receiving extension. #DocsWithDisabilities”

That these students and young professionals are turning to the #DocsWithDisabilities community with these concerns is a testament to the strong group the hashtag has built, full of possible professional mentors and advisors, but is also a saddening statement on the accessibility of in-person help for future physicians going through these sociocultural and bureaucratic issues. That a resident who was in a car crash is being denied accommodations at their place of work has to turn to Twitter is harrowing – they received minimal yet well-intentioned help, but might even want to pursue legal action should the issue continue. Placing the burden of teaching others about disability issues and accommodations is not only undue for people with disabilities, it is unfair, and could even result in discriminatory treatment by school and hospital officials who are not familiar with accessibility regulations. In cases such as these, for an individual with a non-apparent or non-visible disability to disclose their condition is to be placed into the position of expert or teacher for an institution, to assume the burden of teaching others how to provide for them, however it is necessary to disclose in order to receive the accommodations that make completing their training possible.

Institutional Disclosure

In the journey from premedical student to becoming a physician, individuals with disabilities have multiple touchpoints at which they may disclose their disability to institutions that they are or wish to be affiliated with. The ones I focus on include medical school admissions essays, standardized tests such as the MCAT and CASPer (in the context of receiving accommodations), medical school interviews, and interactions with the accessibility services offices at medical schools that individuals have applied or been accepted to.

The Medical School Admissions Essay

The medical school admissions essay is 5,300 characters that applicants are instructed to “use [...] to explain why you want to go to medical school” (Harvard OCS). Students vary wildly in terms of the topics that they choose to focus on in these essays, but all relate to their interest in pursuing medicine as a career choice. Some students use this space to talk about gaps in their academic record, or their personal or family background. “If you believe you grew up in a situation that could be described as disadvantaged, you are allowed to explain this [in the personal essay]” (Harvard OCS). For students with disabilities, this essay poses a critical question: To disclose or not to disclose?

Participants who I chatted with who had not yet begun their medical school application processes were largely unsure of whether or not they would disclose their disability or chronic health condition in their personal statements. Some cited this decision as a source of stress or anxiety, and mentioned the need to speak with advisors in their institutions pre-health professions advising office to assess any possible impacts disclosure might have on their education. One participant mentioned that her psychiatric condition, which she attributes to abuse during her childhood and teenage years, contributes to her status as a “disadvantaged applicant.”

“I think that, in a weird way, med schools probably actually want more disadvantaged students so that they can brag that they have them. You know, it's that weird thing where I... you know, I feel like on paper, they want it to be one thing. But, in practice, they probably want something else. Like, I don't know. I'm honestly very conflicted on all of it.”

Amy, premedical graduate applying to medical school

Whether or not medical schools are looking with particular interest or sympathy towards students labeled in their applications as “disadvantaged” was unknown to my participants, and the extent to which a participant considered themselves to be disadvantaged as a result of their disability varied greatly between individuals. Amy told me that in the medical school application, there was a “box you can check” that labels your application as that of a disadvantaged applicant.

“I don't want to say that there's already a strike against me because I'm already applying as a disadvantaged student. And like, I know that... like- like [my pre-health advisor] told me, literally, a million times that it's not a bad thing to apply as a disadvantaged student, but like, [laughs] disadvantaged's in the name. And, you know, I don't know.”

Amy, premedical graduate applying to medical school

Amy, as an applicant with a psychiatric condition, was particularly concerned about the admissions committees at medical schools finding these “strikes” against her. Her status as a disadvantaged applicant with a disability caused her considerable nervousness about her future success in the medical school application process.

“I have not yet decided [whether or not to disclose her disability in her personal statement.] I was going back and forth on that last year too just 'cause, like, right, you'd like to think that the world is a loving and warm and accepting place. But, like, I like I know that a school would see my history or my disabilities and everything, right. And like, that would make me a gamble to a lot of places, unfortunately. I think that what I've gone through has made me stronger as a person but I could see a lot of people seeing that as a liability, which is a shame. So, yeah, I really don't know.”

Amy, premedical graduate applying to medical school

Amy's worry is not unfounded. Participants and informants cited feelings of inequity in the treatment of applicants with disabilities who applied for entry to medical school and even residency programs.

"I usually tell people that if they ... if their disability is a big part of their identity and it is related to, like, why they want to be a doctor and they want to put in their personal statement, then they should do it. But that, it could have, like, negative repercussions because a lot of admissions committees are just like a lot of people, ableists."

Phillip, practicing physician

This subjectivity in whether or not an individual should disclose in their personal statement based upon how much they consider their disability to be a part of their identity is something that can contribute to the anxiety on behalf of students when making this decision. If their disability is "important enough" they should mention it, however they may also mention it to explain academic difficulties or any gaps in their record. This double-edged sword of personal statement disclosure means that disclosures might be seen for students who inhabit one of these extremes – those who have lived with their disability and have accomplished traditional metrics of success set forth by non-disabled individuals, and those who have lived with their disability and been unable to meet these metrics of success.

"Somehow [doubts of the possibility of medical school success for an individual in the context of admissions] doesn't sound, every bit as like redneck and backwards to them as like, you know, the ethnic stuff. So it's like, it's just, people think it's just like fair game, and um, and so if you don't need to disclose it, if you don't have to disclose it, I mean there may be gaps in people's records that they need to explain, leaves of absence or whatever,

or maybe they've got an awesome story like, you know they started an organization for people with their own disability or something."

Phillip, practicing physician

Disclosing disability, in the minds of the applicants and in the experiences of those reading the applications, might open the window for admissions committee members to doubt someone's suitability for medical school, or their possibility of finishing medical training successfully. Some participants flat-out recommended to future applicants: don't disclose if you don't have to.

"And so, my recommendation would be that if you have an invisible disability, like, don't mention it. And once you're admitted, then you can disclose your disability and ask for accommodations. But it won't impact, um, you know, whether or not [admissions committee members] think you're capable to finish."

Phillip, practicing physician

Participants also acknowledged that there are many cases in which applicants do not have the choice whether or not to disclose their disability.

"For me, I feel like it's better if they don't know I have anything going on, you know. I hate that I'm saying that because I know, right, like, if someone is blind or if they're physically disabled, you know, like they're gonna have to make it very explicit that this is something they're dealing with and that's definitely something that the med school is gonna weigh and take into account."

Amy, premedical graduate applying to medical school

The privilege of "passing" as non-disabled was brought up by multiple participants. These individuals were ones who knew that, if invited for an interview at a medical school, their

interviewers wouldn't be able to tell that they had a disability or chronic condition without expressing it in their personal statement or talking about it during their interview.

A medical student I interviewed said that she did in fact write about her disability in her personal statement, specifically as it related to her drive to enter the medical profession and her passion for justice and righting the wrongs of the world.

"I wrote about my disability [...] My condition that made it see that my form of justice was fighting on behalf of people who like me, had a disability, um, that maybe didn't have the support system both socially and medically that I had, and I hadn't been able to pursue this track."

Emily, medical student

Emily is a student who wants to enter the specialty that her condition falls under. She has done considerable scientific research on her condition and is driven towards making continued medical progress for those who have the same chronic disease. This rite of passage of institutional disclosure functions for Emily –intentionally or not – as informing the institution of her identity and the fact that she might request reasonable accommodations, as well as showing the admissions committee her deep connection to medicine and the reason for her dedication to it as a future path.

Katherine, who has been accepted to medical school during the most recent application cycle, talked about her experience writing the "diversity statement." The diversity statement, an essay in addition to the personal statement, might ask a question such as:

"Do you consider yourself a person who would contribute to the diversity of the student body of our medical school?

How will you contribute to the diversity of your medical school class and [medical school]?

At [medical school], we are committed to building a superb educational community with students of diverse talents, experiences, opinions, and backgrounds. What would you as an individual bring to our medical school community?

What makes you special, someone who will add to [medical school]'s community?"

(Harvard OCS).

Katherine noted that "it's like beyond the realm of this interview of how it's kind of like inherently problematic" to ask medical school applicants to write diversity statements. Though she has never disclosed her disability to her parents or family, she ended up focusing on her learning disability in her diversity essay.

"Um, so yeah, like I don't fall into, um, like a lot of the categories that people would typically, um, typically like discuss in a diversity statement. [...] And I felt like I kind of like, I honestly didn't really want to discuss [my learning disability] in my, uh, application because I felt like it's not very central to who I am academically [...] and then I ended up writing my diversity statement about [my learning disability] and, um, because I was like, okay, like, while this isn't central to, um, like who I think I'm going to be as a physician, I think like what they're trying to get at in those diversity statements is like, 'How do you relate to other people? How does your positionality help you, like see other people?'

Um, and so I guess I just kind of like wrote about how like my experience of being told like you can't simultaneously be academically high achieving, and disabled has kind of like made me a little bit more aware that perhaps in some people about how like the people's experiences, and how they identify as complex, and like people can unexpectedly fall into categories that when you meet them you wouldn't, um, expect. And I think that like, as a physician, um, I hope that like when I meet a patient just because they present in one way, I'm able to like put my assumptions aside a bit more than perhaps some other people would based upon my own experience of, um, the support they might need for me that I like don't expect just based upon the how they superficially present."

Katherine, matriculant to medical school

Katherine's explanation of her rationale behind focusing her diversity statement on her disability acknowledges the disconnect between her personal identity and her condition – she received her diagnosis later in life and has always been very high-achieving academically. To her, it seems antithetical to who others think she is that she also has a learning disability. However, she explores her disability as an identity that makes her “diverse” within this statement, and critically, connects it back to why having a disability would make her a better physician.

The Medical School Admissions Interview

In the medical school interview, schools hope to evaluate an applicant’s personality, professionalism, and maturity (Harvard OCS). Interviewers want to “to hear your motivation to pursue medicine in your own spoken words; to hear how you have tested and confirmed your desire to become a clinician; to learn if you have realistic expectations of life as a physician; and to decide if you are going to be a great colleague and peer” (Harvard OCS). Applicants are advised to prepare extensively for these interviews, and “anticipate what might concern the interviewer (e.g., poor grades, disciplinary action). Have an explanation ready that is not an excuse or rationalization” (Harvard OCS). Pre-health advisors stress that “if you write something in your personal statement, you may be asked about it in an interview. If you do not wish to speak about it in an interview, do not write it [in your personal essay]” (Harvard OCS).

For students with disabilities, the interview can be another opportunity to disclose a condition not previously mentioned in application materials. Some medical school interviews are “open” with regards to the applicant’s file, meaning that interviewers have read an applicant’s materials before interviewing them, while others are “closed.” For “closed” interviews, where the interviewer has not read the applicant’s personal statement where they disclosed their disability, the student may or may not choose to re-disclose to the interviewer.

Emily, for example, disclosed her disability in her personal statement but strayed away from mentioning it in her medical school interviews.

“There's always a part of me that like I continue to deal with [chronic health condition] and it's m- part of me feels like I have to justify that I'm well enough to be here, and that by ca- by talking about my [chronic health condition], I didn't wanna cast any doubt in an interviewer's mind that I was well enough to be here. And I think my accomplishments say that and I think it's probably like a personal fear that's probably unfounded to an extent.”

Emily, medical student

Though an integral motivator for her pursuit of medicine as a career, Emily did not feel comfortable talking about her chronic health condition in her medical school interviews, despite the fact that she had already disclosed in her personal statement. This hesitancy to continue to disclose and engage in pedagogy indicates Emily's worry: that she would talk too much about her disability to the point that her interviewers might doubt that she could handle medical school.

Katherine similarly disclosed her disability in her application materials, but in her case, she mentioned her learning disability in her diversity statement, which was only sent to certain schools.

“Honestly like the interview days kind of like melt together in my mind. But I guess like, I was always a bit like hyper aware, um, the night before the interview. I would always like reread the materials, um, I had sent to the schools. I was like, ‘Okay, does this school know I'm [disabled]? Like, is it a possibility it's going to come up.’ Usually in the interviews they like don't really reference your application materials a lot. [...]”

There was just like one time at this school that, um, they... both of my interviewers, um, were like old white dudes and, um, they... one of them made like another kind of like... I, I work as a rape crisis counselor. He made some like, kind of yikes comments about sexual assault, and like, so I was already kinda like a bit on guard. Um, and then he like, at the

end of the interview he was like, ‘Oh, awesome, my daughter’s dyslexic. It’s amazing that you have made it this far in your education.’

And I was like, “Uh, okay, thanks?” Um, like I guess it was like a bit concerning that he was like so amazed that I had made it that far, when he was like the person interviewing me [laughs].”

Katherine, matriculant to medical school

Katherine expressed concern at her interviewer’s comment. His amazement at her academic success was not simply because Katherine, having attended a prestigious university and scored very well on her MCAT exam, had proved her intelligence. It was caveated by her experience living with a disability. *Despite* living with a disability, he marveled, she made it this far. Katherine took his comment in stride and ended up being very successful in the medical school application process, but these comments are pervasive as qualifying success in medical education (or any field) “despite” living with a disability, rather than “because of” or “alongside” experiences with disability and illness, as other participants have described.

The heroizing of Katherine and other people with disabilities echoes a specific type of story told within disability media studies: that of the “supercrip.” When portrayals of disability in the media are not villainous or linked to the dark side, disabled characters are often played as “remarkable achievers,” who, against all odds, “triumph over the tragedy of their condition” (Hartnett 2000). The supercrip stereotype depicts a person with a disability who, through “astounding personal endeavour” essentially “overcomes” their disability. This trope is criticized as it emphasizes overcoming disability in order to be content or successful in life. Non-disabled individuals conceptualize stories of disability in ways that non-disabled listeners can comprehend, because they fit into their cultural concepts of what disabled characters are like.

Specialty Choice and Residency Applications

Though limited as no residents were participants in this study, other participants and informants mentioned the role of disclosure in the process of choosing a specialty and applying to residency programs. In conversations with accessibility services at medical schools, no details of a disability that a student discloses to an accessibility staff member can be shared with admissions officials at any residency program the student applies to.

“I don't know if a resident app-, residency applications or at some point they're supposed to know. So students will have reluctance to, if they have like, let's say they're struggling with like severe depression or something and they have to disclose to me and they're like, ‘Well, will I have to put this on my residency application?’ to which I say, ‘You do what you think you need to do. I am not going to say anything. None of the information you share here is going to go there,’ with the idea being that they do need to be careful because you know, although they're not supposed to discriminate, discrimination happens. Right.”

Brandon, medical school accessibility services staff

Four years after a student makes the choice whether or not to disclose to medical schools in their applications, they are faced again with this decision when applying to residency programs. Despite their proven success in graduating medical school, key informants admit: “Discrimination happens.” Moreover, the responsibility of deciding whether or not to disclose always falls to the student. Accessibility staff and advisors can give their opinions, but many acknowledge that it is up to the student to decide the best course of action. Placing the onus of this decision on the student means that many reach out to mentors they may have in the field – though as MaryAnn mentioned in her interviews, it is incredibly difficult for young students to find mentors with disabilities in

the medical profession – to ask for advice. Phillip frequently receives requests for advice from premedical and medical students, as well as young trainees.

“Um, I never, I never tell people not to disclose, but I don't ever really encourage them to disclose unless they really want to. And I think the same is true for, so, so m- medical schools, so med school is different compared to a residency, right? Because your MD degree is like an undifferentiated degree. You are a pluripotent MD graduate who theoretically can enter any subspecialty, right? And practice medicine.

And as an undifferentiated degree you're not expected to be an expert transplant surgeon or whatever. But you know, I think that if you've got, um, a disability that is going to become apparent either like very quickly or like going to, that you know is going to affect your training or make it even difficult for you to do your training or finish your training, that, that's a harder one because you will generate a lot of animosity if you match somewhere and like didn't tell them upfront that you know, that you didn't tell your surgical program director that you have like, um, you know, a peripheral neuropathy that makes it hard for you to do surgery or something. You know what I mean?

Um, we don't wanna, at the same time we don't wanna encourage people to like over disclose. So it's just a fine line. I try to, I mean, look at my whole philosophy has been like, don't do things that are just, feel like banging your head up against the wall, right? Like if, like this is a marathon not a sprint, you know, you're going to be practicing medicine, so you're 60 or 70 or whatever, right? E- even the old, an old doctor one day. And do you really want to be like fighting every minute of your career to do something that's so difficult?”

Phillip, practicing physician

Phillip’s advice here, as a practicing physician with a disability who frequently receives requests for advice from younger individuals in the community regarding disability-related issues, is integral to residency choice for physicians with disabilities. As exemplified by MaryAnn’s portrait in Chapter III, some students with disabilities make their residency choice at least in part based upon their disability, such as those dealing with blindness or vision loss entering psychiatry.

If choosing a specialty in which “your disability will become apparent very quickly or make it even difficult for you to do your training,” non-disclosure might be seen as lying or faced with animosity from others, as residency spots are quite competitive. In terms of residency choice, it seems that students with disabilities cannot feasibly make this decision without acknowledging, internally or externally, their disability and the associated accessibility needs that may impact their training.

Liminal Experiences of the Physician-Patient

In the discipline, Talcott Parsons’ “sick role” is often invoked in scholarly discourse surrounding experiences of patienthood and illness, contrasting with his theorization of the “physician role.” Existing in the in-between means that physicians with disabilities or chronic conditions don’t fit neatly into this “sick” or “well” role dichotomy. I specifically find issue with Parsons’ theory in regards to experiences of chronic illness. Parsons’ definition of the “sick role” posits that if someone is sick, they have the following rights:

The sick person is exempt from normal social roles (i.e., the roles that govern functionalism and measure worth based upon contribution to society)

The sick person is not responsible for their condition, and cannot be expected to get well by an act of decision or will.

The sick person has the right to be taken care of.

They also have the following obligations:

The sick person must want to get well.

The sick person must seek technically competent care (Parsons 1951).

These rights and obligations may be viewed as problematic and are frequently broken, skewed, or misapplied in discourse surrounding chronic illness. I believe there's a liminal space in which patients with chronic illnesses exist, where they lose the rights Parsons affords to sick individuals and increasingly must attend to and perform Parsons' obligations.

People with chronic illnesses often hear "I hope you feel better soon," from well-intentioned individuals, even after they have been told that their only course of action is to simply continue managing their symptoms as much as possible (Omejer 2019). Despite the good intentions, the assumption that illness is only temporary undermines the lived realities of chronic illness. The infinite, seemingly hopeless, and often invisible nature of chronic disease can make others believe that the individual does not want to get well, which is a critical obligation in Parsons' theory (Parsons 1951). The disconnect between the sick role's supposed desire to become well and the understanding of the reality of chronic illness means that people with chronic health conditions often have to perform to a greater extent Parsons' first obligation and show others that they truly want to get well.

Many with chronic illness cannot fulfill the normal social roles, which are largely dependent on working and being "productive" in an American cultural context. However, this doesn't stop them from trying – especially before patients are diagnosed, many are pushing themselves beyond their limits. In the American workplace, it is often viewed as a sign of commitment to personal development when employees push their limits, but this practice can seriously impact your physical and mental well-being, especially if you have a chronic illness (Haagaard 2019). Instead of being exempt from normal social roles, as Parsons states, people with chronic illnesses often have to work twice as hard to fit the mold of a productive contributor to society.

Few professions revel pushing oneself to the limit more than medicine. Physicians, especially those in training, subject themselves to subhuman conditions including lack of sleep, poor exercise and diet routines, lack of emotional support and stress relief, and more (Gutkind 2011). This exercise in extreme ability not only means that physicians are at higher risks for substance use disorder, overdose, and suicide (Berge et al. 2009), but also that the physician role is not easily amenable to chronic illness experiences. In addition, Parsons' implicit dichotomization of the sick role and the role of the physician is a poignant example of the hidden curriculum – further positing that these roles are separate and cannot be inhabited by the same individuals (Parsons 1951). The dissonance that comes with the blurring of the physician-patient line is explored in tales of physician experiences of substance use disorder, physicians and the aging process, and physicians who become diagnosed with illnesses.

In Parsons' conceptualization of the physician role, doctors are “affect-neutral” beings who leverage their technical knowledge to help patients, albeit with a good deal of emotional distance between them (Parsons 1951). Patients are meant to submit to the expertise of their doctors, as Tolstoy writes about Ivan Ilyich’s encounter with his physician: there was a “meaningful air suggesting that you just submit to [the doctors], we’ll fix everything – we know, we have no doubts about how to fix everything, in the very same way for any man you choose” (Tolstoy). Thus, when physicians become patients – or more rarely, it seems, when patients become physicians – these lines effectively blur. There is less ability to be affect-neutral as Parsons writes, and a certain cognitive dissonance that comes with moving in the space between asserting oneself as a physician and submitting oneself to other physicians in different contexts.

Becoming a physician-patient is an entry into a liminal space, one in which physicians may begin to understand the way that their patients see them and the ways that they might, just by being

a doctor the way they were taught to be, exacerbate the patient's illness experiences (Biro 2000). This complexity is noted in multiple participant portraits in this study. The general consensus by these participants is that their continued experiences as a patient will make them an empathetic, "better" doctor.

In an example of the physician-patient, an older physician is being cared for in the hospital by a young doctor. The older doctor knows well the industrialized nature of the hospital, which he refers to as a factory, and laments the current state of healthcare (Joseph 2018). He calls for a return to the fundamentals of doctoring – listening to know the patient, caring beyond the symptoms – and in doing so, advocates for a very Kleinman-esque delineation between simply treating and fully healing the sick (Joseph 2018) – showcasing the way in which the physician-patients can in fact leverage their lived experience to improve care. Overall, Parsons' differentiations between the well and the sick, as well as the sick and the physician, fail to acknowledge the liminal spaces taken up by individuals who cross the boundaries freely – namely, people with chronic illnesses and physician-patients.

Chronic Liminality

In this section, I posit a framework for understanding the temporality of liminal experiences and explain the difference between acute liminality, that which is short-lived and within rites of passage that are defined by movement between discrete social roles, and what I call chronic liminality, which is an inhabitance of the liminal space that will not come to an end as a result of its tie to an individual's self and identity. Acute liminality is liminality, such as that faced by the Ndembu chief during his initiation, or the challenging situation we find ourselves in the midst of, that the participants of which know will come to an end, likely in the near future. Chronic liminality is liminality, such as that faced by chronic illness patients or physician-patients, that the

participants of which know will not come to an end. Thus, they must learn to exist in this space, betwixt and between well-defined, fixed opposites.

As an individual with a chronic illness, I exist in the liminal space between sick and well. I am not sick enough to be in the hospital, yet I am not well enough to exist in this world without difficulty. Much of my experience within this liminality is underscored by the invisibility of my condition. In environments when I am not actively identifying in the liminal space, I passively find myself being expected to conform to the fixed, stable identity of a well or abled individual. “Passing” as a fixed or stable identity (such as able-passing in this case) seems to be a key factor in understanding these invisible, chronic liminal conditions of humanity.

By virtue of these chronically liminal experiences being invisible to others, they can become isolating and foster a specifically strong communitas within the disability community – that is, when individuals disclose their liminal identities to others. As aforementioned in this study, receiving the benefits of communitas, of sharing in a common experience, is dependent on the individual feeling comfortable enough within that experience to name it, and to outwardly identify with it (Turner 1969). In naming the liminal experience – in chronically ill individuals or physician-patients identifying outwardly as chronically ill or disabled – there comes a power. Outwardly identifying as an otherwise invisible identity can be a form of empowerment, and generally opens the necessary doors to welcome empathy and communitas through community organizations, advocacy, and activism. However, as people with disabilities are marginalized groups within our society, and disability is not truly welcomed as an additional form of diversity in the medical education system, there are also risks associated with publicly disclosing one of these invisible liminal identities. For invisible experiences of liminality, if one does not take it upon themselves to outwardly identify as a “liminal person,” they may not have access to the

resources, community, or empathy implicit in experiences of communitas. As such, disclosure and one's actions therein can directly impact the access to these resources for those with invisible and chronic liminal identities.

Disclosure as a Rite of Passage

Though disclosing one's disability does not directly follow the tripartite structure of a rite of passage as traditionally defined within the discipline, I argue that it functions similarly, including experiences of separation, liminality, and constant renegotiation rather than acute reaggregation. Disclosure in the context of medical education can contribute to marginalize pedagogy, opening the door for non-disabled individuals to ask those within the disability community to educate them on their needs, as well as communitas, as seen through the discussion of the magic of the ethnographer's disclosure. Future research directions should expand this work to be more intersectional, and specifically look towards queer studies as a scholarly intersection on themes such as disclosure, passing, and what I refer to as chronic liminality.

Chapter V: Conclusion

“Because, you know, I've heard [from someone who] sits on the admissions committee and, um ... tells me about conversations that go on that shouldn't. [...] It's like nobody would ever say like, ‘Oh my god, they're Black. They'll never make it through medical school.’ [...] You know, it's like, sounds like the Ku Klux Klan in Mississippi or something, you know, but nobody has any problem saying like, "They've got Crohn's disease, how are they ever gonna make it through medical school?" You know. So like, "Oh, oh, they've got schizophrenia. Oh yeah, but they, they're gonna have a nervous breakdown on the wards and it's going to be a disaster." You know? And somehow that doesn't sound, every bit as like redneck and backwards to them as like, you know, the ethnic stuff.”

Phillip, practicing physician

In this thesis, I have forefronted the nuance of lived experiences of disability and chronic health conditions in the context of “becoming” in medical education. Through detailed portraits of participants at varying stages in their trajectory to physicianhood, I expose the minutiae of the disabled experience and the ways in which it exists in manners extraneous to the rigid structures of biomedicine. I argue that the experiences of disability and chronic illness in medical education cannot be confined to the theoretical framework of rites of passage, and that additional thought and theorizing must be employed to fit them into narratives of liminality, with specific attention to be paid to the temporality of their liminal states.

The Magic of the Ethnographer's Disclosure

In reflecting on my triplicate identity, I noted how it shaped the creation and design of this study, interactions during recruitment, and the conversations I was able to have in my ethnographic interviews with participants.

Disclosure, as noted in Chapter IV in regards to the medical school admissions process, is highly context dependent. Participants weigh the expected reactions and repercussions of disclosing their disability to others. I observed and deeply value, throughout this study, what I call “the magic of the ethnographer’s disclosure.” It would start at the beginning of an interview with someone, usually from another institution who I had reached out to via a cold email, with a participant asking me how I came to be interested in this topic, or what my post-graduate plans were. In establishing rapport, participants were subtly asking the question: “Why should I share my story with you?” By agreeing to participate in this study, these individuals had already indicated to me that they self-identified as having a disability or a chronic illness. Now, they wanted to know my side of the story.

If a participant asked about my interest in the work, or my post-graduate plans, I answered them honestly, telling them that I’m a student with a disability hoping to go into medicine. Sometimes, participants dug deeper, and my positionality and personal experiences were brought into the conversation as we explored topics such as the process of requesting accommodations.

Phillip: “Well, do you ever feel guilty asking for accommodations? What kind of accommodations do you use?”

Ethnographer: “I mean, yeah, I think, um, I know one of my big ones is, in terms of housing, especially on campus, you know, I live on the first floor, or in a building with an elevator and I think that has led to me, you know Dartmouth is a very old campus and so the only

buildings that are really like truly like first floor accessible, there are no steps to get into the building or that have elevators, are usually the newer ones, the nicer ones.”

Phillip: “Mm-hmm.”

Ethnographer: “And so I remember being like a sophomore and getting a room in, in one of the nicest dorms on campus. And everyone was like, ‘How did you get that? Like, what was your housing lottery number or whatever.’ And I was just like, ‘Oh, like, no, I was just really lucky.’ Um, but I remember feeling guilty about that because I mean some of the dorms are quite old and, and not very nice. And so, um, but-”

Phillip: “But w- would you mind telling me what your disability is?”

I was taken aback. Even in my interviews with participants, I was not asking questions about their disability or illness as blatantly as this individual did. No one else had asked me about my personal experiences in this level of detail. Perhaps this openness was a dual result of my initial disclosure as an individual with a disability as well as his position as a practicing physician – perhaps there was a bit of academic curiosity. So, I explained to him the chronic conditions that I live with.

Ethnographer: “Um, so yeah, it onset in my freshman year of high school, um, I ended up using a wheelchair for a while, and kind of never really getting back to, like we talked about before, like playing soccer and like being as active as I had previously been. I think there's, there's definitely, uh, the upper bound of my activity is, is much lower.”

He continued to ask questions about my condition. This was an exercise in interpersonal disclosure that I wasn't planning to have on this call, especially not with a practicing physician who works at a medical school that one day I might be interested in applying to or attending. I

tried to reflect, in the moment and afterwards, why I was so caught off guard by his questioning, when I was, albeit in a more subtle manner, asking the same openness and vulnerability of him? In the transcription of my speech, I'm struck by my seemingly excessive usage of filler words in a setting where I am otherwise relatively concise and organized. This interaction underscored the importance not only of acknowledging your positionality as an ethnographer, but of the participants' rights to question your authority and inquiry within their personal spaces.

Phillip: "Did something trigger the [chronic condition] or did it just work gradually or what did, what happened?"

Ethnographer: "It was, they never really knew what, you know, like, um, what had triggered, if anything had triggered it, but it had seemed like something had, because it was like a quite rapid onset of, you know, I had been feeling sort of, you know, not great for a couple of days, I knew I was coming down with something and then I, I woke up one morning and just like really couldn't, uh, move or, or walk. Um, yeah, so definitely a, an existential crisis for a 15 year old who, you know, I thought I was gonna be on Broadway by now [...]

Phillip: "Your disability is hard; you've got something that people don't even know what it is or what causes it. And some people think it's all in your head."

Within this magical space, the ethnographer discloses, and identifies themselves as not only a researcher, but a fellow community member. This work goes upon establishing friendly rapport with a participant – it asks of the ethnographer the same type of vulnerability it does of its participants. It is in this way that I argue that this study was complicated yet enhanced by my triplicate identity – academic, advocate, and applicant. Without it, I am unsure if I would have

been able to recruit enough trusting participants to take part in this study or if my participants would have shared their experiences as openly with me.

As people with disabilities, we often espouse, “Nothing about us without us.” Perhaps in these cases of the ethnographer’s disclosure, participants with disabilities feel comfortable sharing “about” themselves, knowing that this work is not “without” an intimate knowledge of disabled perspectives at the forefront.

Future Intersectional Inquiry and Research

I write here to point to directions for future research within this underrepresented area of the scholarship, as well as mitigate the sense of loss I have felt as the ethnographer as a result of not being able to include all that I have learned over the last year about this topic and these participants into this work.

Going Beyond Disclosure

Disclosure, though integral to the experiences of individuals with non-visible or non-apparent disabilities, is but only one frame through which to approach and structure the inclusion of the theoretical in this work. In reapproaching this work as I hope to do post-graduation, I hope to dive deeper into accommodations request processes and the types of disclosure and storytelling done within them. Storytelling, as I’ve written about in past work on this topic, is key in the creation of the disabled self, both internally and externally. Future work must investigate the stories told about physicians with disabilities by themselves, by others, and by mainstream media to more fully understand this population’s place within the American cultural context.

Individualism and Self-Sufficiency

There is a code in my work that I was not able to include in this iteration but that I've titled "suck it up." It is featured across participants and most memorably in Abigail's narrative, where she reveals internalized stigma and a drive towards the individualism and self-sufficiency so prized, not only in American biomedicine, but in American culture in general.

"I think also like there's always been a part of me that's like, why can't you just like suck it up and be a normal person? Which obviously is not something I can just do. But I think sometimes I feel a little bit embarrassed about just not being able to like function at the baseline level that a lot of my peers can."

Abigail, premedical underclassman student

Future research must delve deeper into the American cultural psyche and its impacts on individuals with disabilities, especially in their pursuit of a medical career. The instinct to "suck it up" reflects the value America places on productive bodies and minds, and the way that people with and without disabilities can see the disability community as falling outside the bounds of "productive" as it is traditionally defined. In this way, individuals with disabilities have been told to accept not being able to meet standard metrics of success – "to suck it up." The concept of being able to pull oneself up by one's bootstraps, where if you're not succeeding you're just not working hard enough, can prove particularly pervasive and damaging for individuals with disabilities. One participant noted the role of this ideology in her diagnosis process with a behavioral disability.

"Basically what I was told just to sort of accept this performance that I was having [in school], like, 'A B is not that bad.' Or like I failed seventh grade algebra test and I went home and I redid it on the kitchen table and I got like an A, my mom was like, something's messed up. And my math teacher was like, "Well, some people just can't do algebra." Um,

and like the person that I saw for mental health stuff was more along the camp of just sort of like, ‘You’re being too hard on yourself.’ Um, instead of, ‘Mmh, maybe there’s something we can do to help you like, maybe there’s a reason why you’re not performing to what you think is your potential.’”

Sally, premedical upperclassman student

Once Sally had been diagnosed, however, she found that, with accommodations and by “meeting [her] brain halfway” with targeted study habits that differed from her peers, she was able to perform at her full potential.

“Um, but the diagnosis process I mean it was hard, but like it was truly transformative because I think... Oh gosh, I’m just going to go for it. Um, basically before that I... there sort of has a disconnect between what I like thought I was capable of and what I was producing. Um, and so having a diagnosis sort of validated the fact that like if I took certain steps and if I sort of met my brain halfway that I would be able to perform to what I thought I was capable of.”

Sally, premedical upperclassman student

Sally describes this transformative diagnosis process as one of her main drivers of going into medicine, and acknowledges that within this culture, she functions differently than other students when it comes to the time and effort she puts into studying, and her methodologies for retaining information. “A person with [condition] is successful when other people don’t know they have [condition],” Sally noted. The invisibility of her experience, as well as the time it took for her condition to be diagnosed and appropriately treated, come as direct results of the culture of individualism and self-sufficiency even at the elementary levels of America’s education system.

In a career where hierarchy is king and the responsibilities are super-human, where individuals are not educated on their rights to accommodation in the classroom and workplace, and where only 2.7% of students identify as having a disability to what extent do students and physicians with disabilities find themselves “sucking it up,” and in what contexts? To what extent does the hidden curriculum present in medical education and training contribute to the feeling that students with disabilities must “suck it up” and succumb to individualist systems that prize productivity over sustainability?

Intersections with Queer Theory

Though there is still so much to be explored in a conversation of liminality as it exists in chronic illness patients and physicians with disabilities, I offer a possible direction for intersectional, interdisciplinary future research between medical anthropology, disability studies, and queer studies. Individuals who identify as LGBTQ+ face many similar experiences of disclosing an otherwise invisible or non-apparent aspect of their identity, and the possible discrimination or biases that may stem from others’ perceptions of this identity. Individuals with invisible chronic conditions or disabilities and those who identify as bisexual also specifically experience what I refer to as chronic liminality. Additional research in the future should include a discussion of disclosure and “coming out” in the queer community and its connections or disconnections between the conversations of disclosure had by participants with disabilities and chronic conditions.

Representative Medicine

A goal of this thesis at the outset was to explore representative medicine, the idea that our physician workforce should be representative of the diversity of patients that it serves, and its impacts on the disability community. However, this was nearly impossible given the limited

sample of participants in this study and my hypothesis that there aren't enough physicians in practice who outwardly identify as having a disability for the disability community to feel the benefits of representation in the physician workforce.

In future research, which will hopefully expand the sample of participants with whom I interact, especially those who are residents and practicing physicians, special attention will be paid to the narratives of physicians who have treated patients with disabilities. Additional inquiry might also include speaking with patients with disabilities about their interactions with physicians with and without disabilities.

Concluding Remarks

I find immense comfort in knowing that this thesis is not the end of my foray into this research. It was impossible for me to encompass all of the many nuances of my participants' and informants' experiences into this work, and even if I could, I acknowledge that my sample was limited and less diverse than would be ideal for a full exploration of this issue. I am beyond grateful to have an advisor and participants that are eager to continue supporting this work, as the intersections between disability and medical education are underrepresented, both in anthropological scholarship as well as general discourse within biomedicine. In investigating and honoring the lived experiences of those within this community, I feel confident that we may forge a path towards increased inclusion and accessibility in medical education, such that individuals in the disability community may widely feel the benefits of representative medicine. A range of my participants believed that their experiences with disability and chronic conditions will or do make them better physicians. They cite increased empathy, knowledge of the patient experience, and a desire to be the type of doctor that they never had during their diagnosis and treatment experience.

In beginning to understand the lived realities of physician-patients through this thesis, I plan to ask in future research: Does becoming a doctor-patient make you a more patient doctor?

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