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Un/covering: Making Disability Identity Legible

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Abstract

This article examines one aspect of disability identity among people with non-apparent or "invisible" disabilities: the decision to emphasize, remind others about, or openly acknowledge impairment in social settings. I call this process "un/covering," and situate this concept in the sociological and Disability Studies literature on disability stigma, passing, and covering. Drawing on interviews with people who have acquired a non-apparent impairment through chronic illness or injury, I argue that decisions to un/cover (after a disability disclosure has already been made) play a pivotal role for this group in developing a strong, positive disability identity and making that identity legible to others. Decisions to pass, cover, or un/cover are ongoing decisions that stitch together the fabric of each person's daily life experiences, thus serving as primary mechanisms for identity negotiation and management.

Introduction

This article examines one aspect of disability identity among people with non-apparent or "invisible" disabilities: the decision to emphasize, remind others about, or openly acknowledge impairment in social settings. Although many studies have examined how and why stigmatized people attempt to pass or cover in order to avoid association with a stigmatized group, this paper examines why, how, and with what consequences individuals with acquired and intermittent impairment seek to do the opposite, namely, call attention to their difference in order to assert their disability identity. I call this process "un/covering," and situate this concept in the sociological and Disability Studies literature on disability stigma, passing, and covering. Drawing on interviews with people who have acquired a non-apparent impairment through chronic illness or injury, I argue that decisions to un/cover (after a disability disclosure has

already been made) play a pivotal role for this group in developing a strong, positive disability identity and making that identity legible to others.

I begin by putting three bodies of literature into conversation with each other: the social model of disability and theory of complex embodiment; studies of stigma and passing; and intersectionality analytics. I then provide a brief description of the larger project from which these data are drawn, introducing the participants of an ethnographic study of living with acquired, non-apparent impairment. I then present data drawn from two case studies – the life history of a young man with impaired vision and the experiences of a woman pursuing advanced education after a traumatic brain injury. I draw on theory and sensitizing concepts (Ragin 1994; Bowen 2006) from the previously discussed literatures to orient and explain my findings.

Background

The Social Model of Disability & the Theory of Complex Embodiment

Disability Studies scholars have thoroughly documented the ways in which physical and cognitive impairments have been conflated with "disability" – the latter being a socially constructed status that is dependent on cultural, economic, political and historical context (Shapiro 1993; Linton 1998; Longmore & Umensky 2001; Heyer 2002; Heyer 2007; Schweik 2009). During the latter half of the twentieth century, disability rights activists worked to replace the Medical or Individual Model of Disability with a Social Model that emphasizes barriers to participation in society for people with impairments, and squarely situates disability in the interactions between an individual and the social or built environment (Linton 1998; Longmore & Umensky 2001; Switzer 2003; Barnes and Mercer 2003; Shakespeare 2013.)

Disability theorists are currently wrestling with the binary approach of the Medical versus Social Model of Disability. The Medical Model of disability essentializes disabled people and stubbornly denies the tautological trappings of defect-based classification schemes. By contrast, the Social Model holds the promise of all social constructionist theories: through the power of spreading awareness and cultural reframing, ascriptive differences can be effaced. Tobin Siebers (2008) offers a sustained critique of theorizing disability solely in one or the other of these realms. Siebers builds on feminist scholars' discussions of complex embodiment (Butler 1993; Erevelles and Minear 2010) to argue that particular social locations produce specific epistemological perspectives that simultaneously spring from, and are inscribed upon, the body. In so doing, Siebers (2008) seeks to disrupt overly social constructionist interpretations of disability while reinforcing the need for identity politics. Siebers traces the rise of identity politics in the 1960s and '70s that helped minorities recognize each other and coalesce into groups with shared interests that led to group-based political demands. Siebers argues that as identity politics in academe gave way to social constructionism, the focus was less on shared experiences within each minority group and more on hegemonic norms and attitudes that shape those experiences.

Just as feminist scholars have pushed back on strong social constructionist theories by claiming that such notions erase the materiality of the body (see Wendell 1989; Butler 1993), disability theorists work to re-insert the importance of the bodily experience of living with impairment, including the pleasure as well as the pain and exhaustion that often accompanies such bodies (Siebers 2008). Siebers notes:

> Many social constructionists assume that it is extremely difficult to see through the repressive apparatus of modern society to any given body, but when they do manage to spot one, it is rarely disabled. It is usually a body that feels good and looks good – a body on the brink of discovering new kinds of pleasure, new uses for itself, and more and more power. (2008: 59)

The theory of complex embodiment urges us to conceptualize the experience of disability as a form of complex embodiment, one that sutures together experiences shaped by the social and physical environment but also firmly rooted in the concrete day-to-day experiences of the materiality of the body. Understanding the experience of disability as complex embodiment centers the individual as well as intersectional experience while exposing alignments between one's experience and those of other disabled people.

Linking one's individual experiences to institutionalized practices of discrimination is part of the iterative process of identity-building and group affiliation. Social cognition theory and symbolic interactionism provide important insights for understanding identity. Social cognition theorists locate identity in both group membership (*social identity*) and personal characteristics (*personal identity*). Language, Howard (2000) argues, connects the two traditions, as collective and individual voices generate identities along differing dimensions in differing contexts. Studies of individuals with physical impairments confirm that identities are interactively constructed through language and are contextually dependent (Charmaz 1995; Low 1996; Engel and Munger 2003).

This paper builds upon the studies described above, acknowledging the importance of socialization in disability groups but also highlighting the importance of visibility of impairment in developing a personal disability identity. My results bolster the findings of a small body of scholarship that has explored the differing experiences of individuals with static impairments compared to people with chronic illnesses, people who Susan Wendell (2001) calls the "unhealthy disabled." These scholars document the ways in which people who experience inconsistent levels of impairment due to disease or flare ups are often not fully embraced by disability communities and are sometimes viewed as not legitimate representatives or activists of the disability movement (Wendell 1996, 2001; Humphrey 2000.) Evelyn Nakano Glenn's work on formal versus substantive citizenship illuminates the role of visibility in shaping how groups draw boundaries for their members. She states: "it is matter of belonging, which requires recognition by other members of the community" (Nakano Glenn 2011: 3).

For people with non-apparent impairment, membership in the disability community requires constant, active assertion of one's status, as they can never rest on their status being 'seen' by

others. As a result, complex embodiment takes on a more nuanced dimension for those living with non-apparent impairment, as their membership (and associated stigma) must be established and re-established in an ongoing process of identity assertion.

An Intersectional Approach to Stigma, Passing & Covering

Studying people with invisible impairments provides a unique and important window into to stigma management. Stigma management centers on individuals' ability to control their "discredited identities," meaning, as Goffman puts it: "visibility is crucial" (1963: 48). Individuals with impairments that are both invisible and intermittent have the widest possible range of options open to them for managing stigma, as they may choose to fully disclose, partially disclose, or hide their impairment.

Scholars in virtually every sub-area of sociology have studied stigma and the consequences of living with a stigmatized status. Erving Goffman, in his book *Stigma,* defines this term as "an attribute that is deeply discrediting" (1963: 3). Goffman points out that to understand stigma we need "a language of relationships, not attributes," underscoring the interactionist nature of stigma specifically and identity more broadly (1963: 3). Stigma has also been widely studied by health researchers and social scientists exploring illness (Zola 1982; Frank 1991, 1995; Chaudoir & Quinn 2010). Psychologists Stephanie Chaudoir and Diane Quinn (2010) studied how the first time a person discloses a stigmatized identity correlates to psychological health, finding that positive first-time disclosures are associated with a variety of long term psychological benefits (while negative experiences result in long term detriments.)

This paper also builds upon the work of scholars seeking to add much needed layers of theoretical complexity to the analysis of stigma and passing. Renfrow's examination (2004) of "everyday passing" provides a framework for examining the reciprocal dynamic between presenter and audience in the dance of identity management, delineating reactive passing (being misconstrued as something one is not) from active passing (asserting one is something one is not). Shiri Eisner's analysis (2013) of coercive and intentional passing complements Renfrow's framework while highlighting the power dynamics that are sustained, resisted, or negotiated through passing. Siebers' work (2004) on the disability masquerade also reveals important power dynamics in decisions to pass or disclose. Siebers' borrows the "masquerade" from queer theory to distinguish less discussed forms of disability passing that include exaggerating impairment, feigning one disability to mask another, refusing to overcompensate for impairment, and engaging in disability drag to reinsert agency and political resistance into passing dynamics.

Perhaps the most critical work on disability passing comes from an anthology edited by Jeffrey Brune and Daniel Wilson (2012), which examines the causes, consequences, and framing of passing for varying groups including polio survivors (Wilson 2013), athletes (Rembis 2013), those with mental illness (Cox 2013), and slaves in the antebellum South (Boster 2013), to name just a few. One of the primary strengths of Brune and Wilson's collection is the intersectional approach taken by its authors who critically examine the many dimensions not only of disability

identity, but also class, gender, race, and sexuality, insisting on historicized accounts of marginality.

Applying an intersectional approach to identity that embeds social constructs in their time and place is of paramount importance in analyzing disability, particularly studies of individuals who must actively work to establish disability identity. Feminist scholar Nira Yuval-Davis (2006) urges identity scholars to avoid additive approaches to conceptualizing multiple minority statuses, arguing:

> The point of intersectional analysis is not to find "several identities under one" …. This would reinscribe the fragmented, additive model of oppression and essentialize specific social identities. Instead the point is to analyse the differential ways by which social divisions are concretely enmeshed and constructed by each other and how they relate to political and subjective constructions of identities. (2006: 205)

Disability Studies scholars have taken up this challenge and produced insightful analyses of the intersectionality of disability and race (Erevelles and Minear 2010), disability and gender (Wendell 1989, 1996), and disability and sexual orientation (Eisner 2013). Incorporating intersectionality into the analysis of identity highlights the tensions that occur when individuals feel they must hide or minimize one identity in order to preserve or bolster another in a given context. These ongoing decisions stitch together the fabric of each person's life, consisting of the primary mechanisms for identity negotiation and management.

While managing one's identity, it may cost people with an "invisible" impairment more at some times than others to pass as nondisabled or "normal." As a result, many may choose to partially disclose, or engage in what Goffman (briefly) refers to as "covering" (1963: 102). Covering is an "adaptive technique" used by stigmatized individuals in social situations to reduce the visibility of their stigmatized condition (Goffman 1963: 102). Goffman argues that virtually all stigmatized individuals will engage in this behavior to some degree: "many of those who rarely try to pass, routinely try to cover" (1963: 102). In this way, people with invisible impairments may find their experiences more closely aligned to those of the LGBTQ community who cover their sexual identities. Kenji Yoshino, a Japanese-American lawyer who is openly gay, writes of his experiences in which he and others like him are discriminated against and pressured to downplay their racial or sexual identities. In the introduction to his book *Covering,* Yoshino muses about "an uncovered self" (2006:3) but focuses his analysis on the myriad pressures to cover. Yoshino defines covering as occurring when "the underlying identity is neither altered nor hidden, but is downplayed" (2002: 772). Both Goffman and Yoshino note that covering is used by members of minority groups to assimilate into the mainstream.

This paper makes a unique contribution to Disability Studies by examining the reverse process, that is, active efforts to resist assimilation into the mainstream of nondisabled norms. Drawing on the Social Model of Disability, theory of complex embodiment, and sociological understandings of stigma, the case studies presented here demonstrate the seemingly

ubiquitous contexts in which people with non-apparent impairments are encouraged to pass and the consequences of ongoing decisions to resist that pressure and un/cover.

Data & Methods

This paper presents excerpts from data collected as life history narratives from twelve individuals living in the Pacific Northwest with non-apparent, intermittent impairments resulting from illness or injury. The terms 'life histories,' 'life stories' and 'narratives' have been used widely across the social sciences, in some cases to mean specific techniques, and sometimes used interchangeably (Chase 2005; Laslett 1999; Plummer 2001). Here I use the terms "life history narrative" along with "life history" to mean a narrative account, or a series of narratives, about a person's life before and after acquiring a non-apparent, episodic impairment. Through multiple interview sessions with each participant, I solicited life history information around important moments of disclosure for each respondent, asking them to discuss and reflect upon what Robert Zussman (1996) calls "autobiographical occasions." An autobiographical occasion is a socially contingent moment in which the respondent is called upon to organize, interpret, and present a slice of her life. Social scientists have treated autobiographical occasions as those when individuals must present their histories or disclose information to institutional representatives (e.g., case workers, police officers, doctors, researchers) or to friends or intimates when prompted by a key event (Zussman 1996, 2000; Leonard & Ellen 2007). Taken collectively, these moments present more than a collage of people's lives; when contextualized in the analysis of the group, these moments can provide insight into the underlying social processes of this population. Robert Zussman (1996: 143) argues that biographical tales are "made distinctively sociological by their placement in an analysis of a particular social situation or social type" and that through situating personal narratives into their social, historical, and political context we can gain insight into the complex relationship between society and the self.

Collecting life histories allows researchers to analyze the narrative as process as well as text. The act of organizing and making sense of experiences is both shaped by and shapes identity (Engel & Munger 2003; Smart 2010; Bathmaker & Harnett 2010; Cortazzi 2001; Zussman 2000). Cortazzi (2001) highlights the interactive nature of narrative, acknowledging the ways in which both researcher and respondent engage in the co-construction of meaning during the act of narration. He argues that the act of narration is "an interactive process of jointly constructing and interpreting experience with others, therefore, narrative analysis is potentially a means of examining participant roles in constructing accounts and in negotiating perspectives and meanings" (Cortazzi 2001: 384). As process, the narratives provide further insight into how identities are constructed in the moment, that is, how information is dispensed, reflected upon, and used to construct new meanings, perhaps not considered before the autobiographical occasion of the interview. William Tierney (2000: 546) highlights the spaces opened by conducting personal narratives, asserting: "Life histories are helpful not merely because they add to the mix of what already exists, but because of their ability to refashion identities." In this light, the narrative as process becomes not only an object of analysis, but an opportunity for growth, reflection, and potentially, resistance: "…a goal of life history work in a postmodern age

is to break the stranglehold of metanarratives that establishes rules of truth, legitimacy, and identity" (Tierney 2000: 546).

Following the tradition of many narrative scholars, this paper presents a small number of in-depth case studies and endeavors to keep individual narratives intact while connecting those to large socio-historical and political processes. Narrative analysts (sometimes called "narratologists"), highlight the importance of not breaking apart discrete narratives or stories, arguing that stories are "essential meaning-making structures" and particular quotes or sections should not be disembodied from the narrative whole (Riessman 1993: 4). This type of analysis is used to develop narrative typologies, identify underlying structures, or add to topical genres. Narrative typologies span substantive areas, including heroic agency and tragic fate tales among the unemployed (Ezzy 2000), conflict narratives among teens (Morrill et al. 2000), and origin myths told by parents of disabled children (Engel 1993). This paper contributes to the narrative genres of disability identity development and stigma resistance through analysis of strategic passing and un/covering.

The data presented here reflect a largely white experience of acquired impairment, as only one participant in the study is a person of color. Three men and nine women crafted individual biographies through a series of interview sessions in which we also revisited and revised prior discussion topics. The youngest participant was 29 years old at the time of interview; the oldest was 54. The time since diagnosis or injury also varied notably– roughly 30 percent of cases were diagnosed within the last 3 years, while 30 percent of cases were diagnosed between 10-15 years prior to interview. The most recent diagnosis occurred within 1.5 years of the interview; the oldest was 18 years. All the participants in this study had attained at least some college education: three participants had or were in the process of acquiring a doctoral degree, four had master's degrees and two had completed bachelor's degree. Seven participants were working full time at the time of interview, one was working part time and four were unemployed and not looking for work.

Although all participants have some level of higher education, a wide range of occupation and income levels are represented (and do not map neatly onto education level). Participants include a person who is homeless, teachers at institutions of higher education, biomedical researchers, a security guard, students, health care workers, and government employees. Participants reported impairments associated with car accidents, head trauma resulting from accidental injury or violent assault, Multiple Sclerosis, Crohn's Disease, Chronic Lyme Disease, macular degeneration, cancer, and digestive disorders. Three individuals were recruited through personal referral; six responded to flyers posted at neighborhood clinics or chronic illness specialty clinics; and three were recruited through announcements posted at food banks. The names of participants have been replaced with pseudonyms to protect their privacy.

Importantly, each case presented here involves impairments that may be temporary and/or non-apparent. As a result, these individuals have the widest range of options available to them of fully disclosing, passing as non-impaired, or attempting to cover or minimize their

impairment (Goffman 1963; Yoshino 2006). This decision-making process (and its consequences) reflects and shapes understandings of disability identity.

Findings

All twelve participants described regular efforts to minimize attention to impairments in the work place and social situations. Tammy related her habit of using a shopping cart - even when purchasing only one item - to lean on in stores when she is feeling weak because using a cart makes her seem "more normal" than would an assistive device. Marvina explained that she regularly uses her child's old stroller to carry things from and to her car rather than a more convenient device because no "one ever asks questions" about the stroller. Nina described using "loads of caffeine and sugar" (despite many detriments associated with this) to get through social events in order to avoid drawing attention to her fatigue. Lionel described his efforts to regularly "fake eye contact" during conversations because he doesn't like to be "divergent" of "social expectations." Participants described a variety of motivations for hiding or minimizing their impairments, even from those to whom the participant had disclosed their situation.

Despite the ubiquity of passing and covering, my findings suggest that moments in which these participants are motivated to *un/cover*, or draw attention to their impairment, are in many ways more salient for these participants. Moving through a society structured by ableism (i.e., economically, institutionally, politically, and socially structured to privilege nondisabled individuals) means that the pressure to pass as nondisabled is ubiquitous, especially the pressure to engage in "reactive passing" (Renfrow 2004) or to go along with the assumption that one is nondisabled. This experience is so interwoven into the daily lives of those with non-apparent impairments that passing itself becomes the default mode of social interaction.

In this context, impairment disclosure or "coming out" is indeed a powerful moment for people with acquired and non-apparent impairments. However, given the lack of overt, visible signals of impairment, disclosure can quickly become minimized, forgotten, or disregarded as repeated interactions remain interrupted by impairment. Indeed, the better one is at "managing" their own health or being productive (however defined by the individual), the easier it becomes for colleagues and intimates to dismiss the varied impacts impairments may have on a person. Thus, moments when people choose to openly acknowledge, remind others, or simply discuss their impairments are powerful – and potentially transformative – for individuals with "invisible disabilities."

Below, I present an in-depth analysis of two cases studies – the life history of Lionel, a young, white man with impaired vision and the experiences of Molly, a white woman pursuing advanced education after a traumatic brain injury. The first case illuminates the internal struggle un/covering can entail as an individual begins to experiment with integrating multiple identities, specifically through by asserting one's disability identity. Lionel's story highlights the liminal space or "middle ground" a person with a non-apparent impairment can find themselves inhabiting when navigating a society that assumes nondisability as the default status. The

second case demonstrates the complexities of asserting disability identity among the nondisabled and disabled alike, reflecting the experience of not only ableism in mainstream society, but the internal hierarchies within disability communities. Both of these cases reveal important insights into the process of un/covering.

Lionel: *I'm sort of living in this middle ground…*

Lionel is a young, white man in his late twenties. He is a composer and works as a part-time instructor at a community college teaching music theory. Lionel does not see himself as "disabled." Lionel has, in his words, "a visual condition" that impacts his central vision, so he has a fringe of periphery vision with an ever-growing blank spot in the center. This started around or shortly after puberty, he thinks, but he wasn't diagnosed until the middle of college. This condition has increased over time, at varying degrees, and there is no clear prognosis, meaning that doctors are unable to tell him whether he will eventually go completely blind, and if so, at what rate.

As Lionel described living with a visual condition, he repeatedly indicated ambivalence about "what the right thing to do is" in situations where people are indeed aware of his condition, but forget about its impacts. He discusses these decisions in language reflecting internalized ableism, framing his dilemma in terms of overstepping boundaries to force others to deal with his personal problems. To illustrate, Lionel gave examples of situations in which he has to decide whether and how to remind others of his visual condition. For example, Lionel related, with irony, how even his family members often forget the ways his impairment impacts him in social situations. He states:

> *Well, even with my family, like, they absolutely more than anyone else that I know understand specifically what visual condition I have. I have spent a lot of time talking to them about it and they have been very supportive, but there are still times when they – for example, we don't eat out very much, but when we do, like at a fast food restaurant there will be a display, and I can't see the display – the brightness is the biggest issue there. I'm uncomfortable in that situation because fast food restaurants never have written menus. You just go in and it's like "well, I'll have a number three." Whatever that turns out to be. [Laughs.]*

Lionel framed his decision not to press the issue of having access to the menu at a restaurant as not wanting to inconvenience others with his requests. His rhetoric firmly roots his understanding of impairment in the language of the Medical Model, describing his reluctance to make other people "deal with *his*" problem. Describing the fast food scenario, he continues:

> *I've done that before. It makes more sense for me to copy whatever someone else got rather than guessing randomly. [Chuckles.] I don't know, I don't know what the right thing to do is there. I could say "could you tell me what is on the menu?" you know, have them read it to me, but then it's like I'm making too much effort for the other people just to deal with my little visual condition. I really don't want to do that. Maybe I should be*

more willing to do that, but especially if there are other people waiting behind me in line, I'll just say "give me number three". I don't know. That's just an example, my family will sometimes forget in that kind of context and that's something that I struggle with.

We discussed at length his vacillation between being frustrated and not wanting to impose his "special needs" on others. Lionel indicated he was often reticent to ask others for help "just to deal with [his] little visual condition."

When talking about his work environment, Lionel reports that he has not requested any special accommodations at work, choosing instead to work mostly from home. He does, however, arrange his classrooms in particular ways, drawing the blinds and dimming the lights in order to maximize the vision he does have. The first day of each class he teaches, Lionel explains his visual condition to his students as part of the reviewing the syllabus, and outlines the ways his condition may impact the classroom and his interactions with students. He explained that when he first started teaching, he disclosed his visual condition to his students with a one-liner: "…during the presentation of the syllabus and talking about class I'll say: 'I have a visual condition, it's not that big a deal' and then I will immediately start talking about something else. I will minimize… It's like – wham! - I have a visual condition, it's not that big a deal and I immediately start back stepping." As he became more comfortable in the classroom, he expanded this first-day disclosure to include some information as to why he lowers the blinds and dims the light, but still doesn't linger on detailed explanations.

Although covering is thus a familiar strategy to Lionel, he also described key moments in which he elected to un/cover. During our conversations, Lionel reflected on what if felt like when he chose not to "fake it" and instead made his condition more visible to his students. Importantly, incidents such as these were already in the process of being reframed in Lionel's narrative. In the following, he describes drawing attention to his visual condition in order to address a student's question about a quiz:

> *So I will have to take the quiz, hold it up close and then, it doesn't matter really, I guess, but it just makes it a thing. It just makes it real. I was… Before I took that active role of moving the quiz close I was faking it – maybe I'm not – but in my mind I was faking it and they couldn't tell that I am visually impaired at all. Taking those active steps to make myself different is, uh, is on my mind.*

Lionel clearly saw his move to un/cover his impairment as differentiating his way of functioning from the ways most of his students do: "Taking those active steps to make myself different is, uh, is on my mind." He talked of other times when he faced decisions to downplay his visual condition or explicitly acknowledge his low vision. He consistently ended stories about bringing attention to his impairment with explanations of how it did not turn out to be "that big a deal" and confirmed that he didn't notice any difference in the ways, for example, that his students interacted with him after un/covering in the classroom.

Lionel's story reflects not only his experience as a person who has acquired low vision, but also reflects the webs of social class, gender, and political systems in which his experiences are embedded. Lionel describes his childhood in a middle class home with a large yard in which he and his siblings played. His family's financial security enabled him to attend college and graduate school without taking out loans or having to work. Indeed, he points to the fact that during his master's program he was the only one in his cohort not working as a teaching assistant as one more experiential difference that deepened the divide between him and his classmates. Although Lionel has struggled to find steady employment at times, this financial security has also sheltered him from pursuing social security or private disability insurance, side stepping one of the primary mechanisms for exploring ones' status as "disabled." Indeed, when pressed about his thoughts on the label of disability, he asserted that he was pretty sure one needed to "register with the government" in order to be considered disabled, despite initially describing himself as "legally blind." He explained he hadn't done that as he was reluctant to "deal with all the paperwork" and preferred "not to ask for help."

Understandings of gender are also deeply entwined in Lionel's framing of having to "ask for help." Notably, his discussions of moments when he encounters barriers, for example, when he cannot read a menu off a lighted board, are not framed in his need for access to a menu, but through the lens of revealing weakness and burdening others with his needs. Lionel explicitly linked many strategies he uses to cover his impairment to gender conceptions – noting that sometimes being perceived as a man helps and other times hinders his ability to pass. For example, when discussing his attempts to maintain eye contact during conversations he explains "I think men in general – women tend to lock eyes more whereas men tend to, when they are talking, they tend to do what I do, which is look away. And in some ways, my behavior doesn't seem that weird, it just seems like guy behavior." By contrast, Lionel expressed that asking for assistance in reading things such as food labels in grocery stores advertises his "shortcomings" to women, making him not a "potential good mate." Lionel shared stories of women in his life that were more comfortable demanding others do things for them than the men he grew up with. At one point, he described his failure to be able to assist a student in the classroom due to his low vision as "emasculating." He explained:

> I would speculate that females who are disabled have a different mindset about their disability than males that are disabled, in general. I would guess that males that are disabled don't slip into the victim mentality as much. I guess that's part of what I'm talking about. Being unable to do something feels like it might for a male a little bit more… It sounds sexist but I'm not trying to be.

We discussed this phrasing several times and he later sent me this note clarifying what he meant:

> The change is really from adult (independent) to child (dependent). It is complicated because our society sometimes puts men in one group and women & children in another group. (I am thinking of the sinking of the Titanic with women and children getting into the life-boats first, or the news reports about "even women & children" being killed.) But

the point I am trying to make is this: My status as a capable, responsible, self-reliant adult is what is called into question (at least in my mind) because of my visual condition.

Lionel's association of masculinity with independence, and femininity with dependence, has been shaped by the social and political culture of his time. Although his reference to the Titanic may seem dated, the conceptual split between "men" and "women and children" remains steadfast in today's parlance.

However, in more recent events, and during our discussions of these incidents, Lionel indicated growing ambivalence about downplaying his situation. He mused that the need to disclose each quarter with each new group of students was making disclosure in general easier to do. He also noted that he was becoming increasingly comfortable with mentioning or referring to his visual condition in the classroom after disclosure:

I think I'm getting better at [reminding people of the visual condition] – or at least I'm being forced to deal with it. .. being forced to deal with it is probably good. If I didn't have students, I wouldn't be forced to deal with it. Which is good.

In the excerpt above, he reflects on the experience of un/covering as something he's "getting better at," adding "being forced to deal with it is probably good." This self-reflection reveals that he thinks un/covering is a positive, if still uncomfortable, move or one that is "probably good."

Lionel also described moments when reminding others of his visual condition made things easier and alleviated stress. He described making a study guide for his students using a grid with different shades of color that seemed clear on his computer screen, but all looked the same color to him when printed out on the copier. He tried adjusting things that didn't seem to make a difference and started to "freak out" about how useless this tool was going to be. In that instance, he decided rather than continuing to stress about how to fix it to just directly ask students if they could see what he could not. He prepared exactly how he would explain the situation to his class and began by telling them the copies "looked weird" to him and asked if they could differentiate the grid. He prepared for questions and probing about his condition or the severity of his low vision, "but they were like 'oh, we can see it fine.' And that was it." He laughed after sharing this story, commenting that it turned out really to "not be that big of a deal." Although Lionel's decision to un/cover may not have been a 'big deal' to his students, the reduction in stress and worry over explaining or justifying his impairment has clearly had a lasting effect on him.

As Lionel catalogued occasions when he downplayed his visual condition and moments when he openly acknowledged the impacts of it, he began discussing how those interactions might have turned out if had done the opposite. This led him to discussing what the "ideal" accommodations would be for him. For example, in an ideal world, he would simply wear sunglasses in most of his classrooms and the office to reduce painful headaches and further obscured vision due to fluorescent lighting. He states such behavior would act like a beacon

calling attention to his visual condition. However, as he discussed the potential consequences of such action, he concluded that managing reactions from colleagues and students would not be that dire. He mused:

> *Maybe it would be a better thing for me to do in terms of my own – I mean, everything would be out there. It would be weird at first, but then maybe the weirdness would go away after I just came to terms with that. Right now, I'm sort of living in this middle ground. I don't know, it might be better for me to just say: "I have a visual condition and it is what it is."*

Lionel expressed frustration as he described instances when people "in the know" about his visual condition forgot how it impacts him; however, he also admitted to feeling a bit embarrassed when recounting instances when he downplayed his visual condition. Narrating these events in juxtaposition to each other, Lionel repeatedly ended vignettes of un/covering with comments like "I'm working on that" and "I'm getting better at that," indicating his conviction that, despite still being uncomfortable, un/covering is increasingly important to him.

Molly: *I am not disabled enough…*

Molly grew up in a large, white, Catholic family in which generosity, compassion and social justice were dominant themes of family life. She attended Catholic schools through college. After college, Molly joined the Peace Corps and became a teacher. After a few years of teaching, she decided to enroll in graduate school to pursue a Ph.D. in Education. Near the end of her first year, Molly fell backwards down a flight of concrete stairs, resulting in traumatic brain injury (TBI). After four weeks in the hospital, Molly began an intensive and long process of rehabilitation and therapy. Being interviewed a few years after the injury, Molly described her primary impairments as deafness in her left ear, loss of sense of smell, and changed cognitive processing. Molly opted to have a bone anchored hearing aid (BAHA) surgically implanted to provide improved hearing in her left ear, but even with the BAHA Molly cannot locate sound sources and cannot follow multiple speakers at once. As a result, Molly and her family explored options for accommodations in school.

Still processing how TBI would impact her life, Molly described initially not wanting to call attention to her new way of being. Molly worried about the stigma that a cognitive impairment might carry in an academic program. Upon returning to her graduate program, she decided to inform professors and colleagues of the situation, but after disclosing information regarding her impairments she intentionally avoided talking about her changed needs in the classroom. She explains:

> *I wasn't really ready to talk about it, and I was really worried when I came back to school that people—I wasn't comfortable with what had happened to me, and I guess I didn't want the look of pity, but I did want people to be understanding.*

Torn between wanting to be able to fully engage with her graduate program but not wanting to draw attention to her situation, Molly downplayed her TBI and tried to use minimal accommodations. She quickly determined that audio recordings of reading material was not enough, and realized that she required other means to participate in class discussions. Accessing additional accommodations, however, highlighted her impairments in ways she had not anticipated.

> *It was hard… When I was invisible those first two months in the classroom with just audio recording, I—it wasn't noticed by anyone. …. But when the accommodations changed to include a CART provider, my injury became visible, and in the beginning I didn't—it didn't affect me, but as my awareness grew, and my self-advocacy formed, I realized how, uh, compromising that—that accommodation was to my identity in the classroom.*

Molly explained the myriad of ways that having a CART (Computer Access Realtime Translation, a system for realtime transcription of speech) provider in the classroom improved her ability to get the most out of her classes. She also described how making her impairments visible through this accommodation exposed her to students' reactions to having their ableist privileges challenged. Molly gave an example:

> *I had an experience in one of the newer classrooms that is fully teched out and has microphones on the tables, but [also] a CART provider. [The CART provider] couldn't identify who was talking because they didn't raise their hands very well in this room, and they'd didn't like using the microphones, and they verbally said out loud, "This makes me feel weird." And that's when I felt full-on bias, uh, discriminated against because everybody knew it was for my benefit. And that's how I started feeling: that everybody knows to talk one at a time, to raise their hand, to speak loudly for **my** benefit. And that is gross.*

Molly confirmed that none of her fellow graduate students directly complained to her about having to accommodate her impairments. However, Molly felt the sting of this reaction to her difference in every eye roll or sigh made when students were reminded to raise their hand or talk one at a time.

Since those initial, sometimes painful, experiences upon returning to school, un/covering has played an important role in Molly's ability to socialize her colleagues and intimates into adjusting their behaviors to allow her to fully engage with them. Early on, Molly recognized the delicate balance between maintaining her privacy and reminding those around her of a different way of functioning. As a result of those initial interactions, she became more conscious of times when she felt pressured to downplay her impairment, but in doing so, also became aware of the tension and frustration of minimizing her needs:

> *So I try to blend in as much as I can. That said—[sigh]—there's a little bit of relief when I have someone with me, [or when] my disability is visible because I live with invisible*

disabilities, and the majority of my every day, nobody knows. And it stinks when people will not give you any—will not give you a break because you can't prove you have a brain injury.

The "bit of relief" Molly describes, when with someone who, for example, knows to move to her right so that she can hear them most clearly or those who refrain from talking over others in social situations, was earned by repeated reminders of her impairments. No one, Molly emphasized, "just gets it," but after a few reminders such behavior adjustments become habitual.

In the two years following her injury, Molly concretely experienced the socially constructed nature of disability through international travel. Disclosing and un/covering her impairments in a different cultural context brought American attitudes toward impairment into sharp relief. As part of her Ph.D. program, Molly spent time in Cambodia laying the groundwork for her dissertation work. In the lengthy excerpt below, she describes the contrast from disclosing her impairment in the U.S. to sharing this information with colleagues in Cambodia:

> *When I-when I got my device [bone anchored hearing aid], I then started to have to explain it, or at least, I felt I had to explain it because it was there. So the device helped me share that I was deaf in one ear, and the response [to] the deaf in one ear was complete pity accommodation. That was the [American] response. It was, like, "Oh. I'm so sorry," face droop, "Aww," concerned eyes. And then, "Oh, can you hear me now?" Like, so—an accommodation of people being louder.*
> *…*
> *Where in Cambodia—so I don't know the language. Those who do know English, it's limited. … I didn't know if they understood what deaf meant. So I would say, "My ear is broken." There was no change of facial affect. There was no change on, "Oh, what can I do for you?" It was a simple, neutral, "Okay." So there was—so all that-all that uncertainty-or, um, discomfort with personal presence in America simply never happened in Cambodia. And as I was there over time, I came to learn that—and I say this in my own work, is that disability is part of their social fabric, that there is so much disability that there is no… They simply say, "Oh. Okay." It's just another thing. And it's a common, a common understanding. There's no prejudice about it.*

This experience of "a common understanding" that reduced social stigma surrounding impairment and the "simple, neutral" reactions when reminded to move to her right when speaking to her, contrasted sharply with the awkwardness, discomfort, or reactions of guilt or pity when reminding most Americans of her hearing impairment. As her own research began to center the dynamics of disability in education in international contexts, Molly reported an increasing awareness of her impairment as a source of identity as a disabled person in America.

However, as a person with an acquired, non-apparent impairment, Molly also struggled to find a place among local disability communities. Seeking support, Molly sought out others with impaired hearing. When describing her first experience with a local Deaf community, she says

flatly: "I quickly learned I'm not big D. I'm little d." When asked to clarify the difference, she explains:

> *Sure. Big D is, um, the Deaf community, and in order to belong in that circle, you have to have,—[pause]—a hearing loss in both ears and have lost the ability to hear very early on, if not born with it. And big D community is a very strong community, that wants to maintain its, uh, American Sign Language and has very strong opinions about cochlear implants and assistive technology. …big D is a—is not just a community. It's a culture with its own living language. And small d is a diagnosis…*

Molly said the people she met in that group "were all very respectful" but she felt "the odd one out" and eventually stopped attending. Molly describes eventually finding her "community," comprised of other people with TBI, but it is a small, dispersed group. She finds a sense of solidarity with them because they face many of the same barriers in society and can un/cover their ways of functioning without having to provide long, detailed narratives of the injury itself to explain how the impairments came about.

Despite her immersion into academic research on disability and a growing sense of empowerment of her own identity as a disabled person, Molly does not report feeling entirely accepted by or included in local disability communities. When asked about her experiences with broader disability groups (compared to TBI groups or Deaf groups) in her area, Molly expressed ambivalence and emphasized the ways having acquired an impairment – particularly a non-apparent one – distinguished her from many other disabled people. In the following exchange, Molly voices her feeling of 'otherness' even among those with impairments:

> Heather: *What about the broader community of people with other types of disabilities?*
>
> Molly: *I don't feel that I'm accepted.*
>
> Heather: *Tell me more.*
>
> Molly: [Sigh] *In the disability community, the others with disability—[sigh]—I'm a newbie. I don't 'understand the history'* [she makes air quotes with her fingers]. *… I don't fit. Nobody looks at me and knows, and I don't—I guess I just—I'm not in the quick yet.* [long pause] *And I really do see it like that. I see the disability community as pretty closed.*

In a later conversation, Molly returned to the topic of not fitting in with disability activists, despite her own efforts at increasing awareness of disability among her colleagues and in her field:

> *And I feel at times some people who are really very much active in disability rights do not put it very gently to me. And it's abrasive, and it's hard, and it makes me feel like I don't belong, that "because I don't have all of your shared experiences, I am not one of you."*

And—[pause]—I walk away with feeling that mine is not severe enough. …Like I am not disabled enough…
…
But they don't see that the crack is always there, and it always will be. It's always gonna be there, and it's always gonna be invisible, but it's felt. … I recently heard that, um—in talking about race—that some people wake up every day, and they—have this thing that they have on their shoulders— before they go into their day, and I just wanted to scream, "I get it." But it doesn't feel socially acceptable for me to say that. When we talk about inequity, I'm not included. This disability is not at the same level, and especially because it's invisible.

Molly thus describes making fellow students "feel weird" when having to accommodate her impairments in class, juxtaposed with feeling "not disabled enough" to fit in with disabled people. Thus, while Molly may experience the stigma of disability among the nondisabled, she also faces stigma among disabled people who have lived their entire lives with impairment and who have become steeped in disability history and activism.

Despite experiences of marginalization in a variety of contexts, Molly remains a strong advocate for herself and others with impairments. She ends each of these stories explaining why it is so important for people with non-apparent impairments to talk about and acknowledge the ways in they function differently and how improved our lives can be through oftentimes very simple accommodations. Now, several years after her injury, she reports that the sting of discrimination hasn't necessarily lessened, but that disclosing and having ongoing conversations about her impairments has been integrated into her social and work lives. When asked why, she states:

As a teacher, I see every child in a holistic way as much as I possibly can, and I do that with all of my friends and my colleagues as well. I want to know them as much as I possibly can so that our work together is mutually beneficial and mutually challenging. … And I guess—let's flip it. Why do I need to tell the group? Because I want them to see me holistically. I want them to see my passion and hear a little bit of my story, and I don't ever wanna cut something out of my life or my identity. …I feel like by not disclosing or talking about it, we are continually perpetuating this, "It's a big deal. It's a big deal. Tip-toe around me." …So I just—I feel like we need—we need to be a little more honest with each other, and honesty hurts at times, but the more honest we are, the less painful it is. Right? But maybe that's me being optimistic…

Molly's optimism is no doubt tied to the strong family support structure she has and an upbringing that emphasized the importance of social justice. Her narrative reveals the important ways that the practice of un/covering – beyond the impact of simple disclosure – helps socialize her colleagues and intimates into understanding her as a more complete person and enables her to work with others in ways that are "mutually beneficial and mutually challenging." Beyond her own relationships, Molly uses the practice of un/covering to

broadcast the message that, when acknowledged and accommodated, impairment isn't, in her words, "a big deal."

Discussion

Un/covering plays a distinct role separate from disclosure or passing. While the practice of un/covering is situated on a spectrum bookended by disclosure and passing, my findings indicate that repeated decisions to un/cover provide space for deepening disability identity and make that identity legible to others in small but normalizing ways. In my initial analyses of my interview data, I treated incidents and decisions like those discussed here - to remind others of one's impairments - as moments of "mini-disclosure," muddling my coding trees with myriad of leaves labeled things like "disclosing again," "impairment reminders," "people not getting it," and other half descriptions. Upon systematic analysis, however, I began to see how these moments differed from disclosure. First-time disclosure carries big risks: changed perceptions based on impairment disclosure can have extremely impactful consequences on social relationships, career opportunities, and personal self-esteem. Un/covering happens in the relatively safe zone after the big risks have already been taken. Moments of un/covering may also be fraught with trepidation, frustration, fear of stigma, and the uncomfortableness of insisting upon acknowledgement of one's differentness, but un/covering also serves to assert and openly accommodate difference. This articulation presents repeated opportunities to narrate one's ongoing experiences and thus integrate those experiences more fully into one's identity.

Indeed, the practice of un/covering plays an even more important role than disclosure in disability identity formation among people with acquired, non-apparent impairments. Lionel, for example, is not alone living in a "middle ground" between downplaying his different way of functioning and actively reminding the people around him that simple accommodations for his visual condition could make his life easier. Nor is Molly the only disabled person to recognize the seemingly innocuous comment "this makes me feel weird" (when asked to use a microphone, for example) as code – code for protesting the request to deviate from able-bodied social norms. Many participants in this study argued that small accommodations (such as the privilege of ordering food that one might actually like to eat a restaurant) are relatively trivial, but all participants also expressed frustration with having to constantly assert their differentness in order to get basic accommodations or remind others of their needs.

The experiences of Lionel and Molly demonstrate the very practical impact of un/covering in obtaining accommodations or facilitating important information exchanges. Lionel and Molly are cognizant of their sense of relief when with friends and associates who are aware of their impairments and who make efforts to interact with them accordingly. Aside from stress reduction, both describe how much easier it is in the workplace to be able to openly acknowledge impairment (such as Lionel's decision to just ask his students if they could read the printed study guide that he could not.) As these moments are reiterated, the impacts of impairment become more legitimized and less of a "big deal."

Un/covering plays a unique role in the lives of people living with non-apparent impairments precisely because it calls attention to their variation in functioning in a way that creates a form of visibility that can be read by the nondisabled and disabled alike. It is worth emphasizing the potentially transformative impact of repeatedly, explicitly acknowledging the impacts of non-apparent impairment in rendering legible an invisible condition, and thus a disability identity. This articulation situates a person's experiences among those of other disabled people in American society today, offering the potential recognition of taken-for-granted barriers in the social and physical environments to that individual as well as other disabled people. This legibility also exposes one to socially constructed hierarchies within disability communities, however, as Molly discovered when encountering a local Deaf group. Whether those encounters are positive or negative, they sharpen one's disability identity. Naming barriers (i.e., reminding others of accommodation needs) also signals and perhaps invites others to see their own experiences as being aligned with discrimination against disabled people more broadly.

Finally, un/covering is a mechanism by which people who have acquired impairment work to process a new way of being (or for some, an ever-changing way of functioning) that reflects the lived realities of that impairment. Each time Lionel has to explain the middle ground in which he finds himself, he is called upon to make sense of his changing vision and related experiences in a holistic way. It provides the opportunity to update a narrative of one's experience and deepen an identity that incorporates disability into the intersections of other identities, including one's race, gender, sexuality, or class.

Cataloguing the roles of un/covering across these case studies is not meant to erase the intersectional experience of disability, but rather to highlight it. The tension Lionel describes between his perception of masculinity and desire to acknowledge his impairment remains powerful for him. Lionel's views on the nature of men and women, and the socioeconomic privilege that has shielded him from engaging with bureaucracies seeking to categorize or label his impairment, have provided him with his own, unique experience of low vision. Unlike Lionel, Molly's experience of international travel disrupted notions of what is "natural" and crystallized the socially constructed nature of disability. These experiences, coupled with her life-long spiritual connection to social justice, implanted in her a resistance to the social stigma associated with her impairments.

Conclusion

The narratives of people living with acquired, non-apparent impairments highlight the importance of un/covering. These interview data demonstrate that repeated decisions to un/cover carve out deeper space in one's identity for disability and make disability identity legible to others. For those whose variation in functioning is non-apparent, un/covering may be the only way to signal impairment to others and as such, serves as a site of resistance to pressures to pass as nondisabled. For those who have acquired impairment, un/covering plays an important role in allowing the individual to process a new way of being. Integrating a new way of being involves making that identity legible to others.

Making one's disability identity legible serves different functions for different audiences. Ongoing reminders of one's variation in functioning help normalize impairment for nondisabled peers. Un/covering signals to disabled peers a shared experience of barriers and thus as a foundation for shared political identity. Overtly discussing barriers through un/covering invites others experiencing impairment to begin to see their own experiences of discrimination in a political way. For all audiences, un/covering also serves a very practical purpose: ongoing reminders and discussions of the impacts of varied functioning not only ease communication with others regarding appropriate accommodations but also bolster the legitimacy of accommodation requests (particularly ever-changing requests based on fluctuating needs.)

Perhaps the most profound impact of un/covering is on the self: narrativizing impairment integrates variation of functioning into other identities. Moments when one chooses to un/cover are in themselves autobiographical occasions (Zussman 2000). When participants describe moments when they chose to un/cover, their rhetoric reflects a growing sense of self-confidence and comfort in wearing the cloak of differentness. Each time that a person explains, acknowledges, or reminds others of the ways that variation in functioning impacts his or her daily life, that person is called on to craft a story of their own relationship to disability. Thus, repeated iterations of un/covering deepened these individuals' sense of disability identity. My findings support scholarship asserting that the act of narration itself is an important part of identity construction (Engel & Munger 2003; Smart 2010; Bathmaker & Harnett 2010; Cortazzi 2001; Zussman 2000). Decisions to pass, cover, or un/cover are ongoing decisions that stitch together the fabric of each person's life, thus serving as primary mechanisms for identity negotiation and management.

Fostering robust, political disability identities is not only empowering for individuals with impairments, but important for the disabled community more broadly. Un/covering, like masquerading (Siebers 2004), serves as a site of resistance against ableism more broadly. As Siebers eloquently states:

> Overstated differences and feigned disabilities serve as small conspiracies against oppression and inequality. They subvert existing social conventions, and they contribute to the solidarity of marginal groups by seizing control of stereotypes and resisting pressure to embrace norms of behavior and appearance. (2004: 19)

Un/covering differs from masquerading in that there is no exaggeration or faking of impairment, it is simply a reminder – articulated through words or actions, not prosthetics – of one's differentness. Most starkly, un/covering occurs among people who are already aware of the impairment, and is not a performance used to communicate disability to strangers. Nonetheless, un/covering also subverts existing social conditions and signals to others disability identity and solidarity.

Understanding disability as a minority identity is pivotal to building rights-based claims for empowerment. Thus, a resurgence of identity politics - based on both bodily and socially constructed shared experiences – would seem to provide the most traction for fostering

disability-based identities that enable individuals to see their personal struggles as windows into institutionalized discrimination against people with disabilities and thus form the basis for political engagement. In this light, creating safe spaces for people with non-apparent impairments to practice ways of un-covering their impairments and articulating strategies for optimal productivity are primary pathways to deepening individual disability identities and fostering coalition building centered on a shared minority status. The more people with acquired, non-apparent impairments who make their identities as disabled people legible, the more opportunities will present themselves for coalition-building among disabled people and allies.

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