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Crippling the Medical Humanities: Disability, Ableism, and Access Intimacy

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Abstract: In recent decades, medical humanities scholars have increasingly looked to patient-authored narratives of illness to help medical practitioners better understand patients' lived experiences of disability. However, within the medical humanities itself, disabled people remain underrepresented as normative conventions of research and teaching systematically exclude disabled scholars. This paper interrogates the medical humanities' complicity in reproducing relations of power that reinforce biomedicine's dominance over disabled people. I adopt a cripistemological approach to centre first-person lived experiences of disability as a way of knowing and examine how knowledge about disability is produced through the academic consumption of illness narratives. Drawing on auto-ethnographic observations as a disabled literary scholar working in the medical humanities, I look at how access barriers and micro-ableism from nondisabled physician-researchers at conferences "other" disabled academics. I explore how access intimacy can be developed in the medical humanities to challenge institutional ableism and build intersectional solidarity with queer, non-white disabled people. I reiterate the need for medical humanities researchers and disability activists to collaborate and create a more caring and inclusive society.

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Introduction: The Case for a Crip Medical Humanities

The field of medical humanities emerged in the late 1960s in response to what some medical practitioners and educators perceived as the dehumanisation of medicine caused by the commercialisation of health care and over-emphasis on technical scientific knowledge in medical education. In 2001, Robert Arnott et al. defined the medical humanities as “a sustained interdisciplinary inquiry into aspects of medical practice, education and research expressly concerned with the human side of medicine”(Arnott, Bolton and Evans). Medical humanities attempt to rehumanise medicine by using art, literature, and philosophy to foster “respect for individuals, protection of the vulnerable, tolerance of difference, care for those in need, equality of access, and the pursuit of justice”(Cole, Carlin and Carson 13). First-person narratives of illness like Nancy Mairs’s *Waist-High in the World* and Audre Lorde’s *The Cancer Journals* are routinely taught in medical humanities programmes to “illuminate the social context that is left out of a biomedical perspective on disability and illness” and help physicians develop empathy and disability cultural competence(Garden, "Disability and narrative" 72). Creative arts and literature are also beneficial to physician wellbeing and support the development of physician identity as they allow physicians to process the trauma they witness at work and prevent care burnout. Since the 2010s, medical humanities scholars increasingly borrow critical approaches from gender studies, race studies, queer studies, disability studies, and cultural studies to examine how experiences of illness and disability interconnects with concepts of race, gender, and class. This second-wave or critical medical humanities conceive of the medical humanities as a site of “messy and mixed hybridities ”that “prizes experimentation, reflexive practice,

collaboration, and modes of sceptically risky thinking that are not easily wedded to a fixed role with regard to biomedicine' (Viney, Callard and Woods 4).

As the medical humanities continue to evolve and invent new ways of doing research, it is also important to reflexively evaluate how imbalances of power within the field itself contribute to inequalities in medicine and healthcare. Writing on structural racism in the medical humanities, Olivia Banner argued that "racism is not simply enacted in selected interpersonal interactions; it is inscribed in the institution of medicine, and no amount of re-training individual physicians will fix an institution"(26). For all the empathic interpretative skills physicians might derive from narratives, they "do little to overcome the racist practices and biases embedded in medicine" that are "institutionally reproduced, not intrinsic to interpersonal relations". This is partly because the literature with which medical humanities scholarship engage and analyse are "authored by people who do not experience the daily visible and invisible insults of racism" (27). This is also true of structural ableism in medicine and the medical humanities. Medicine has played a direct role in the historical oppression of disabled people through institutionalisation and the production of concepts of normalcy that legitimated ableist attitudes and eugenics policies(Davis). Applying a similar critique to disability and ableism in medical humanities, how are physicians made products of structural ableism? In what ways do the medical humanities contribute to structural ableism and reinforce medicine's power over disabled people? How accessible is the medical humanities as a field and how does the dominance of nondisabled scholars in the medical humanities impact on research on disability?

This article critically rethinks the role of medical humanities in the production of knowledge about disability. Drawing on cripistemology, an epistemological framework developed by disability studies and crip theory scholars, I assess the extent to which the field participates in and contributes to structural ableism. The word "crip", derived from the derogatory term "cripple", is used by disabled people

in the UK and North America to reclaim their disability as a social and political identity, and signal their pride as part of a disability community. In critical disability studies, to crip is to interrogate the processes of pathologisation that construct disabled bodies as abnormal and examine how disability intersects with other identities like gender and sexuality. Using autoethnographic studies of my own experiences as a disabled literary scholar working in the medical humanities, I identify structural access barriers that impede inclusion and propose that a disability justice-oriented approach to research and teaching can help make the medical humanities become a more inclusive and caring field.

The Medical Humanities and Disability Studies: A Contested Relationship

While the medical humanities have done much to educate medical students about the suffering caused by the medical objectification of patients' bodies, they have paid significantly less attention to disability and the suffering caused by medical ableism. Despite frequent contact with disabled people, many health professionals continue to harbour ableist assumptions and biases. In clinical encounters, physicians' assumptions that disabled people are mentally incapable of speaking or making decisions for themselves hinder communication with disabled patients and create barriers to care. Biases against disabled people as dependent and less capable than nondisabled patients of looking after their health lead physicians to be more patronising towards disabled patients. Disability activists call this kind of discriminatory behaviour and prejudice against disabled people "ableism" (Siebers 81). David M. Peña-Guzmán and Joel Michael Reynolds argue that marginalised groups like disabled people are disproportionately affected by medical errors because of "epistemic schemas rooted in prejudice" such as ableism (206). Epistemic schemas are implicit meaning-making networks that process information and structure how one engages with the world as a knower. Prejudicial epistemic

schemas like racism and ableism not only affect how one thinks about and interacts with others from marginalised groups but also encourage epistemic ignorance, a wilful ignorance of information that otherwise contradict and discomfort one's beliefs.

To this end, scholars argue that teaching physicians to critique notions of health and disability through a disability studies lens can help physicians understand their own roles in the medicalisation of disability and find ways of building more positive relationships with disabled patients. Disability studies emerged in the UK and the US in the 1980s from the work of disabled activists and theorists who sought to critique the history and representations of disability in society. As a discipline, it is concerned with "the social meanings, symbols, and stigmas attached to disability identity and asks how they relate to enforced systems of exclusion and oppression" (Siebers 3). Rebecca Garden suggests that the incorporation of disability studies perspectives in medicine through critical engagement with narratives can shift the balance of power in the clinic and improve healthcare for disabled patients ("Disability and narrative" 74). G. Thomas Couser argues that teaching disability studies to medical students can consolidate their "disability literacy" by showing them how the concept of disability is historically and socially constructed (29). Both disability studies and medical humanities are concerned with the ways in which bodies are "*constructed* through narrative, and other verbal, visual, and material representations" (Holmes 13). More recently, Joanne Hunt has argued that the integration of disability studies in a structurally competent medical curriculum will allow a more nuanced, contextualised understanding of disability in clinical practice and help physicians better understand chronic conditions like long COVID (3).

Although both emerged at the end of the twentieth century, the medical humanities and disability studies have radically different relationships with medicine. Whereas the medical humanities were developed by physicians and

medical educators as a way of addressing the “empathy decline” that affects medical students as they progress through their training, disability studies emerged in conjunction with the disability rights movement (Bleakley 5). Biomedicine follows a medical model of disability that locates disability in the person’s bodily impairment or dysfunction. By contrast, disability studies focus on a social model which frames disability in terms of social relations and views disability as produced by social, physical, and cultural barriers that disadvantage the person with impairment. In the UK, disability activist groups the Union of the Physically Impaired Against Segregation (UPIAS) and the Disability Alliance argued in their 1976 manifesto that “disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society” (Siebers 4). Affirming disability as a social identity, disability studies scholars work to “reverse the negative connotations of disability” by highlighting how these connotations are culturally conditioned by ideologies of ability that frame nondisabled bodies as natural and ideal, while generating fear and repulsion towards disabled bodies. In other words, disability studies aim at changing policies, environments, and society, while the medical humanities seek to “improve the status quo” (Herndl 595).

Of the kinds of research that are conducted in the medical humanities, studies that involve the application of art or arts-related activities as therapeutic interventions to promote health and wellbeing receive by far the most funding and media interest. In the US, where medical humanities are mostly taught in medical schools as part of the medical curriculum, many medical humanities scholars refrain from criticising medicine for fear of alienating physicians and losing their academic influence and financial support (Herndl 595). In its role as medicine’s “supportive friend”, the medical humanities “counterbalance” biomedicine’s reductive materialism but does not “actively seek to challenge pre-existing power structures and epistemological divisions of labour within biomedicine” (Viney, Callard and Woods 3). There have been some attempts to redress the imbalance of power by

renaming the field *health humanities* to expand critical focus beyond medical education and situate health in the context of broader social issues(Garden, "Who's Teaching Whom?"). Yet there have been no considerations as to how structural inequalities within the field itself impact on the production of knowledge about marginalised groups like disabled people. For all their work in advocating for the importance of disability studies to the medical humanities, none of Garden's, Couser's, or Holmes's articles directly addresses ableism as a problem within medicine and medical humanities. Diane Price Herndl only mentions ableism once in reference to her own biases as a nondisabled person. Joanne Hunt recognises ableism as entwined with neoliberalism and complicit in the marginalisation of chronically ill patients who fail to achieve the ideal of the self-sufficient, healthy citizen. Yet Hunt does not frame this critique reflexively within medicine and the medical humanities as an institution.

Disabled in the Medical Humanities

One area that has received barely any critical attention is the problem of disability representation within medical humanities itself. Martha Stoddard Holmes and Diane Price Herndlare both cancer survivors whose work are informed by personal experiences of illness. However, they do not identify as disabled. Apart from Travis Chi Wing Lau, a queer Asian scholar of disability studies and history of medicine who lives with multiple sclerosis (MS), there are few visible non-white disabled scholars in the medical humanities. The lack of disability representation is largely due to structural ableism in academia. Structural ableism is "a series of entrenched structures" built by the system of social policies, institutional practices, cultural norms, and inaccessible buildings that privileges nondisabled bodies and excludes disabled ones(Dolmage 53). Disclosing one's disability is dangerous because "claiming membership in 'the disabled' means being associated with social and

sexual stigma, reduced work opportunities”, and becoming susceptible to “subtle to blatant discrimination”(Holmes 13). To survive in the hyper productive, competitive culture of academia, disabled scholars are forced to constantly overwork and “prove” their academic competence at the expense of their health.

Identifying as disabled in the medical humanities also brings a further set of problems. Working in the medical humanities involves frequent engagements with physicians and health professionals. Interactions between disabled researchers and physician-researchers can unconsciously replicate the clinical relationship and mirror the dynamics of power between the patient and the doctor. This can occur when a nondisabled physician-researcher speaks over a disabled colleague while espousing medical knowledge about their disability or condition. Mansplaining, a neologism that arose around 2008 in online discourses, refers to the set of gendered conversational practices where the privileged conversant (usually male) lectures, interrupts, or corrects the conversation partner (usually female) in a patronising way, even when the information dispensed is incorrect or when the partner has superior expertise in the subject (C. R. Johnson). This kind of biased conversational norm not only applies to gender but also age, race, class, and ability. Other “-splaining” practices include whitesplaining, straightsplaining, cissplaining, and ablesplaining(Sayers 98). Like mansplaining, ablesplaining refers to occasions where a nondisabled person condescendingly explains to a disabled person about disability despite the disabled person having more extensive knowledge about disability from experience. Ablesplaining constitutes a form of disability micro-aggression or micro-ableism, subtle behaviour and actions that cause harm to disabled people. Micro-ableism can include even well-meaning gestures and seemingly inadvertent phrases like “blind review” (Lorenz).

As a female disabled researcher of colour who uses a wheelchair, ableism permeated my experiences of academia and the medical humanities. Most academic conferences, even ones on disability, do not provide access information unless

requested and sign language interpreters are perennially absent from events. I have attended lectures where I had to travel to different floors in different buildings using two lifts, only to be seated at the far end of the theatre in the corridor, with the door wedged open by my wheelchair. I have been to conferences where the only accessible bathroom was in the basement or out of order altogether. Hearing the uses of blindness, deafness, and paralysis as metaphors or hyperboles by nondisabled scholars make me uncomfortable, but I keep quiet because it is difficult to speak up as a young disabled Asian graduate student in a room full of white, senior academics and physicians. While my paraplegia is visible, my autoimmune disease and pain are not. When attending conferences, I regularly shift in my chair to avoid pressure sores and ease the pain of sitting for long hours. Yet these actions are interpreted as signs of impatience by others and seen as disrespectful to the presenters. When I speak to nondisabled physician colleagues about my experiences of disability and frustrations with access, they swiftly proceed to talk about their own patients and family members who used wheelchairs. The materiality of my disabled body makes me hypervisible in public spaces, but it also invisibilises my person as I become my disability. Being most often the only visibly disabled person in the room, I also become the de facto disability “expert” as questions about disability are automatically redirected to me, even when I have no experience or knowledge of the condition at hand. Paradoxically, discussions about chronic illness and autoimmune diseases, of which I have years of lived experience, are in turn dominated by physicians.

The Subjugation of Crip Knowledge

In his 1976 “Two Lectures”, Foucault described what he called the insurrection of subjugated knowledges against the institutionalisation of scientific discourse. According to Foucault, subjugated knowledges are knowledge that have previously

been dismissed and delegitimated as being “beneath the required level of cognition or scientificity”(82). This includes the irrational, discontinuous, working knowledge of patients, doctors, and other marginalised people whose local histories and traditions have been suppressed by dominant totalising hierarchies of knowledge.

I also believe that it is these unqualified, even directly disqualified knowledges (such as that of the psychiatric patient, of the ill person, of the nurse, of the doctor – parallel and marginal as they are to the knowledge of medicine – that of the delinquent etc.), and which involve what I would call a popular knowledge (*le savoir des gens*) [...] that it is through the re-appearance of this knowledge, of these local popular knowledges, these disqualified knowledges, that criticism performs its work. (Foucault 82)

Historically, disabled people have always been treated more as objects of knowledge than knowing subjects. Mentally ill and learning-disabled people are routinely denied the right to make decisions about their own care because they are deemed as incapable of comprehending the complexities of their conditions. Rebecca Garden suggests that through analysing illness and disability narratives, medical humanities scholars attempt “to speak for the underrepresented, for those who are marginalised in our societies and cultures and in the healthcare setting”(“Who Speaks for Whom?” 78). However, when researchers misrepresent and appropriate patients’ stories for their own purposes or benefit, they can also speak *over* and disempower the very people they claim to empower (78-9). As Garden acknowledges, as a nondisabled educator herself she inevitably participates in the objectification and othering of disabled people when she refers to disabled people as “they” and “them”(“Who's Teaching Whom?” 211). Jeffrey Bishop also questions the extent to which medical humanities and narrative medicine truly humanise medicine and emancipate patients. Narrative competence is taught in clinical practice because it helps doctors establish trust in the therapeutic relationship and enable them to persuade patients to adopt certain health-promoting behaviours. In other words, far from liberating patients from medical dominance, narrative medicine effectively enhances the doctor’s influence and control over patients (8).

In critical disability studies, the process of using embodied knowledge of disability to critique how assumptions about disability are produced is called “cripistemology”. Cripistemology is an epistemological framework developed by queer crip theorists Robert McRuer and Merri Lisa Johnson as a new methodology to question “what we think we know about disability and how we know around and through it” (130). Crip knowledge, knowledge of disabled embodiment and crip temporality acquired through lived experiences of disability, is intimately linked to crip identity and subjectivity. As Foucault suggested, the work of the critic is to recover subjugated knowledges from the margins and expose the power structures that uphold hegemonic systems of organising knowledge. This involves not only amplifying subjugated knowledge but also acknowledging that critics are themselves part of the oppressive system. The critic must work with marginalised people to undermine the structures that perpetuate epistemic injustices. In other words, the process of recovering crip knowledge is not so much a matter of speaking *for* the underrepresented as a practice of collaborative knowledge co-production *with* crip theorists and disabled people(139).

Disability Justice and Access Intimacy

In her essay, Banner draws on Metzl and Hansen’s concept of structural competence and proposes that medical humanities and narrative medicine could contribute towards “aims of structural competency if the fields were to foster textual readings that elucidate how ideologies of race, gender, and disability inform social, political, economic, and institutional structures, which then inform health and illness”(27). A curriculum that teaches medical students to identify the ways in which structural racism permeates the medical institution would “shift the reparative focus from individual interactions between physicians and patients to the institutions and structures that delimit those interactions”. In a similar vein, I contend that to counter

structural ableism in the medical humanities, we must engage with disability both as theory and praxis. This requires a fundamental shift in practices of reading and teaching disability that is informed by crip knowledge and disability justice.

First theorised by Patty Berne, Mia Mingus, and Sins Invalid, a community of disabled, queer artist-activists of colour, in response to gaps in the mainstream disability rights movement, disability justice is an intersectional model of social justice activism that frames access as collective and interdependent with other liberation movements such as the racial and gender justice movements. Disability justice is inextricably linked to access intimacy. Mia Mingus describes access intimacy as an “elusive, hard to describe feeling when someone else ‘gets’ your access needs [...] a freeing, light, loving feeling [that] brings the people who are a part of it closer; it builds and deepens connection” (“Access Intimacy”). Access intimacy can be fostered between disabled and nondisabled people, between close friends, as well as complete strangers. It can be experienced not just by disabled people but also women, people of colour, trans, and queer folks. Access intimacy is a powerful tool for challenging structural ableism because it “reorients our approach from one where disabled people are expected to squeeze into able bodied people’s world, and instead calls upon able bodied people to inhabit our world” (Mingus, “Access Intimacy, Intedependence and Disability Justice”).

Although I have experienced barriers to access, I have also experienced many moments of joy while working in the medical humanities. For me, access intimacy is when colleagues sit down to talk to me, so I don’t have to strain my neck to look up at their faces. It is when they book wheelchair accessible venues for conferences and locate the nearest accessible bathrooms for me in advance. It is when I feel internalised ableist guilt for being slower than my peers, and they remind me that my disability is an asset, not a burden to the field. It is these connections with colleagues and support from mentors and supervisors that have allowed me to find a home in the medical humanities. Yet disability justice goes beyond physical access

to buildings and access intimacy in interpersonal relationships. As Mingus suggests, obligatory access and access provided out of charity is not access intimacy. It is not enough to just reinforce “inclusion” and “equality” policies if we do not change the very structure that excludes disabled people (Mingus, "Access Intimacy, Interdpendence and Disability Justice").

In calling for a crip medical humanities that is structurally grounded in access intimacy and disability justice, I am extending Vine, Woods, and Callard’s provocations for greater engagements with political activism and critical theory in the field(7).As a framework that grew organically out of grassroots disability activism, disability justice is about collective access through cultivating interdependent relationships of care that acknowledge and value vulnerability in bodies of all colours, sizes, ability, and genders. Applying disability justice in the medical humanities means inviting all researchers to “attend to their own ‘body signifiers’ and embodied experiences of research processes” to address power differentials between researchers and research participants, as well as between privileged researchers and researchers from marginalised backgrounds(Brown and Boardman).If the medical humanities are to foster “equality of access” and justice in medicine as Arnott et al. had argued, then it must first admit its part in perpetuating institutional injustices and develop strategies to counter structural oppression in academia and beyond. How can we make the medical humanities more inclusive and accessible as a field? How do we make the medical humanities a safe space for queer, non binary, trans, black, disabled researchers and students? How do we apply crip knowledge in research and pedagogical practices to challenge hegemonic systems of organising knowledge about disability? How might crip-led research inspire alternative approaches to health and illness?

Conclusion: Envisioning a Crip Future for the Medical (Post)humanities

In 2017, Anna McFarlane noted that with the “increasing availability of complex biotechnologies”, there is a need to develop a “medical *posthumanism*” to foster “discussions of how humanity might change with technology over time”. This emergent medical posthumanism would “consider the ways in which the concept of humanity has already been shaped by medical, technological intervention and humanist assumptions”(“Medical Humanities”). The posthuman is “a complex assemblage of human and non-human, planetary and cosmic, given and manufactured”(Braidotti 159). In the wake of the climate emergency and COVID-19 pandemic outbreak, there have been renewed interests in posthumanism and its relevance to medicine and healthcare. A posthumanist model of health situates the human as living in symbiosis with the planet, including the animals, environment, and even pathogens. In this macroscopic/microscopic paradigm of health, human health is reimagined as entangled with ecological health and global public health, both threatened by and dependent on the viruses and bacteria that live in our bodies (Ağın and Horzum).

Similar engagements with posthumanism have been found in disability studies. In *Posthuman*, Rosi Braidotti commented that the “fast-changing field of disability studies is almost emblematic of the posthuman predicament”(146). Developing this connection, Dan Goodley, Rebecca Lawthorn, and Katherine Runswick-Cole argue that disability is “perfectly at ease with the posthuman because disability has always contravened the traditional classical humanist conception of what it means to be human”(342). Disability troubles traditional normative concepts of the human as an independent, self-sufficient, autonomous agent. Disabled people habitually rely on assemblages of healthcare workers and assistive technologies and animals. *Adishuman* position helps “develop theory, research, art and activism that push at the boundaries of what it means to be human and disabled” and “foregrounds dis/ability as the complex for interrogating

oppression and furthering a posthuman politics of affirmation” (Liddiard, Runswick-Cole and Lawthom 156).

Reflecting on her 2005 essay at the Modern Languages Association Annual Convention in Seattle in 2012, Diane Price Herndl appraises that the health humanities have since “gone a long way to incorporate” disability studies. However, it remains to be seen how the health humanities and disability studies will develop this relationship in the face of “institutional pressures” and “habitual imbalance in power between a humanities-based study of the body and biomedicine”(Holmes 15).As I have argued in this article, while it remains important to facilitate dialogues between the two fields, the more urgent issue at hand is not how to integrate disability studies and the social model into medical humanities, but how to “cultivate a sense of self-knowledge (even self-criticality)” of the ways in which the field benefits from and reinforces structural oppression and inequalities(Lau).The growing trend towards a third “posthumanist” wave in the medical humanities signals fresh opportunities to break down disciplinary divides and build new collaborative relationships with disability studies. Yet even as we explore posthumanism’s potentials to disrupt anthropocentric modes of thinking about health and medicine, it is essential that we continue to root out exclusionary, ableist practices in medicine and academia that treat disabled people as *less than* human. The posthumanist future of medicine and medical humanities must also be post-ableist.

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