Research and Resource Rounds

Transcript: Episode 23

Article: Political disclosure: resisting ableism in medical education, Neera R. Jain
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Introduction

Lisa Meeks: Hello! And welcome to the Research and Resource Rounds Podcast, an offshoot of our Docs With Disabilities Podcast.

Peter Poullos: Each mini-cast reviews a research article or commentary about disability in medical education.

Zoey Martin-Lockhart: We bring you, the listener, an easily digestible way to become familiar with this growing body of literature.

Research outcomes and calls to action within the literature are then paired with parallel resources for improving the inclusion of healthcare learners, trainees, and professionals with disabilities.

We also explore publications that address the status of, need for, and benefits of disability representation among the medical education curricula.

Lisa Meeks: In the process we hope that you, our listeners, learn more about the research and resources in this area

Peter Poullos: and find some new ways to conceptualize disability and why it belongs in medicine.

Lisa Meeks: I'm Lisa Meeks,

Peter Poullos: I'm Peter Poullos

Zoey Martin-Lockhart (ZML): I'm Zoey Martin-Lockhart, the curator and co-host of research and resource rounds and we are thrilled to bring you this important and impactful information.

[Summary]

ZML:

This episode opens our fifth thematic collection of Research and Resource Rounds, "Disclosure: the social, political, cultural, and legal dimensions of the choice to disclose disability in the health sciences." Disclosure has threaded through many of our previous episodes — it's come up in discussions of professionalism, identity safety, the hidden curriculum, and clinician-client interactions. In this collection, we turn to it directly.

Today on Research and Resource Rounds we're discussing "Political Disclosure: Resisting Ableism in Medical Education" by Neera R. Jain, published in Disability & Society in 2019.

At the top, Jain poses a particular argument for studying disclosure practices of disabled people in medicine. She highlights the “potential power of disability epistemologies, if permitted to flourish in medical education.” That is, Jain is proposing that great value may be brought to medicine by a disabled or disability-informed approach to knowing and knowledge-making. Jain finds that disability lived experiences inform and motivate many medical students’ approach to and reasons for disclosure—even when most of these students are not familiar with disability studies and disability movements that have theorized or organized around principles developed from and grounded in lived disability experience.

This article is both timeless—in that disclosure will likely *always* be a multifaceted phenomenon and, for some, a difficult choice—AND it is deeply grounded in a particular moment in the evolving atmosphere around disability in medicine, circa 2018-2019.

Jain coins the term *political disclosure*, specifying that it is unique in that it “comprises actions that leverage one’s disability identity for collective benefit” (Jain, p. 17). She writes, “Acts of political disclosure go beyond daring to exist in the environment and request accommodations; they take control of a narrative and enroll others to reconstruct collective understandings” (Jain, p. 17).

Of course, the reasons and contexts for medical students’ disclosure of disability vary. Most commonly, individuals disclose disability in limited circumstances in order to access and implement accommodations in educational and work environments. Jain is careful to distinguish *political disclosure* from this logistically motivated disclosure.

Jain positions the experiences of disabled medical students and her theorization of political disclosure within a macro-landscape of disability stigma in medicine. Drawing on disability in medicine research and social theory, Jain diagnoses the current sources of disability stigma in medicine: first, despite rights and pride movements, in the collective social ether, “disability is understood to be a negative social identity” (Jain, p. 3). Second, biomedicine—and thus medical culture—are rooted in a paradigm that classifies disability as a pathology and medicalizes impairment, foreclosing any imagination of it as a positive or community-building social identity. However, it appears that plenty of people immersed in medical social worlds nonetheless are able to imagine and enact other ways of framing disability, drawing on their own lived experiences. Indeed, Jain points out that stigma is always socio-politically dependent and therefore is a social phenomenon. This is true, too, in medicine, which—although guided by painstaking scientific research—is practiced and built by *social* humans whose biases creep into culture, the framing of ideas and methods, and research findings. Medical “knowledge” is not neutral. Moreover, Jain reminds us that

people from stigmatized groups recognize stigma and how they are seen or understood in dominant narratives and representations. They do not have to agree to be affected.

Jain's article emerges from a larger study—that comprised her dissertation. This article emerged from interviews with 19 disabled medical students and 27 school faculty and administrators across four medical schools. Careful, iterative analysis was conducted using a constructivist grounded theory methodology. The publication describes the methods and presents participant demographic data in detail.

Patterns emerged in interviewees' approaches to and motivations for political disclosure. Individual differences and situational factors also contributed to predisposing or deterring individuals to *political* flavors of disability disclosure.

The types of intervention and change that students aspired to in acts of political disclosure varied, although all related to the destigmatization of disability or the re-orientation of conceptualizations of disability and disabled people, especially disabled medical patients and providers.

The first form of political disclosure Jain identifies is about visibility: disability is shared without a logistical *need* for disclosure and with the intention of countering stigma and creating an environment where more people can also "be open," as Jain puts it.

The second form is practiced by people who seek to disrupt ableism (intended or not) by being an upstander—that is, the opposite of a bystander. These political disclosers engaged with behaviors by others that perpetuated stigmatization of disability with the goal of countering this. Jain lists some of the approaches: "speaking openly in a group setting, following up with someone one to one after an uncomfortable interaction, or using formal channels to complain about behavior perceived to reinforce stigmatization of disability" (p. 9).

A third form of political disclosure marshaled revealing or sharing the experience of disability towards activist ends. Concerned by the exclusively medicalized lens in which disability was discussed in medical education—if it was discussed at all—students used themselves to bring lived experiences of disability into medical education, where they found that perspective lacking.

[Musical interlude]

Political disclosure had personal effects for students, too:

In some cases, disclosing disability led to the coming together of a small disability medical student community. Hence, a greater and more holistic sense of belonging emerged for students who found a cohort within which disability-related experiences in medical education could be discussed and empathized with in shorthand.

Other students' disability disclosures allowed them to feel more authentically themselves.

Jain identifies additional motivations, intentions, contexts, and individual differences that tilted students towards political disclosure.

Some students conceptualized their own disability experience as part of a larger collective community and noted the connections between individual, microcosmic instances of disability stigma and erasure and systemic discrimination and exclusion. These students were more likely to engage in political disclosure. Others felt a duty to change medical culture, destigmatizing disability. Students contextualized this drive within the context of reflecting on their privileged and influential position in medicine.

Whether or not they disclosed disability for the reasons previously stated, Jain's interviewees reflected that they were—or anticipated they would be—more willing to disclose as they became more senior and established a foothold in medicine.

A natural tendency toward outgoingness and self-disclosure broadly also seemed associated with individuals' propensity toward political disclosure.

Reasons for students' choice NOT to disclose are likely familiar to many of those engaging with this episode. Repercussions on future schooling and career were primary concerns. Jain found that concern for protecting the perception of disabled people in medicine was also a factor in students' decision not to disclose. Others tolerated insufficient accommodations and did NOT ask for the accommodations they truly needed to avoid being seen as difficult. The latter was especially true for students with visible disabilities where disclosure options were more limited.

Medical school administrators and officials interviewed by Jain revealed varied perspectives on disability disclosure for purposes out of or beyond securing and implementing accommodations. Some felt a protective need to caution students about the potential future effects of political disclosure. Other interviewees felt organizing around disability was important for shifting the same dominant medical culture that prompted some other officials to discourage political disclosure. Intriguingly, some administrators did not perceive students as invested in political disclosure, organize disability advocacy, nor to build disability social groups.

Disabled faculty, meanwhile, tended to see lived disability experience as an asset, and regarded it as such when disclosed on applications.

Jain links students' orientation towards political disclosure with a conceptualization of disability that recognizes a resonance between their own disability or illness experience and those of people with very different disabilities or impairments. Jain joins many of the authors from prior Research Rounds episodes in calling for widespread disability education in medicine, grounded in a disability studies perspective.

At the end of each episode, we like to suggest related reading and resources. Links to everything are embedded in the episode transcript.

A core of political disclosure is forging connection around shared disability experience, the rewriting of what disability means in medicine, and, in some cases, organized advocacy for greater disability inclusion across medicine. Particularly in the six years since Dr. Jain's article was published, a fantastic cadre of medical disability groups has been founded and flourished, perhaps indicating a next, more communal era of political disclosure. I suggest that you check out this universe, which includes:

1. Medical Students with Disability and Chronic Illness (MSDCI) is an organization with both a national body and chapters at 65 medical schools.
2. The Disability in Medicine Mutual Mentorship Program (DM3P) has monthly events and social time on the third Wednesday of each month.
3. The Disability Advocacy Coalition in Medicine (DAC-Med), which has chapters across many institutions and organizes a yearly conference.
4. The Canadian Association for Physicians with Disabilities (CAPD), a group for networking and support, offers a mentorship program pairing medical students and trainees.

Links to each group's website are embedded in this episode's transcript.

Next, the ACGME and DWDI collaborated on a disability hub, which we've mentioned before. It includes a section on "Disclosing in an Application," which includes links to a "Transition from UME to GME Webinar Panel" and links to "Examples of Disclosure in Personal Statements."

We welcome your ideas and feedback. You can find us on Twitter @DocsWith or email us at docwithdisabilitiespodcast@gmail.com, Subject line: Research and Resource Rounds Podcast.

Thank you for listening and reading along!