

Exploring Human Stories of Illness
The Health Humanities Portrait Project

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The Medicalization of Trans Lives

Teaching Guide

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Reading List

First-Person Narrative

- Enriquez A. "How Microdosing Testosterone Changed My Life", *Vice*, 2019.
[How Microdosing Testosterone Changed My Life](#).

Scholarly Readings

- Appendix from Sharman Z., ed. *The Remedy: Queer and Trans Voices on*

Vancouver, CA: Arsenal, 2016.

- Clare E. "Selections." *Brilliant Imperfection: Grappling with Cure*, Duke UP, 2017, pp. 41-43; 139-141; 177-179.
- Stroumsa D, Roberts EFS, Kinnear H, and Harris LH. (2019). "The Power and Limits of Classification — A 32-Year-Old Man with Abdominal Pain." *NEJM*. 2019: 380 (20), 1885-1888. [The Power and Limits of Classification — A 32-Year-Old Man with Abdominal Pain](#).

Recommended Readings / Additional Resources:

Linton S. "Disability Studies, Not Disability Studies". *Disability & Society*. 1998: 13(4), 525-539. <https://doi.org/10.1080/09687599826588>.

DasGupta S. "Medicalization" in Serlin D, Reiss B, & Adams R. *Keywords for Disability Studies*, New York: New York University Press, 2020. pp. 120-121. <https://doi.org/10.18574/9781479812141>.

Giffort DM and Underman K. "The Relationship between Medical Education and Trans Health Disparities: A Call to Research." *Sociology Compass*. 2016: 10(11), 999–1013. <https://doi.org/10.1111/soc4.12432>.

Lev A. "Gender Dysphoria: Two Steps forward, One Step Back." *Clinical Social Work*. 2013: 41(3), 288-296. <http://dx.doi.org/10.1007/s10615-013-0447-0>.

Mackinnon KR, Ng SL, Grace D, Sicchia SR, and Ross LE. "Protocols as Curriculum ? Learning Health Advocacy Skills by Working with Transgender Patients in the Context of Gender - Affirming Medicine." *Advances in Health Sciences Education. Theory and Practice*. 2020: 25(1), 7–18. <https://doi.org/10.1007/s10459-019-09899-0>.

Rosenberg C. "Introduction. Framing Disease: Illness, Society, and History." *Framing Disease: Studies in Cultural History*. Charles Rosenberg and Janet Golden, eds. New Brunswick: Rutgers University Press, 1992: xv-xxvi.

This teaching guide is divided into two sections. Section One provides instructors with an overview of the HHP and important terms and modes of inquiry that will be used throughout the HHP. Also included in this section are key terms and definitions that instructors should draw from when using the powerpoint. Section Two provides the outline of the class session and guides for moving students through the HHP's exploration of trans health.

Section One

1. Learning Goals & Objectives

- Provide an Overview of Trans Health Disparities
- Introduce Disability Studies as an interpretive lens and analytical framework.
- Define medicalization and analyze its potential as a concept that shapes identity, as well as medical and social practices.
- Identify the ways a linear narrative of cure determines diagnosis and treatment.
- Disrupt binary thinking in order to recognize the ways trans lives exist outside of or beyond such thinking.

The primary goals of this HHP are: to help (1) facilitate knowledge of medicalization through the critical analytical skills Disability Studies provides; (2) increase students' understanding of medicalization as a social issue that impacts trans identity; (3) to provide students with tools to critically understand how the concepts often marshaled in discussions of trans health, such as *diagnosis*, *cure*, and *treatment*, can actually lead to disparities in trans health and healthcare.

2. Overview of Trans Health Disparities

Trans people experience higher rates of mental distress, substance use, homelessness, sexual, verbal, and physical assault, and higher rates of suicide (Sharman 17-19). Trans people are also far more likely to experience traumatic events and violence throughout their life. At the same time, trans people are more likely to be uninsured and have had negative experiences with healthcare professionals. "One in five trans people

report having been denied access to care. Trans people of colour are even more likely to report being denied care” (Sharman 236).

It is vital for healthcare professionals to understand these health disparities and work to address the transphobia that leads not only to the denial of care that trans people experience but also the scope of actions that create negative and traumatic experiences for trans patients. Within healthcare, these actions include mis-gendering (using the wrong gender in addressing people) and dead-naming (the use of an old name rather than a chosen name—often justified through policies requiring patient names match formal IDs) to the complicated negotiations with diagnosis (the need to secure a Gender Identity Disorder diagnosis in order to receive gender-affirming care). Physicians have a vital role in addressing these disparities through gaining cultural and structural competency in trans-healthcare and addressing transphobia in healthcare systems. There are several resources available to gain the knowledge and skills to do this work. The continual interrogation of the assumptions about bodies, minds, and the trajectory of care that shapes the ideology of cure is also central to addressing health disparities. While not separate from cultural/structural competencies, this portrait tackles the ideas that lead to and bolster health disparities by centering the processes of medicalization as a social issue.

3. Introduction of Content

The overview below provides an introduction to modes of inquiry, important terms, and definitions used throughout the HHP. Portions of the overview are also included in the Notes section of a number of slides in the powerpoint.

- **Disability Studies**

Disability studies is an interdisciplinary field of research that focuses on the social, cultural, historical, political, and economic structures that impact disabled people’s lives, experiences, and futures. Deeply tied to disability rights, disability culture, and (increasingly) disability justice movements, disability studies understands disability as a source of unique knowledge and creative expression.

Disabled people make up as much as 20% of the world’s population. However, disability is still largely understood as only an isolated individual and/or medical problem that requires individual and/or medical solutions. These solutions, in turn, are often aimed at the elimination, cure, or minimization of said problem through intervention into the body/mind of the disabled person. While medical and rehabilitative care are crucial to many disabled people’s lives, the distillation of disability down to *only* or a *predominantly*

medical problem misses the breadth and scope of disabled people's lives. The issues many disabled people face in navigating a world built by and for non-disabled people not only far exceed the "medical" but are often a direct result of the medicalization of disability.

Medical sociologist Peter Conrad (2007) defines medicalization as, "a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorder" (4). Disability studies has extended this understanding to view medicalization as the larger processes that construct non-normative bodies and/or minds into problems that require medical or rehabilitative interventions (targeted within the body or mind). Disability studies' understanding of medicalization places an emphasis on the narrow lens that this process causes (the distillation of experiences of the body and/or mind to *only* or predominantly individual problems) and on the location of the intervention (in the individual body or mind).

Disability studies, in a critique of this singular view of the "problem" of disability, illness, and impairment, highlights the disabling effects of social, environmental, political, and economic structures. In this sense, disability studies can also be thought of as a field that turns the focus away from the body and/or mind outward, onto society. Troubling an individualistic understanding of and response to disability, the field asks questions about the ways in which society *disables* people and seeks to intervene in the environments that limit disabled people's lives. These environments might be built (like roads without curb cuts or buildings without ramped entrances), attitudinal (like assumptions that disabled lives are either pitiable or inspirational or that people with mental illness are dangerous), or structural (like the policies that segregate people in institutions or allow businesses to pay disabled people less than minimum wage).

Disability studies, then, offers an analytic lens that centers the lived experiences and insights of disabled people, but does not necessarily make disability (or the disabled body and/or mind) the object of study. Rather, the field's object of study focuses on the social, cultural, political, and economic structures that disable people's lives. This means asking questions about how systems and structures limit the pasts, presents, and futures of disabled people, and how we can improve the lives of people with disability by working to dismantle those structures.

- Medicalization

Medicalization shapes the belief that all disabled people require, desire, and should actively be working toward a cure. This belief, in turn, shapes much of the systems and structures that emerge to manage disabled bodies and minds, including medicine. The critique of medicalization has been one of the key insights that disability studies analyses

offers. Writer and trans* disability studies scholar Eli Clare describes these beliefs as an “ideology of cure.” This ideology encompasses not only assumptions that all people with disabilities want and need a cure, but also that the imagined trajectory of diagnosis, treatment, and cure is (if not always straight-forward) an objective, pre-determined, and singular path. Disability studies scholars have mapped many of the unconscious ways in which these assumptions manifest both within the general public and medical practitioners, from presumptions of able-bodiedness to assumptions about the quality of life of disabled people to the barriers in access to care for those who fall outside of or refuse to adhere to this trajectory.

Eli Clare theorizes from his experience as a trans disabled man to describe the ways in which this singular trajectory of diagnosis, treatment, and cure limits and harms the lives of both trans and disabled people by imagining clear and rigid binaries between sick/well, disabled/non-disabled, and men/women. Disability studies makes clear the ways in which medicalization positions healthcare as a trajectory from one (sick and/or disabled) to another (well and/or non-disabled). The role healthcare provides, then, is imagined as transitioning people from one to another through diagnosis and treatment. Similarly, trans health care is often implemented in ways that imagine a relatively singular trajectory of care that, upon diagnosis of Gender Identity Disorder, a person receives treatment and transitions from one gender to another, upon which they are “cured.” While diagnosis, hormones, surgery, and gender transition are central components of trans health care, these are not always straightforward nor exhaustive of the complexity of issues that trans people experience in their lives or in their healthcare experiences.

This portrait centers the insights of trans and disabled people to explore the medicalization of trans healthcare in ways that approach trans health disparities from a disability studies lens. **This is not to equate trans people with disabled people or to name trans identity as a disability** (for more on these debates see, Baril 2014; Mog and Swarr, 2008). **Rather, this portrait offers a disability studies critique of how the process of medicalization creates assumptions about trans lives and trans healthcare that limits and harms trans people.** Other fields of study and analytical approaches offer similarly fruitful means of approaching trans health disparities (see Hanssmann 2018 for a discussion of the overlaps between feminist health studies and trans studies critiques of medicalization). This portrait chooses a disability studies’ lens because the field’s critique of the ideology of cure provides a different and generative viewpoint through which to understand trans health disparities.

The “ideology of cure” that the portrait presents and asks students to think through operates as a *way of viewing* bodies and minds. Cure, in this sense, operates not necessarily

as a fixed category, a specific procedure/medication, or a concrete treatment plan, but as a set of ideas. Therefore, while healthcare providers may not explicitly view transition as a “cure” in the same way that we might understand antibiotics to “cure” a bacterial infection, the set of ideas and beliefs captured within the concept “ideology of cure” illuminates key assumptions within the practices of healthcare and within the conceptualization of bodies and minds that this portrait highlights. The ideas and contexts presented in this portrait are deeply tied to fixed notions of gender (that someone is either a man or a woman) and cannot be separated from the broader analyses of race, class, gender, sexuality, age, nation, and religion. Therefore, while the portrait foregrounds a disability analysis of medicalization and troubles the ideology of cure as it operates within trans health care, a broader intersectional analysis can add important nuance to this discussion.

Section Two

Notes at the outset:

The following guide begins with an Opening Exercise to encourage students to consider different explanations for trans health disparities.

It then moves to an introduction of disability studies through a short video. Learners will then be asked to identify how Clare’s essay incorporates a Disability Studies framework into his discussion of being a trans* disabled man. This will offer an opening discussion that lets the instructor assess and, if necessary, facilitate learners’ understanding of the Disability Studies framework. Discussing Clare’s text will also open a discussion of the framework for understanding trans experiences.

Next, the instructor will lead a discussion about the short article “The Power and Limits of Classification”, published in the *NEJM*. During this discussion, instructors will first ask learners to discuss briefly the limits of classification raised in the *NEJM* article. Next, instructors will ask learners to apply a DS framework for the purpose of asking, “How do cure, diagnosis, and medicalization more broadly lead to what happened to Sam?” If time permits, ask students to consider how adherence to a linear narrative of cure undermines even well-intentioned healthcare professionals. Finally, instructors will ask learners to discuss the first-person narrative, “How Microdosing Testosterone Changed my Life” using a DS framework. In the process, they will explore the ways that Alyza’s non-binary trans experiences relate to or conflict with the simplicity of the health/illness binary.

Introduction: *The following points should guide the instructor's introduction to the session.*

Trans folks experience substantial health inequalities in the United States (and elsewhere) due both to barriers to healthcare and practitioner bias. Our focus, in this session, however, will instead be on the binaries (both medical and gender-related) that impact and inform trans individuals' experiences.

We will begin with a short introduction to disability studies and the concept of medicalization. We will move into a discussion of the text you read by a trans disabled scholar discussing cure, medicalization, and intersecting identities. We will then briefly explore a short essay published in the NEJM in order to better understand a rigid medicalized view of trans experiences impacts health and well-being. While this essay provides some analysis of the limits of classification, we will add a disability studies framework to this discussion to highlight the limits of the health/illness binary. Finally, we will further complicate this binary by examining the personal narrative featured in the micro-dosing article.

The NEJM article serves a critical function by beginning from a place that does not centralize hormones and/or the process of transitioning. We begin here in order to disrupt notions of what constitutes trans healthcare and the linearity of transitioning. This essay works with the primary personal narrative (micro-dosing article) to offer an additional perspective on transness. In another sense, it exposes the perils of a binary approach to gender within the practice of trans health care while also providing a means through which to draw out an analysis of cure and medicalization.

Outline of Session

1. **Brief Overview of Trans Health Disparities**
(Slides 1-2)
2. **Opening Activity: What are some of the most common explanations for Trans health disparities?** (~ 5-10 min)
(Slide 3)
3. **Overview of Session and Goals:** (~5 min)
(Slides 4-5)
4. **Introduction to Disability Studies** (~10 mins)
(Slide 6-8)
5. **Apply Disability Studies framework to our discussion of Eli Clare's *Brilliant Imperfection*.** (~10 minutes)
(Slides 9-10)

How does Clare's text examine the concept of cure?
(Slides 11-12)

How does Clare's text complicate the health/illness binary? How does he problematize the gender binary?

6. **Discuss the *New England Journal of Medicine* article.** (~20 min)
(Slides 13-16)
 - ***How does this article challenge your notion of trans health?***
 - ***How does the article raise questions about the health/illness and gender binaries?***
 - ***How does cure function within Sam's story?***
 - ***How do we apply DS/trans theory to this case?***

Sam's narrative reveals how viewing transition as a "cure" from being "born in the wrong body" or the disease of transness limits his access to care, directs his treatment, and causes harm.

7. **Apply these concepts to the article, "How Microdosing Changed My Life."**
(~10 mins)

(Slide 16)

You are going to look at a few specific quotes from the article and discuss them using what you've learned today. (~15 mins)

(Slides 17-21)

- ***“I was assigned a dosage according to my lie” (pg. 5)***
- ***“ Looking at images of trans men was both comforting and not—a haze of uncertainty. I spent my therapy sessions describing this haze while maintaining a cool exterior to show that I wasn’t upset by questions that locked me into ‘male’ and ‘female’” (pg. 4).***
- ***““Do you want to be a husband someday, versus a wife?’ my therapist asked” (pg. 4)***
- ***“For non-binary people, [the “complete” medical transition] can serve as reinforcement that popular narratives about transness, in otherwise cis contexts, are premised on how far along an individual is in their “complete” medical transition. Microdosing rejects that notion because it is a process that is without a hard and fast “end.” (pg. 6)***

8. Wrap up Comments (~5min.)

(Slides 22-23)

Eli, Sam and Alyza all have experiences that complicate the notion of “complete” transition. They also have very different relationships to and experiences with testosterone outside of the transition process. What does this tell us about the cultural and professional investment in “cure” within medicine?

Appendix

Suggested Class Activities that encourage students to use the tools and insights presented in the HHP:

- a. Ask students to imagine what Sam's story would be in "The Power and Limits of Classification — A 32-Year-Old Man with Abdominal Pain." How might his personal story differ from the authors of the article about his experience under their care?
- b. As a first exercise, ask students to draw "gender" and "cure." Emphasize that there is no correct representation. The point is for students to consider the challenges of producing visual representations of these commonly used words.
- c. Engage students in close readings of the text. Assign specific passages to students working in groups and then ask them to report back to the entire class.
- d. Ask students to find first-person narratives by and scholarly articles about trans women that students then analyze through the concept medicalization.

Comments about pedagogy

Viewing medicalization as a social issue is a complicated task for physicians when diagnosis and treatment are core components of their jobs. The goal of this portrait is to give you the tools to think critically about the assumptions that medicalization carries within the practice of medicine and for the larger social and cultural contexts in which people live their lives and experience their health. In thinking about what to "do" with the ideas the portrait raises, it is important to keep in mind that a primary role of the portrait is to produce further questions, rather than answers, because questions constitute the portrait's desired actions/outcomes. In other words, questioning *is* the action that the portrait seeks to cultivate.

This portrait also reflects deliberate choices to include a scholarly article that also incorporates first-person experiences. This choice reflects a centering of trans experiences at each level of the portrait in order to provide voice to members of marginalized communities whose experiences so often are not incorporated into mainstream education. It

also complicates clear divisions between personal narratives and scholarship. The interweaving of personal narrative and scholarship is certainly not distinct to Disability Studies but does reflect a common approach within the field. More than this, the portrait seeks to highlight the utility of stories/case studies as a best practice within medical literature.

Specifically, in this portrait, we highlight the frequent use of scholarly analysis interwoven with personal narrative in Disability Studies, as well as the use of story/ the case methodology to teach about best practices in medical literature.