Southeast Region Hemophilia
Technical Assistance Meeting

OHSU Portland State University | SCHOOL OF PUBLIC HEALTH

SEX, GENDER IDENTITY, GENDER MODALITY, INCLUSION AND REPRESENTATION IN THE BLOOD DISORDERS COMMUNITY

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MAY 18, 2021

About me

Transgender, transsexual, and occasionally a drag performer

Epidemiologist

Social justice activist

Collaboratively work for the just and accurate representation of people with gender minority experience and sex minority experience (GSM)

A recent collaborator within the blood disorders community, I have not lived with these kinds of health conditions.

Why I am here

My collaborators are people with GSM experience and sexual minority experience and public health professionals motivated by justice for GSM.

One such, is ATHN's Dr. Mike Recht who sought guidance about gender and sex minority inclusiveness from transgender health advocates at OHSU's Trans Health Program

Amy Penkin, director of THP, being familiar with my work in this area, referred Dr. Recht to me, and my interview and email exchanges with Dr. Recht, and my input on draft standards, contributed to the form of ATHN's new policy.

This presentation lays out some of my own perspective regarding the logic in this new policy, and why just and accurate representation of GSM matters.

Sex, gender & transgender experiences have some independence:

Was your sex assigned at birth (select one): Male, Female, Intersex

Gender identity (select all that apply):
- Masculine/man/young man/boy
- Feminine/woman/young woman/girl
- Non-binary
- Agender
- Questioning

Are you currently transgender (select one): Yes, No, Questioning

All questions should allow “Prefer not to state.”

Just & accurate representation of *sex* specifically 4

Our social habit of thinking of sex as binary, and compassing exactly two conditions is a convenient fiction, for sex is both multi-dimensional—e.g., chromosomal, anatomical, physiological (hormone levels, dynamics, and receptors), and legal (and varying by jurisdiction)—and, even at the chromosomal level, sex is *bimodal* not binary.

Practice is not there yet, but a patient's interests would be best met by representing sex using anatomy inventories and physiology inventories, without assuming that any particular answer precludes another.

Of course, the validity of such inventories in *survey form* will be contingent on how much one can actually know about one's body.

Gender categories start with simple bimodal descriptors: **masculine** and **feminine**, and we commonly use gender roles to categorize gendered experiences by age: **man** and **woman** or **boy** and **girl**.

Agender: those rejecting masculine/feminine roles and identities, or even rejecting any participation in gender.

Non-binary: Some people occupy both masculine and feminine roles and identities, in androgyny (simultaneously masculine and feminine), through **fluid** expressions that are labile with internal or external contexts, and some through situational specificity (e.g., work gender vs. home gender). People with non-binary gender identities may or may not identify as agender.

Just & accurate representation of *gender modality* 6

Gender modality distinguishes **transgender** and **cisgender** experiences.

First, transgender identity can only be self-ascribed (i.e. transgender cannot be diagnosed by another). Second, transgender identity is not limited to occupying categories relative to the sex/gender binary. From these two principles, I define transgender as those individuals who transgress against or transition away from or through the gender they were assigned at birth. Cisgender is the logical complement.

Treating transgender as a subjective experience, akin to proprioception, pain, enjoyment, etc. is necessary to rejecting it as pathology.

Separating transgender from (binary) sex at birth makes room to understand why people raised agender, or non-binary, may not identify as transgender.

Why this matters i: The sex/gender binary 6

To the detriment of epidemiology and clinical practice in the service of patients' needs, sex and gender are both treated as the same thing, and this sex/gender thing is treated as having only two categories. The result is that:

Health experiences affected by social roles, and their performance (i.e., gender) are sometimes falsely attributed instead to chromosomes, reproductive organs, or other biological differences in sex.

Health experiences rooted in sexual biology are sometimes falsely attributed to differences in gendered behavior and social roles.

Sex and gender both drive health experiences, but the dimensions of neither are perfectly captured by binary categories.

Why this matters ii: Erasure of GSM people

GSM persons have been programmatically excluded from representation in both epidemiology and the clinic. For example:

What are GSM persons' admission rates to your hospitals and clinics? What health inequities are between categories of GSM and majority cis-binary persons?

How many GSM persons exist in the U.S., Georgia, or Tallahassee?

Current narratives by right-wing pundits and politicians proclaim the non-existence of gender (i.e., assigned, performed, and contested social roles), and the ontological primacy of a binary sex.

We have statistics for many kinds of experience—education, occupation, health, mortality—but usually not for GSM persons.

Why this matters iii: Pathologization of difference 8

Researchers and clinicians have enacted harm of GSM persons by treating gender diversity as pathological.

This orientation is perhaps captured by the question **Why do gender (or sex) minorities have worse health than gender majorities?** and also by the statement **Being a gender minority is a risk factor for disease**.

The pathologization of difference can lead to a malefic stance that demands that the GSM patient cease existing—as with the literal erasures implied by so-called conversion therapy.

Why this matters iv: GSM as condition 9

Gender diversity and sex diversity may instead be recognized as simply health-relevant conditions (as the ICD and DSM both now do).

Consider how the questions **What causes people with gender minority experience or with sex minority experience to have the highest levels of health?** and **What reduces health inequities between gender and sex minorities and majorities?** present a very different stance towards patient well-being compared with the pathologization of difference.

Why this matters v: Empathy & cultural humility 10

Centering active patient participation and autonomy in the clinic necessitates both empathy for the patient's needs and cultural humility.

Empathy is requisite both for valuing and understanding their immediate and long term health & health care needs, but also in terms of their relationship with a provider in a clinical context. (Researchers also!)

At the same time the provider's cultural humility in recognizing the limits of their own knowledge of the patient's experiences is a necessary part of a good-faith invitation to share in decision making.

Because our sexual biology is so socially laden with meaning, and because our gender experiences are for so many central to our immediate conceptions of self, we must strive for inclusion with GSM, who historically have been systematically excluded from representation.

Why this matters vi: Equity & sanctioned ignorance 11

We expect inequities in GSM health relative to cisgender-binary health, because:

> we have to educate our providers about our bodies and our genders, while in clinical settings,
> we have to navigate health systems which assume that it is fine to operate using the sex/gender binary,
> we have more economic barriers to access, and often geographies of violence to navigate.

In the words of of epidemiologist Nancy Krieger "If you don't know, you can't act."

Can you help us see those inequities? Can you ask these questions? Can you act?

The questions here—when paired with appropriate corresponding standards of conduct at reception, with assistants, and care providers—can build more inclusiveness into GSM patient experiences in the clinic.

By what name should we address you? (Do you have other names we should know about, such as for correspondence, insurance, dependent/guardian relationships, etc.?)

Which pronouns do you prefer to use, if any?

They/Them/Their
She/Her/Hers
He/Him/His
I prefer not to use pronouns
Not listed

Implementing these questions will invite push back. Some cisgender and binary gender persons will not see the point, or may respond with **Can't you tell?** Some GSM people will prefer to remain anonymous. Some people will become exercised.

It will help to develop **response matrices** of scripted answers guiding people having these kinds of reactions back to the points: we try to make space for everyone; people of different sexes, genders, or gender modalities are treated differently (when they should not be), and this helps us be accountable.

It was once verboten to ask a patient whether one had female sexual partners *and* whether one had male sexual partners, yet resistance to such questions has diminished, and such questions are commonplace in clinics.

Conclusion 14

Sex, gender, and transgender/cisgender are somewhat dependent and somewhat independent categories of experience that are socially patterned with respect to inclusion, celebration, and discrimination.

Sex, gender, and transgender experiences are more complicated than can be captured by a single question with a binary outcome.

The usefulness of these broad categories (male/female/intersex, masculine/feminine/agender/non-binary, transgender/cisgender) are limited, but, with **Questioning**, **Not listed**, and **Prefer not to state** categories, form a minimum of just representation that we should strive to use in representing who we are as researchers, care providers, and patients.