National Hemophilia Foundation
Wednesday Webinar

THE JUST & ACCURATE REPRESENTATION OF SEX, GENDER IDENTITY, & GENDER MODALITY IN THE BLEEDING DISORDERS COMMUNITY

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About me 1

Transgender, transsexual, and occasionally a drag performer

Epidemiologist

Social justice activist

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

A recent collaborator within the bleeding disorders community, I have not lived with bleeding disorder health conditions.

Why just and accurate representation matters 2

People in some groups have specific health care needs. Just and accurate representation facilitates getting appropriate care to those who need it in a timely fashion.

People from some groups are treated with systematic advantage or disadvantage within health practice in ways that affect health care access or quality. Just and accurate representation permits accountability around such unfair and unnecessary practices.

Some groups have been historically marginalized and oppressed by ongoing institutions in society at large. Reaching for inclusion through visibly just and accurate representation coupled with training and practice strives towards equity, and a healthier and more just clinic.

Health professionals can behave with bigotry. Recognize & change.

A minimal set of questions for the just and accurate representation of sex, gender identity, and gender modality are:

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 many of the 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 the internals of one's body.

Sex minority experiences

People with SM experiences are those whose bodies fall away from expectations that bodies fit neatly into one of two categories—female or male—with regard to sexual anatomy and physiology. Such experiences can include:

- Sex chromosomes which are neither all XX nor all XY (e.g., XO, etc.)
- Unusual distributions of estrogen or androgen receptors
- Surgically modified sexual characteristics such as a radical mastectomy, orchiectomy, genital reassignment surgery, etc.
- Rare patterns of development of the gonads, genitals, or secondary sexual characteristics;
- Biological fertility countering expectations from external sex

People with SM experiences may be male, female or intersex, may be transgender or cisgender, may have any or no gender identity.

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). Some people occupy **third gender** categories. People with non-binary gender identities may or may not identify as agender.

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

Principle 1: Transgender identity can only be self-ascribed (i.e. transgender cannot be assigned by another). **Principle 2:** 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 its logical complement.

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

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

People with GM experiences are those whose gender identity is neither cisgender man (or young man or boy), nor cisgender woman (or young woman or girl).

These include transgender people, people with agender identity, and people with non-binary gender identity.

The validity of both population health research and clinical practice in the service of patients' needs suffer when 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 aspects of 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 2: Erasure of GM & SM people 10

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

What are GM persons' admission rates to your hospitals and clinics? What health inequities are between categories of GM and gender majority persons?

How many SM persons exist in the U.S., Maine, or Kansas City?

Current narratives by right-wing pundits and politicians proclaim and demand 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 GM or SM persons.

Why this matters 3: Pathologization of difference 11

Researchers and clinicians have enacted harm of GM persons & SM persons by treating gender minority experiences as pathological.

The orientation towards **pathologization of difference** for GM persons & SM persons is perhaps captured by the question **Why do GM (or SM) populations have worse health than gender majority populations?** and also by the statement **Being a gender minority is a risk factor for disease** as well as by the research and professional practices that transact in such "risk factors."

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

Why this matters 4: GM & SM as conditions 12

GM experiences and SM experiences may instead be recognized as simply **health-relevant conditions** (as the ICD and DSM both now do) which make up parts of the social and biological diversity of our species.

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 GM and gender majority populations or between SM and sex majority populations?** present a very different stance towards patient well-being compared with the pathologization of difference.

Why this matters 5: Empathy & cultural humility 12

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 patients' immediate and long term health & health care needs, but also for a good 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 around health care.

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 of GM persons & SM persons, who have been systematically excluded from representation.

Why this matters 6: Equity & sanctioned ignorance 13

We expect inequities between GM populations health relative to gender majority population health, and between SM populations health relative to sex majority population health, because GM persons & SM persons:

Have to educate our providers about our bodies and our genders, while in clinical settings,
Have to navigate health systems which assume that it is fine to operate using the sex/gender binary,
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? Can you ask these questions? Can you act?

Why this matters 7: Bleeding disorders 14

The just and accurate representation of sex and gender helps because:

Some bleeding disorders link to the sex chromosome, not to gender.

Some bleeding disorders have a special significance for people who menstruate.

Some genetic bleeding disorders affect fertility, inform mating strategies, and are bound up in cultural values around gender roles in mate selection, and disease management: so sex & gender both signify.

People with some bleeding disorders pursuing gender-affirming surgeries (e.g., ‘top surgery,’ genital reassignment surgery, etc.) require a multidisciplinary team, including a specialist in the relevant bleeding disorder in order to achieve the lowest risks, and best outcomes.

Good faith welcome and inclusion 15

The questions on this slide—when paired with appropriate corresponding standards of conduct at reception, with assistants, and care providers—can build more inclusiveness into GM persons' & SM persons' 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, please use: _____

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 GM persons & SM persons will prefer to remain anonymous. Some people will become exercised. Permit discomfort.

Developing **response matrices** of scripted answers guiding people having these kinds of reactions back to the points will help: 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 now commonplace in clinics.

Conclusion 17

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

Experiences of sex, gender identity, and gender modality 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.