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On the Just and Accurate Representation of Transgender Persons in Research and the Clinic

Alexis Dinno

Portland State University, alexis.dinno@pdx.edu

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ON THE JUST & ACCURATE REPRESENTATION OF TRANSGENDER PERSONS IN RESEARCH & THE CLINIC

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ALEXIS DINNO, SCD, MPM, MEM

built on a collaboration with

Molly C. Franks

Jenn Burleton

Tyler C. Smith



About me and why I am here...

Transgender

Transsexual

Drag performer

Epidemiologist

Social justice activist

My collaborators are likewise:

sexual and gender minorities

public health professionals

motivated by social justice

We desire just representation of transgender persons.

Aside: basics of epidemiology

Epidemiology is the study of health and disease *in populations* with the aim of improving health in those populations.

Many of the figures epidemiologists produce are derived from two concepts:

Prevalence: how common a health condition is at a moment in time

Incidence rates: how fast new cases of the health condition arise in a population; also: risk of the health condition in the population

Epidemiology's more sophisticated measures are based on these concepts.

About epidemiology 2

A critical distinction between epidemiologists and clinical health researchers is located in the *population perspective*.

Put briefly, a small change in *risk*—even one so small as to be meaningless to an individual—implies a large number of cases when multiplied across a whole population.

Epidemiologists are therefore concerned with policies, planning and environmental change: the causes of prevalence and incidence in a population are *not* the causes of being a case in an individual.

Epi has largely failed transgender persons

What are the top causes of death in transgender populations?

What are the top health concerns faced by transgender persons?

We can parse out the prevalence and incidence of *many* causes of health, morbidity and mortality by race/ethnicity, by economic conditions, by geography, by sex, and age...

...but we cannot present even limited pictures for transgender persons.

Why?

We have identified several biases in the academic health literature:

- Transgender is studied as disease outcome, rather than as a population of persons with their own particular health determinants and concerns
- Transgender persons are far more likely to be studied as vectors of HIV and other STIs
- **We—epidemiologists—simply *tend not to represent transgender persons* in basic epidemiologic research. (And when we do we often create more problems.)**

Principle 1 for representing of transgender

1. *Transgender should not be subsumed within a question about sex.*

Example:

Are you (pick one): Male Female Transgender

Results:

- Transgender persons excluded from analyses of male & female experience
- or—
- Invites the unjust exclusion of transgender from representation when transgender persons opt to respond “Male” or “Female”

Transgender persons typically *are also* male or female.

Principle 2 for representing of transgender

2. Do not include transgender identity in questions about sexual orientation.

Example:

Are you (pick one): Heterosexual Homosexual Transsexual

Results:

- Perpetuates blindness toward the health concerns of transgender people
- Directs attention away from the health needs of transgender and gender non-conforming children, for whom gender is often salient long before sexual orientation.

Every person has both gender identity and sexual orientation.

Gender identity intersects with sexual identity (and age, family relationships, religion and many other signifiers).

Principle 3 for representing of transgender

3. *The timing of transgender identity and transitions in gender identity during an individual's life should be represented.*

Example:

Have you taken cross-sex hormones? () Yes () No

How old were you when you first began taking cross-sex hormones?

Results:

- Includes diversity in when during the life course gender shifts
- Captures transgender experiences as children that may bear on health in different ways than transgender experiences during adolescence or adulthood
- Potentially represents many different transitions (not just hormones!)

Principle 4 for representing of transgender

4. *Do not prioritize any mode or direction of gender transition or transgression.*

Example (for an female-born transgender person): How long have you wanted to be a man?

Results:

- Builds tacit assumptions about a transgender person's developmental trajectory
- May subtly exclude some transgender persons from representation

Transgender persons do not necessarily want the same transitions.

Wanting to not be a woman does not necessarily equate with wanting to be a man.

Principle 5 for representing of transgender

5. *Although inclusiveness is desirable, avoid “select all that apply” modes of soliciting different flavors of transgender identity in structured surveys*

Example:

Are you (select all that apply):

- Transsexual Transgender Cross-dresser
 Pink-boy Boy-girl

Results:

- Misses lady-boy, hijra, stone butch, gender-fuck, fluid, third gender, drag queen, drag king, reconstructed femme, gender-queer, gender-punk, radical faerie, Sister of Perpetual Indulgence, and many more...

Transgender is a rich domain: identify specific parts relevant to health.

Principle 6 for representing of transgender

6. Simple and straightforward language is desirable.

Example:

People may identify themselves as transgender if they do not conform to other people's expectations based on their birth sex.

Do you identify yourself as transgender: () Yes () No

Principle 6 and children

Age-appropriate language is important. This may present a challenge, and may require qualitative inquiry into children's language around gender.

For example, in my personal experience, very young English-speaking children on the West Coast of the USA very readily understand and use the term 'boy-girl.' However, different languages, times and places may render this term meaningless.

Language to identify both transgender & cisgender will grow more complex as children mature and their social realities gain nuance.

Parsimony in survey design: 0 questions

Surveys are expensive, and each question costs real money.

We recommend the following *minimal* set of questions pertaining to gender identity, prioritized according to the number of questions about transgender permitted on a survey.

When no questions about transgender will be explicitly included, at least two questions should be asked to identify the respondent's sex over the lifetime:

1. What was your sex at birth?
2. What is your sex currently?

Surveys may naturally include intersex responses.

Parsimony in survey design: 1 question

A straightforward yes or no question asking if the respondent self-identifies as transgender should be included. This question should be separate and in addition to a question about the respondent's sex:

Do you identify yourself as transgender: () Yes () No

Parsimony in survey design: 2 questions

A follow up question for those answering 'Yes' to transgender self identity:

When were you first aware that your gender identity either did not match your body or other people's perception of your gender?

Age: _____ () As long as I can remember.

This will help understand the role of *transition* and transgender identity on health across the *life course*.

This will also facilitate the differentiation of the 'As long as I can remember' and those transgender persons who developed transgender identity in adolescence or later.

Back to epidemiology

We have no prevalence, incidence or more sophisticated measures for the health of transgender populations in the USA because we are not collecting the most basic data required for the numerators and denominators. (Are we collecting these data elsewhere?)

Without these basic measures, we cannot assess the changes in risk of death and disease among transgender persons that result as a consequence of, for example, organizational, institutional and governmental transgender anti-discrimination policies that affect the health of transgender populations.

Into the clinic

How I as an epidemiologist use the term *clinic*.

How can we best use the *identification* of transgender in the clinic?

Motivations for representing transgender identity in the clinic:

- *Actively* welcoming transgender patients (c.f. documentary *Southern Comfort*)
- Identifying transgender-specific health needs that are specific to different kinds of transgender experience (e.g. interpersonal/legal/biological transitions, coping, support, violence)
- Understanding how transgender persons affect the health of others (i.e. transgender patients, or patients with transgender family members or partners)
- Building knowledge about the health needs of transgender patients

Anecdote 1: my first mammogram

Diagnostic mammogram and ultrasound ordered by my primary care physician

Openly and explicitly transsexual on intake

Very comfortable X-ray and ultrasound by radiology nurses, and radiologist MD

Admonished by MD for waiting until the age of 43 before first mammogram

When asked about breast cancer risk given that my breasts were are about 12 years younger than a 43yo cisgender woman's, MD baselessly asserts that my risk is "the same" as my cisgender age peer.

Analysis of anecdote 1

MD (and other clinicians) given my (1) transgender identity, (2) transsexual identity, and (3) the timing of the trajectories of 1 and 2 with respect to the anatomical/physiological subject of my visit.

MD misrepresented knowledge of breast cancer risk given the absence of clinical and population epidemiology on MtF breast cancer.

Conclusion: ‘transgender’ and ‘transsexual’ identities are worthy of serious clinical scrutiny for:

- valid assessment of patient risk of disease;
- valid patient *and* population risk from radiation exposure;
- deserve an honest “we do not know.”

Anecdote 2: MtF transsexual sexual histories 1

A junior clinical epidemiologist developing clinical sexual history questionnaire to be trans inclusive (both for transgender patients, and for cisgender patients with transgender partners): how to do this?

If motivated by understanding that the neo-vagina of a post-operative MtF transsexual has heightened physiological risk of HIV infection, then solicit transgender identity *specific* to that circumstance.

And as with cisgender women partners, we probably want to intersect with sex work (MtF transsexual whores have much higher risks of HIV infection than post-op m2f transsexual epidemiologists, for example.)

But then are we asking about class of partner at time of sexual encounter or class history?

Anecdote 2: MtF transsexual sexual histories 2

There are many factors contributing to both risk *and* protection for transgender persons (MtF or FtM) which are both determinants of sexual behavior and sexual opportunity:

- being successfully out as transgender versus being closeted;
- having access to education and employment;
- having access to affordable quality health care;
- being pre-operative or non-operative as opposed to post-operative;
- having a stable identity (i.e. 'done' with transitions)

Analysis of anecdote 2

There is not a simple question or two to get at these kinds of social and biological vulnerability through transgender identity.

The tl;dr: “transgender” is a complex set of realities that intersect with the social circumstances of the individual and their partner(s) in many ways.

Having a transgender partner is not in and of itself a “risk factor.”

Conclusion:

- *specific forms* of clinical representation of transgender identity need to be motivated by *specific clinical needs* for screening, diagnosis and treatment, and grounded in appropriate social, behavioral and bio-medical theory
- no one representation of patient transgender identity fits all needs

Breakout and Report Back sessions 1

Your turn for input! We have articulated six principles:

1. *Transgender should not be subsumed within a question about sex.*
2. *Do not include transgender identity in questions about sexual orientation.*
3. *The timing of transgender identity and transitions in gender identity during an individual's life should be represented.*
4. *Do not prioritize any mode or direction of gender transition or transgression.*
5. *Although inclusiveness is desirable, avoid “select all that apply” modes of soliciting different flavors of transgender identity in structured surveys*
6. *Simple and straightforward language is desirable.*

Are any of these useful in application to clinical identification of transgender patients?

Breakout and Report Back sessions 2

Self-select into one of four areas

1. Actively welcoming transgender patients
2. Identifying transgender-specific health needs for patients
3. Understanding how transgender persons affect the health of others
4. Building knowledge about the health needs of transgender patients

Discuss issues with identifying transgender persons in the service of your area using the six principles (feel free to critique!).

Select a note taker to present insights, disagreements and conclusions

Reconvene and present