GLOBAL HEALTH RESEARCH AMONG TRANSGENDER POPULATIONS: CONSIDERATIONS AND APPROACHES

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Outline

• **Considerations**
  • Cultural humility & power imbalances
  • Current issues in global health research among trans populations

• **Research methods**
  • Including the community perspective
  • Methods for enrolling stigmatized populations

• **Example: my research**
Considerations: Cultural humility and power imbalances
Cultural humility: a construct to approaching global health research

Dimensions of cultural humility:

• Lifelong learning and critical self reflection
• Recognize and challenge power imbalances
• Develop partnerships that advocate for others
Acknowledge what you don’t know

- Include **voices** and **knowledge** from the community

- Do **research that is needed** by the community, not just to serve intellectual curiosity

- **Learn** from the community and **adapt** your research plan to address their needs

- Due diligence to **understand the cultural and historical background**, not just the disease/health

**Important for both research integrity and ethics**
Recognize and address power imbalances

“Cisgender researchers receiving funding for research with trans populations have an ethical obligation to address the power imbalances that contribute to their receipt of such funding in the first place.”

How?

- Partner with trans investigators
- Engage trans community throughout your research process
- Promote leadership and mentoring of trans scientists
- Ensure your trans collaborators receive authorship
Considerations: Current issues in global trans health research
Problem 1. Trans women often conflated with men who have sex with men (MSM)

Too small of sample size
excluded from analyses
analyses not stratified by gender
Conflation of MSM and trans women

Conflation due to:

- Common anatomy and mode of transmission (anal sex)
- Trans women difficult to engage in research
- Failure to capture appropriate gender in surveillance
- Lack of understanding of gender vs sex assigned at birth

Result:
Lack of data among trans women
→
Worse outcomes and uptake of interventions

Poteat 2016; Perez-Brumer 2016
What can we do?

- Conduct research tailored to trans populations

- If targeting both trans populations and other gender groups:
  - Use recruitment strategies and language that directly target trans populations
  - Plan your power and recruitment based on subgroups
  - Track recruitment of subgroups and adjust recruitment if needed
  - Disaggregate results for analysis and reporting
Problem 2. Sexual and gender identity not appropriately captured

- Sexual orientation and gender identity lumped into single descriptor
- Gender assessed through a single yes/no question
- Fail to include a range of gender identification options
  - “Transgender woman” or “transgender man” doesn’t represent everyone
  - Gender non-conforming or non-binary persons not represented in most research
Gender and sexual orientation not uniformly defined

- Culture-specific language around gender identities and sexual behavior
- Language to describe gender and sexual orientation might be rooted in deeper historic or cultural meaning

Problem 2. Sexual and gender identity not appropriately captured

Example: HIV study in Peru
- Only asks about current gender identity, no information on sex assigned at birth
- Not all trans women identify using this language
- Combined gender and sexuality: if they said yes to 11, question 12 was skipped
  - Not appropriate in US context, but appropriate in Peru?

11.- ¿Se considera una travesti/transgénero/transexual?[*] [179BBAK]
Marque sólo una opción.

- No 0, Si 1

12.- ¿Cómo te consideras respecto a tu sexualidad?[*] [179BBAL]
Marque sólo una opción.

- Homosexual 0, Bisexual 1, Heterosexual 2
What can we do?

Two-step Ascertainment

Example of two-step ascertainment as used by the Public Health Seattle King County STD Clinic:

- Section Header: Gender Information
- What is your gender?
  - 0 Male
  - 2 Female
  - 3 Transgender Woman/Transfeminine
  - 4 Transgender Man/Transmasculine
  - 5 Non-binary/Genderqueer
  - 6 Not listed, please specify

- Please specify gender
  - (Write in response)
  - text, Required
  - Field Annotation: @CHARLIMIT=30

- What sex was recorded on your original birth certificate?
  - radio, Required
  - 0 Male
  - 2 Female

- Which pronouns do you use?
  - radio
  - 1 He/him
  - 2 She/her
  - 3 They/them
  - 4 Not listed, please specify

Tordoff 2018
What can we do?

Existing guidelines on inclusive data collection should be adapted to local context with the involvement of trans people

Scheim 2019

BEST PRACTICES FOR ASKING QUESTIONS TO IDENTIFY TRANSGENDER AND OTHER GENDER MINORITY RESPONDENTS ON POPULATION-BASED SURVEYS

Created by the Gender Identity in U.S. Surveillance (GenIUSS) group, a multi-disciplinary and multi-institutional collaboration

Problem 4. Not enough research asking the right questions

- Research among trans women not targeted to them
- Trans masculine populations vastly underrepresented in research
- Research among trans populations heavily focused on HIV and “gender transition”, not well represented in other health topics
**Problem 4. Not enough research asking the right questions**

Example: iPrEx

- Lacked targeted recruitment of trans women
- Poor language to indicate gender identity
- Mis-gendered participants, did not stratify in original reporting
- Did not properly address issues important to trans populations
  - Drug-drug interaction of PrEP with feminizing hormones
  - Gender-affirming care

**Transgender Women in Clinical Trials of Pre-Exposure Prophylaxis**

Grant, Robert M. MD, MPH; Sevelius, Jae M. PhD; Guanira, Juan V. MD; Aguilar, Jana Villayzan MPH; Chariyalertsak, Suwat MD, DrPH; Deutsch, Madeline B. MD, MPH

doi: 10.1097/QAI.00000000000001090
What can we do?

- Conduct research tailored to trans populations
- Include trans populations, including trans men, in research of other health issues
- Include trans researchers:
  - Invite a trans researcher to collaborate as PI, contribute to planning and preparation
  - Involve a trans health consultant: https://www.transhealthconsulting.com/
  - Include trans staff in implementation
Research Methods: Including community Perspective
Need input on a wide range of study aspects

- How to reach the community
- What the community wants
- Incentives for them to join research
- Barriers to joining research
- Language that is appropriate, understood, and means the same thing you think it means
- The role of stigma, discrimination, and legal persecution: differs widely
Involvement of trans community

- Key informant interviews
- Trans investigators
- Trans study staff
- Community advisory boards
- Member check (informant feedback, respondent validation)
- Focus groups
Qualitative aim within study

- Focus groups → groups of participants
- In-depth interviews → individual participants

Why?

- Inherent bias in ways we collect data and interpret outcomes
- Provide depth and context to quantitative data
- Can discover things you didn’t know to ask
Research methods: Enrolling stigmatized populations
Often, stigmatized populations can’t be reached through random population sampling

- Small populations
- Difficult to find and/or engage in research
- Distrust of researchers due to oppression/discrimination

Alternative methods of data collection:

- Venue based/Time-space sampling
- Snowball sampling
- Respondent-driven sampling
Piloting your study

- Pilot your study in your key population
  - Identify issues with implementation
  - Areas of confusion in questionnaires
  - Assess willingness of participation
Other tips:

- Trust building between communities and researchers takes time; work within existing networks
  - Can volunteer or attend community events
- Adapt to needs to participants
  - Choose study locations that cater to the community
  - Consider online research or other methods to protect identity in places where stigma/discrimination is a consideration
Practical Applications: My Research
Background

- HIV is not a generalized epidemic in Peru: <1% overall prevalence
- But, there are epidemics in subgroups
  - 12-18% prevalence among MSM
  - 29-39% prevalence among trans women
- Little is known about the sexual partners of trans women

**Objective:** To characterize the partners of trans women
Community support and buy in

- **Worked with organizations** that were well integrated with community
  - Epicentro and Impacta: NGOs working with trans women
  - The Feminas House: a social support center for trans women

- **Key informant interviews**
  - Spoke with community members, activists, other researchers, health care providers

- **Focus groups with target populations**
  - Separate groups that are key to study such as trans women, sexual partners

- **Pilot testing**
  - Both informal and formal piloting
Incorporating lessons:

- Hired staff from the target community
- Changed the language we used around gender identity
- Modified recruitment methods
- Changed payment process and study hours to better serve our population
- Added links and information about HIV testing
Method to reach population: Respondent-driven sampling

- Begin with seed participant
- Each recruits 3 social contacts
- Each of those recruits can recruit 3 contacts
- Branch out in “waves” of participants through the social network

Assumption that with enough waves, you move away from the bias in the seed selection and have a sample that is representative of the population
Adapting to community needs: Online data collection

**Traditional RDS:** conducted in-person at a study site

**Modification:** online data collection to protect privacy

- “Anonymous” online survey
- Available on any device with internet access
- Collected phone numbers for reimbursement and forward recruitment
- Allowed for recruitment via WhatsApp
Dissemination and sustainability

- Disseminated results to Impacta, Epicentro, and Feminas
- Drafted new grant proposal to translate findings to improvements in HIV testing and care delivery
- Publish: more published research focused on trans communities specifically is needed!
  - Include trans collaborators and staff in my publications
Thanks!

More information about my research:

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