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# Keeping Secrets or Disclosing Health Information?: Accounting for Women's Concerns about HIV Disclosure in Maternity Care

Conflict of Interest  
Disclosure: I have no  
conflicts of interest

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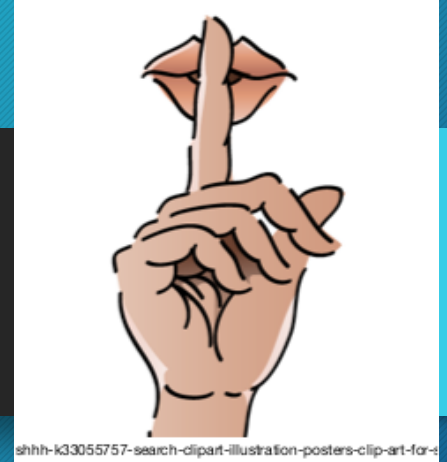
For more information:

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of the social organisation of perinatal care for women living with HIV in Canada.  
*Culture, Health & Sexuality*, 1-15. <https://doi.org/10.1080/13691058.2019.1604996>

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# Background



- Many women living with HIV often choose to keep their HIV status a secret from friends, family, etc. due to fear of rejection and HIV-related discrimination
- In healthcare settings a woman's HIV status facilitates a referral to specialist maternity care
  - HIV status informs the provision of perinatal care, as well as communication and action between the healthcare providers involved
- There is a disjuncture between how 'HIV disclosure' is 'known' and experienced by women living with HIV and perinatal healthcare providers
  - Women: HIV status as a 'secret' to be kept
  - Healthcare providers: work is informed by HIV status as 'personal health information' that guides care practices
  - This disjuncture became an entry point to explicate the social organization of 'HIV disclosure' within perinatal care for women living with HIV



# Research Strategy & Methods: Institutional Ethnography (IE)

- Institutional ethnography operationalizes the critical feminist scholarship of Dorothy Smith
  - Smith argues that research should begin from the standpoint of people located in a particular setting → women living with HIV as they navigate care during the perinatal period
- The goal in IE is to investigate the relationship between local, lived experiences and the generalized social relations that organize and govern such experiences
  - How are women's experiences related to HIV disclosure connected to the work of maternity care providers and social relations that organize and govern our everyday worlds?
- Focus on work and text during the inquiry - the researcher examines texts that guide organizational processes inherent within the ruling relations and uncovers how work is coordinated to understand why people do the things they do within healthcare settings
- IE inquiry was conducted within regional hospital in Ontario
- Interviews with 4 mothers living with HIV and 12 HIV and maternity care providers between March 2016 and April 2018
  - All women raised disclosure, or their HIV status becoming known and shared by people working in the healthcare system, as a concern
- Mapping of text-work-text sequences of action to uncover how HIV disclosure is socially organized in maternity care



# Making 'HIV Disclosure' Visible Through Institutional Work Practices

- Healthcare providers instituted measures to respond to women's concerns about HIV disclosure prenatally, during childbirth, and postpartum
  - Documenting women's concerns during prenatal appointments
  - Disguising medication during childbirth
  - Assigning women to a private room postpartum
- Healthcare providers revealed variation and subjectivity in the organizational rationale to assign women to a private room postpartum
  - Historically: infection control concerns, reducing other women's exposure to HIV
  - Current practice: ensuring women's privacy & confidentiality
  - Hearing different interpretations about assigning women to a private room illuminated how some actions that treat mothers living with HIV differently than other mothers receiving care on the same postpartum ward can be problematic
- Providers' work is coordinated & organized by provincial privacy legislation
  - Disclosure of HIV status is permitted without woman's explicit consent to facilitate communication between providers
  - It is through this connection between the legislative text and the frontline work of healthcare providers that the conditions are produced for a woman's HIV status to be revealed to people working in healthcare who she doesn't feel need to know and/or to people in her life who she does not want to find out

If a woman is labouring, and she's got her AZT running, and there's somebody there with her as a support...we usually put a brown bag or something over it...to disguise the label

We put all of our HIV positive women in private rooms. And it's not for isolation...it's just for confidentiality. So that if a physician has to go in and talk to them about, you know, their viral loads... that's not necessarily something that their roommate needs to hear about, right?

It's circle of care...and it's best practices. Everybody who is taking care of you should know what's going on.

We did have a case where the patient didn't want us to tell her partner that she had [HIV] ...This baby was receiving medication... as part of their standard care. And the father didn't know about it...Is it my responsibility to tell him? Do I ask somebody else to tell him? ... It was just never put down on paper but everyone's sort of, "Okay, don't say [HIV] in front of her partner" kind of thing...how do you handle those situations?



# Implications for Practice & Policy



- Framing HIV as something to be ‘feared’ and kept ‘secret’ was embedded in the language of women living with HIV & perinatal care providers
  - It is important to recognize the lingering ‘fear of contagion’ discourse in current practices that was prevalent at the start of the epidemic
- Tensions exist between formal institutional policies and unwritten work practices
  - Regulatory policies can be subjectively interpreted as protecting privacy rights while also granting permission to share personal information when delivering care
  - These are the conditions in which inadvertent disclosure of a woman’s HIV status occurs
- Privacy legislation governs the collection, use, and disclosure of personal health information, but does not go far enough to account for the complexities and sociopolitical nuances of HIV disclosure
  - Healthcare administrators have the authority to develop concrete, step-by-step, holistic care protocols that go beyond treatment regimens
  - Such protocols can offer perinatal care teams guidance about how to ensure individualized care that responds to women’s social and emotional concerns related to disclosure and beyond