



# (M)Othering with HIV: Reconstructing Experiences of Health and Social Surveillance

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# The Project

- The experience of finding out about a pregnancy, being pregnant, giving birth and becoming a mother is an emotional time for all women.
- As for all women, women living with HIV will experience a range of feelings and emotions depending on a range of factors...we wanted to find out what those factors are from the perspective of the women themselves.
- There had been some amazing work on fertility and pregnancy planning but a gap in the research literature on the experiences of becoming and being a mother living with HIV in today's current context.

# Methodology: Telling Stories

- Observational study, visits in pregnancy and post partum, range of methods used to collect the data and achieve project goals.
- Our team: needed to think critically about how the methods and data collection would put the women's voices at the centre of the research.
- We decided to listen to stories and let go of our biases, assumptions, hypotheses, speculations.
- Emerging from broader stories of pregnancy and motherhood as HIV-positive women were stories about formal and informal experiences of health and social surveillance that position HIV-positive mothers inside the criminalization of HIV debate .

# The Social Construction of Motherhood

“A woman has to confront the requirements of being a ‘good mother’ identified by social norms.” (Adrienne Rich)

“Mothers are policed by...the ‘gaze of others...teachers, grandparents, mates, friends, employers, even an anonymous passerby can judge a mother.” (Sara Ruddick)

# The “medical gaze” and social control function of social work and allied health care providers

“as a consequence of the extended medical surveillance, pregnancy is situated today in an intermediate space between health (normal pregnancy) and disease (pathological pregnancy)...Throughout motherhood, women are a target for expert advice (related to prenatal screening, breastfeeding, rearing of children, and so on) that defines legitimate and illegitimate maternal practices” (Burton-Jeangros 421).

Particularly challenging consequences for women living with HIV during pregnancy, birth and motherhood.

# Social Construction of HIV-positive mothers

“When people hear that you are HIV-positive they automatically think, ok, you shouldn’t be having babies, then it’s defending my right to have babies, you know?”

- The “gaze of others” that HIV-positive mothers are under result in having their authority as mothers undermined, challenged and, at times, appropriated.
- This is reflected in the surveillance of their maternal bodies during pregnancy, birth and the months that follow.
- Surveillance = Policing =  
criminalizing HIV-positive mothers

# The Criminalization of HIV-Positive Mothers

How does this happen?

1. When HIV-related stigma and socially constructed ideals of motherhood collide.
2. HIV+ women are in a position of having to defend their choices to have sex, become pregnant and to mother.
3. Surveillance of bodies during pregnancy, child birth and motherhood in the context of the formal and informal criminalization of women living with HIV in Canada

The Stories...



# Pamela's Story

*"An HIV diagnosis during pregnancy changes everything"*

*"As a patient, you're always thinking in your head, what are they thinking?"*

## After the Diagnosis

*"Finding everything out...it changed my whole pregnancy cause I had to get monitored more and then...when you go into the hospital there's always a random person that's checking your file so it's like everyday you are, like, melting cause you're like, Oh God!, one more person has seen that."*

*"It was a lot of, like, just unsettledness...not knowing who you are going to run in to, who's going to see you there, who's going to say something, when you're constantly meeting new people...or having to go to the hospital...the less places that I am, where they don't know..."*

## After the Birth

*"I remember after the baby was born...the nurses were there for the clean-up process...I remember them saying, 'So what are we supposed to do now with the placenta and blood and stuff?' I remember them talking to each other and... listening and thinking, what the heck?... Thinking in my head I know why they are saying this, do they know that I know why they are saying this?...I'll never forget that moment...it's just burned into me."*

## Reflecting Back

*"It definitely makes you reflect on whether you would do it again..."*

*"when I think about the whole process...It's nice to have that all done and not have to keep going to doctors and getting on with your life...Now we can just have a normal life...the making baby part, the whole thing brings it back to the forefront."*

## Elizabeth's and Lydia's Stories

*"Why aren't you breastfeeding"*

## Thoughts About Infant Feeding

*“Before this situation, I planned that I was going to breastfeed for 2 years, now I can’t do it at all.”*

*“It was the first thing I asked when the doctor told me and I was the first patient he ever had that was HIV-positive which made it worse, and he goes ‘ya your test came back (positive)’, and the first thing I said was, can I breastfeed? I remember that.”*

## surveillance of infant feeding practices

*"She kept asking me, she had asked me on the phone if I'm breastfeeding, I told her, yes, I was breastfeeding...She came and asked me again, I was going to get upset, but I just didn't want any misunderstanding, like, why will you keep asking me this same question? ...she's a doctor so she...really knows how to ask the questions." (Elizabeth)*

*"that's also why I don't want my friends to come to the hospital to visit me because they are going to be why are you, how do you know you can't breastfeed, why are you just bottle feeding right away, I can't say oh well the baby wouldn't latch on like I can't say those things cause you can see I haven't even tried, It's a big thing for me to come up with us something to say." (Lydia)*

*"I go to church every Sunday...If I go now and she's struggling with the bottle...They will be asking me to breastfeed her and I don't want to be lying...I'll tell them that I don't breastfeed in the day...God forgive me, I don't like lying, but I don't want to start explaining too many things."*



# Serena's Story

*"I've been doing everything I'm supposed to."*

## Child Protection?

*"I'm open with people, like other professionals... 'cause I expect that respect and being professional, right?... I did everything, I've got all my appointments, I've been doing everything I'm supposed to... I have to get a letter and kind of, you know, cover my back that way I guess cause I know once this baby comes... it could become a big issue, so I need to be prepared."*

*"She [CAS worker] ended up turning it against me saying, well, you know, you could drop dead any minute and ... you shouldn't be around the kids, you shouldn't risk them... they are not very knowledgeable about that."*

# Policing Mothers...Criminalizing Mothers

*"They said I knew I was pregnant...and I should have started my medication right then but...there was no possible way I could have known...I went right away to the doctor and got referred and went through the whole process, everything was fine, the doctor was completely happy I did everything on time and started my medication on time and my virals were low and just to be safe for the baby, you know, I have to take the medication so I've done everything I had to, but CAS is, like, you should have started it in [sooner]... so I gave them all of the dates...and they are still using it against me."*

## Fighting for Motherhood

*"I know I'm gonna have to fight for this baby and I'm...scared what's going to happen and especially with the medicine and the treatments and I don't want them to think I'm not doing what I can for this baby...with the CAS they think I shouldn't have a baby, I shouldn't be pregnant."*

## Three Moments in Time...(and possibly four)

- HIV-positive mothers are particularly subject to both formal and informal modes of surveillance by health and social care providers, family and friends.
- This increased surveillance occurs during pregnancy, immediately following birth, and in the early stages of motherhood.

# Criminalizing of HIV-positive mothers

These stories demonstrate that although the mothers who we interviewed did not engage in what *we* view as “criminal” acts under the law, by virtue of being HIV-positive, the acts they do or *do not* engage in, were treated as such by the very people who would normally provide support.

Examples: Pamela’s nurses, surveillance of infant feeding practices (by everyone!), child and family services

# “Criminality is a social construction”

“Informal criminalization is the societal or social construction of certain behaviour as criminal. Formal criminalization is the legal definition of certain behaviour as criminal, expressed by ways of statutes, and sanctioning by judicial authorities. These definitions do not necessarily overlap. Not everything that is legally criminal is also considered criminal by society and vice versa” (Wim Huisman, in Mathieu Deflem, 2011).

# The social construction of Informal Criminalization

How does this happen?

- Sometimes this was due to lack of education and ignorance
- Sometimes its experienced vis-à-vis blatant acts of discrimination;
- sometimes this was due to a deep-seeded belief in what it means to be a “good” mother.



- The marriage between surveillance and interrogation is a strong one, and continues throughout pregnancy and after birth.
- Medical surveillance during pregnancy and birth overlapped and then is shifted to the hands of family and friends and in some cases, child protection workers.
- The consequence of these deep seeded and formalized modes of surveillance results in defining socially and culturally acceptable ways of doing pregnancy and motherhood and in turn, may have harsh emotional consequences for women who aren't "doing" it right.

# Responding to Surveillance: Where do we go from here?

It is our belief that any response to the social construction of HIV-positive mothers and their experiences of surveillance, interrogation and criminalization should start with the mothers themselves.

There were countless stories of resilience, reframing and revolutionizing constructions of mothering with HIV.

## Caroline's Story

*"I feel like I'm an exotic creature 'cause it's not something, you know, people hear about...I'm not only very open with my status I'm also very inquisitive and I'm willing to challenge people's thoughts...so I'm kind of, in a sense, paving the way for other HIV-positive mothers."*

# HOPE

*"I'm hoping in 25 years people that I've mentored that have HIV can turn around and say, you know what?, I'm HIV-positive and I can breastfeed because we found technology that enables us to do so...and I'd also like to see positive women be able to have birth at home."*

Caroline's hope is that surveillance of HIV-positive mothers will be minimized to enable HIV-positive mothers to engage in practices that society considers a "normal" part of the motherhood experience:

# Supporting HIV-Positive Mothers

*“if we want girls to grow into free women, brave and strong, we must be those women ourselves” (Arcana, 1983).*

The question remains: how do we move from a state of social surveillance, monitoring, interrogation and criminalization of HIV-positive mothers to a state of social care through which mothering with HIV is normalized, accepted, and as Pamela states “left alone”?

# Supporting HIV-Positive Mothers

- Need for adopting a holistic approach to supporting HIV-positive mothers that must include a contextualized understanding of the biomedical, psychosocial, cultural and economic factors that may be influencing their experience as women and mothers.
- New ways of supporting HIV-positive mothers throughout their pre and post-natal trajectory: develop creative ways to respond to the onslaught of questioning regarding their birthing and infant feeding choices.

- When we shift our gaze onto the 'culture of healthcare' "in showing us how practices, policies and research approaches can themselves create marginalizing conditions and inequities " (Browne et al., 2005), we can ensure HIV-positive mothers are not left feeling diminished and disempowered when accessing health and social care.
- Collaborative working relationships with researchers, HIV care specialists and HIV-positive women to develop education, training and advocacy tools that normalize pregnancy for women living with HIV and ensure appropriate care and supports.
- Attend to the "cultural safety" of HIV-positive mothers who represent various ethnoracial communities (Browne et al., 2005).

# In conclusion....

It is critical that HIV-positive mothers themselves are leading these discussions.

HIV-positive mothers must be viewed and treated as equal partners and leaders by health and social care professionals, researchers and policy makers. to

This will ensure that their unique historical and current day realities, experiential and professional intelligence, and active and meaningful involvement are central to the development, implementation and evaluation of training, practice and policy initiatives.



Thank you!  
Questions?



# Thank you to our study team!

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