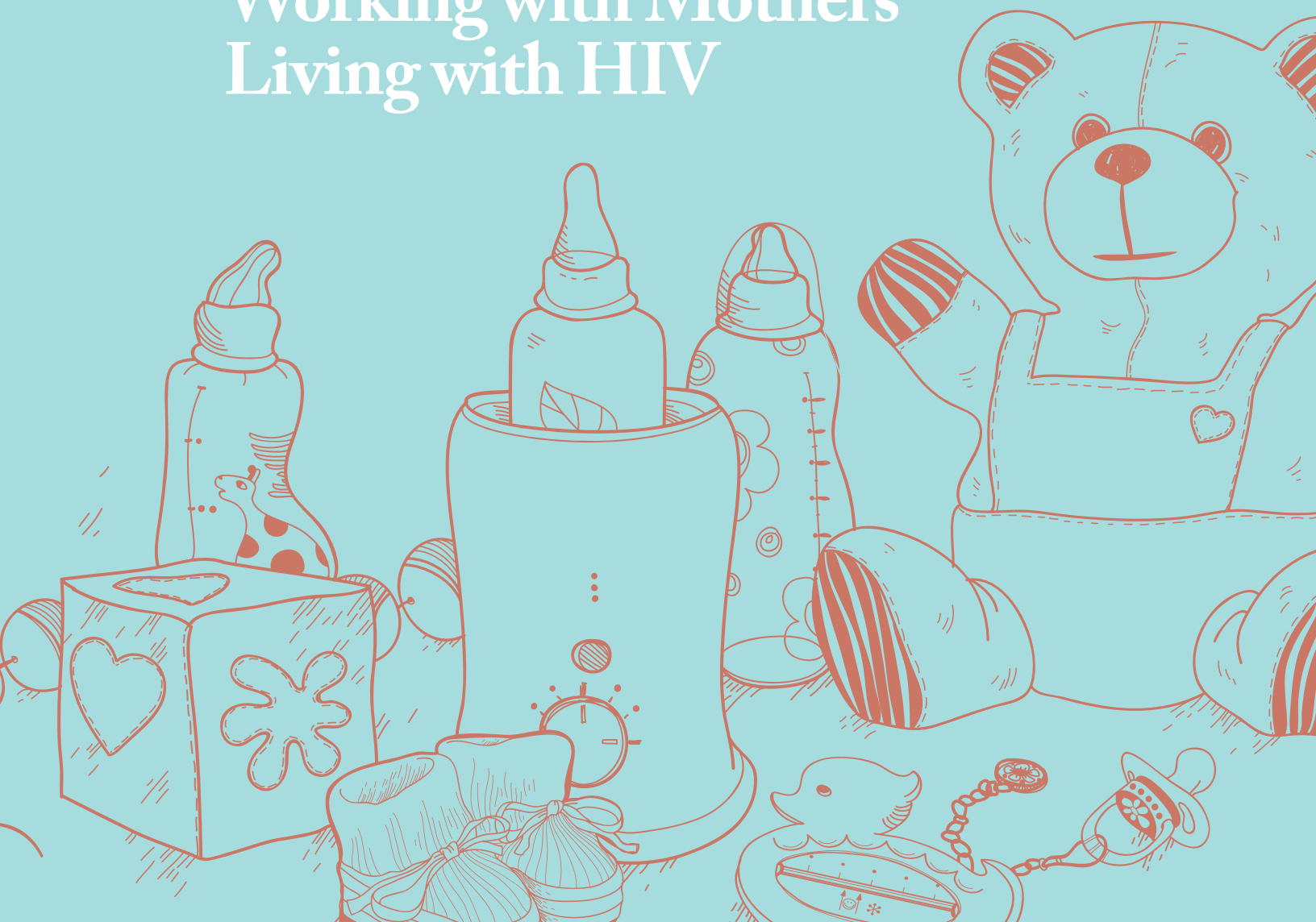


SUPPORTING MOTHERS IN WAYS THAT WORK

A Resource Toolkit
for Service Providers
Working with Mothers
Living with HIV



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Date

January 2016

Published by

The HIV Mothering Study Team
& The Ontario Women's HIV/AIDS Initiative
(WHAI)

Suggested citation

Khosla, P., Ion, A., & Greene, S. (2016).
*Supporting Mothers in Ways that Work:
A Resource Toolkit for Service Providers
Working with Mothers Living with HIV.*
Hamilton, ON: The HIV Mothering Study Team
and the Ontario Women's HIV/AIDS Initiative.



Our Social Justice Approach

This toolkit is the culmination of multiple conversations over many years with women living with HIV, researchers, clinicians, nurses, social workers, HIV support workers and other community-based service providers who are committed to addressing issues of social justice and care for mothers living with HIV.

This toolkit was developed by a large team including mothers living with HIV and community-based researchers with the goal to support health and social care providers in effectively meeting the needs of mothers living with HIV. We aim to increase awareness and understanding of the psychosocial needs and experiences of women living with HIV during pregnancy, childbirth and early motherhood.

This toolkit is for all health and social care providers who may interact with women living with HIV during pregnancy, childbirth and postpartum including general practitioners, nurses, social workers, frontline workers at shelters and community health centers, child welfare/child protection workers, Public Health officials, and other service providers at hospitals and community-based organizations, including AIDS Service Organizations (ASOs).

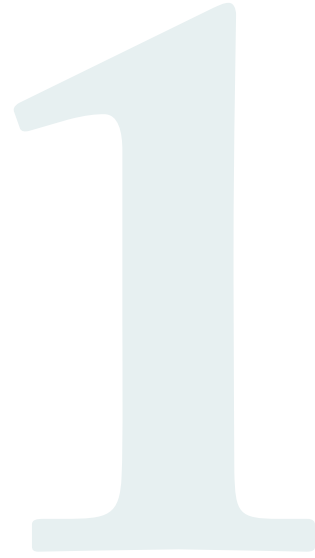
Because of complex medical procedures and psychosocial challenges, it is imperative that all health and social care providers who interact with women living with HIV during pregnancy, childbirth and postpartum are equipped with the knowledge and skills to effectively and appropriately support women during this time.

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Mothers Living with HIV in Canada: Background and Current Issues



MOTHERING AND HIV IN CANADA —THE OVERALL PICTURE

MOTHERS LIVING WITH HIV IN CANADA

Approximately 25% of people living with HIV in Canada are women. Women in their childbearing years are the fastest-growing group to acquire HIV infection.¹ There are between 5,100 and 8,000 women living with HIV in Ontario. Each year, about 1 of every 6 people diagnosed with HIV in Ontario is female.

Women living with HIV in Canada are increasingly becoming pregnant and having children. Advances in HIV treatments have resulted in the successful reduction of HIV transmission during pregnancy, at the time of childbirth and postpartum.²

Treatments are increasingly making motherhood a reality for women living with HIV. In a 2009 survey conducted in Ontario, nearly seven out of ten (69%) women living with HIV indicated they wanted to be mothers and a majority (57%) were planning to start soon.³ Low risk of transmission means pregnancy rates among women living with HIV will continue to rise.^{3,4}

WHAT IS THE CHANCE OF HIV TRANSMISSION DURING PREGNANCY AND CHILDBIRTH?

Perinatal transmission (also referred to as vertical transmission) has been dramatically reduced in Canada as a result of the success of antiretroviral therapy. Using antiretroviral therapy in the context of pregnancy reduces the chance of HIV transmission to the fetus/baby to less than 2%;⁵ transmission can be reduced further to 0.4% when antiretroviral therapy is started more than 4 weeks before delivery.²

KEY MOMENTS OF PREVENTION SUPPORT

Supportive care during pregnancy, childbirth and early motherhood is critical. Healthcare providers recommend that women living with HIV follow a protocol of tests and treatments to reduce the chances of HIV being transmitted to their infant including:⁶

- HIV treatment for the mother during pregnancy
- Vaginal deliveries are now considered the standard of care for women living with HIV. A Caesarian section delivery may be recommended depending on the level of HIV in the mother's blood.
- HIV treatment for the infant at the time of childbirth and up to 6 weeks postpartum
- HIV testing of the infant at multiple points from birth up to 12–18 months
- Breastfeeding avoidance and exclusive formula feeding

REALITIES FOR MOTHERS LIVING WITH HIV

Becoming a mother can create a renewed reason to live. It can be a catalyst for women to take care of themselves so they are available for their children.⁷

People living with HIV are two times more likely to be diagnosed with major depressive disorder compared to people who do not have HIV.⁸ Feeling blue is a reality for many women living with HIV and the prevalence of depression in women living with HIV during the perinatal period can range from 32% to 57%.⁹

Public ideas about HIV are also slow to change. This means mothers living with HIV face unique issues during the perinatal period. Medical, emotional and social issues shape their experiences of pregnancy, childbirth and motherhood. Mothers may also have concerns about HIV disclosure, transmission to the newborn, care of infants, HIV-related stigma and the negative effects of maternal HIV on their children.⁷

IMPLICATIONS FOR CAREGIVERS

Mothers living with HIV have the experience, knowledge and expertise to inform best practices. Mothers living with HIV have stated that in order to develop and maintain supportive relationships with their care providers, they require:

- Care providers to practice from a place of support, rather than surveillance
- Empathy instead of stigma
- Care providers to work with them to transform discrimination into equal rights
- To be a trusted partner in their care
- Care providers to have and seek out up-to-date knowledge about what it means to live with HIV —up-to-date knowledge and skills are essential to provide women with effective and appropriate support during the perinatal period

NEED MORE INFORMATION ABOUT HIV INCLUDING TRANSMISSION, PREVENTION, CARE AND SUPPORT DURING THE PERINATAL PERIOD?

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Language Check

REFLECTING ON RESPECTFUL LANGUAGE

Use	Don't Use	Why?
HIV	AIDS	HIV is a chronic illness— Most people living with HIV do not have an AIDS diagnosis
“Living with HIV”	AIDS patient, HIV-positive woman	Put the person before their HIV, e.g. woman living with HIV, mother living with HIV
Vertical or Perinatal Transmission	Mother-to-child Transmission	Vertical/Perinatal transmission is defined as HIV transmission during pregnancy, childbirth or postpartum—mother-to-child transmission perpetuates “mother blaming”
Infant Feeding	Breastfeeding	Women living with HIV are recommended to formula feed their infants—by not referring to their infant feeding practices as “breastfeeding” helps to normalize their experience

Myth Check

UNDOING COMMON MISCONCEPTIONS

Myth	Myth Busted
HIV is a death sentence	Clinical advances have shifted HIV infection from a fatal to chronic illness that can be effectively managed with combination antiretroviral therapy (ART)—with ART, women living with HIV can now expect a life expectancy similar to the general population
Women living with HIV should not get pregnant	Women living with HIV have the right to get pregnant and have children
HIV will automatically be passed to a baby during pregnancy or childbirth	ART can significantly reduce the chance of HIV transmission during the perinatal period to less than 1%

The HIV Mothering Study: An Overview

PURPOSE OF THE STUDY

The HIV Mothering Study was initiated due to the lack of research on the experiences of mothers living with HIV across Ontario. By sharing the pregnancy, birth and postpartum concerns and realities of women living with HIV across Ontario, the HIV Mothering Study stimulated a conscious dialogue and opportunities for action to improve the lives of mothers living with HIV.

OUR FOCUS

The study started in April 2010 and ended in March 2014. The focus of the research and analysis was on the social realities of mothers living with HIV including their community, intimate and familial relationships, and connections with social and health services. This toolkit summarizes the stories and experiences that HIV Mothering Study participants shared during qualitative interviews. Pseudonyms have replaced real names throughout this toolkit to protect the confidentiality of study participants.

THE TEAM

The HIV Mothering Study brought together community-based HIV researchers, clinicians, frontline service providers and women living with HIV to design the study, collect the data and interpret the findings. An important aspect of our research approach was to involve Peer Research Associates (PRAs). By connecting with participants as women and mothers living with HIV during the data collection process, the PRAs enabled a deeper level of sharing and connection with participants. Meeting with PRAs was also an opportunity for some participants to feel reassured that they were not alone, and that they were connected to a community of other women living with HIV.

OUR PARTICIPANTS

77 women living with HIV from across Ontario agreed to participate. Participants connected with our study through the places they accessed HIV or obstetrical care. Study visits took place during pregnancy (3rd trimester) and at 3, 6 and 12 months postpartum.

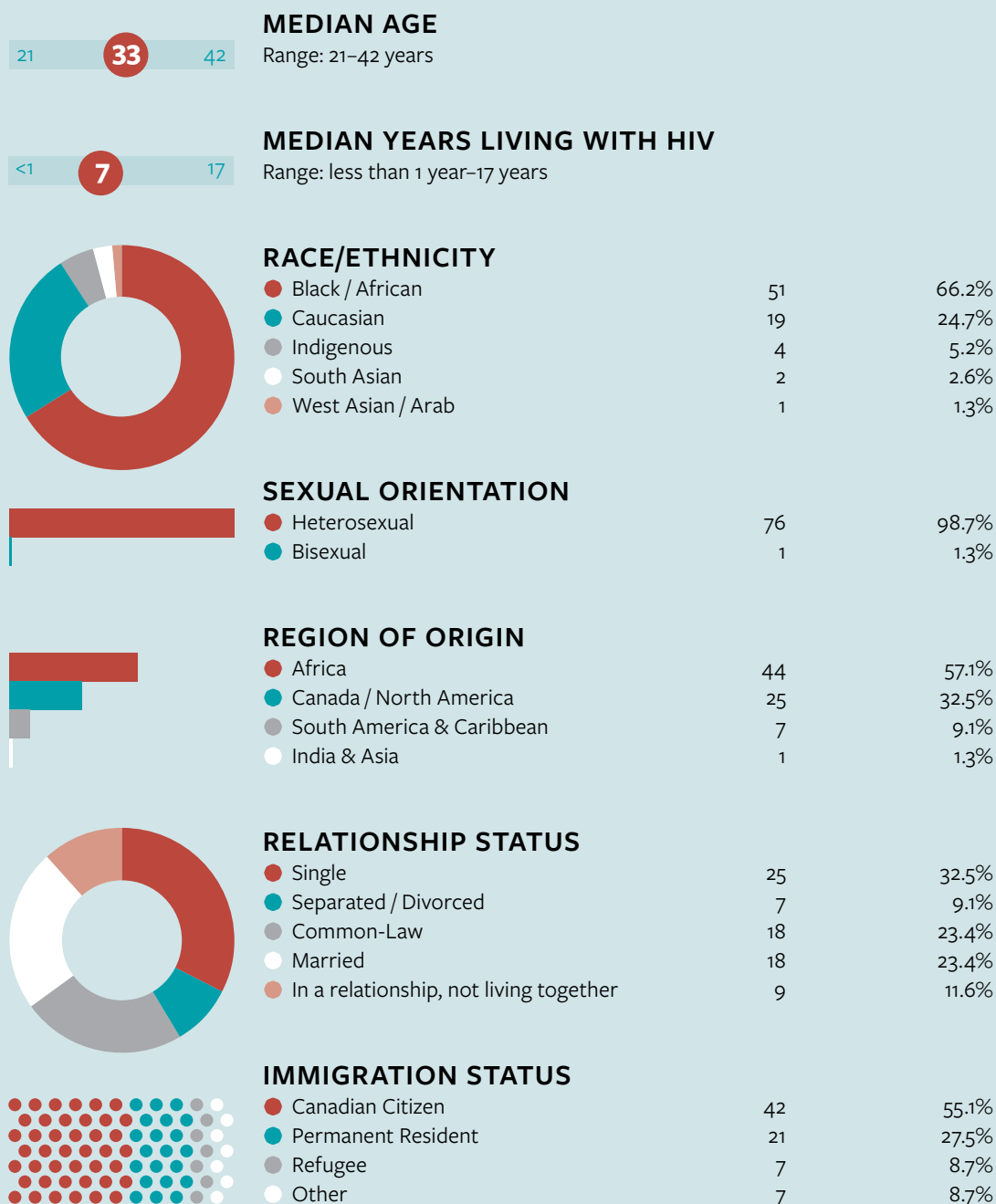
A DIVERSE GROUP

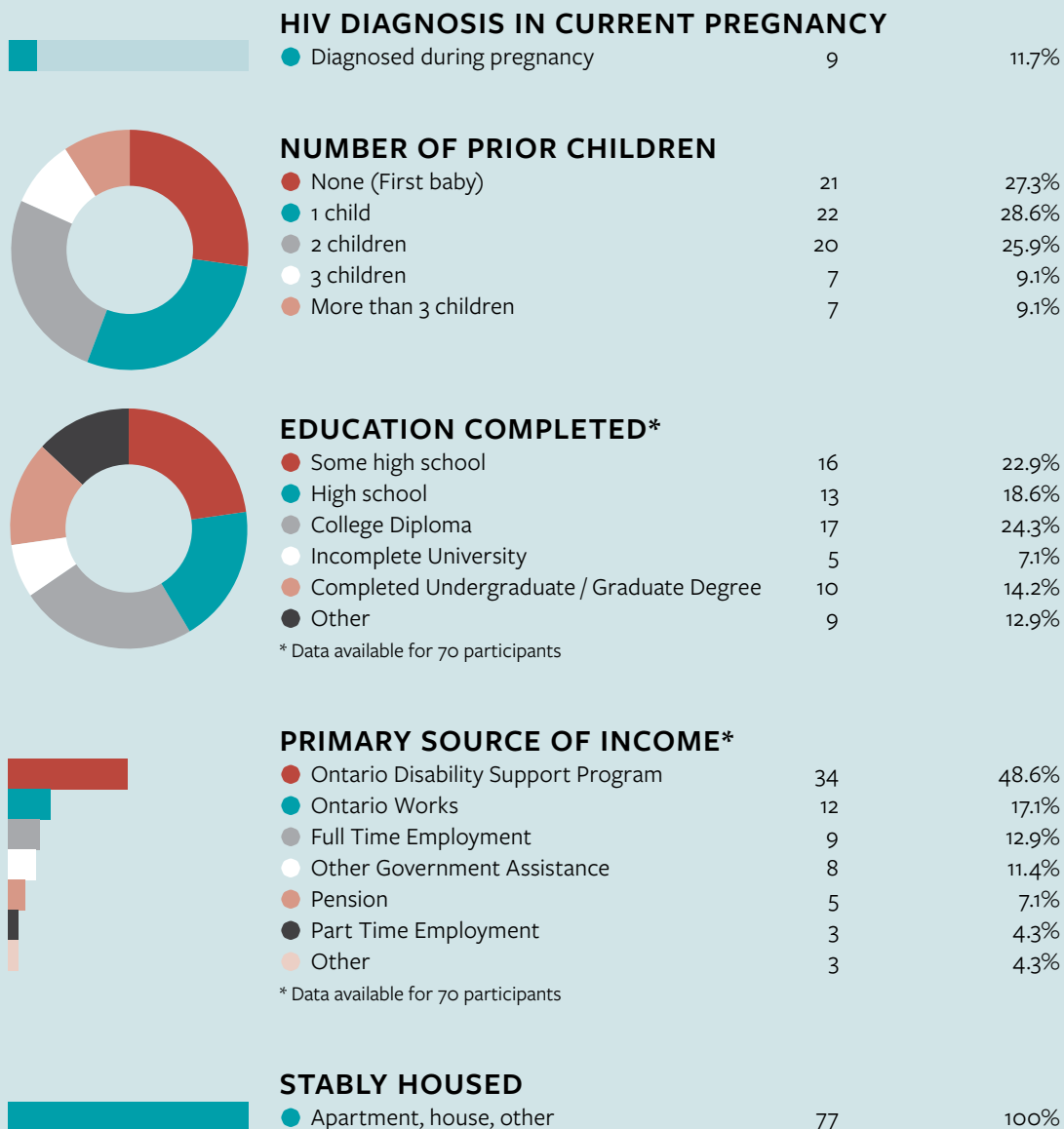
Participants had an average age of 33 and 66% identified as Black or African. Almost half of the mothers were sole parenting during their 3rd trimester (41.6%). Nearly a third had a history of prior depression (29.9%) or another psychiatric diagnosis. Most participants had permanent residency or citizenship in Canada (82.6%) and all were stably housed.

HIV MOTHERING STUDY PARTICIPANTS

A NOTE REGARDING THE DEMOGRAPHIC CHARACTERISTICS OF HIV MOTHERING STUDY PARTICIPANTS

Although none of the HIV Mothering Study participants identified as transgender, and we did not include fathers in this study, we believe this information should be considered when working with any individual living with HIV who is pregnant and/or parenting. More community-based research is needed that focuses on other populations of parents living with HIV.







Perinatal Care: What Works and What Needs to Change



What We Know

MOTHERHOOD

Anticipation of motherhood is both joyful and stressful for all women. For women living with HIV, pregnancy, childbirth and postpartum can include a unique layer of pressures and possibilities. Those dealing with stigma, shame or blame are more likely to feel blue, anxious and unwell as they make the transition into motherhood, and this can affect everyday family and social life.

CHALLENGES TO CONSIDER

Lack of drug coverage, few transportation options, unstable housing, job demands, family and other care giving responsibilities and the complexities of HIV disclosure and stigma are just a few of the challenges women living with HIV may have to clear to access care and support. Women of colour, Indigenous women and low-income women are up against the harsh realities of everyday racism and discrimination.

ADDED RESPONSIBILITIES

In the early days of adjusting to life with a newborn, mothers must make immediate and important decisions about HIV testing and antiretroviral therapy for their babies. Treatments and tests can be nerve-wracking for both mother and baby, but are important (and recommended) to prevent HIV transmission during pregnancy and postpartum.

NEW LEASE ON LIFE

Motherhood can give women living with HIV fresh inspiration and motivation in their lives. In spite of being overwhelming at times, taking care of a baby can be an inspiring time that results in joy, happiness and positive life changes.

What Women Told Us

The stories mothers living with HIV told us about experiences with pregnancy, childbirth and early motherhood are a rich resource for community, health and other workers. They show us both sides of the picture of care: which practices work and where changes are needed.

POSITIVE CARE EXPERIENCES

COMMUNICATION

Open lines of communication are critical. Pregnancy, delivery and postpartum unfolds over a significant amount of time and procedures can be confusing and overwhelming. To digest all the processes and information, mothers need to talk over issues more than once with different workers. Andrea's interaction with a social worker who was willing to repeatedly discuss her questions and concerns built her confidence.

“It was nice to have the conversation with [social worker], too, and have her explain to me a little bit more in depth. I mean, [pediatrician] does, but I think at that time too, there's so many other questions and so many other things to cover that she doesn't really explain in depth...Maybe she did and I just needed more confirmation...Because it's confusing.”
(Andrea, 35, Canadian-born Caucasian mother of two)

BEING HEARD

Forging trusting relationships with women living with HIV is key. Multiple barriers can make it hard for women to keep medical appointments, stick to treatment plans or ask important questions. Care providers who make time to understand and accommodate women make them feel supported and heard.

“I'm so thankful for the kind of doctor God give to me, she's just like my sister. There is nothing that I wouldn't tell my [doctor]...because I so trust her...She just have time for everybody.”
(Jolie, 41, African-born Black mother of three)

“I just trust her...I've done a lot of things, like there's so many appointments I haven't gone to...she doesn't get angry with me about it and all the other doctors have and they've even told me they don't even want me as a patient anymore...I'm just one of those people, going to doctors is very difficult for me.” (Rona, 32, Canadian-born Caucasian mother of three)

ACCESSIBLE AND RESPONSIVE CARE

Workers who identify and pay attention to the varied issues keeping women living with HIV from accessing medical and social supports have more success setting up care that responds to mental health, wellbeing and medical needs. As a woman living with HIV, Tina didn't think she could have children until she met her healthcare team. They normalized and celebrated Tina's pregnancy and demystified what she needed to do to have a healthy baby.

“*The support system here that I have overall, is the best...if I had let the stigma of what people said about this disease allow me to make a completely different decision, I don't know where I'd be today and I'm so thankful...[if I] had any other type of doctors, I would have made a completely different decision [having my baby]...it is the most fulfilling feeling having a child.*”
(Tina, 28, Canadian-born Black mother of one)

Access is also about accommodating for particular needs and abilities.

“*I never had to go into the doctor's office. No doctor's ever done that to me. She was prescribing prescriptions to me over the phone...to deal with my anxiety...I think that's really important. I could not get out of the house.*” (Rona, 32, Canadian-born Caucasian mother of three)

SENSE OF BELONGING

Caregivers who respect and make women feel welcome make a world of difference. When Beth decided to put a history of drug use and street involvement behind her and become a mother her medical team labeled her “high risk” and referred her to child welfare for an assessment. Her HIV specialist found her a new team. Their responsiveness gave her a sense of belonging that resulted in a very positive experience of pregnancy.

“*They're much more understanding...I'm not labeled. They realize that I have a past, but they also see that I've changed and that I continue to change and it's for the better...They were amazingly patient and kind and comforting and understanding and just an amazing group of people...and that's what you really need...even HIV aside, just being pregnant. It was such a drastic emotional roller coaster time that to be—not even isolated, but just to feel like you don't belong in a place—at [hospital] you feel like you belong there.*” (Beth, 30, Canadian-born Caucasian mother of one)

NEGATIVE CARE EXPERIENCES

LACK OF COMMUNICATION

Medications and procedures are often confusing. Many mothers living with HIV are unclear why their newborns need to be tested for HIV and be given antiretroviral therapy. This is especially true for women who find out they have HIV during pregnancy or are having their first baby. Many are confused about how things unfold and what support they can ask for during early motherhood. Maria discovered she was HIV-positive while pregnant with her fifth child.

“*At first I wasn't comfortable with one of the doctors...I didn't know...what I have to do after...I wasn't sure if they, like, give them blood work and keep an eye on them and check them...I didn't know there was medication involved. They never really explained to me what the medication was for. They just, pretty much, take it for six weeks...You just do it...at the time you're just so overwhelmed with everything that sometimes...you don't think until after, like, why are you taking this anyways?*”
(Maria, 30, Canadian-born Caucasian mother of five)

SILENCING

Mothers can feel shut down when they ask questions. If one provider is confusing, unwilling to share information or is less than supportive it can carry over so women may stop asking others as well. This can leave women in the dark regarding important issues including infant feeding. When she realized breastfeeding was not recommended for mothers living with HIV, Mireille needed to know what to feed her baby, but did not get the help she was requesting.

“*I asked the doctor after he told me that I'm not supposed to be breastfeeding...what is the best milk, what kind of milk or the best one I should give to the baby and the doctor told me that is not his job...I was afraid to ask the other doctor because they're telling me not to breastfeed, but not extending or giving me other options. I was afraid that the other doctor would also tell me it's not his job, so I kept it to myself.” (Mireille, 26, African-born Black mother of four)*

HIV STIGMA

Shaming and humiliation of women living with HIV creates dangerous breakdowns in care and communication. HIV-related stigma has a serious impact on how safe, healthy and supported women feel during pregnancy, childbirth and into motherhood. Degradation is both an everyday and exceptional experience for mothers living with HIV. They told us it happens in overt behaviour, comments and through the misuse of routine precautions by care providers who do not have up-to-date information about HIV. Stress and HIV-related stigma prolonged Lynn's delivery and sent her baby into fetal distress.

“*The doctor came in...turned around, looked at me. Said that we're not equipped for AIDS...I've never seen this doctor a day in my life...And I started to cry...I yelled out that he had bad bedside manner. That this is a hospital. This is the place to feel safe, not discriminated...Because of the stress of that, [baby] ended up...not moving. The contractions went away...He looked at me and he says, I don't even want to hear how you got...He came back into the room, he had a shield on. He had gloves right up to his shoulders. He was totally covered...I mean, was this guy going deep sea fishing or was he preparing for a baby? And it's not like he's going to get HIV from me!...I'm undetected.” (Lynn, 39, Canadian-born Caucasian mother of seven)*

CONFIDENTIALITY AND DISCLOSURE

Too often healthcare providers talk about a women's HIV status in front of visitors, family and friends. All personal health information is confidential and this violation of privacy is often unconscious as care workers deliver medications and test results. Still it can have serious effects and rupture important social relationships and supports for a woman and her baby. Celeste had a close call when members of her church group were visiting her in hospital.

“*[Nurse] just came, [guests in room] didn't hear her, I'm sure they didn't hear...Your baby, she's okay...Her status, and, you know, your situation, like, I know you have HIV, and, ah, the formula is already set up, you don't need to worry...She didn't tell me, like, you know, I need to talk to you, like, is that okay?, you know, privacy, whatever, nothing...she just, boom!” (Celeste, 30, African-born, mother of two)*

POWER IMBALANCES

Even women who are comfortable to advocate for themselves may feel vulnerable when interacting with medical and community workers. Real differences in authority, knowledge and control sometimes make it impossible for mothers living with HIV to challenge the behaviour of trained professionals.

“*Want me to tell you why I probably didn't say anything? ...Do I want to go ruffling feathers when these are the people that are taking care of me and my son? No. No I don't. I'm just going to shut my face and take it. And take my baby home and love my baby...What's done is done.” (Andrea, 35, Canadian-born Caucasian mother of two)*

What Women Need

A CONTINUUM OF CARE

Pregnant women living with HIV need tailored supports. Access to clinical and community-based care must become a seamless net that supports women throughout the perinatal period. Helpful medical staff and community workers are pillars on which mothers need to be able to lean.

COORDINATED CARE

Medical and social care of mothers living with HIV needs to be synchronized. The lack of communication and consistent practice between hospitals, clinics, community health centres, doctors offices, government, children's and community agencies results in gaps in care and support.

MEANINGFUL ACCESS

Women living with HIV need access to culturally sensitive information, a comprehensive array of services that fit their needs, training of health and social care providers that is HIV-sensitive and speaks to their social positions as racialized, working class and/or low-income women.

CARING FOR MOTHERS

Many mothers experience care as focused on the baby, rather than themselves. This reinforces distorted views of pregnant or new mothers living with HIV as deviant and undeserving of care.

NON-JUDGMENTAL AND COMPASSIONATE RELATIONSHIPS

Relationships with health and community workers are central. Lack of patience and consideration can make or break the experience of pregnancy, childbirth and postpartum for a woman living with HIV.

SOLID AND CLEAR INFORMATION

Mothers need resources and information about prevention of vertical HIV transmission, birthing procedures, and postpartum care that are easily understandable.

ACCOUNTABILITY TO EASE INEQUALITIES

Unequal power is structured into systems of care. Counterbalancing these inequities requires care workers to listen to women's needs, concerns and issues and take steps to address them. Women living with HIV who use drugs and are racialized, LGBTQ, working class and/or low-income need a particular emphasis on this as part of their care.

TRAINED COMMUNITY AND MEDICAL STAFF

Care delivered with compassion and awareness is essential. Up-to-date information must inform clinical and community care workers' practice. This will optimize maternal care and postpartum support for women living with HIV.



KEY PRACTICE IMPLICATIONS

- Create an environment of trust, openness, and belonging for pregnant women and mothers living with HIV.
- Consider how your agency or organization can address HIV-related stigma in order to become more accessible to women living with HIV.
- Develop mechanisms to protect the confidentiality of mothers living with HIV. Concerns may be more heightened for these mothers than in your general experience.
- Offer medical and community-based supports for pregnant women and new mothers living with HIV that are coordinated, consistent, safe and compassionate.
- Provide support that meets the needs of the whole family.

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Why Aren't You Breastfeeding?: Infant Feeding and HIV



What We Know

BREASTFEEDING OR FORMULA?

Mothers living with HIV face a complicated dilemma about feeding their babies. Canadian clinical practice guidelines call for formula feeding to avoid transmission of HIV. But is formula the healthiest way? Do mothers even have a choice? The answers are fraught with social pressures, personal risks and heavy costs.

Contradictory messages cloud the picture on infant feeding for mothers living with HIV and guidelines vary around the world. Health Canada encourages breastfeeding as the “normal” and best way to ensure protection, growth and development of babies and toddlers.¹ This message is in tension with HIV clinical practice guidelines, which recommend that mothers with HIV who live in Canada should avoid breastfeeding and use formula in order to prevent HIV transmission, which is possible through the consumption of breast milk.^{2,3} Canada follows World Health Organization (WHO) guidelines that call for mothers living with HIV in high-income countries to avoid breastfeeding and use formula regardless of their circumstances and whether they are on antiretroviral therapy.²

POWERFUL PRESSURES THAT “BREAST IS BEST”

The notion that breastfeeding is *always* best to promote mother-baby attachment is not supported by sufficient evidence.⁴ This belief is supported more by cultural values, beliefs about “natural” parenting, and campaigns promoting breast milk as “nature’s perfect food.” The message that “breast is best” undermines formula feeding as a healthy alternative for children of women living with HIV.

What Women Told Us

CAN I BE A “GOOD MOTHER” AND NOT BREASTFEED?

All new mothers struggle with social and cultural standards of motherhood. The pressure to breastfeed has a unique impact on mothers living with HIV. Not being able to breastfeed leaves many feeling like they’re risking baby’s physical and emotional health and missing out on motherhood.

“*It makes me feel, um, like I’m not performing my full womanly duties as a mother.*”
(Claire, 35, Canadian-born mother of six)

“It was important, it is important. I mean that is what we are equipped to do, you know, it’s just part of mothering . . . and all those books that I read, the pregnancy books they always say breastfeeding is way better than bottle fed babies, I wish they would just split it in half to make us feel better, you know?”
(Kathy, 32, Canadian-born mother of two)

MIXED MESSAGES ON INFANT FEEDING FROM CARE WORKERS

Women get confusing instructions from medical and community care workers. Hospital and health workers closely scrutinize how women feed their babies. Lack of coordination means some workers use government guidelines to stop women from breastfeeding while other workers push breastfeeding and lactation supports.

EVERYONE ASKS WHY I’M NOT BREASTFEEDING

Everyday monitoring of how mothers feed their infants is challenging. Family, friends, care providers and strangers feel entitled to ask women why they are using a bottle rather than the breast. Handling these questions can take a heavy toll on mothers adjusting to caring for newborns.

“It was difficult, I mean, I had so much company coming over here when I first had the baby and they all asked me why I wasn’t breastfeeding, every single person.”
(Sheila, 32, Canadian-born mother of two)

BREASTFEEDING IS A CULTURAL PRACTICE

Cultural ideals about infant feeding leave women torn. In many African countries breastfeeding is key to the relationship between mother, baby, the wider family and community. Mothers want the best for their babies and are proud of their heritage. This leaves them torn about feeding their kids formula.

“In our culture it’s, it’s, you need to [breast]feed your baby if they don’t see it they say you are killing the baby.” (Mireille, 26, African-born Black mother of four)

“It hurts. Because of that, I asked many questions at the hospital. I am not sure if White women share my opinion, but for African women if you can’t breastfeed, it’s hard. It’s like you abandon your child or it feels like your child won’t love you. I think a lot about that, it’s hard. But what is important is the baby’s health.” (Estelle, 33, African-born first time mother)

BEING WATCHED—FEARS ABOUT HIV DISCLOSURE AND STIGMA ARE REAL

Many women steer around stigma by keeping their HIV status confidential. Most women only disclose their HIV status to care providers and partners. Constant curiosity of family, friends, and community members about why they aren’t breastfeeding leaves them anxious about being found out and exposed. Keeping their status private is particularly important for women from African countries where bottlefeeding is seen as a sign of HIV infection.

“I’m thinking if I don’t breastfeed, people will know.” (Adele, 32, African-born mother of two)

“It’s so sad because most people, like most Africans, they know that the Moms who do not breastfeed are Moms who has HIV. They know about that, so sometimes if they come to your apartment, they’ll be watching to see if you’re gonna give the baby milk.”
(Carine, 33, African-born mother of two)

RESISTING QUESTIONS WITH CREATIVE COMEBACKS

Women worry formula feeding will expose their HIV status. Social and cultural questions and a general lack of understanding about HIV make threats of losing privacy and safety very real. The possibility of being shamed, shunned and losing community support has a big effect on the emotional health and well-being of mothers living with HIV.

“ We had to lie to everyone... researching different diagnoses that I could have because you don't want to tell anyone the truth, and then it's like, well, why aren't you breastfeeding... no one knew... the hospital staff knew, but my family didn't know, his family didn't know, friends didn't know, we didn't want anyone to know... there was this paranoia, constant paranoia that someone was going to walk in... who's hearing things and who's listening or who is going to see something.”
(Pamela, 30, Canadian-born mother of two)

STORIES AS SAFETY PLANNING

Women go to great lengths to hide formula feeding. Responses to protect themselves and their babies are a survival strategy that mothers living with HIV plan out well in advance. Stories like “there's no breast milk,” “I don't breastfeed in the day,” or excuses about being on “high doses of iron” are common. One woman bought a breast pump to stop people's questions.

“ Just to show them. If they ask me of what are you doing, I say... I don't breastfeed, but I do the pump, I put it in the bottle for him to drink that's it... because it's a lot of questions, why? can't you give him direct easy? I say, no, I use a pump machine and it's okay.”
(Grace, 37, African-born first time mother)

CREATIVE COMEBACKS AS CONFLICTED RESISTANCE

Having to lie about breastfeeding leaves women living with HIV feeling torn. Many are clear that it is an important part of their personal safety plans. Some mothers find relief in this but others find the lie hard to live with.

“ I hate to be made to feel that way... We're expected to be perfect.”
(Alice, 37, African-born first time mother)

“ I feel bad, like I don't want to have to tell people excuses or it's pretty much a lie, but I also don't think everybody needs to know.” (Bonnie, 27, Indigenous first time mother)

GUILT AND LOSS

Mothers living with HIV struggle with their own ideas about infant feeding. On top of managing multiple external pressures, women living with HIV have to deal with delicate personal grief about not being able to breastfeed and feeling bad about depriving their babies the experience of breastfeeding.

“ The heart breaking side of it, I feel like when I had him I was almost getting into depression cause I couldn't breastfeed him, I love him so much that I want to breastfeed him but I know and I love him a lot too and I don't want him to get HIV so I was always crying that I could not breast feed him but I never did... I know how they love breasts and all that so not being able to breastfeed is emotionally dramatic for me.” (Evelyn, 37, African-born mother of one)

“ Unfortunately... with all the big boobs I have, my child cannot enjoy my breast... It's really sad, but sometimes I think about the risks of giving the child contaminated milk, right, but because my breast milk [is] contaminated... it's better for me to protect the child because I don't want the child to live like me.” (Samira, 33, African-born mother of two)

BEYOND “BREAST IS BEST”

Women living with HIV are changing the message that “breast is best” and are reshaping motherhood and intimacy with their newborns. Acceptance of the situation, managing feelings, and being practical are all key to this process.

“*It is something I would have liked to try, you know... but I knew from the get-go, um, even before we tried getting pregnant, that in my life I wouldn't be able to breastfeed my kids.*”
(Annette, 34, Canadian-born mother of one)

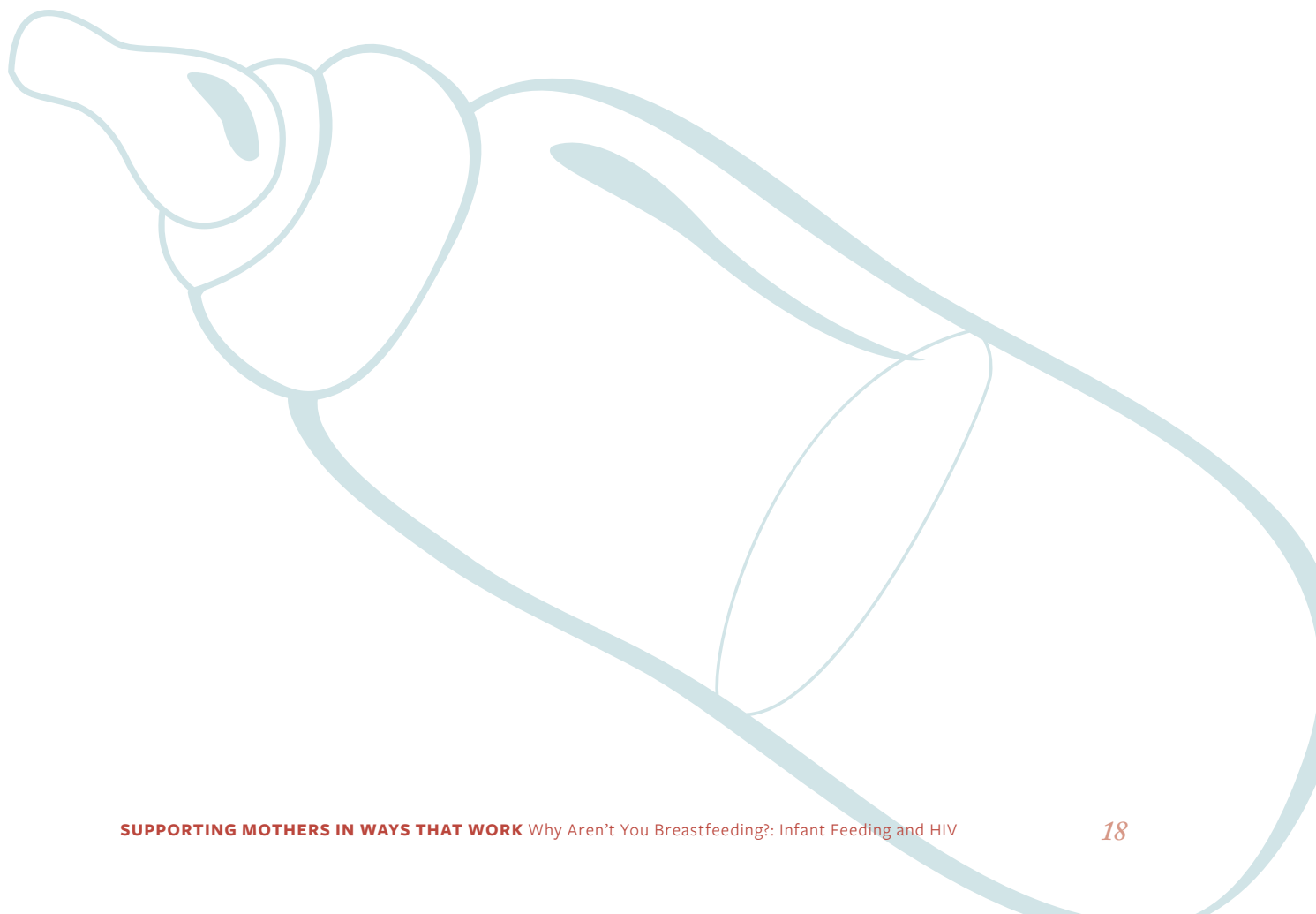
“*Of course it's hard, it's hard that you cannot do it for your child, but, again, you want the best for them and the best for them is to be protected from HIV.*”
(Sophie, 37, African-born first time mother)

THE UPSIDES OF FORMULA FEEDING

Women focus on improvements in formula and the positives of bottle-feeding. It means partners and older children can be more involved in feeding the baby. Breaking down the myths they also realize formula-fed children grow up to be as strong and healthy as breast-fed babies.

“*I realize that over time with research they've really tried their best ... to make it a replica of the mother's milk ... so I don't feel guilty about it ... and I've done a lot of research on formulas.*”
(Angelina, 28, first time mother from the Caribbean)

“*Looking at my daughter...she's healthy, she's growing so well... She's doing so great, so it's the same thing, doing formula or breast milk...you see breastfed kids and you see her, she's more healthy than some of those kids that are breastfed.*” (Christine, 37, African-born mother of one)



What Women Need

ATTENTION TO INFANT FEEDING AS A CENTRAL ISSUE FOR MOTHERS

Care workers need to understand that infant feeding is an emotional quandary for many mothers living with HIV. Each woman is unique and faces a different set of social and cultural issues.

RECOGNITION THAT CARE WORKERS PLAY A UNIQUE ROLE

Care providers are in a privileged inner circle of trust for mothers living with HIV. HIV specialists, obstetricians, nurses, clinical staff, community workers and HIV advocates are all critical supports for mothers as they manage and resist overwhelming cultural and social pressures to breastfeed.

INFANT FEEDING SUPPORTS FROM PREGNANCY TO EARLY CHILDHOOD

Infant feeding information, social support and care are needed throughout the perinatal period. Mothers living with HIV need ongoing reassurance that formula is not a bad infant feeding approach. This means starting discussions about formula feeding early during pregnancy, asking women what they need, and honouring their unique sociocultural experiences and anxieties.

CARE WORKERS MUST SHIFT FROM SURVEILLANCE TO SUPPORT

Care workers must change their stance. Sensitive support is far more effective than pushing guidelines. This would ease stress and lessen mothers' fears and anxieties about public HIV disclosure, HIV stigma and discrimination. Breastfeeding practice guidelines also need to be rethought so they are mindful of the structural, historical and cultural realities of mothers living with HIV.

RESPECT THE PRIVACY OF WOMEN LIVING WITH HIV

Women have a right to privacy with respect to their infant feeding practices and HIV status. In care settings this means addressing the relentless medical and social pressures that promote "breast is best" messaging. Care providers must be alert to the dangers of disclosure associated with questions about women not breastfeeding and provide meaningful and attentive support to mothers.

HELP MOTHERS LIVING WITH HIV TO RESIST "BREAST IS BEST" AND RECLAIM LOST "CHOICE"

Mothers living with HIV need support to strategize and plan around social pressures. They need backing for their stories and help dealing with everyday questions, assumptions about motherhood, cultural ideals of breastfeeding as well as HIV-related stigma and discrimination from family, friends, professionals and community.

COORDINATE CARE AND END ROUTINE ENCOURAGEMENT OF BREASTFEEDING

Hospital, clinical, public health and community workers need to coordinate and ensure they are providing mothers living with HIV with consistent and conscientious care. Messaging regarding infant feeding should be clear and not laden with values that idealize breastfeeding.

HELP WOMEN ADJUST TO FORMULA FEEDING AND SELF-CARE

Women living with HIV need information about formula feeding. They need knowledge and reassurance about its health, social and nutritional adequacy. Learning how to care for their breasts while formula feeding is important for self-care and empowerment.



KEY PRACTICE IMPLICATIONS

- Provide mothers living with HIV with physical, emotional and social support, as well as information and educational resources about formula feeding.
- Change the infant feeding narrative to include women who do not breastfeed.
- Support women who do not breastfeed to learn about the multiple ways in which they can emotionally bond with their babies.
- Recognize and attend to the deep social, cultural and emotional experiences related to infant feeding that are present for mothers living with HIV.
- Support mothers to develop a plan for how they can respond to surveillance and questions about their infant feeding practices.

NEED MORE INFORMATION ABOUT INFANT FEEDING AND HIV?

- The Teresa Group, a provincial HIV/AIDS service organization based in Toronto, offers free formula for a year to new mothers living with HIV who live anywhere in Ontario. For more information visit www.teresagroup.ca or call (416) 596-7703.
- Is Formula Good For My Baby? Order or download this free resource for mothers living with HIV at www.catie.ca

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Mothers Under the Gaze: Health and Social Surveillance

What We Know

CRIMINAL LAW AND HIV IN CANADA—DISCLOSURE

In Canada, people living with HIV must disclose their HIV status in a very narrow range of circumstances. HIV disclosure is legally required to a sexual partner before having any sex that poses a “realistic possibility” of HIV transmission. This legal duty is the result of a 2012 decision by the Supreme Court of Canada and means that people with HIV live with routine scrutiny and legal control.

The “realistic possibility” of HIV transmission is determined by considering the specific sexual acts, the person’s viral load, and whether condoms were used.¹ Charges can be laid whether or not HIV is actually transmitted. If convicted for not disclosing, a person living with HIV can spend time in jail and will be registered as a sex offender. In most other circumstances, there is no obligation under the criminal law to disclose one’s HIV status.

CHILD PROTECTION LAWS AND MOTHERS LIVING WITH HIV

Other laws may also be relevant to the actions of mothers living with HIV—beyond criminal obligations to disclose to sexual partners. For example, section 215 of the Criminal Code of Canada says that failure to provide the “necessaries of life for a child under the age of 16 years” by a legal parent, guardian or head of a family without a legitimate excuse is an offence. A parent who is not following medical recommendations in the care of their child (e.g. medications, tests) could be charged under this provision. Similarly, laws relating to child protection could be applied against a parent who is seen as not providing appropriate care to her child.

SOCIAL POLICING AS INFORMAL CRIMINALIZATION

Formal laws are only one side of the equation and people experience the phenomena of “criminalization” as a result of both formal laws and informal surveillance and judgment. Some women living with HIV report that they feel as if they are under constant surveillance by health and social care providers, family, friends and society in general. This undermines their humanity and personal dignity. This is particularly the case for women who are living in poverty, women who use drugs, racialized women, women who have a precarious immigration status, and Indigenous women who continue to confront the long-term effects of colonization.³

AGENCY AND RESISTANCE

Although women living with HIV bump up against the emotional and social challenges of motherhood while living with HIV, they are also actively paving the way for future mothers living with HIV. Mothers living with HIV are engaging in a range of activities that are aimed at changing societal attitudes about pregnancy in the context of HIV and about mothering with HIV.

CRIMINALIZATION AND SURVEILLANCE OF WOMEN LIVING WITH HIV IN CANADA

FORMAL SURVEILLANCE —LAWS AND REGULATIONS

Although it is not illegal for women living with HIV to have children, the current law requiring people living with HIV to disclose their HIV status under certain circumstances can result in the surveillance of pregnant women and mothers living with HIV by health and social care providers.

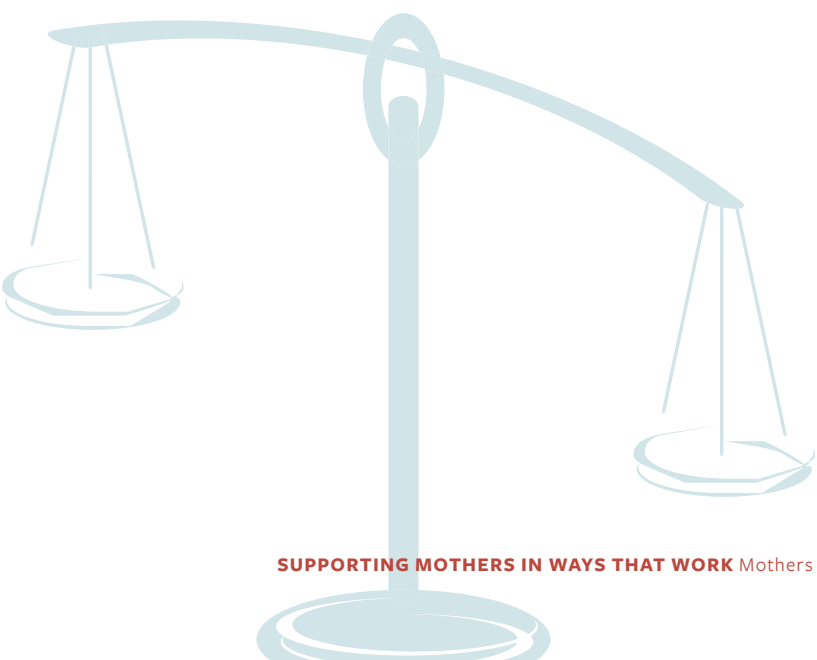
While it is not considered criminal for a woman living with HIV to become pregnant, her pregnancy may raise questions about her method of conception and the possibility of HIV transmission. For example, whether the woman disclosed her HIV status to the baby's father and whether she followed medical advice to prevent HIV transmission to the fetus/baby could be considered through formal laws and regulations.

The policing of women's bodies during pregnancy and childbirth and in their role as mothers puts women living with HIV in the position of having to defend their choices to have sex, to become pregnant and to mother. This is perhaps most acute for mothers living with HIV who have child welfare system involvement. Lack of information coupled with HIV-related stigma can exacerbate already existing relationships with child protection officials for mothers living with HIV.

INFORMAL SURVEILLANCE

Women living with HIV have shared concerns about the ways in which their bodies and their behaviours are sometimes under the surveillance of health and social care providers. Although much of the surveillance experienced is to ensure the good health of the mother and her baby, there can also be a feeling that this surveillance is about ensuring that mothers do not put their babies or children "at risk" for HIV. Monitoring a mother's body and behaviour can be viewed as stigmatizing when the experience of care shifts from that of supportive care to surveillance. A visibly pregnant body can also lead to questions about a mother's method of becoming pregnant and her adherence to antiretroviral therapy. Surveillance may continue after childbirth by health and social care providers to ensure she is formula feeding and providing antiretroviral therapy to her baby during the first 6 weeks postpartum as prescribed. Ensuring that mothers have all the necessary information regarding their health and the health of their baby is critical. Providing care in ways that normalize her pregnancy experience is imperative to ensure that she experiences care as supportive, rather than as a form of social and medical surveillance.

Of particular importance is the provision of support that mothers require when they come under the gaze of family and friends who may not be aware of their HIV status. These family and friends may also question mothers' birthing and infant feeding choices.



What Women Told Us

PAMELA'S STORY: A BODY UNDER SURVEILLANCE

NO PRIVACY

Pamela lives in a small rural Ontario town. Having a second child as a mother living with HIV she remembered the complete loss of privacy that came with her HIV diagnosis during her first pregnancy.

“It changed my whole pregnancy cause I had to get monitored more...[in] 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.”

HIDING OUT

With her pregnant body under constant surveillance by healthcare staff, Pamela decided to keep her head down and hide her HIV status.

“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.”

WHOSE BODY IS IT?

After the pregnancy, delivery and postpartum appointments, treatments, testing and other inspections ended, Pamela's body became her own again. She wonders whether she could handle the surveillance of having another child.

“It definitely makes you reflect on whether you would do it again...I would like to, but...It's nice to have that all done... Now we can just have a normal life because I just have to go for my four checks a year and my blood work. And as long as...my drugs are working, then it's non-existent...the making baby part... [This] brings it back.”

*“An HIV diagnosis
during pregnancy
changes everything”*

ELIZABETH AND LYDIA'S STORIES: ALL EYES ON INFANT FEEDING

ENDLESS BREASTFEEDING QUESTIONS

Elizabeth is a mother from west Africa who now lives with her husband and children in a mid-sized city in Ontario. Not being able to breastfeed her second baby was a personal struggle. When she was diagnosed during her first pregnancy five years before, she decided that no one, not even family and close friends, should know her HIV status. The pressure she experienced from her sister-in-law about breastfeeding was extremely stressful.

“*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? ... My brother was telling me that he already told her not to bother me with personal questions... she's a doctor so she... really knows how to ask the questions.*”

SITES OF SOCIAL SURVEILLANCE

Questions about infant feeding can become a dangerous kind of social surveillance. Women can too easily lose control over who knows their HIV status. They have to make up reasons for not breastfeeding. Lydia found it hard to create a cover story so she ended up avoiding friends.

“*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... It's a big thing for me to come up with something to say.*”

Spaces where women go for social support can be the hardest to navigate. Elizabeth found herself having to lie about infant feeding to friends and family in church.

“*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.*”

29%

of HIV Mothering Study participants reported either historical or current involvement with the child welfare system

SERENA'S STORY: CHILD PROTECTION

DISCLOSING TO CHILD WELFARE WORKERS

Serena, a young Indigenous woman, lives in rural Ontario. A domestic abuse survivor, she had six children with her violent ex-partner. The Children's Aid Society (CAS) put all of her children in her parents' care. When she was diagnosed with HIV, a supportive HIV care team helped rebuild her confidence. A year later she was expecting a baby with her new partner. To keep everything above board she shared her HIV status with her CAS worker.

“*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... 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.*”

DEEP INSENSITIVITY

The CAS worker was not respectful or professional about Serena's HIV disclosure. Her lack of training and understanding about mothering with HIV resulted in an inappropriate response.

“*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.*”

POLICING INSTEAD OF CARE

Serena's decision to disclose her HIV status shifted the balance of her HIV and pregnancy care from support to surveillance. In spite of “doing everything she was supposed to” and the validation of her HIV specialist, Serena was not supported or believed by her CAS worker.

“*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... 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...still using it against me.*”

CHILD WELFARE CHALLENGES

Some mothers living with HIV, especially Indigenous and racialized mothers, can often face an uphill battle with child protection authorities. Even if, like Serena, they work hard to provide optimal care for their children.

“*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.*”

CAROLINE'S STORY: CARVING OUT A NEW PATH

“*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 mothers [living with HIV].*”

TURNING THINGS AROUND

Caroline was five months pregnant, street-involved, in the sex trade and under police arrest when she first arrived in the town she now calls home. Five years later she's pregnant with her third child and has become an inspired HIV educator. Giving back to the community that connected her to HIV care and helped her get stable housing for her family is important to her. By being open and engaged, Caroline was also able to overcome the feeling of surveillance.

“*I'm very blessed I guess to be open with my status...and be willing to educate...If I reach out and only one person hears me...that's one person who's heard me...not a hundred who've not.*”

COURAGE AND PRIDE

Acceptance of her HIV status didn't happen overnight for Caroline. It was a long journey. Deciding to be open about being a mother living with HIV was a big step towards carving the new path.

“Probably about the 3rd year of my diagnosis is when I just decided, you know what? I am going to be open with people. I don't care I'm an HIV-positive mom, I can't breastfeed, who cares, kind of thing, and I still have people in town who are like Abhh!—whatever, I don't care.”

LEADING CHANGE FOR MOTHERS LIVING WITH HIV

Caroline came to view herself as a leader in her community. She wants to change how mothers living with HIV are treated and envisions a time when they won't be considered any “different” from other mothers. Minimizing surveillance so mothers living with HIV can experience “normal” motherhood is her goal.

“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... I'd also like to see positive women be able to have birth at home.”

What Women Need

SHIFTING PRACTICE APPROACHES AND PROVIDING HOLISTIC CARE

Transform social surveillance, monitoring, interrogation and criminalization into social care, acceptance and normalization of mothering with HIV. Health and social care providers need to adopt a holistic approach to supporting mothers living with HIV. This means developing treatment and care protocols that address the biomedical, psychosocial, cultural and economic factors shaping their experiences.

FROM SURVEILLANCE TO SUPPORT

Commit to providing respectful and supportive care. Clinical and community workers are strongly encouraged to discontinue intrusive monitoring and questioning. Instead, providers should respectfully explain infant feeding guidelines, infant testing processes, and the process of providing antiretroviral therapy to infants in the postpartum period. Care providers can provide a safe space to discuss the feelings and social consequences of formula feeding while working with mothers to develop strategies that deal with the surveillance they may bump up against throughout the infant stage.

HIV DISCLOSURE

Don't assume family and friends know a mother's HIV status. Women have the right to decide when and with whom to share their HIV status. Support women to develop creative responses and strategies to the onslaught of questions on birthing and infant feeding. Investigate the policies and procedures at your organization and ensure strict confidentiality protocols are in place that protect the privacy of women living with HIV.

REVIEW AND UPDATE CHILD PROTECTION PROTOCOLS

Child protection workers play an important role to ensure children are not at risk. HIV is not a child protection issue in and of itself, however, and child protection workers can provide important support to families affected by HIV. It is critical that child welfare workers receive up-to-date information and training about HIV to ensure the support they provide is effective and appropriate. CAS agencies are also encouraged to review and revise child protection protocols to reflect the current reality of what it means to live with HIV. As more women living with HIV decide to have children it is important that outdated knowledge about vertical transmission and the framing of mothering with HIV as a child protection issue be rooted out.

ADDRESS INEQUALITIES THROUGH EDUCATION

Make anti-oppression training mandatory for all health and social care providers who work with mothers living with HIV. Changing entrenched ideas about motherhood, addressing the realities of mothers who use drugs and are racialized, LGBTQ, working class and/or low-income requires systemic changes. Educating health and community workers is an important first step.

MOTHERS WITH HIV IN THE LEAD

Mothers living with HIV know where change is needed. They must be equal partners and leaders alongside health and social care professionals, researchers and policy makers in order to create strategies that break down patterns of surveillance, policing and criminalization.



KEY PRACTICE IMPLICATIONS

- Educate yourself on the criminalization of HIV non-disclosure within the Canadian context and consider how the law, misunderstandings of the law, and media coverage of prosecutions may impact on the attitudes of health and social care providers and the delivery of health and social care.
- Recognize that pregnant women and mothers living with HIV are under intense scrutiny and that health and social surveillance is enacted both formally and informally. Look beyond the formal legal framework and consider how women are made to feel criminalized through their experiences with clinicians, social workers, and society more broadly.
- While providing information on infant feeding is an important aspect of care, recognize that informing women of the medical recommendations is not sufficient to meet their needs. Support with respect to infant feeding requires going beyond providing information and attending to the emotional, social and cultural needs and desires of the women to whom you provide support.
- During pregnancy, begin working with women to help them develop personal strategies to protect their privacy. Working with women early in their pregnancies will equip them to deal with questions about their birthing and infant feeding choices.
- Work in partnership with healthcare providers and child protection workers who play an important role in caring for the health and well-being of both mothers living with HIV and their children. Facilitate communication, education and support between the family and health and social care providers if concerns related to health and/or safety of the mother and/or the infant are raised.
- Most importantly, celebrate her pregnancy and birth!

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Experiences of Stigma and Discrimination



What We Know

WHAT IS STIGMA?

Stigma is a widespread social process that separates “insiders” from “outsiders.” Stigma is more than an individual with a bad attitude—it can involve personal shaming, blaming, exclusion and mistreatment of people, especially those with less social power. Stigma can occur without overt discrimination and can be seen as legitimate and “normal” behaviour.

STIGMA, DISCRIMINATION AND HIV

People living with HIV face systematic stigma and discrimination. Among other things, HIV-related stigma can include holding people responsible for contracting HIV, assuming they are immoral, blaming them for being ill, and/or typecasting them as “abnormal” disease “carriers.” Stigma creates inequality for people living with HIV and can mean a real loss of social power and status.¹

HIV-RELATED STIGMA IN HEALTHCARE

HIV-related stigma is common in medical settings. Exaggerated ideas about how HIV is transmitted and the potential risk for care providers can result in unspoken stigma.² Exaggerated ideas merge with everyday HIV-phobia, lack of training and outdated information to create stressful and negative care environments for people living with HIV. Care workers can participate in stigma without realizing the harm they cause.

MOTHERS, MEDICAL STIGMA AND SOCIAL DISCRIMINATION

Stigma heightens fears of disclosure for women living with HIV. Women are fearful that family members, employers and friends will find out about their HIV status during pregnancy, childbirth and hospital admissions, especially if clinical staff are not cautious with their personal health information. Past experiences of HIV-related stigma can exacerbate mothers’ anxieties.³

INTERSECTING OPPRESSIONS

Poverty, racism, drug use, history of colonization and immigration status can complicate women’s experiences of stigma. Marginalization and HIV-related stigma can intersect and overlap to create challenging interactions between mothers, medical teams and care workers.

What Women Told Us

WHY DID YOU GET PREGNANT?

“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?” (Lisa, 25, Canadian-born Caucasian mother of three)

Women living with HIV are stigmatized for wanting to be mothers. Their choices to get pregnant and have children are openly challenged. The pressures can be harder for women from small and ethno-racial communities.

“Among our Afro-Caribbean group, not all women agree with me being pregnant. They hide, they talk between themselves. Some of them had the courage to really tell me. Why are you pregnant? What were you thinking?” (Notisha, 33, African-born Black mother of two)

DISCOURAGING MOTHERHOOD

Medical providers may advise women living with HIV not to have babies. A doctor's HIV-related stigma becomes clear as they break the news about pregnancy by telling mothers that it is likely they will transmit HIV to their babies. This exposes dangerous gaps in medical knowledge.

“When I went to the women's health unit they scared the shit out of me, even the doctor 'cause he didn't know and it's like no it's possible, like now I know myself from experience it's possible to have a healthy baby.” (Tina, 28, Indigenous mother of three)

Care workers may also advise mothers to abort their pregnancies. Tina's nurse suggested this even after she expressed her desire to keep her baby, and this can be experienced as HIV-related stigma.

“She (the nurse) called me like for an update. (I said) I'm like you know I'm gonna keep it because... my baby could be healthy. And she's like are you sure? I'm like yes I'm sure. She's like, well you only have a couple days to change your mind, are you sure you're gonna to keep the baby? She asked me 10, 20 times and told me she was still gonna hold my spot for the abortion after I told her over and over again I was keeping my baby.” (Tina, 28, Indigenous mother of three)

CHALLENGES IN RURAL SETTINGS

HIV-related stigma may be increased in settings that do not typically provide care to women living with HIV, for example, rural and remote settings and community hospitals. Not all community hospitals have medical staff with expertise and knowledge of the most up-to-date clinical protocols to deliver care to women living with HIV during pregnancy and at the time of childbirth. Some medical staff may also lack HIV-specific training.

“They don't deal with people like me. They felt very, I don't know, against it... I went to have a backup plan with the doctor, and just in case like—my water broke and I couldn't make it to (hospital in the larger city)... He told me...they're not going to want to touch you here. They're going to be scared of you, you know, and he told me not to come back to the clinic.” (Doris, 29, Indigenous mother of seven)

MOTHERS FEAR THEIR HIV STATUS WILL BECOME PUBLIC

Many women living with HIV fear unwanted disclosure of their HIV status. Dread grows as they prepare for childbirth and the stigma that may follow. This fear has immediate and long-term emotional and practical consequences for mothers living with HIV. A mother who works at the hospital where she delivered her baby worried about how easily colleagues could find out her HIV status.

“*I’m really scared of people knowing about my HIV status; like it makes me so ashamed seeing my profession when people hear that somebody’s HIV positive...that’s my major concern all the while, like I don’t want to them to know.*” (Okwengue, 37, African-born Black mother of two)

INADVERTENT DISCLOSURE OF HIV STATUS

In the process of delivering care, providers can accidentally reveal a woman’s HIV status. It may be assumed that family and friends are aware of the woman’s status. This assumption can leave women concerned that their HIV status will be casually shared and discussed.

“*Well, they were calling my mom’s house, I don’t know why. Some doctor kept calling my mom’s house ‘cause they couldn’t get a hold of me ‘cause my cell phone number changed and I called her and I said why you calling my mom’s house? And she said because that’s our other contact number, your emergency, and I said but it’s not an emergency, like you’re just calling about an appointment, you know what I mean? Like you can’t do that!’*” (Susan, 24, Canadian-born Caucasian first time mother)

PRIVATE ROOM OR QUARANTINE?

Women living with HIV need and ask for confidentiality. In some care settings, this may involve providing them with a private room. Women appreciate this privacy, but are sometimes unsure if the private room was granted to maintain their confidentiality; some women may feel like they are being placed in medical isolation. Women may feel stigmatized as “sources of infection” by being separated from other women in the delivery unit—it is important to communicate the reason behind providing a private room—to protect their privacy.

“*I felt like I was being isolated from the other patients because of my HIV status.*” (June, 38, Canadian-born Caucasian mother of eight)

DISTRESSED DURING DELIVERY

Hospital admissions can be upsetting for mothers living with HIV. Anxieties about disclosure of their HIV status and the possibility of disrespect by healthcare providers can be heightened as they go into labour and delivery.

“*As soon as we got to the hospital I did get like really nervous and it wasn’t about having the baby, it was more how many people were going to read and where was it on my chart that I was diagnosed HIV?... (the nurse’s husband) was a teacher and worked in the same board... she’s gonna go home and tell her husband... That totally consumed me and it was all I could think about... My mind wasn’t even on like the procedure that was gonna about to happen.*” (Pamela, 30, Canadian-born Caucasian mother of two)

TURNED AWAY DURING LABOUR

Women have been refused care during labour including being turned away from the nearest hospital just hours before giving birth. This refusal can be experienced as HIV-related stigma.

“*They told me they can’t deal with my issue because I’m HIV positive...and the nurses...were like they just they were staring at me as if I’m something, that I’m strange, you understand? The doctor came to me and she was like ‘oh we cannot deal with your issue you have to go to one of those hospitals downtown.’*” (Grace, 33, African-born Black mother of three)

INAPPROPRIATE INTERACTIONS

How medical providers present themselves at the time of delivery can cause harm and can be experienced as HIV-related stigma. Hurtful comments and the inappropriate use of personal protective equipment can leave mothers feeling insecure and insulted when they are most vulnerable and desire compassionate care.

“The doctor came in...turned around, looked at me. Said that we're not equipped for AIDS...I've never seen this doctor a day in my life...And I started to cry...I yelled out that he had bad bedside manner. That this is a hospital. This is the place to feel safe, not discriminated...He looked at me and he says, I don't even want to hear how you got it... He came back into the room, he had a shield on. He had gloves right up to his shoulders. He was totally covered...I mean, was this guy going deep sea fishing or was he preparing for a baby? And it's not like he's going to get HIV from me! I'm undetected.”
(Lynn, 39, Canadian-born Caucasian mother of seven)

CHANGING THE CHILDBIRTH EXPERIENCE

Giving birth is an experience that all mothers remember. Distressing experiences of stigma can overshadow the joys of baby's arrival.

“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...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.” (Pamela, 30, Canadian-born Caucasian mother of two)

LACK OF KNOWLEDGE CAN HAVE REAL CONSEQUENCES

Lack of appropriate education and training of health and social care trainees and providers can result in inappropriate and negative experiences for women living with HIV. This is in sharp contrast with the empathy and understanding shown by staff with up-to-date and correct knowledge.

“The student doctor, once she found out I had HIV she doubled up on her gloves, she was terrified, cause I tore, to stitch me up...my nurses there were amazing I loved them all...those two ladies stood by me, hold hand when I cried, they hugged me and told me it's okay...but the doctor and the um student doctor were the worst I've ever seen in my life. I would never recommend anyone to if a person has to go through that and have him I would say screw it. Have your baby on the street before you have him.” (Lisha, 32, Canadian-born Black mother of two)

IS IT INFORMATION THAT YOU NEED TO KNOW?

Asking probing questions can be inappropriate. For example, asking women living with HIV how they got the virus can violate their safety and comfort, and it's most often information that is not relevant to providing care and support. Casual inquiries about how HIV was acquired can also disregard the possibility that HIV transmission occurred through a traumatic experience that women living with HIV do not want to be reminded of.

“Something that really makes me mad is somebody that's in the health care and you tell them that you're HIV positive and they ask you how you got it...I just hate it when people ask me that and especially if you're working in like as a nurse or a doctor... So that happened a few times while I was in the hospital.” (Jacqueline, 30, Canadian-born first time mother)

What Women Need

HIV-RELATED STIGMA IS REAL

It is important to recognize the many forms of HIV-related stigma. The experiences of mothers living with HIV tell us that it is pervasive across health and social systems in particular during pregnancy and childbirth.

MAKE EQUITY A PRIORITY

HIV-related stigma deepens race, gender, sexual and class discrimination. How HIV-related stigma intersects with social inequality in healthcare settings needs specific attention. Mothers living with multiple social inequities require additional recognition, resources and advocacy to ensure proper care.

NORMALIZE PREGNANCY AND BIRTH FOR WOMEN LIVING WITH HIV

Mothers living with HIV want to be treated like other mothers. They deserve health and social care that gives them all the accommodation, compassion, empathy, excitement, joy and entitlements associated with becoming a mother. To accomplish this, health and social care providers may need to update information, training and supports to ensure women living with HIV can have normal pregnancies and memorable birth experiences.

SYSTEM-WIDE CHANGE

Review and reform policies, protocols and practices for perinatal care for women living with HIV. Direct and purposeful interventions⁴ are essential to meaningfully end and prevent HIV-related stigma in medical settings. This requires assertively challenging and shifting everyday societal and institutional cultures.

ADVOCATES ARE KEY TO EQUITABLE CARE

Health advocacy teams can be created to support mothers, as well as spearhead and implement institutional and clinical changes in the medical settings women living with HIV use for perinatal care. Social workers with special training who work both within and outside medical settings can play an important role in eliminating stigmatizing practices.

HONOUR MOTHERS LIVING WITH HIV

Respect is crucial for the elimination of HIV-related stigma, which includes listening to the individual and collective voices of women living with HIV in both personal care and systemic reform. Taking care of women's personal boundaries, privacy, advocacy and medical needs is as important as making room for their dreams and desires as women and mothers.



KEY PRACTICE IMPLICATIONS

- Recognize that HIV-related stigma and discrimination is pervasive and systemic in the lives of pregnant women and mothers living with HIV.
- Ensure that all health and social care providers in your agency or organization have up-to-date information and training opportunities about HIV, in particular, the care and support needs of pregnant women and mothers living with HIV.
- Reflect upon individual practice and agency-wide initiatives to uncover any possible places and spaces that stigmatizing practices and policies may exist.
- Shift individual practices and agency-wide policies and practices to reduce HIV-related stigma and overt acts of discrimination.
- Ask questions that are appropriate to deliver care and support rather than to feed personal curiosity. Be reflexive regarding if and how probing questions could result in stigmatizing experiences for mothers living with HIV.
- Recognize that HIV-related stigma can occur without open discrimination and may be intensified for mothers who face marginalization on the basis of other inequalities including race, class and sexual orientation.
- Be cautious regarding how practices and policies may result in inadvertent disclosure of one's HIV status. Although disclosure by health and social care providers is often unintentional, it can have tremendous consequences and is closely connected with experiences of stigma for women living with HIV.

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Taking Action

Action on All Fronts

CARING MATTERS MOST

Conscientious, tailored and empathetic health and social care is critical. It makes pregnancy, birthing and motherhood a positive experience for women living with HIV.

REVOLUTIONIZING THE CULTURE

Public ideas and social values about HIV need to change. This means rooting out HIV-related stigma, challenging assumptions about HIV transmission and shifting ideals of motherhood.

HUMANIZING PRACTICE

Shifting from surveillance and policing of women's bodies to supportive and client-centered practice is vital. Providing compassionate support includes challenging biases and assumptions and being accountable to women living with HIV.

THE WILL TO CHANGE

Care workers are often overworked. Social, medical and community services are under continuous financial and political pressure. Despite these challenges, providing people with respectful and equitable care continues to be a top priority. Change means making an individual and institutional commitment.

Breaking it Down

POSITIVE ENGAGEMENT

Listening to the individual and collective voices of mothers living with HIV and integrating their needs into the development, design and delivery of services and supports.

PUBLIC EDUCATION

Making accessible, culturally appropriate and up-to-date information about HIV, pregnancy, transmission risks and the issues and needs of expectant and new mothers widely available.

COMMUNITY DEVELOPMENT

Developing workshops for community-based groups on the realities, concerns and needs of women living with HIV as they make the transition to motherhood. Invite mothers living with HIV to share their experiences.

INSTITUTIONAL ADVOCACY

Creating an ongoing system of social work advocates to support mothers living with HIV, to train staff and to revise system-wide policies, protocols and practices.

ACCOUNTABLE PRACTICE

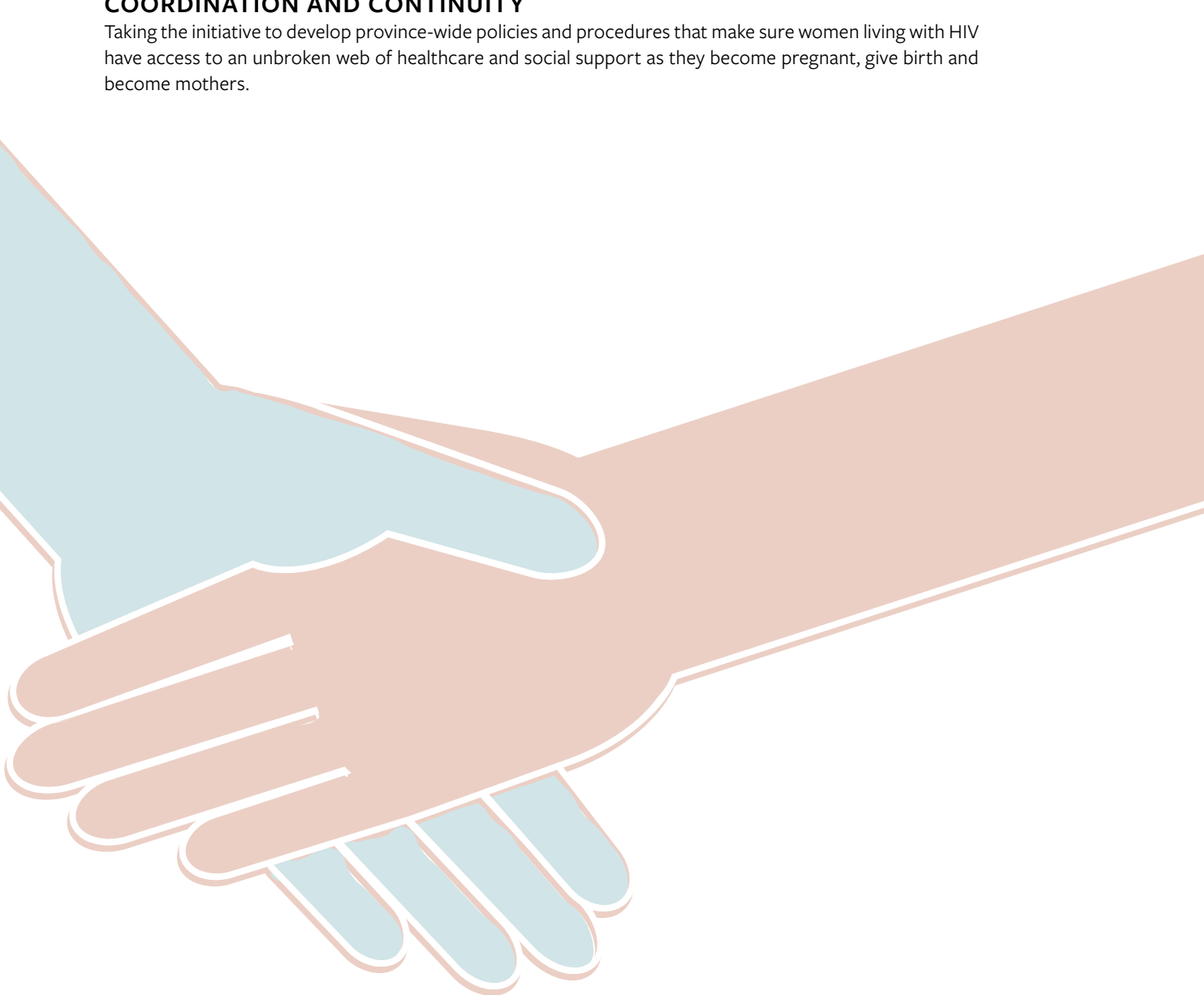
Putting checks and balances in place to create everyday accountability by care workers towards the women living with HIV they serve.

EFFECTIVE SERVICES

Turning the culture of service from policing, surveillance, criminalization and stigma to self-reflexive, socially conscious and supportive care.

COORDINATION AND CONTINUITY

Taking the initiative to develop province-wide policies and procedures that make sure women living with HIV have access to an unbroken web of healthcare and social support as they become pregnant, give birth and become mothers.



Making it Happen: What You Can Do

AS AN INDIVIDUAL

- Shift language to promote respect, compassion, dignity and empathy. Consider how the language you and others use can result in women feeling judged and/or stigmatized.
- Appreciate challenges women may have accessing health and social services, for example, the distance they may travel and the time they spend attending appointments, other responsibilities they have including children, work, school, etc.
- Take privacy and confidentiality seriously and consider the impact of openly discussing one's HIV status in any care and support setting, especially when others are present. Don't assume anyone else knows about a woman's HIV status.
- Women living with HIV may not be comfortable accessing support from an HIV-specific organization because of fear of HIV disclosure, stigma and rejection, therefore you may be an important source of HIV-related support even if you do not consider yourself to be an HIV "expert."
- Become an advocate to facilitate access to health and social care. Ask women what they need from you to facilitate access to health and social services.
- Be open to learning, continuing education and reflecting on your practice. HIV continues to evolve as a chronic illness. Make sure you are equipped with up-to-date information.

AS A COLLECTIVE AND SYSTEM

- Women living with HIV should have access to a multidisciplinary care team throughout the pregnancy-motherhood trajectory to ensure their diverse and unique needs are considered.
- Women-centered and holistic care is imperative—care must respond to women's biopsychosocialspiritual needs.
- Peer support is an important source of support for many women living with HIV. Explore ways to increase access to peer support within your agency or organization, or create a referral system to facilitate access for women living with HIV who are interested in peer support.
- Develop, implement and evaluate any programs, protocols or policies pertaining to mothers living with HIV. Meaningfully involve mothers living with HIV in all stages of program and policy development, implementation and evaluation.

Acknowledgements

Thank you to all the mothers from across Ontario who participated in the HIV Mothering Study

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SUPPORTING MOTHERS IN WAYS THAT WORK FORUM

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THE HIV MOTHERING STUDY WAS FUNDED BY

Ontario HIV Treatment Network
Canadian Institutes of Health Research

The publishing of this toolkit was supported by the Provincial Women and HIV/AIDS Initiative. Funding for the Women and HIV/AIDS Initiative is provided by the AIDS Bureau, Ministry of Health and Long Term Care.



