Postpartum support for mothers living with HIV: what works and what doesn't

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Conflict of Interest Disclosure

- No conflicts of interest.

Background

- Impending motherhood is a joyous and stressful time for all women.
- Women living with HIV face unique concerns postpartum
  - Increased risk for depression and other psychosocial stressors (Kelly, 1993; Rotheram-Borus et al., 1999; Schuster, 2000)
  - Mothers who perceive greater HIV-related stigma also report higher levels of depression, anxiety, poorer functioning on medical outcomes (Murphy et al., 2002)
- Motherhood intensifies concerns related to HIV disclosure, perinatal transmission, stigma and worry about effects of HIV on children (Sandelowski & Barroso, 2003).
- Motherhood effects sense of responsibility and caring for oneself in order to care for their children (Sandelowski & Barroso, 2003).

HIV Mothering Study

- Observational, mixed methods, community-based study
- Goal: enhance understanding of the psychosocial experiences and needs of women living with HIV across Ontario in pregnancy and the first year of motherhood
- Data collection: 3rd trimester, 3, 6 and 12 months postpartum
  - Surveys
  - Information from medical records
  - Narrative interviews
- 77 pregnant women enrolled at HIV and obstetrical care centers from March 2011 to December 2012
- Community leadership: team of mothers living with HIV to advise research process, lead data collection/analysis

Methods

- Narrative interviews: women asked to describe their experience in pregnancy/motherhood
  - Interviews recorded and transcribed verbatim
- Reflexive team debriefing: decision to focus on mothers' perspectives of healthcare interactions
  - ART of mother
  - ART administration to infant
  - Infant HIV testing
- 74% of participants from Toronto and Hamilton regions
  - Thematic analysis reflects interviews conducted with Toronto (n=32) and Hamilton (n=19) participants in pregnancy and at 3 months postpartum

Interview participants (n=51)

Age	Median = 32, Range = 24-42
Ethnicity	Black or African = 71% White = 20% Aboriginal = 4% South Asian = 4% Other = 1%
Place of Origin	Africa = 61% Canada = 25% Caribbean = 8% South America = 4% India = 2%
Immigration Status	Canadian Citizen = 51% Permanent resident = 25% Refugee / Refugee Claimant = 18% Other = 6%
Marital Status	Common-Law / Married / Relationship, not living together = 55% Single / Separated / Divorced = 45%
Years living with HIV	Mean = 5 , SD = 3.7
HIV Dx in Pregnancy	14%
First baby	27%

Positive vs. Suboptimal Care

- Effective communication
- Sense of belonging
- Being heard
- Accessible

- Lack of communication
- Silencing
- Stigmatizing
- Confidentiality/ disclosure concerns

Positive Care:

Effective Communication

"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."

Positive Care:

Sense of Belonging

"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."

Positive Care:

Being Heard

"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."

Positive Care:

Accessibility

"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."

Suboptimal Care:

Lack of Communication

- Postpartum procedures (infant HIV testing, ART) poorly communicated:

"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."

(Mother diagnosed with HIV in pregnancy)

Suboptimal Care:

Silencing

- Mothers were unsure about infant feeding options:

> "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."

If women are shut down, they may not open up at the next encounter.

Suboptimal Care:

Silencing

"He told me that the baby has to be on medication...that was so shocked...all I heard from him was the medication...and then, you have any question? Obviously...I couldn't say anything cause I'm choked, right?...I think I may be confusing"

"They never really explained to me what the medication was for. They just, pretty much, take it for six weeks...I didn't understand what it was doing...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? But you just do what you're told."

Suboptimal Care:

HIV Stigma

"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."

Suboptimal Care:

Confidentiality and Disclosure

"Two separate nurses come in my room [and say]...so [son] needs his HIV medication now... I've got two visitors in the room. [I'm] not happy! Two separate occasions [nurses disclosed my status when I had visitors] that didn't know, yes!...I would have rather it have been my choice. I kind of felt like it was taken away from me."

Consequences…

"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."

Conclusions and implications

- How relationships with healthcare providers are established and maintained can impact how mothers experience childbirth and postpartum
- For many mothers, having trusting and open relationships facilitated positive health outcomes for mom and baby
  - Clarity and confidence: testing, treatment of baby
- Important to consider how power dynamics between mother and healthcare provider affect these interactions
- Highlights need for education, training and knowledge translation tools for healthcare providers to optimize care and support postpartum

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