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A Complicated Dilemma: HIV and Infant Feeding

Logan Kennedy, RN

Dr. Lena Serghides,

Dr. Saara Greene,

Tuesday November 25, 2014



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**The webinar will commence
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**All participants will be muted
until the question period.**

HIV-positive parenting in Canada

A webinar series co-organized by IHPREG and CATIE

IHPREG brings together Ontario's leaders on the issues associated with HIV during preconception, pregnancy, postpartum and in any circumstance following pregnancy.

CATIE is Canada's source for up-to-date, unbiased information about HIV and hepatitis C. We connect people living with HIV or hepatitis C, at-risk communities, healthcare providers and community organizations with the knowledge, resources and expertise to reduce transmission and improve quality of life.

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Today's webinar is the second in a three-part series that will explore issues related to HIV, pregnancy and parenting in Canada. Stay tuned for:

Life With Baby: A Round-table Discussion on Positive Parenting

December 16th 2014, 1:30 – 3:00pm (ET)

**A French version of this webinar series
will be presented in 2015.**



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Logan Kennedy MN, RN is an Advance Practice Nurse in the field of women's health with a focus on pregnancy and HIV. Currently Logan is working as a Research Associate at the Women's College Research Institute in Toronto. She also teaches in the Collaborative Nursing Degree Program at Ryerson University and works at Maple Leaf Medical Clinic in Toronto. Her ongoing clinical and research interests include pregnancy, women and HIV, sexual and reproductive health care needs for young women and men living with HIV, and nurse-based interventions for people living with HIV.



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A Complicated Dilemma: HIV and Infant Feeding



Setting the Stage for the Canadian Context

V Logan Kennedy MN, RN

Research Associate and Clinical Nurse Specialist

Conflict of Interest

No conflict of interest related to the topic of infant feeding and HIV

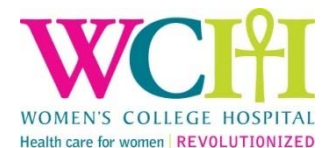
The Questions

- **What are the guidelines/recommendations in Canada?**
- **Why is this a complicated dilemma?**



In a Nutshell....

- All HIV and Infant Feeding policy around the globe is informed by **three types** of science:
 1. Basic Science on Risk of HIV transmission through breastmilk (ie – Dr. Serghides talk)
 2. Infant morbidity and mortality epidemiological data
 3. Clinical trial data on reduction of transmission via breastmilk with cART
- In addition to population-based information about the regional context in terms of:
 1. Access to potable drinking water
 2. Access to formula
 3. Mixed feeding vs exclusive breast feeding



Canadian Clinical Practice Standards

- Guided by the WHO (2010) comprehensive guidelines for high resource settings which have the main goal of:
 - “support[ing] the greatest likelihood of HIV-free survival”
- **Avoid breastfeeding altogether** because the **risk of HIV transmission far outweighs the risks associated with replacement feeding**

http://www.who.int/maternal_child_adolescent/documents/9789241599535/en



Canadian Clinical Practice Standards

- Based on:
 1. The science that transmission through breast milk cannot be completely eliminated
 2. the premise that we meet the WHO Guideline for high-resource settings

Avoid breastfeeding altogether because the **risk of HIV transmission far outweighs the risks associated with replacement feeding**

- Health Canada and recent CPARG/SOGC statement guides this practice



Health Canada

- **Nutrition for Healthy Term Infants:
Recommendations from Birth to Six Months**
- Widely promotes breastfeeding however notes that breastfeeding is contraindicated in women who are living with HIV
- Rationale

“consistent with the WHO's recommendation in countries where suitable breastmilk substitutes are available”

<http://www.hc-sc.gc.ca/fn-an/nutrition/infant-nourisson/index-eng.php>



First Complication

Variability in National Guidelines on
HIV and Infant Feeding based on the
WHO Recommendations

Examples

Guidelines	Recommendation Related to Breastfeeding
WHO HIV and Infant Feeding ¹	Exclusive breastfeeding in <u>low and middle resource</u> settings as it may provide a greater chance of survival even when antiretrovirals are unavailable
United States (DHHS) ²	Breastfeeding is not recommended for HIV-infected women in the United States, including those receiving ART
United Kingdom (BHIVA/CHIVA) ³	Recommend the complete avoidance of breastfeeding for infants born to HIV-infected mothers, regardless of maternal disease status, viral load or treatment but acknowledge rare instances when a mother will breastfeed

1. http://www.who.int/maternal_child_adolescent/documents/9789241599535/en

2. <http://aidsinfo.nih.gov/contentfiles/lvguidelines/perinatalgl.pdf>

3. <http://www.bhiva.org/documents/Publications/InfantFeeding10.pdf>

Second Complication

People's Lives do not always 'fit' neatly
into the guidelines

AFASS Principles

- **Acceptable: Issues at micro (individual), meso (family and culture) and macro ('breast is best' society) levels for women = STIGMA, FEAR OF DISCLOSURE, GUILT, LYING....**
- Feasible: time, knowledge, skill and support to manage formula feeding is person dependent
- Affordable: we manage this in Ontario with the provincially funded formula program
- Sustainable: as above
- **Safe: complex issue in terms of personal safety of mother is status is exposed and also that we make assumptions in Ontario (high resource setting) that all mothers to clean water and formula storage**

<http://motherchildnutrition.org/info/afass-principles.html>



WORLD HEALTH ORGANIZATION

FORMULA FEEDING CONDITIONS

- **Safe water and sanitation are assured at the household level and in the community;**
- Caregiver can reliably provide sufficient infant formula milk to support normal growth and development of the infant;
- Can be prepared cleanly and frequently enough so that it is safe and carries a low risk of diarrhoea and malnutrition;
- **Caregiver can, in the first six months, exclusively give infant formula milk;**
- **Family is supportive of this practice;**
- Caregiver can access health care that offers comprehensive child health services



http://whqlibdoc.who.int/publications/2010/9789241599535_eng.pdf



Third Complication

With changing science and variations in recommendations around the world, discussions are emerging in Canada about the feasibility of breastfeeding. How do we discuss this while honouring the needs/rights of mother and those of the children?

Factors to Consider

Maternal

- Right to informed choices about body, parenting, including infant nutrition
- Personal and cultural pressures to breastfeed
- Issues of disclosure and stigma
- Desire to provide 'best' start for their child

Child/Infant

- Right to informed choice in terms of risk (?issue of harm reduction?)
- Bonding with mother
- Cultural/familial acceptance issues
- 'Best' start in life

Fourth Complication

The benefits (health and social) of breastfeeding are well known. So what happens if a mother chooses to breastfeed?

Considerations for Clinicians

- If breastfeeding is disclosed clinicians often worry about:
 - ETHICAL
 - LEGAL
 - CHILD PROTECTION RESPONSIBILITIES
- We need to talk about this more to develop a clearer understanding of what each so these mean to different providers (MD, RN, SW, RM, Support Workers etc.)



Statement from CPARG and CPS

- 2014 publication with important considerations in terms of organizational/institutional policies impacting families

If an HIV-infected woman is found to be breastfeeding, she and her child should be referred urgently to a pediatric HIV expert. It is important to clarify the mother's understanding of the risks of HIV transmission via breast milk and to determine the reasons for her choosing to breastfeed. An automatic referral to child protection services is not warranted (8), but may be considered in some instances after consultation with a pediatric HIV specialist.

IN ONTARIO WE ARE AIMING FOR ZERO...

In order to achieve this, clinicians, policy makers, and community members cannot place undue confidence in adherence to guidelines. Open discussion about what informs guidelines and how families can manage the implications of these guidelines are paramount for optimized care. For now, we remain committed to the science as presented by Dr. Serghides but are equally as committed to transparent, equitable discussions about evolving science and considerations for Ontario

Thank you!

Questions



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Dr. Lena Serghides is a Scientist at the Toronto General Research Institute and the Sandra Rotman Centre for Global Health at the University Health Network. She received her Ph.D. from the Institute of Medical Sciences at the University of Toronto. Her research is focused on improving maternal and infant health in the face of infection. She is especially interested in understanding the impact of HIV infection and HIV antiretroviral treatment on placenta and fetal development, and on infant health.



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A Complicated Dilemma: HIV and Infant Feeding

Breast milk and HIV - The Basics

Lena Serghides

Toronto General Research Institute and
Sandra Rotman Centre for Global Health

Catie Webinar

Tuesday November 25, 2014





Some facts

- About 40% of pediatric HIV infections happen during breastfeeding
- ARV therapy reduced chances of HIV infection by over 60% - but **did not** prevent all infections
- ARV exposure of the baby via breastfeeding affects the baby – but we don't know how severely and for how long yet



Breast milk an overview

- Breast milk satisfies the baby's nutritional and hydration needs
- Enhances the baby's immune system
 - Protects against pathogens
 - Protects against development of allergies
 - Contains factors that can modulate the immune development of the baby
- Guards the integrity of the baby's gut
 - Delivers antimicrobial factors
 - Delivers anti-inflammatory factors
- In addition to these health benefits, the act of breastfeeding promotes psychological development



Breast milk the good

- Newborn babies are vulnerable to disease
 - Immature and incomplete immune system
- Breast milk compensates by conferring defenses and helping the immune system of the baby mature
- Antibodies in breast milk target infectious agents – mother-offspring immune dyad



Breast milk the bad

- Risk of vertical transmission through breast milk
- Increased risk of transmission caused by:
 - Viral load
 - Length and intensity of breastfeeding – exclusive breast feeding for 6 months less risk of transmission
 - Inflammation of the mammary gland - mastitis, breast abscess, engorgement increases HIV shedding in milk
- Baby exposed to antiretrovirals through breast milk – unknown risk



WHO recommendations for preventing HIV transmission through breastfeeding

Where safe alternatives are not available!

- WHO recommends exclusive breastfeeding of infants born to HIV+ mothers until 6 months of age and continued breastfeeding until 12 months with maternal cART and peri-exposure prophylaxis in infants using nevirapine.
 - cART to mom starting at 14 weeks and continued until 1 week after baby exposure to milk ends, plus nevirapine or AZT to the infant until 6 weeks of age (Option B)
 - cART to mom for the rest of her life, plus nevirapine to infant for 6 weeks of age (Option B+)
- HIV resistant strains emerging in treated infants



What is in breast milk

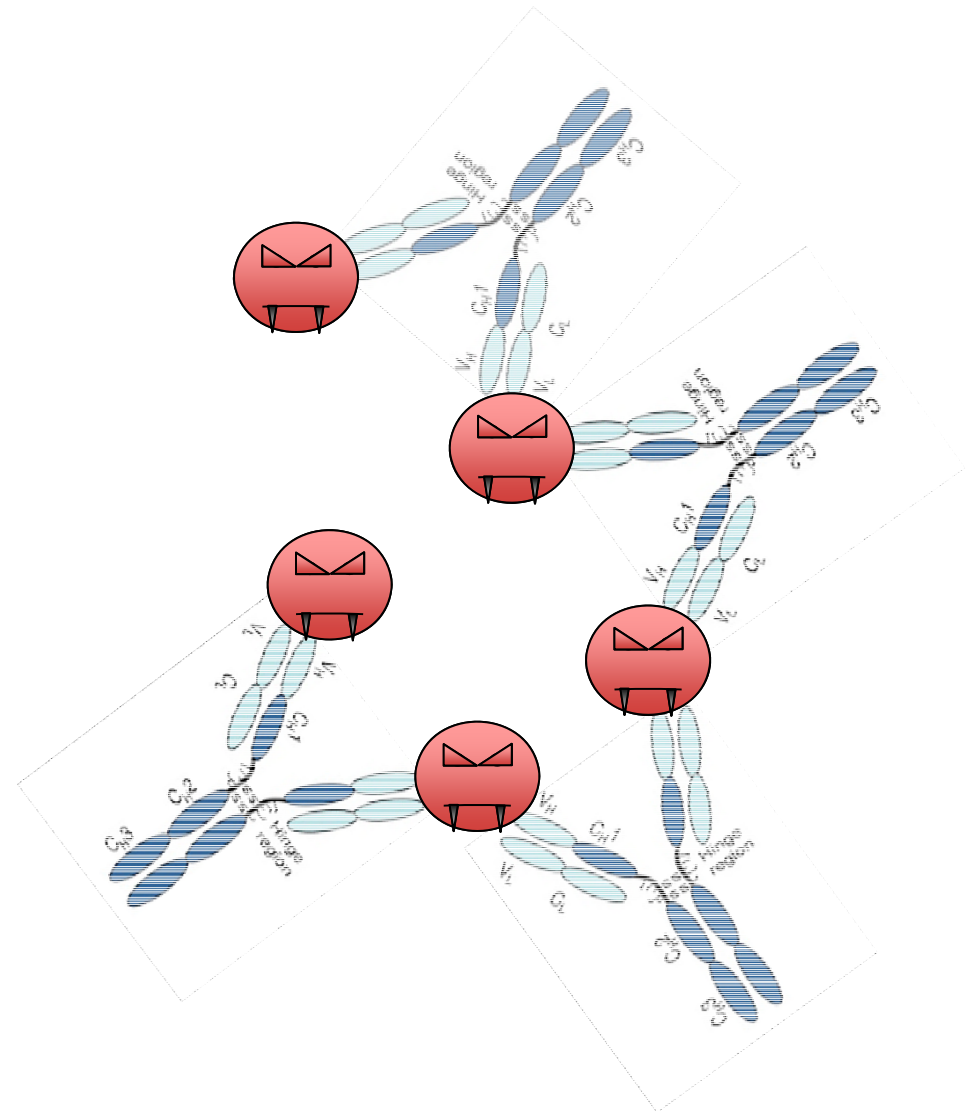
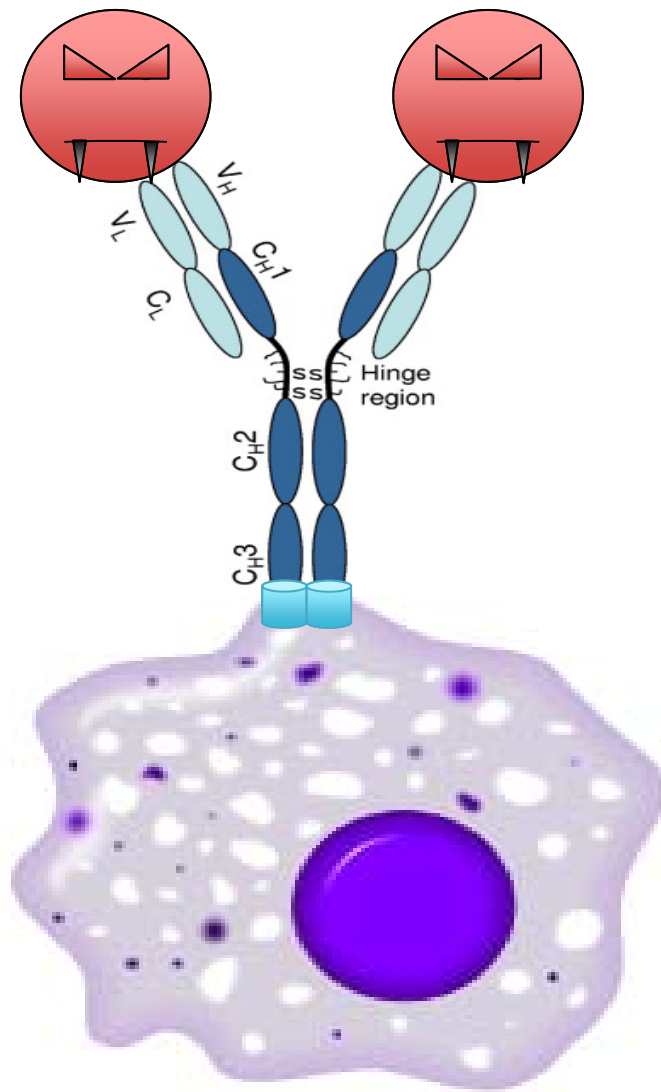
- Antibodies - IgA
- Anti-microbial factors
- Immune modulators
- Immune cells



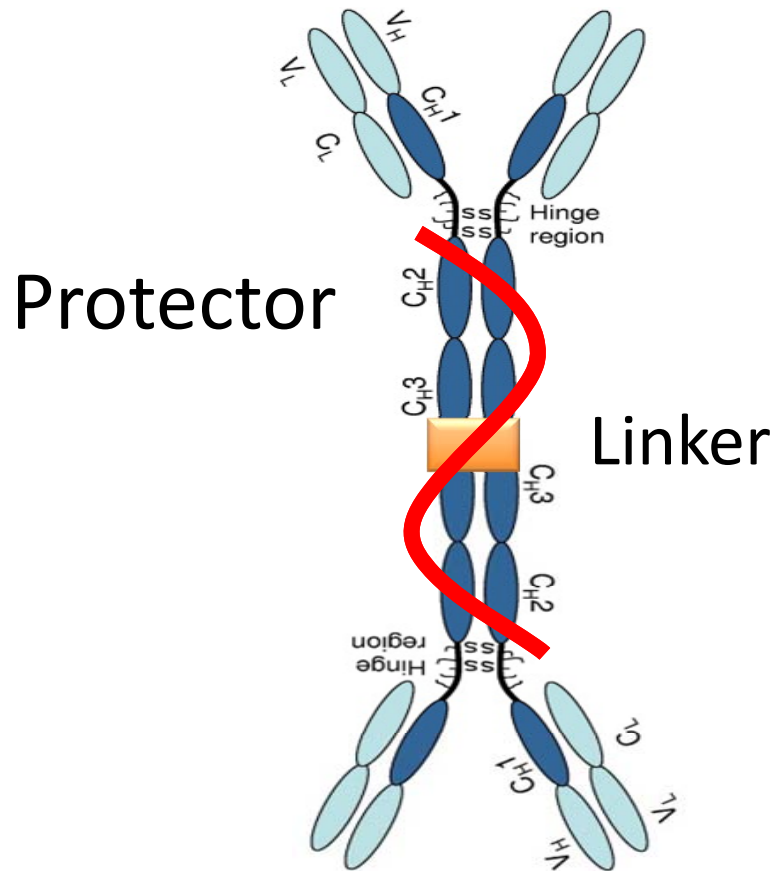
Protective mechanisms: IgA

- Able to survive in the baby's gut
- Guards against microbes common to mother and infant
 - prevents bacteria and viruses from attaching to mucosal surfaces by immune exclusion
 - Protects mucosal surfaces by mucosal painting – covering of surfaces with a thin layer of antibodies
 - Neutralizes microbial toxins

Antibodies – how they work



IgA in breast milk

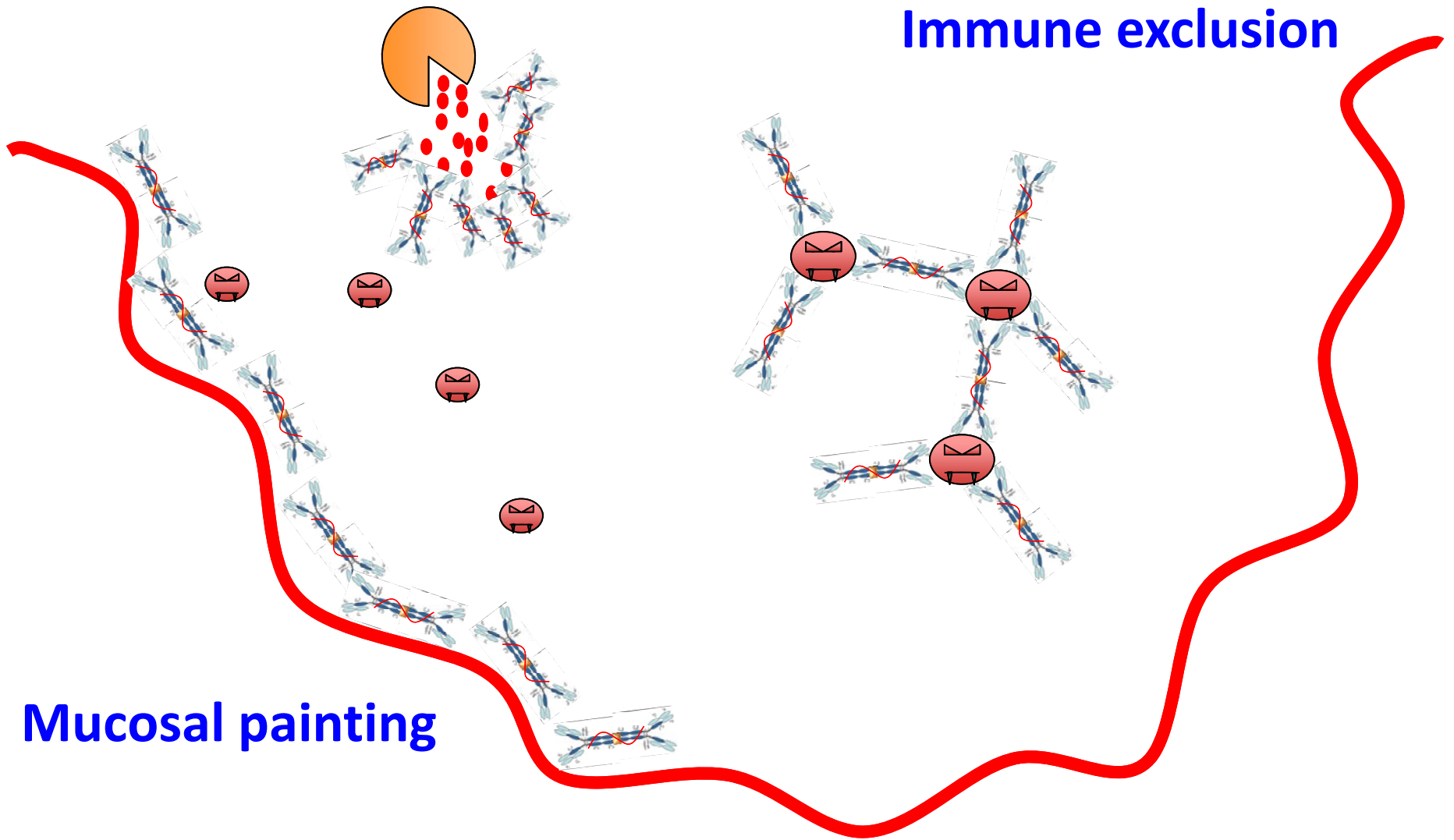


- Made as a dimer by plasma cells
- Protector protects the IgA from being digested in the gut of the baby
- Survives in the baby and guards against microbes

Protective mechanisms: IgA

Toxin neutralization

Immune exclusion





Protective mechanisms: Innate factors

- Kill bacteria by lysis or inactivation
 - Lactoferrin, lysozyme, free fatty acids
- Boost the immune response to bacteria
 - sCD14, sTLR, β -defensin-1
- Block pathogens from attaching to the baby's cells
 - Lactadherin binds rotavirus and prevents it from infecting the baby's gut – may also work for HIV
 - SLPI can inhibit HIV entry into cells (in vitro)
 - Lactoferrin, mucin-1, and Tenascin-C (TNC) shown to neutralize HIV

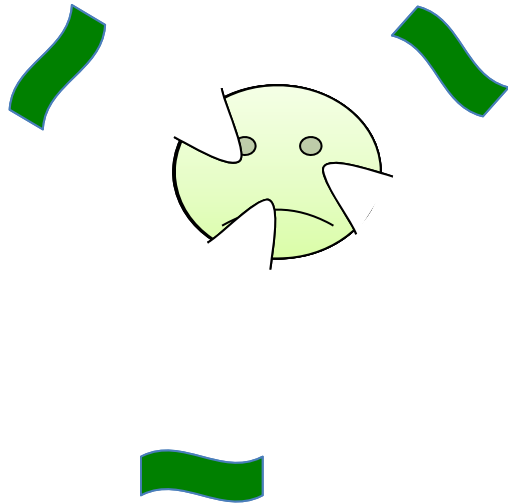


Protective mechanisms: Innate factors

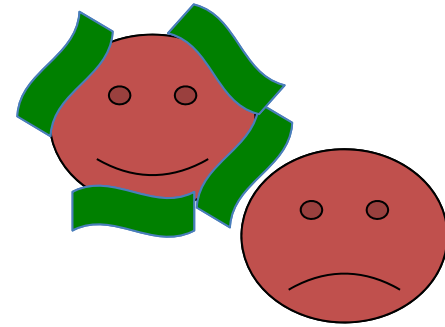
- Reduce inflammation in the baby's gut
 - Baby's gut exposed to new antigens (microbes, food) that can induce inflammation
 - Factors in milk prevent immune responses
 - e.g. lactoferrin inhibits NFkB and stops T-cells from releasing inflammatory proteins
 - Erythropoietin, TGFb, IL-10 – can inhibit the release of inflammatory proteins from the baby's gut cells

Protective mechanisms: Innate factors

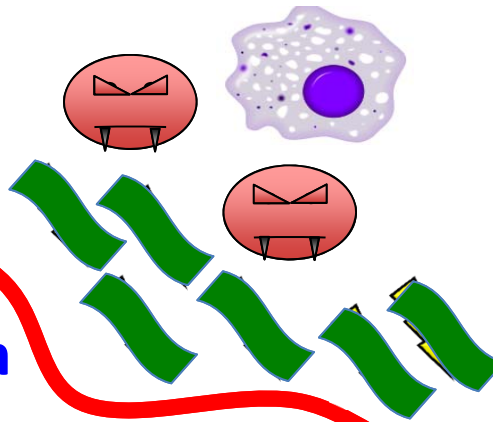
Microbial inactivation and lysis



Prevent attachment and entry



Reduce inflammation





Protective mechanisms: Immune cells in breast milk

- Most abundant in colostrum and transition milk
- In mature milk there are between 10,000 – 50,000 immune cells per ml of milk
- Different from blood immune cells
 - higher proportion is activated and memory
 - Highly active – ready for action!

Immune cells in milk

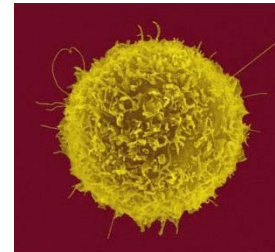


Neutrophil – 80%

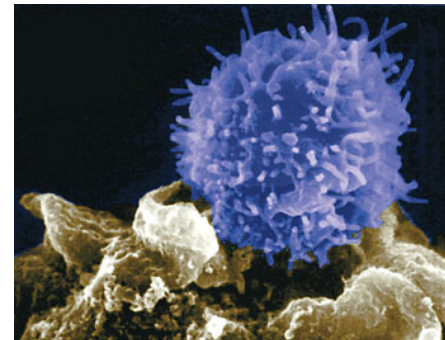


Macrophage – 15%

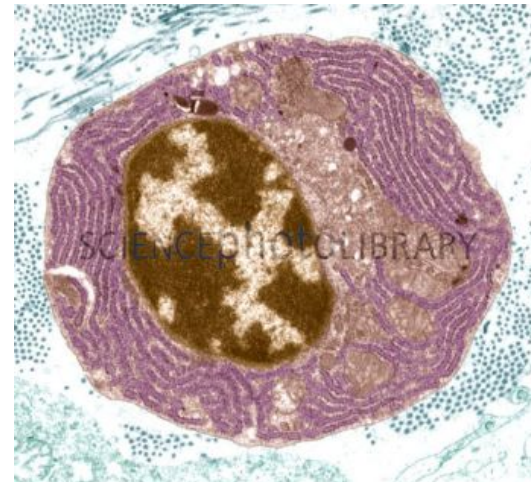
Lymphocytes – 5%



CD4 T cells



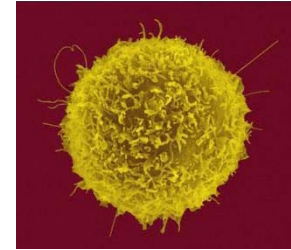
CD8 T cells



B cells

Lymphocytes in milk

– CD4 T cells

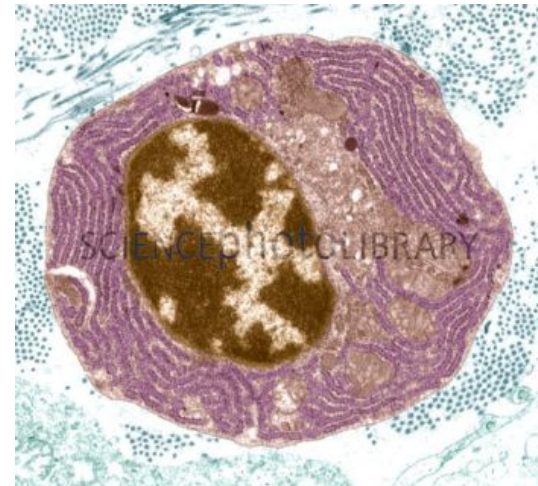


- Breast milk has almost exclusively activated memory T-cells / effector memory
 - **ready for action**
- Most breast milk CD4 T-cells express high levels of CCR5 and CXCR4 the HIV co-receptors, and $\alpha 4\beta 7$ which interacts with gp120 facilitating HIV infection
 - **ideal targets for HIV infection**
- During feeding the infant gets exposed to over 1 million maternal CD4 T-cells each day
 - **risk for infection!?**



Lymphocytes in milk – B cells

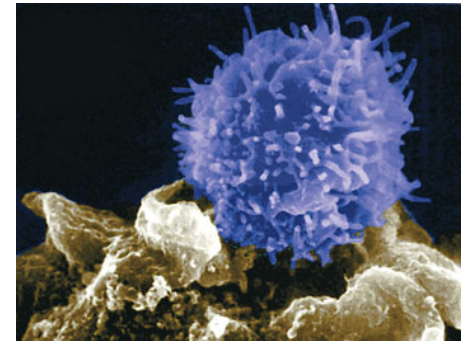
- Breast milk has almost exclusively memory B-cells
- Also plasmablasts and plasma cells
- B-cells in milk are primed and **ready to secrete antibodies**





Lymphocytes in milk – CD8 T cells

- Most CD8 T-cells in breast milk are activated
- HIV specific CD8 T-cells are more frequent in milk than in blood
- **May help to limit HIV production by infected CD4 T-cells**





Macrophages in milk



- Differ from blood monocytes
- Have higher phagocytic capacity and more effective defense against pathogens
 - **super macrophages**
- Profusely secrete soluble factors such as lactoferrin, and complement C3 and C4 (innate immune factors!)
- BUT express DC-SIGN
 - used by HIV for transport between tissue



Summary so far...

- Protective mechanisms of breast milk
 - Antibodies
 - help the baby's immune defenses
 - Innate factors
 - help enhance the baby's immune defenses
 - help kill pathogens
 - help keep the baby's gut from getting inflamed
 - Immune cells
 - Make antibodies
 - Help attack pathogens

- **But how about the risks of HIV transmission through breast milk???**



Risk of transmission: HIV reservoirs in milk

- Mammary epithelial cells
- Latently infected resting CD4 T-cells
- Activated CD4 T-cells
- Macrophages
- Cell-free HIV particles



HIV reservoirs in milk – mammary epithelial cells

- Mammary epithelia cells
 - Major cellular component of milk
 - Susceptible to HIV infection
 - Express CCR5 and CXCR4 and CD4
 - Can be infected in vitro by exposure to infected CD4 T cells
 - May enhance HIV infection in vivo by transcytosis
 - Also express protective factors against HIV like:
 - APOBEC3, MUC1, CCL28
- **These cells may transport HIV into milk**
 - **but no replication of HIV in these cells so likely not an active reservoir**



HIV reservoirs in milk – latently infected resting CD4 T-cells

- Latently HIV infected resting CD4 T-cells
 - Harbour HIV pro-viral DNA
 - Rare cell type
 - Have a very long half-life – 44 months
 - Not affected by ART
 - Inducible reservoir of HIV producing cells
 - Activation leads to 10x more efficient transcription and translation of HIV from latently infected cells in milk vs. blood



HIV reservoirs in milk – activated CD4 T-cells

- Activated CD4 T-cells productively infected with HIV
 - Source of almost all HIV RNA
 - Short lived, spontaneously secrete HIV antigens and produce HIV RNA in vitro
 - Can support HIV replication even in ARV-treated individuals
- ART can decrease HIV RNA in milk but does not significantly impact cell-associated DNA
 - In breast milk from successfully treated women can detect CD4 T-cells spontaneously secreting HIV antigen
 - In culture can induce cells to secrete HIV that is infectious.
- **HIV antigen producing T-cells can be identified in samples with no detectable HIV RNA**



HIV reservoirs in milk - macrophages

- In colostrum and transition milk 0.1-1% of macrophages are HIV infected and can actively produce viral particles
 - Longer lived than T-cells
- Milk macrophages express DC-SIGN
 - May help transport HIV to the baby's gut
 - May increase cell to cell infection of infant T-cells



HIV reservoirs in milk – cell free HIV particles

- Detectable HIV RNA in the whey of 80% of untreated HIV infected women
 - but also sequestered in the lipid fraction and on surface of milk cells
- Women on ARV therapy can have HIV RNA in their milk occasionally
- Often different viral load between the two breasts
- Affected by mammary gland inflammation



Risk of transmission

- The more HIV infected cells in breast milk the higher the risk of transmission to the baby
 - Each log increase in infected cells associated with 3x increase in risk of transmission
- High concentrations of cell free HIV RNA in milk associated with HIV transmission
 - Each log increase in cell-free HIV RNA doubles the risk of transmission
- In 2 studies: 15% of HIV+ moms who transmitted the virus by breastfeeding had undetectable HIV RNA

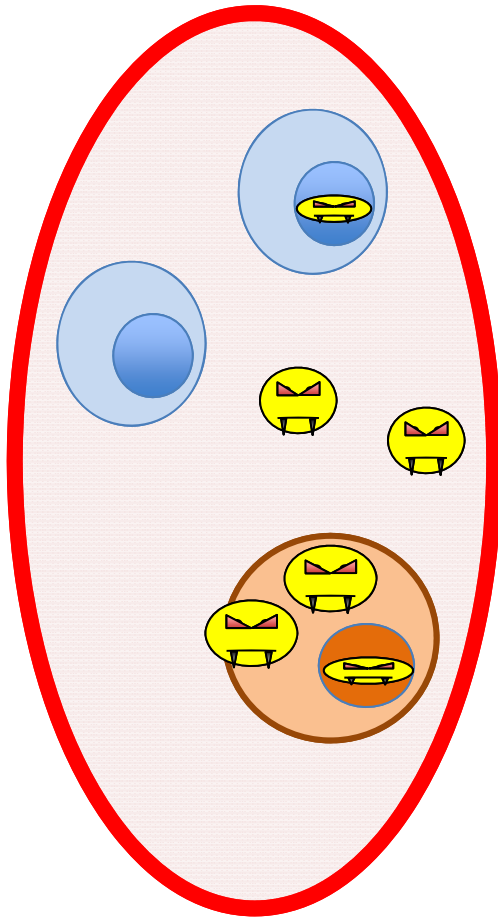


Risks

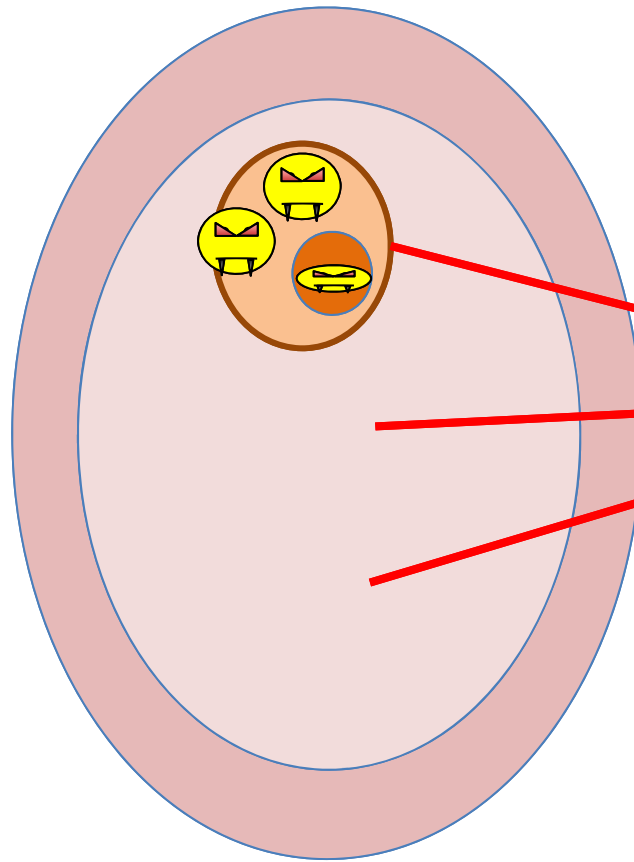
- In HIV+ moms who initiated triple ARV therapy during breastfeeding, ARVs reduced transmission by only 50-60%
- With WHO “option B” – triple ARV therapy for mother – seeing high rate of resistance to ARV drugs in babies that become infected despite maternal prophylaxis
 - Suboptimal concentration of ARVs in breast milk

HIV+ untreated

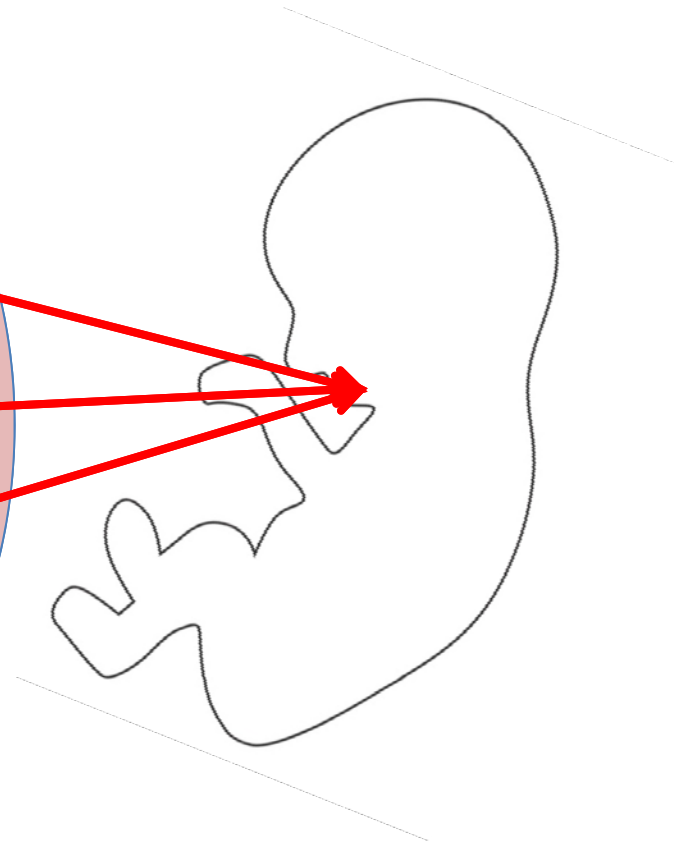
Blood vessel



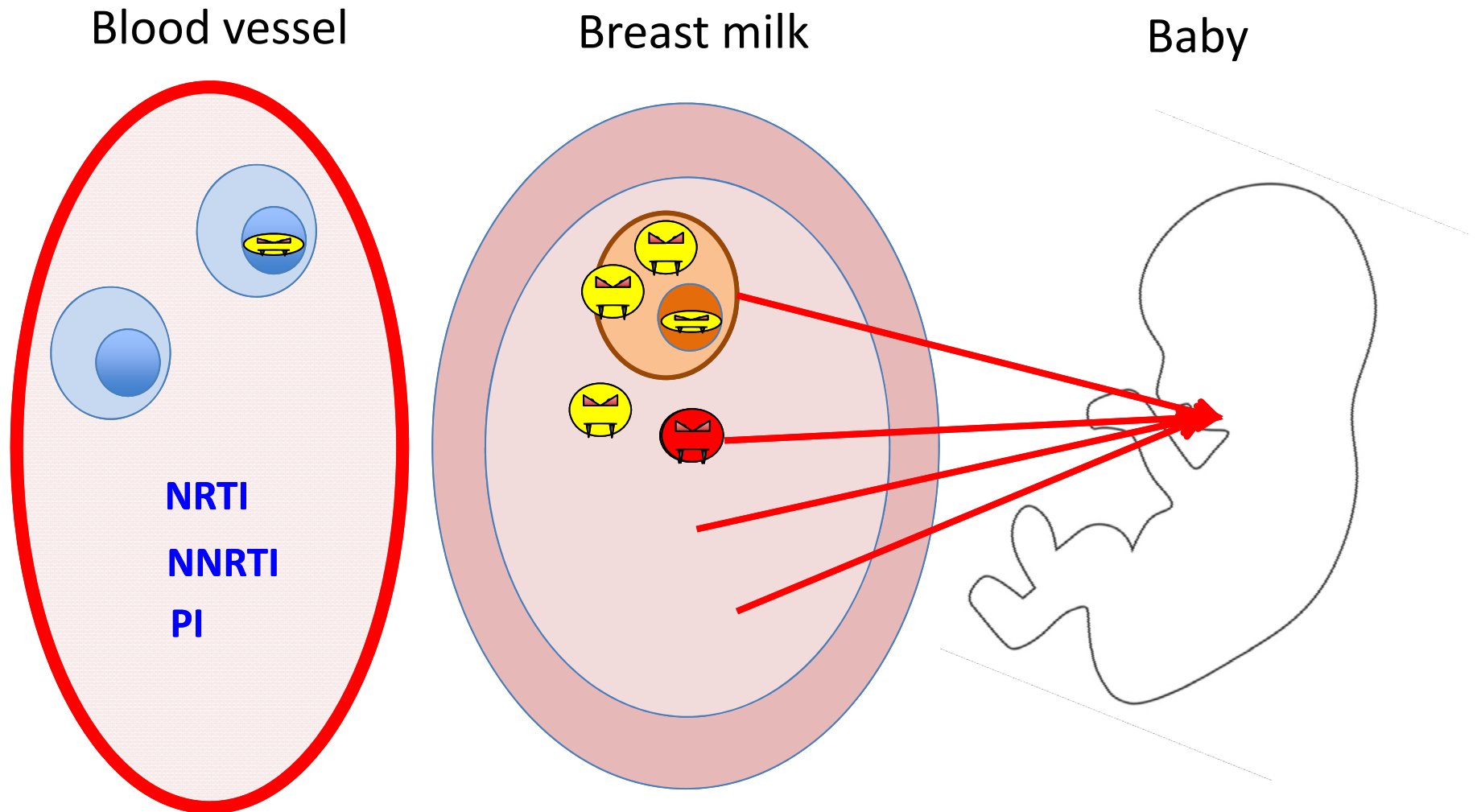
Breast milk



Baby



HIV+ ARV treated (and controlled)





Questions

- Are the immune benefits of breast milk affected by HIV or by antiretrovirals?
- Is the nutritional content of breast milk affected by HIV or antiretrovirals?
- What is the risk of HIV transmission in a fully controlled HIV+ woman?
- What factors can increase the chance of HIV transmission in a treated woman and how easy are they to detect and control?
 - e.g. mastitis, infection, viral load
- Is there an effective and easy way to make breast milk safe but maintain its nutritional and immune benefits?
- Is there an effective and easy way to protect the infant from HIV infection?



Questions

- What is the best ARV regimen for breastfeeding?
 - Lowest chance of vertical transmission
 - Reduce chance of drug resistance in the baby
 - Reduce side effects to the baby
- What are the effects of antiretroviral exposure through milk to the baby?
 - Immune development
 - Endocrine development
 - Neurocognitive/behavioural development
- Are there other ways to promote the psychological development provided by breastfeeding, without breastfeeding?
 - Kangaroo care

Questions or Comments??



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Dr. Saara Greene is an Associate Professor in the School of Social Work at McMaster University who is involved in a number of community-based HIV/AIDS research studies funded by both the Canadian Institutes for Health Research and the Ontario HIV Treatment Network. Most recently, her research has focused on mothers living with HIV and how the intersection of gender, race, culture and HIV related stigma impact their experience of health and social care. Saara's current research is called the Positive Parenting Pilot Project aimed at developing an HIV education and training module for Child and Family Service workers in Ontario.



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“Oh! You’re not breastfeeding?”: HIV-positive mothers’ experiences of infant feeding in a ‘breast is best’ world

Dr. Saara Greene, MSW, PhD

Associate Professor

School of Social Work, McMaster University





HIV Mothering Study: Background

- HIV-positive women face significant stressors during pregnancy and early motherhood.
- HIV-positive women require multiple forms of support throughout pregnancy, however, the presence of HIV-related stigma complicates access to and experiences of HIV and/or pregnancy supports.
- The unique health and social needs of HIV-positive pregnant women remain poorly understood.
- Goal of HIV Mothering Study: to understand the experiences, needs, psychosocial stressors, mental health concerns, and structural and systemic facilitators and barriers that impact HIV-positive mothers during pregnancy and the first year of motherhood.

What we know...

- Across Canada, women living with HIV are increasingly having babies
 - 1990s: 50 to 80 infants per year
 - 2012: 225 infants
 - In Ontario: 52 infants in 2001 → 101 infants in 2011
- Pregnancies will further increase due to:
 - Successful combination antiretroviral therapy (cART)
 - Vertical transmission rates less than 1%
 - Normalization of pregnancy for women living with HIV across Canada
- Ontario survey of women living with HIV:
 - 69% wanted to have children
 - 57% expect to conceive

What we know cont.

- Impending motherhood can be a joyous and stressful time for all women.
- Social determinants can challenge women's mental health and experiences of motherhood:
 - Younger age
 - Lower socioeconomic status & living in poverty
 - Non-resident immigration status & recent migration
- Social determinants may exacerbate the experiences of mothers living with HIV who also contend with structural, social and psychological complexities of living a chronic, stigmatizing illness.

Mothering with HIV: unique considerations

- Unique concerns of women living with HIV are documented in the literature:
- Motherhood intensifies concerns related to HIV disclosure, perinatal transmission, stigma and worry about effects of HIV on children.
- Motherhood effects sense of responsibility to care for oneself to be available to children.

Methods

- 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 (Baseline), 3, 6 & 12 months pp
 - Scales: Perceived Stress Scale (PSS), Edinburgh Postnatal Depression Scale (EPDS), Berger HIV Stigma Scale
 - Medical record data extraction
 - Narrative interviews in pregnancy, 3 and 12 mo pp
- 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



Qualitative methodology

- March 2011 to March Dec 2013: 77 in-depth interviews with HIV-positive pregnant women from across Ontario in their 3rd trimester enrolled in the HIV Mothering Study.
- Narrative methodological approach: Women asked to describe their overall experience of pregnancy in the context of living with HIV.
- Interviews recorded and transcribed verbatim.
- Narrative analysis and reflexive process between researchers and peer research assistants: rich understanding of women's perspectives of breastfeeding.

Interview participants (n=40)



Age	Mean = 32, Range = 21-42
Ethnicity	Black or African = 21 (52.5%) White = 13 (32.5%) Aboriginal = 4 (10%) South Asian = 1 (2.5%) West Asian / Arab = 1 (2.5%)
Place of Origin	Canada = 19 (47.5%) Africa = 18 (45%) Caribbean = 2 (5%) South America = 1 (2.5%)
Immigration Status	Canadian Citizen = 25 (62.5%) Permanent resident = 9 (22.5%) Refugee = 3 (7.5%) Other = 3 (7.5%)
Marital Status	Common-Law / Married / Relationship, not living together = 26 (65%) Single / Separated / Divorced = 14 (35%)
# of children	Mean = 1.9, Range 0-8
# of children in their care	Mean = 1.1, Range 0-6
First baby	9 (22.5%)

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)

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

Breast is Best?

Breastfeeding is a socially constructed and socially controlled process (Bowes and Demokos, 1998).

“10 reasons to breastfeed”

“Breastfeeding helps mothers respond to stress”

“Why aren’t more women breastfeeding?”

“stand up for mothers who can’t or don’t want to breastfeed!”

“Help, I don’t want to breastfeed!”

Breastfeeding and HIV: Current Guidelines

Guidelines	Recommendation Related to Breastfeeding
WHO HIV and Infant Feeding ¹	Exclusive breastfeeding in <u>low- and middle-income</u> countries as it may provide a greater chance of survival even when cART is unavailable
United Kingdom ²	HIV-positive mothers refrain from breastfeeding and be supported to formula-feed their infants Breastfeed if required under “exceptional” circumstances
United States (Department of Health and Human Safety) ³	Breastfeeding is not recommended including those women receiving cART
Canada ⁴	Complete breastfeeding avoidance regardless of HIV treatment or virologic suppression/plasma viral load

1. http://www.who.int/maternal_child_adolescent/documents/9789241599535/en.
2. British HIV Association. (2010). BHIVA and CHIVA Position statement on Infant Feeding in the UK. Retrieved from <http://www.bhiva.org/BHIVA-CHIVA-PositionStatement.aspx>.
3. <http://aidsinfo.nih.gov/contentfiles/lvguidelines/perinatalgl.pdf>
4. <http://www.hc-sc.gc.ca/fn-an/nutrition/infant-nourisson/index-eng.php> + Burdge et al., 2003

Findings

- Social Construction of Breastfeeding
- Social and cultural expectations
- Disclosure and Stigma
- Guilt and loss

Agency and Resistance

- Planning
- Moving forward
- recommendations

The Social Construction of Breastfeeding

"It makes me feel, um, like I'm not performing my full womanly duties as a mother."

"It was important, it is important. I mean that is what we are equipped to do, you know, it's just part of mothering so, that's why I feel bad that I am pregnant; like I knew all this stuff, you know, 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?"

Social and Cultural Pressure

"A lot of people keep asking, 'Why don't you breastfeed the baby? Why you giving him formula?', so you always have to come up with some other excuse..."

"I feel guilty...I really felt bad because my family...I didn't know what to tell them...I have an aunt, she was like, 'Oh my God, do this, do this, do this,' it was too much pressure on me!"

"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."

HIV-Related Stigma

"I'm thinking if I don't breastfeed, people will know"

"the challenges from not breastfeeding is the people around me right? It's so sad because most people, like most Africans, they know that moms who do not breastfeed are moms who has HIV. They know about that so sometimes if they come to your apartment or they'll be watching to see if you're gonna give the baby milk..."

Loss

"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 breast feed 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."

"...it's sad because you see some moms doing that and you miss that experience. You want to experience how it feels...I think that's a mom experience."

"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."

Planning

"we have to come up with a convincing answer"

The women's excuses ranged from telling people that *"there's no breast milk"* to saying that they *"don't breastfeed in the day"* to explaining that they were on a *"high dosage of iron."*

One woman bought a breast pump in anticipation of breast feeding 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..."*

“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, so then you are making up all these lies about 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.”

“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.”

- Tension between needing to lie in order to protect against HIV related stigma on the one hand, and how 'lying' made the women feel about themselves.

Moving Forward/Reclaiming Agency

“It is something I would have like 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.”

“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.”

“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.”

Resistance

"I'm lucky. Like I know some females would say, oh they wanted to, but me, I'm just like no 'cause I know my son is gonna wanna feed the baby, so if I'm breastfeeding how's he gonna be able to feed the baby?"

"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."

"You know, I feel I can bond with my baby in another way."

Discussion

- HIV-positive mothers experiences a complex range of emotions that are affected by cultural, social and politicized messages and about breastfeeding in general.
- This has an emotional Impact regarding identity that influences thoughts and behaviors.
- Many of the mothers in our study came from African countries where breastfeeding is experienced as a “complex relationship between mother and baby, the wider family and community...” (Dykes, 2005, p. 2292).

Recommendations

- Resistance and agency are central themes that can ground us in our practice
- Shift attention to how HIV-positive mothers can be supported by healthcare professionals in both hospital and community-based settings.
- Work with and Support HIV-positive mothers in coming to terms with other infant feeding choices and accepting and creating alternative images and discourses of motherhood
- Respond to the ways that gender, race, culture and HIV-related stigma intersect with infant feeding practices and experiences

Recommendations cont.

- Value and support the planning and navigating practices that HIV-positive mothers employ when confronting questions and curiosity within clinical, community and personal spaces by placing value on their lived experiences and “expert” knowledge of alternative infant feeding discourses.
- consider how breastfeeding practice guidelines can be implemented in ways that reflect an understanding of the structural, historical and cultural factors that are pervasive in the lives of HIV-positive mothers including gender, race, culture and HIV status.

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References

- World Health Organization (2010). *Guidelines on HIV and infant feeding*. Available at:
http://whqlibdoc.who.int/publications/2010/9789241599535_eng.pdf
- Department of Health (2004). *HIV and infant feeding: Guidance from the UK Chief Medical Officers' Expert Advisory Group on AIDS*. Available at:
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4089893.pdf
- Burdge, D.R., Money, D.M., Forbes, J.C., Walmsley, S.L., Smaill, F.M., Boucher, M., Samson, L.M., Steben, M. and the Canadian HIV Trials Network Working Group on Vertical HIV Transmission. (2003). Canadian consensus guidelines for the management of pregnancy, labour and delivery and for postpartum care in HIV-positive pregnant women and their offspring (summary of 2002 guidelines), *CMAJ*, 168(13), 1671-1674.

Q & A Period



Type your question in the Chat section, and it will be answered by one of our presenters.

Thank you!



Next webinar in our series
HIV-positive parenting in Canada:

**Life With Baby:
A Round-table Discussion
on Positive Parenting**

December 16th 2014

1:30 – 3:00pm ET

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