View metadata, citation and similar papers at core.ac.uk

brought to you by CORE

provided by Simon Fraser University Institutional Repository

"I beg you…breastfeed the baby, things changed": Infant feeding experiences among Ugandan mothers living with HIV in the context of evolving PMTCT guidelines

by

Emma Dunkley

B.A., McGill University, 2008

Project Submitted in Partial Fulfillment of the
Requirements for the Degree of
Master of Public Health

in the
Faculty of Health Sciences

© Emma Dunkley 2015

SIMON FRASER UNIVERSITY

Summer 2015

All rights reserved.
However, in accordance with the *Copyright Act of Canada*, this work may be reproduced, without authorization, under the conditions for "Fair Dealing." Therefore, limited reproduction of this work for the purposes of private study, research, criticism, review and news reporting is likely to be in accordance with the law, particularly if cited appropriately.

Approval

Name: **Emma Dunkley**

Degree: **Master of Public Health**

Title: ***"I beg you…breastfeed the baby, things changed": Infant feeding experiences among Ugandan mothers living with HIV in the context of evolving PMTCT guidelines***

Examining Committee: **Chair:** Angela Kaida
Assistant Professor

Angela Kaida
Senior Supervisor
Assistant Professor

____

Nicole Berry
Second Reader
Associate Professor

____

Date Defended/Approved: ____

Abstract

For women living with HIV (WLWH) in low- and middle-income countries, breastfeeding represents both an HIV transmission risk and the best way to ensure infant survival. The 2013 World Health Organization (WHO)-led strategy for the Prevention of Mother to Child Transmission (PMTCT) recommends exclusive and continued breastfeeding alongside lifelong antiretroviral therapy (ART) for all pregnant and breastfeeding women to optimize maternal and infant health while reducing perinatal HIV transmission risk. There have been four major changes to WHO's infant feeding guidelines since 1992, but few studies have explored how these evolving recommendations affect the pregnancy and postpartum experiences of WLWH. To address this gap, this study explores infant feeding experiences of twenty WLWH on ART in Uganda navigating new PMTCT guidelines. Findings reveal that women are making choices about infant feeding that run counter to current guidelines amid uncertainty about optimal infant feeding practices, fear of HIV transmission through breastfeeding, privileging of infant formula alongside fears about child survival and failure-to-thrive while exclusively breastfeeding, and maternal stress related to breastfeeding duration. Results highlight an urgent need for clearer communication about guideline changes and supportive infant feeding care for WLWH, including training for healthcare providers.

Acknowledgements

Thank you to the study participants and the research team in Mbarara, Boston, and Vancouver, and particularly the expertise, analysis and insight of Lynn T. Matthews, Scholastica Ashaba, Christina Psaros, Bridget F. Burns, and Angela Kaida, without whom this work would not exist. I would like to specifically acknowledge the ongoing support and encouragement from Angela Kaida. Angela has helped foster my research interests from the beginning, giving me the opportunity to support this valuable research as an RA and encouraging me to undertake this analysis for my MPH capstone. I would also like to thank Nicole Berry for her guidance throughout my time at SFU and for kindly agreeing to be my second reader.

Lastly, thank you to my wonderful family and my husband, Andrew, for supporting me through the last two years; I could not have done it without you.

Table of Contents

Approval ii

Abstract iii

Acknowledgements iv

Acronyms vii

Glossary viii

1) Introduction 1

2) Problem Statement and Objective 3

Problem Statement 3

Objective 4

3) Critical review of relevant literature 4

Infant feeding guidelines 4

Infant HIV Testing 7

Experiences of infant feeding among women living with HIV 10

4) Methods 11

Study overview 11

Study setting 11

Sampling and recruitment 12

Ethics 13

Data Collection 13

Data Analysis 13

5) Results 14

1. Uncertainty about infant feeding practices 14

2. Fear of HIV transmission through breastfeeding 16

3. Privileging of infant formula and concerns about infant malnutrition, failure-to-thrive and survival associated with EBF 17

4. Influence of socio-structural factors on infant feeding practices 18

5. Duration of breastfeeding, child HIV testing and maternal stress 20

6) Discussion 21

7) Limitations 24

8) Implications 24

9) Critical reflection 26

References 27

List of Tables

Table 1: Summary of changes to WHO-led infant feeding guidelines for women living with HIV in resource limited settings[14] 8

Table 2: Participant Characteristics at study enrolment 14

Acronyms

AFASS	Acceptable, Feasible, Affordable, Sustainable and Safe
ART	Antiretroviral Therapy
ARV	Antiretroviral drugs
EBF	Exclusive Breastfeeding
HIC	High Income Countries
HIV	Human Immunodeficiency Virus
IQR	Interquartile Range
LMIC	Low and Middle Income Countries
MUST	Mbarara University of Science and Technology
PMTCT	Prevention of Mother to Child Transmission
RF	Replacement Feeding
SFU	Simon Fraser University
UARTO	Uganda AIDS Rural Treatment Outcomes
WHO	World Health Organization
WLWH	Women Living With HIV

Glossary

Antiretroviral Therapy	A combination of at least three antiretroviral (ARV) drugs taken to suppress the HIV virus and stop disease progress.[1]
Early mixed feeding	Defined as giving an infant other liquids and/or foods together with breast milk to infants under 6 months of age, particularly water, gripe water, non-human milk, teas, oils and cereals. Note: defined herein as 'early' mixed feeding to distinguish from mixed feeding in months 6-12 that constitutes recommended supplementation of infant diet with complementary foods.
Exclusive breast feeding (EBF)	Defined as an infant receiving no other liquids or solids, except breast milk (including milk expressed or from a wet nurse) for 6 months of life, excluding drops and syrups (vitamins, minerals and medicines).[2]
Mixed feeding	Mixed feeding is defined as feeding an infant other non-human milk, liquids and foods while breastfeeding, including complementary foods such as cereals, protein sources including meat, eggs, and poultry, as well as fruits and vegetables.[2]
Perinatal HIV transmission	HIV transmission from mother to child that occurs during pregnancy, labour, delivery, or breastfeeding. Also known as vertical transmission or mother-to-child transmission.[3]
Replacement feeding (RF):	Defined as "the process of feeding a child who is not receiving any breast milk with a diet that provides all the nutrients a child needs." During the first six months of life, this constitutes a breastmilk substitute, such as formula. After the first six months, RF should consist of a breastmilk substitute in combination with appropriate, nutrient-rich complementary foods.[2]

1) Introduction

A forty-year-old woman living with HIV in Mbarara, Uganda has four children, one of whom is HIV positive. When her fourth child was born, she decided not to breastfeed. She had already seen one of her children struggle living with HIV, and she feared her new baby would be infected through breastmilk. Her husband was angry and asked her to reconsider her decision not to breastfeed. He enlisted a doctor who tells the woman: "I beg you, children are these days breastfed, breastfeed the baby, things changed."

Without intervention and with breastfeeding, perinatal HIV transmission occurs in an estimated 30-45% of births among women living with HIV.[4] With implementation of comprehensive infant feeding recommendations and prevention-of-mother-to-child transmission (PMTCT) practices, including sustained maternal antiretroviral therapy (ART) during pregnancy and postpartum, perinatal HIV transmission can be reduced to 2-5%.[5-8] However, each year an estimated 240,000 infants acquire HIV perinatally[9] with approximately half of these transmissions occurring during the breastfeeding period, overwhelmingly in the absence or suboptimal use of maternal and infant antiretroviral treatment and/or prophylaxis.[10]

For mothers living with HIV, while breastfeeding confers a risk of perinatal HIV transmission, it also provides nutritional, health and immune benefits to infants.[11] International infant feeding guidelines have changed dramatically over the last 25 years, particularly for women living with HIV (WLWH) in low and middle income countries (LMICs). For WLWH in high-income countries (HICs), infant feeding guidelines have consistently recommended replacement feeding since the mid-1980s, prioritizing the complete avoidance of perinatal HIV transmission risk through breastfeeding as replacement feeding options are generally acceptable, feasible, affordable, sustainable, and safe.[12] For WLWH in LMICs, however, where safe and affordable replacement feeding options may be more limited, WHO-led infant feeding guidelines have been modified every three to five years, incorporating evolving evidence regarding the balance between perinatal HIV transmission risks and maximizing infant survival outcomes, particularly as HIV treatment options became increasingly available. While the earliest guidelines for WLWH in LMIC recommended avoidance of breastfeeding, evidence emerged revealing significantly elevated non-HIV related infant morbidity and mortality risks associated with replacement and mixed feeding, compared with breastfeeding.[13-16] Moreover, evidence revealed that improving access to and sustained use of antiretroviral therapy alongside an increased standard of HIV

treatment yielded both improved clinical outcomes for maternal health and survival as well as perinatal HIV transmission prevention benefits.[17,18]

In light of this new evidence, in 2010, infant feeding guidelines for WLWH in LMIC shifted from exclusive breastfeeding and rapid weaning to recommending exclusive breastfeeding, followed by an extended period of mixed feeding (breastfeeding while introducing complementary foods), alongside maternal antiretroviral treatment.[11] These guidelines incorporated the dual aims of improving maternal health and survival and improving infant outcomes, including reducing perinatal HIV transmission risk and non-HIV related infant morbidity and mortality.[11]

In 2013, the World Health Organization published updated HIV treatment guidelines[18] that expanded access to ART among pregnant WLWH in LMIC and has profound implications on PMTCT practices. The guidelines recommended that all pregnant and breastfeeding WLWH, regardless of CD4 count or clinical stage of HIV disease, were eligible to initiate lifelong ART, a program known as 'Option B+'.[18] Between 2010 and 2013, maternal ART was used as prophylaxis and was discontinued at the end of the breastfeeding period among women otherwise medically ineligible for ART. The shift to Option B+ in 2013 promoted women's on-going access to ART even after breastfeeding concluded, for their own health, and further underscored the importance of maternal viral load suppression to minimize perinatal HIV transmission risk.[18] Together, the 2010 infant feeding guidelines and the 2013 ART recommendations introduce a more comprehensive, single standard of care with the goal to simplifying HIV treatment eligibility criteria[18] and infant feeding counseling,[11] and to further decrease perinatal transmission risk while promoting maternal and infant health.[11,18]

Research has begun to highlight the experiences of WLWH as they navigate these quickly evolving guidelines regarding infant feeding within PMTCT. Studies have found that WLWH often choose infant feeding strategies that may not correspond with national or international recommendations.[19-24] Research from Uganda in 2011 found that 57% of WLWH adhered to national infant feeding guidelines at 3 months postpartum.[20] In particular, studies have explored why and when women discontinue exclusive breastfeeding (EBF) and the reasons for practicing early mixed feeding (before six months).[23-25] EBF in the first months of life has been recommended for WLWH since 2001, but the practice is often challenged by cultural norms promoting early mixed feeding,[20,26-28] a lack of family and partner support, [27,28] and uncertainty

about HIV transmission risks and how to promote optimal child health through infant feeding.[26,28,29]

The suppressed HIV viral load achieved through adherence to maternal ART is also critical to prevention of perinatal transmission and improving maternal health.[30,31] While early evaluation of Option B+ shows promising results for coverage, counseling and support from health care providers for ART initiation and adherence through pregnancy and postpartum needs improvement.[18,32] Recent evidence also shows that ART adherence drops off postpartum, increasing the risk of transmission through breastfeeding.[30,31] There is further suggestion that the relative proportion of infants who acquire HIV during breastfeeding is increasing because of inadequate ART coverage and adherence during the postnatal period as compared to pregnancy, labour and delivery.[18]

Infant feeding practices alongside maternal treatment are a linchpin in the efforts to eliminate perinatal HIV transmission and promote maternal health among WLWH. While new evidence is incorporated into the recommendations for PMTCT, changes in recommended practices may not be clearly and effectively communicated to community members by health care providers and public health professionals. This, in turn, can contribute to uncertainty about best practice and attendant risks, both among health care providers and WLWH.[25,29,33,34] Evidence about perinatal HIV transmission risk and strategies to promote maternal and infant health and survival continue to evolve. However, limited work has explored WLWH's infant feeding experiences in the context of the most recent infant feeding and ART guideline changes in 2010 and 2013. To address this, the below study explores experiences of infant feeding among WLWH receiving ART in the context of these new PMTCT guidelines.

2) Problem Statement and Objective

Problem Statement: In recent years, new evidence has informed infant feeding recommendations to prevent perinatal HIV transmission and optimize infant and maternal health and survival. In this changing landscape and in the context of the newly released 2013 guidelines supporting lifelong ART for all pregnant and breastfeeding women, there is need for additional understanding about how women on ART experience and respond to changes to PMTCT recommendations, particularly as they pertain to infant feeding.

Objective: To explore experiences of infant feeding among recently postpartum mothers living with HIV on ART in Mbarara, Uganda.

3) Critical review of relevant literature

Infant feeding guidelines

Guidelines for infant feeding differ greatly between HICs and LMICs. Since the first evidence of HIV transmission through breastmilk was reported in the late 1980s,[35] WLWH in HICs have been advised to exclusively practice RF to eliminate all risk of HIV transmission through breastfeeding.[36] While breastfeeding is promoted among HIV-uninfected women in HICs, the relative safety and affordability of RF in HICs is deemed to render the risk of HIV transmission through breastfeeding unacceptable.

In resource limited settings such as Uganda, perinatal HIV transmission risk through breastfeeding must be balanced with the nutritional, health and immune benefits conferred to an infant through breastmilk.[12] Breastmilk substitutes are largely unaffordable and families may lack access to safe water and sanitation, making formula preparation unfeasible. More importantly, because pneumonia, diarrheal disease and malnutrition continue to constitute a serious threat to child health and survival, the protective benefits of breastmilk are significant.[11,12]

Studies from LMICs with high burdens of HIV have consistently shown higher mortality rates among HIV-exposed infants who were replacement fed, or weaned before 6 months, as compared to HIV-exposed infants who breastfed exclusively for 6 months.[12] For example, a randomized clinical trial from Botswana (n=1200) found a higher mortality rate among formula fed HIV-exposed infants at seven months (9.3%) as compared to breastfed, HIV-exposed infants undergoing zidovudine prophylaxis (4.9%).[37] Noting, however, that the 7-month HIV infection rates were 5.6% in the formula-fed group as compared to 9.0% in the breastfed plus zidovudine group.[37] Another study of HIV-exposed infants (n=958) in Zambia found a 2-4 fold increase in child mortality due to weaning before 4 months.[38] Evidence from Uganda among WLWH on ART showed a 6-fold greater risk of death among infants who breastfed for less than 6 months as compared to those who breastfed for 6 months or more, independent of maternal CD4 count.[23] With a push for increased access and adherence to maternal ART, the

combination of treatment and breastfeeding offers significant potential for safe infant feeding, increased child survival and improved health outcomes for WLWH in LMICs.

This conclusion - that breastfeeding, even in the absence of maternal ART, is superior for the overall health and survival of HIV-exposed infants in LMICs - is the culmination of decades of research. As evidence and treatment options evolved, so too did infant feeding guidelines. Since the first documentation of HIV in breastmilk in 1987, infant feeding recommendations for WLWH in LMICs have seen a full pendulum swing from breastfeeding, to formula feeding and back to breastfeeding. There have been four major changes to infant feeding recommendations, as a subset of PMTCT, since the first comprehensive guidelines were published in 1992: in 1998, 2001, 2006, and 2010. In 2013, ART guidelines were significantly expanded with implications for infant feeding among WLWH in LMICs, though 2010 infant feeding guidelines remained consistent as a subset of these recommendations. The major changes to WHO-led guidelines for WLWH as they relate to infant feeding in LMICs are summarized in Table 1.

Early evidence about HIV transmission pathways led to uncertain conclusions about the safety of breastfeeding for WLWH. In 1992, WHO-led guidelines downplayed the risks of HIV infection through breastmilk and encouraged breastfeeding among WLWH in LMICs.[36] By 1998, new evidence showed significant risk of HIV transmission through breastmilk,[35] and updated guidelines relayed the international health community's uncertainty about the safety of breastfeeding among WLWH. Specifically, that while RF was the only way to prevent transmission through breastmilk, the safety and feasibility of breastfeeding alternatives in LMICs was not well understood.[39] If WLWH chose to breastfeed, they were recommended to discontinue as early as possible.[36]

The 2001 WHO guidelines continued to recommend RF, but introduced the AFASS principle: that RF should only be adopted when acceptable, feasible, affordable, sustainable and safe (AFASS).[40] This shift came after new evidence showed that infants who breastfed exclusively for the first 3 months were not at excess risk of HIV transmission[13] and that transmission risk greatly increased with early mixed feeding (before six months).[13] If AFASS conditions were not satisfied, EBF should be practiced for the first 3-6 months of life, after which women were recommended to quickly wean their infants and move to RF.[40] The guidelines also introduced maternal and infant prophylaxis to reduce postnatal transmission, with a range of potential drug

regimens that extended 1 week postpartum for mothers and between 1-6 weeks for infants. Infant feeding counselors were advised to present women with their options and support them in their choice.

In an important move, the 2006 guidelines shifted to firstly recommend EBF for 6 months unless AFASS conditions were fully satisfied. Guidelines recommended an ARV regimen if required for the mother's health as per treatment eligibility criteria, and further emphasized the risks of mixed feeding.[41] Counseling guidelines were simplified to discuss only two options with patients: exclusive breastfeeding (EBF) and exclusive replacement feeding (RF).

The 2010 guidelines saw several important shifts for WLWH in LMICs including 1) to only recommend EBF (rather than also discussing RF) for months 0-6; 2) that maternal ART or ARV prophylaxis are a means to reduce transmission risk through breastfeeding rather than solely for maternal health, 3) that the breastfeeding period should be extended to 12 months (EBF for months 0-6, mixed feeding for months 6-12) and 4) an extended weaning period from as little as 2-3 days up to a month.[11] The final two recommendations are particularly important as they clearly recommend mix feeding in months 6-12, where previously any mixed feeding was discouraged.

In 2013, the WHO published HIV treatment guidelines that had implications for infant feeding.[18] While infant feeding recommendations remain consistent with 2010 guidelines, lifelong ART for all pregnant and breastfeeding WLWH in high burden countries is strongly recommended, regardless of CD4 count or clinical stage ("Option B+").[42,18] Prior to the 2013 guidelines, many pregnant and postpartum women would not have been medically eligible for ART. As a result, their PMTCT treatment regimen would have included prophylactic maternal and infant ARV treatment; when they stopped breastfeeding, they would also discontinue treatment. With the introduction of Option B+, all pregnant and postpartum women should be on ART, further minimizing perinatal transmission risk and reducing the pressure to fully discontinue breastfeeding at 12 months.[18] Countries like Uganda that have adopted Option B+ have seen a rapid increase in the number of women on ART, as well as changes to health systems to better integrate ART services with maternal and newborn care.[32]

Infant HIV Testing

Under current recommendations, the schedule and frequency of HIV testing of HIV-exposed infants differs between non-breastfed and breastfed children. HIV-exposed, non-breastfed children are recommended to undergo a virological test at 4-6 weeks of age and a serological test at nine months to determine their HIV status. If a child demonstrates any symptomology consistent with HIV infection within the nine month window, they are advised to undergo virological HIV testing.[43] HIV-exposed, breastfed infants undergo the same tests, however, the window for HIV testing based on suspected HIV symptoms continues for as long as they are breastfeeding. Additionally, a final HIV test must be conducted six weeks after the cessation of breastfeeding to definitively determine their HIV status.[43]