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Making Sense of Mother-to-Child Transmission (MTCT) and Prevention of Mother-to-Child Transmission (PMTCT) of HIV: Social Representations in Written Narratives by African Youth from Five Countries in 1997, 2005, and 2014

By

Landy Kus
Master of Public Health

Hubert Department of Global Health

_____

Kate Winskell, PhD
Committee Chair

_____

Gaëlle Sabben, MPH
Committee Member

_____

Robyn Singleton, MPH
Committee Member

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By

Landy Kus

Bachelor of Arts
Macalester College
2012

Thesis Committee Chair: Kate Winskell, PhD

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Abstract

Making Sense of Mother-to-Child Transmission (MTCT)
and Prevention of Mother-to-Child Transmission (PMTCT) of HIV:
Social Representations in Written Narratives by African Youth
from Five Countries in 1997, 2005, and 2014

By Landy Kus

Of the estimated 2.1 million new HIV infections in 2015, about 150,000 were in infants and children. Most occurred in sub-Saharan Africa and were a result of Mother-to-Child-Transmission (MTCT). MTCT can occur during pregnancy, at childbirth or through breastfeeding, but methods for Prevention of Mother-to-Child-Transmission (PMTCT) exist. However, information and recommendations regarding breastfeeding and biomedical drugs for PMTCT have changed over time. This study looks longitudinally to understand how sub-Saharan African youth make sense of MTCT and PMTCT in the context of changing recommendations. It also examines how they represent barriers to PMTCT. Thematic analysis was conducted on 47 written narratives submitted to the Global Dialogues scriptwriting competitions by youth 10-24 years of age from Burkina Faso, Kenya, South-East Nigeria, Senegal and Swaziland in 1997, 2005, and 2014. PMTCT barriers identified in the narratives include stigma in the form of mistreatment and lack of support, not knowing one's HIV status, not accessing appropriate medical care during childbirth, lack of monetary means, and disclosure of HIV status. PMTCT facilitators include support from family members and friends, HIV testing, knowledge of HIV status, accessing and receiving proper medical care, receiving counseling about HIV/AIDS from health professionals, and mothers' fear of MTCT. 2014 narratives discussing breastfeeding state HIV positive mothers should not breastfeed yet 2010 WHO recommendations encouraged exclusive breastfeeding even if ARVs were not available for PMTCT. EGPAF, UNAIDS and PEPFAR work towards eliminating pediatric AIDS and new HIV infections among children. Programs supported by these organizations particularly focus on improving access to PMTCT services. Findings from this study demonstrate it is not only about availability of PMTCT services, but also about how the social and situational context informs mothers' abilities to access PMTCT services. Family members, friends, and community members should be informed about how they can contribute to PMTCT. There is a need to prioritize addressing social contextual issues influencing access to PMTCT services, improve communication about PMTCT for mothers and community members, and improve how health care workers are informed about PMTCT recommendations.

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INTRODUCTION

Introduction and rationale

In 2015, about 36.7 million people were living with HIV worldwide and about 19 million of these were in East and Southern Africa alone (UNAIDS, 2016c). Of the estimated 2.1 million new HIV infections in 2015, 150,000 were in children. Most of these infections in children were in sub-Saharan Africa and the result of Mother-To-Child Transmission (MTCT) (UNAIDS, 2016c). These numbers are down from previous years. In 2000, over 600,000 children were newly infected with HIV worldwide, most due to MTCT, and 90% of these infections were in sub-Saharan Africa (WHO, 2001b). An estimated 400,000 children were infected through MTCT globally in 2009 and 240,000 in 2013 (WHO, 2015).

MTCT can occur during pregnancy, at childbirth or through breastfeeding; however, there are methods to prevent MTCT. Since 1999, recommendations regarding breastfeeding and biomedical drugs (antiretroviral prophylaxis and antiretroviral treatment) have been the focus of strategies to prevent MTCT (UNAIDS, 1999). In 2015, about 90% of HIV-infected pregnant women in Eastern and Southern Africa and about 48% of HIV-infected pregnant women in Western and Central Africa accessed ARVs (antiretroviral) for PMTCT as either prophylaxis or lifelong antiretroviral therapy (ART) (UNAIDS, 2016d; UNAIDS, n.d.a). However, these statistics vary by country. For instance, in Swaziland about 95% of HIV-infected pregnant women accessed ARVs for PMTCT compared to only about 36% in Senegal in 2015 (UNAIDS, 2016d; UNAIDS, n.d.a). Approximately 1.6 million new infections in children have been prevented since 1995 by providing HIV-positive women with ARV medication during pregnancy and breastfeeding period (UNAIDS, 2016b). However, a large number of children still continue to be infected through MTCT, particularly in sub-Saharan Africa.

Problem statement

Information about MTCT and recommendations regarding PMTCT have been changing over time with scientific discoveries and progress in HIV treatment. ARV use for PMTCT was first introduced in 1994 (WHO, 2001b) and the World Health Organization (WHO) released its first recommendations on the subject in 2000 (WHO, 2004; WHO, 2010a). These recommendations were updated and revised in 2004, 2006, 2010, 2013 and 2016 (McIntyre, n.d.; WHO and UNICEF, 2016). Recommendations about infant feeding and HIV were first introduced by WHO and the United Nations (UN) in 2000 (WHO, UNICEF, UNAIDS, & UNFPA, 2007). Breastfeeding and replacement feeding recommendations were later updated and revised by WHO in 2006, 2010 and 2016 (WHO et al., 2007; WHO & UNICEF, 2016). In the context of these changing and often conflicting recommendations for PMTCT, it is essential that communities are kept informed.

To my knowledge, there are no studies that have taken a longitudinal approach to explore the reception and effects of changing MTCT/PMTCT recommendations, and how these recommendations have been interpreted by target populations. Additionally, there is little knowledge about African youth perspectives on MTCT/PMTCT; yet, currently of the 16 million adolescents aged 15-19 who give birth each year, more than 50% are in sub-Saharan Africa (WHO, n.d.a), and in 2014 “[m]ore than 4 in 10 new infections among women [in sub-Saharan Africa] are in young women aged 15-24” (UNAIDS, 2014).

Purpose statement

This study will look longitudinally at social representations of MTCT/PMTCT, related recommendations, and existing barriers in narratives written by youth 10-24 years of age from Burkina Faso, Kenya, Nigeria, Senegal and Swaziland in 1997, 2005, and 2014.

Research questions

Quantitative:

- What are the outcomes of the narratives? How many stories have hopeful endings (i.e. PMTCT)?
- What are the outcomes of the narratives within the larger five-country study?

Qualitative:

- How are breastfeeding and replacement feeding for PMTCT represented in the narratives?
- How are biomedical drugs for PMTCT represented in the narratives?
- How do authors represent barriers to PMTCT?
- How do authors represent facilitators to PMTCT?
- How is blame for a mother's HIV infection and MTCT represented in the narratives?

Significance statement

Given that PMTCT recommendations have been changing over the decades and most recently in 2016, it is possible that the general population, including young people, may be uncertain about MTCT/PMTCT and current recommendations. Findings from this study will provide insight into sense-making about MTCT/PMTCT in the context of changing

recommendations. If populations are receiving mixed messaging, this makes PMTCT practice and adherence a challenge. This knowledge will also assist with identifying how to better inform populations about MTCT/PMTCT.

Definition of terms

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy, combination of three or more ARV drugs for treating HIV infection
ARV	Antiretroviral, medicine used to treat HIV infection
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
HIV	Human immunodeficiency virus
MTCT	Mother-To-Child-Transmission
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PMTCT	Prevention of Mother-To-Child-Transmission
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

LITERATURE REVIEW

Literature reviewed for this study includes a combination of qualitative studies, quantitative studies, and government and WHO documents. This study seeks to look at social representations of MTCT and PMTCT among sub-Saharan African youth. The literature reviewed addresses education and communication about MTCT/PMTCT, breastfeeding, barriers to PMTCT services, barriers to adherence to ARVs for PMTCT, and stigma in relation to MTCT/PMTCT. Documents from national governments and WHO reveal in detail how recommendations for PMTCT have changed over time, particularly over the time period covered by the narratives analyzed for this study.

History and policy of MTCT/PMTCT

MTCT of HIV can occur during pregnancy, at childbirth or through breastfeeding. In 1999, Africa made up only 10% of the world's population but UNAIDS estimated that 9 in 10 HIV-infected babies were born in Africa (UNAIDS, 1999). Of the estimated 2.1 million new HIV infections in 2015, 150,00 were in children and most of these vertical infections were in sub-Saharan Africa (UNAIDS, 2016c). For over two decades, various agencies and international organizations have made efforts to prevent MTCT by providing recommendations and implementing policies and programs. As science has evolved, there have over time been changes in recommendations and policies about MTCT and PMTCT, particularly regarding breastfeeding, replacement feeding, and biomedical treatment (as prophylaxis and in the context of a mother's ART) (see Table 1).

Breastfeeding and replacement feeding

Currently, according to UNAIDS, half of all MTCT occurs during the breastfeeding period (UNAIDS, 2016d, p. 20). Policies and recommendations about breastfeeding and replacement feeding have changed, especially regarding the introduction or duration of these feeding practices. Prior to 1999, the main strategies for PMTCT were preventing HIV infection in women of reproductive age, preventing unwanted pregnancies by providing family planning services, and providing abortion options in countries where abortion is legal (UNAIDS, 1999). In 1999, UNAIDS discussed the introduction of another strategy whereby HIV-positive mothers would take ARVs for the purpose of prophylaxis and the child would be given replacement feeding. However, this recommendation brought up the "complex" issue of the safety of replacement feeding (UNAIDS, 1999, p. 10). Conflicting recommendations were given. Though replacement feeding was encouraged, policy-makers were told to be wary of "undermining breastfeeding generally," but also to consider whether clean water and infant formula were available (UNAIDS, 1999, p.10). In 2000, WHO introduced the recommendation that HIV-positive mothers should avoid breastfeeding if "replacement feeding is acceptable, feasible, affordable, sustainable and safe…" (WHO, 2001, p. 12). If replacement feeding was not possible, then exclusive breastfeeding was recommended for "the first months of life" (WHO, 2001, p. 12). Additionally, it was also recommended to stop breastfeeding "as soon as feasible" to minimize MTCT risk (WHO, 2001, p. 12). Once a mother stopped breastfeeding, the recommendations state that she should be given "specific guidance and support for at least the first 2 years of the child's life to ensure adequate replacement feeding" (WHO, 2001, p. 12).

Prior to 2010, WHO recommended an "individualized approached" when it came to breastfeeding and replacement feeding; that is, an HIV-positive mother was counseled on

feeding options based on the context and circumstances of her household (WHO & UNICEF, 2016, p. 10). In 2010, in the context of widely expanded access to ART, WHO started to recommend "ARV drug interventions to prevent postnatal transmission of HIV through breastfeeding" (WHO & UNICEF, 2016, p. 1). Additionally, WHO stated that a country's health authorities must decide whether to focus on breastfeeding and ARV interventions for PMTCT or to focus on avoiding all breastfeeding (WHO & UNICEF, 2016). The 2010 WHO recommendations stated that even if "ARVs for both maternal health and also prevention of HIV transmission to infants" are not available, a mother should be encouraged to practice exclusive breastfeeding for the first 6 months (WHO, 2010b, p. 4). Complementary foods should be introduced after the first 6 months, but the mother should continue breastfeeding for the first 12 months. If the child is HIV-positive, then the mother should be encouraged to breastfeed for the first 6 months (WHO, 2010b; WHO & UNICEF, 2016). The 2010 recommendations also discouraged sudden weaning (WHO, 2010b). Instead, a HIV-positive mother who chooses to stop breastfeeding "should stop gradually within one month," and if the mother or child has been taking ARV prophylaxis then it should be continued for one week after breastfeeding has been stopped (WHO, 2010b, p. 34). WHO recommendations were revised most recently in 2016 with a different breastfeeding duration and HIV treatment. Current recommendations state that HIV-positive mothers should breastfeed for at least 12 months while on ART (WHO & UNICEF, 2016). Similar to 2010 recommendations, if a child is HIV-positive, the mother should be encouraged to breastfeed for the first 6 months (WHO & UNICEF, 2016).

Biomedical treatment

Policies and recommendations about biomedical treatments for HIV/AIDS have also changed over time with scientific discovery and progress. ARVs were first introduced for PMTCT in 1994 (WHO, 2001b). In 1999 UNAIDS discussed a new "option" available for HIV-positive mothers wanting to have children (UNAIDS, 1999, p. 6). HIV-positive mothers were to take ARVs and the child was to be given replacement feeding. This 1999 UNAIDS document states that "sometimes" the child may take ARVs (UNAIDS, 1999, p. 6). WHO first introduced recommendations in 2000 for "short courses of ARV drugs started in late pregnancy or during labour" for PMTCT (WHO, 2004, p. 2; WHO, 2010a). Later, in 2004, WHO recommendations state that if a HIV-positive mother does not have ARV treatment for herself, then she should be on ARV prophylaxis for PMTCT (WHO, 2004). WHO stated in 2010 that ARV access must be ensured for maternal health and PMTCT, and further stated that HIV-positive mothers should receive lifelong ART (WHO, 2010a). It was in 2011 that Option B+ was first implemented in Malawi (WHO, 2013). Option B+ is providing all HIV-positive pregnant and breastfeeding women with lifelong ART regardless of the woman's CD4 count (WHO & UNICEF, 2016). Most recently in 2016, WHO put out recommendations stating that all individuals, including children, should receive lifelong ART when they are first diagnosed with HIV (WHO & UNICEF, 2016).

It is not only recommendations about when to use biomedical treatments for PMTCT that have changed, but also the types of biomedical treatments. WHO 2001 ARV recommendations state that the treatment to be used should be chosen by taking into consideration the "feasibility, efficacy, acceptability, and cost" (WHO, 2001b). The 2001 recommended ARV regimens for PMTCT were four weeks of Zidovudine (AZT) alone or combined with AZT and Lamivudine

(3TC), or a single dose of Nevirapine (NVP) for the mother “at the onset of labour” and a single dose for the infant “soon after birth” (McIntyre, n.d.; WHO, 2004, p. 2). Revised WHO recommendations in 2004 were starting AZT at 28 weeks of pregnancy and single-dose NVP for the mother at labor (McIntyre, n.d.). Revised WHO recommendations in 2006 were starting AZT at 28 weeks of pregnancy, single-dose NVP for the mother at labor and delivery, and infant prophylaxis for one week after birth (McIntyre, n.d.; WHO, n.d.b). In 2010 the recommendations changed to receiving Option A or Option B. Options A is AZT for the mother and NVP for the infant (WHO, n.d.b). Option B is triple ARV for the mother until the end of breastfeeding. This treatment could be continued after breastfeeding if the mother was eligible for ARV treatment for herself. In 2013 WHO recommendations became Option B or B+ as they wanted to start promoting ART for all pregnant and breastfeeding women (McIntyre, n.d.). As of 2016, WHO recommends Option B+ (WHO & UNICEF, 2016).

Table 1. Evolution of WHO PMTCT recommendations

	2000	2001	2004	2006
ARV for PMTCT		4 weeks AZT; AZT + 3TC, or SD NVP	AZT from 28 weeks + SD NVP	AZT from 28 weeks + sdNVP + AZT/3TC 7 days
ART		No recommendation	CD4<200	CD4<200
Breastfeeding and replacement feeding	• Avoid breastfeeding if replacement feeding is "acceptable, feasible, affordable, sustainable and safe…" (WHO, 2001, p. 12) • If replacement feeding not possible, then exclusive breastfeeding for "first months of life" (WHO, 2001, p. 12) • Stop breastfeeding "as soon as feasible" (WHO, 2001, p. 12) • When breastfeeding stopped, mother should be given "specific guidance and support" for the child's first two years of life "to ensure adequate replacement feeding" (WHO, 2001, p. 12)			• Avoid breastfeeding if replacement feeding is "acceptable, feasible, affordable, sustainable and safe…" (WHO et al., 2007, p. 4) • If replacement feeding not possible, then exclusive breastfeeding for first 6 months of life (WHO et al., 2007) • If replacement feeding not possible at 6 months, continue to breastfeed with complementary foods. Stop breastfeeding "once a nutritionally adequate and safe diet without breast milk can be provided" (WHO et al., 2007, p. 7) • Strongly encourage "mothers of infants and young children who are known to be HIV-infected…to continue breastfeeding" (WHO et al., 2007, p. 7)

Adapted from: McIntyre, J. (n.d.)

Table 1 continued. Evolution of WHO PMTCT recommendations

	2010	2013	2016
ARV for PMTCT	Option A (AZT + infant NVP) Option B (triple ARVs)	Option B or B+ Moving to ART for all pregnant women/breastfeeding	Option B+
ART	CD4≤350	CD4≤500	Lifelong ART for all individuals (including children) as soon as diagnosed with HIV
Breastfeeding and replacement feeding	• If ARV for "maternal health and…prevention of HIV transmission to infants" is not available, mother should exclusively breastfeed for first 6 months (WHO, 2010b, p. 4) • Mother should be encouraged to breastfeed for first 6 months if child is HIV-positive • No sudden weaning. If mother chooses to stop breastfeeding, it should be done "gradually within one month" and if the mother or child has been taking ARV prophylaxis then it should be continued for one week after breastfeeding has stopped (WHO, 2010b, p. 34).		• While on ART, breastfeed for at least 12 months, can continue for up to 24 months • Mother should be encouraged to breastfeed for first 6 months if child is HIV-positive • If ARV drugs not available, mother should exclusively breastfeed for first 6 months. Should continue breastfeeding after month 6 if possible. • Similar to 2010 recommendation, no sudden weaning. If mother chooses to stop breastfeeding, it should be done "gradually within one month" and if the mother or child has been taking ARV prophylaxis then it should be continued for one week after breastfeeding has stopped (WHO, 2016, p. 8). However, lifelong ART is recommended rather than ARV prophylaxis.

Adapted from: McIntyre, J. (n.d.)

Barriers to PMTCT

Quantitative studies about PMTCT often focus on adherence to medication and attendance at PMTCT programs. The literature has identified factors that may be associated with adherence and attendance such as maternal education, maternal age, PMTCT knowledge, stigma and disclosure (Bwirire et al., 2008; Gourlay, Birdthistle, Mburu, Iorpenda, & Wringe, 2013; Mepham, Zondi, Mbuyazi, Mkhwanazi, & Newell, 2011; Odeny et al., 2016; Peltzer, Mlambo, Phaswana-Mafuya, & Ladzani, 2010; Tam, Amzel, & Phelps, 2015). While quantitative studies have identified PMTCT barriers, the qualitative literature provides nuance and context.

Literature utilizing qualitative research methods provides insight into the barriers associated with individual uptake of PMTCT recommendations. In-depth interviews and focus group discussions are the primary qualitative methods utilized. Most often study participants are HIV-positive women, but other participants have also included health workers or partners of HIV-positive women. Main barriers that have been identified by previous studies include stigma related to exclusive breastfeeding, lack of education about HIV transmission or biomedical treatments, lack of support, fear of disclosure, and stigmatization (Bwirire et al., 2008; Gourlay et al., 2013; Mepham et al., 2011; Odeny et al., 2016; Peltzer et al., 2010; Tam et al., 2015).

Recommendations regarding exclusive breastfeeding in relation to PMTCT have changed over time from advocating replacement feeding in 1999 to advocating exclusive breastfeeding for the first 6 months even if a mother is not able to access ART in 2016 (UNAIDS, 1999; WHO & UNICEF, 2016). A recent study conducted in urban Kenya that included both HIV-positive and HIV-negative women found that stigma associated with being HIV-positive was the main factor contributing to the non-practice of exclusive breastfeeding (Odeny et al., 2016). Exclusive breastfeeding is considered a practice for HIV-positive mothers alone (Odeny et al., 2016).

Negative views towards exclusive breastfeeding resulted in both HIV-positive and HIV-negative women choosing not to exclusively breastfeed (Odeny et al., 2016). The study explains that much of the health education and counseling about exclusive breastfeeding are carried out in health clinics and typically target HIV-positive women, which could lead to exclusive breastfeeding being associated with a positive HIV diagnosis (Odeny et al., 2016).

Lack of health education about HIV transmission and medication have been identified as reasons for poor adherence to biomedical drugs for PMTCT or poor attendance at PMTCT programs (Gourlay et al., 2013; Mepham et al., 2011; Peltzer et al., 2010). One study from rural South Africa found, for instance, that among women who did not properly adhere to the medication, women discussed not knowing or understanding the medication instructions (Mepham et al., 2011). A different study conducted in a rural province of South Africa found that women did not know or understand why they should be taking ARVs (Peltzer et al., 2010). If women are not well informed about HIV transmission and PMTCT, women cannot be expected to properly adhere to the medication or attend programs focused on PMTCT.

Stigma in relation to disclosure of HIV status is presented as another barrier to PMTCT. Studies have identified that a woman's disclosure of her status to her partner, family or community plays a role in her uptake of and adherence to PMTCT medication or seeking services for PMTCT (Bwirire et al., 2008; Chinkonde, Sundby, & Martinson, 2009; Gourlay et al., 2013; Tam et al., 2015). It is particularly the fear of stigma and mistreatment associated with being HIV-positive that has been noted as affecting a woman's disclosure decision and decision to seek PMTCT services. Women in one study noted that their participation in a PMTCT program would signify to others in the community that they are HIV-positive (Chinkonde et al., 2009). Another study found that fear of disclosure was related to the possibility of a HIV-

positive status leading to conflicts in the household, blame, or the possibility of divorce (Bwirire et al., 2008). In relation to disclosure and fear of stigma or mistreatment, lack of support was also related to non-participation in PMTCT services (Chinkonde et al., 2009; Gourlay et al., 2013). Chinkonde et al. (2009) specifically mentioned lack of husband support as a contributing factor. Several studies mention that lack of partner or family support are barriers to medication adherence (Gourlay et al., 2013).

This study

Since the late 1990s, there has been changing and conflicting information regarding recommendations for PMTCT. Literature from health organizations show how recommendations and policies have evolved over time. The quantitative and qualitative literature have provided information and insight into PMTCT medication and service uptake, and existing barriers to the uptake of recommendations. However, there is little literature that takes a longitudinal approach in looking at PMTCT recommendations and barriers. Few studies have utilized written narratives as the source of data on sense-making around MTCT and PMTCT. There is also a paucity of literature that primarily focuses on youth perspective of MTCT/PMTCT. This study will build on existing literature as it will incorporate a longitudinal approach spanning 1997, 2005, and 2014, and utilize narratives written by youth from five sub-Saharan African countries. WHO recommendations are intended to be global recommendations, but often the recommendations may not be adaptable to every context. This study will longitudinally explore how youth have made sense of MTCT and PMTCT in the context of evolving PMTCT recommendations and existing barriers.

METHODS

The purpose of this study is to longitudinally explore youth social representations of MTCT/PMTCT, PMTCT recommendations, and PMTCT barriers in five sub-Saharan African countries. Data for this study comes from Global Dialogues, formerly known as Scenarios from the Sahel and Scenarios from Africa, an HIV communication process started in 1997. Youth under 25 years of age are invited to submit fictional narratives or stories on HIV/AIDS that can be used to create a short film. A series of juries select winning narratives that are then transformed into short fiction films by African directors. The films are intended to educate communities about HIV/AIDS, and are broadcast on television and Internet. Since 1997, 47 films have been created and are available in 32 languages (D. Enger, personal communication, January 30, 2017). As of 2017, stories have been submitted by more than 250,000 people from 80 countries, 49 of which are located in sub-Saharan Africa (D. Enger, personal communication, January 30, 2017).

Population and sample

The data for this study are written narratives that were submitted to Global Dialogues during three specific time points: 1997, 2005, and 2014. This study is part of a larger five-country study examining youth social representations of HIV between 1997 and 2014. The narratives are from Burkina Faso, Kenya, Nigeria, Senegal and Swaziland. Given the cultural heterogeneity of Nigeria, only narratives from South-East Nigeria were included in the sample. There were 1,652 submissions in 1997 from Senegal and Burkina Faso alone, 10,577 in 2005 from all five countries, and 5,842 in 2014 from all five countries. These five countries were chosen because they are non-contiguous, represent diverse estimated adult HIV prevalence rates,

and more than 500 narratives were submitted from these countries in 2005. Overall, Senegal has had the lowest prevalence and Swaziland has had the highest prevalence. Adult prevalence has also varied across the years within each country (see Table 2).

Table 2. Estimated adult (15-49 years of age) prevalence (%) of HIV/AIDS by country and year

	1997	2005	2014
Burkina Faso	3.2%	1.4%	0.9%
Kenya	12.7%	7.0%	6.0%
Nigeria	4.1%	3.7%	3.2%
Senegal	0.5%	0.9%	0.6%
Swaziland	20.9%	25.7%	28.7%

Source: UNAIDS, n.d.a

Narratives were ineligible for inclusion in the study sample if written by a team or in response to a thematic story starter. Data were then stratified based on sex, rural/urban location, and age (10-14, 15-19, 20-24 years of age) of author. Ten narratives were randomly selected into each stratum. A summary was written for each of these narratives. Summaries were then independently double-coded with up to six keywords. Coding discrepancies were resolved through inter-coder dialogue. There are 47 possible summary codes, one of which is "MTCT/PMTCT." A total of 47 narratives from 1997, 2005 and 2014 had a summary coded with "MTCT/PMTCT" (see Table 3). Narratives thematically coded with "MTCT/PMTCT", but not with the "MTCT/PMTCT" summary code were also reviewed to determine whether or not they should be included in the study sample. None were added to the study as the discussion of MTCT or PMTCT was not central to the story line or MTCT was simply mentioned as a possible mode of transmission. The 47 narratives with "MTCT/PMTCT" summary code were analyzed for this study. The data and study findings are not representative of youth in sub-Saharan Africa

or the five countries from which the narratives are from since contest participants self-select to compete.

Table 3. Number of narratives in study sample (*n*=47)

	1997	2005	2014	Total
Burkina Faso	0	6	1	8
Kenya	0	7	3	9
Nigeria	0	4	4	7
Senegal	6	9	2	17
Swaziland	0	3	2	5
Total:	6	29	12	**47**

Procedures

Narratives were transcribed verbatim in English or French. Transcriptions and summaries were then entered into MAXQDA 12 qualitative data analysis software (VERBI Software, 1989-2016). Summaries were coded, and the narratives themselves were thematically coded with 62 possible codes. Codes for the narratives included a combination of deductive codes (e.g., "breastfeeding/replacement feeding"), coming from the literature on MTCT and PMTCT, and inductive codes (e.g., "personal reaction"), coming from the narratives themselves. Thematic analysis was conducted on the 47 narratives to describe longitudinal representations of MTCT/PMTCT, PMTCT recommendations and related PMTCT barriers. Quantifiable characteristics were also identified and analyzed, such as whether or not a narrative had a hopeful ending. Quantitative data were independently double entered into Qualtrics (Qualtrics, 2015). Discrepancies were reconciled by a third reader. Quantitative data was analyzed using Microsoft Excel. Quotes from narratives that have been included in the subsequent sections are provided verbatim. This study involves secondary data analysis that was approved by the Emory University Institutional Review Board.

RESULTS

Of the 47 narratives, 24 are written by female authors and 23 by male authors; proportions differed by year of submission (see Table 4). There were fewer female authors in 1997 compared to about 50% in 2005 and 2014; and, the percentage of urban authors increases over the three time periods (see Table 4).

Table 4. Author demographics by year (*n*=47)

Year	Number of narratives in study	% female author	% urban author	Median age
1997	6	33	33	16
2005	29	55	52	17
2014	12	50	83	15

Across the 47 texts, there were more narratives about MTCT than about PMTCT (see table 5). 15% of narratives in 2005 included prevention due to PMTCT whereas 0% of narratives did in 1997 and 2014 (see Table 5).

Table 5. % narratives about MTCT and PMTCT by year (*n*=47)

Year	Number of narratives in study	% narratives about infection due to MTCT	% narratives about prevention due to PMTCT
1997	6	83	0
2005	29	48	14
2014	12	67	0

Similarly to the 47 narratives, there were more narratives about MTCT than about PMTCT within the larger five-country study (see Table 6).

Table 6. % narratives in larger five-country study about MTCT and PMTCT by year (*n*=1,983)

Year	Total number of narratives in larger five-country study	% narratives about infection due to MTCT	% narratives about prevention due to PMTCT
1997	135	7	0
2000	154	6	0
2002	228	3	0
2005	502	5	1
2008	351	6	2
2011	69	7	0
2013	177	7	2
2014	367	6	0

Story categories

MTCT/PMTCT is the central theme in the 47 narratives. However, MTCT/PMTCT within the narratives is presented in combination with other themes. Co-occurring themes present in these narratives include: partner infidelity (primarily a male partner), multiple sexual partners, and a family member's or friend's support for an HIV-positive individual. Across the three time points, several narratives represent the impact of HIV/AIDS on a family, such as how a male partner's infidelity leads to his and his family's infection or a widow marrying her husband's younger brother leads to the infection and death of other family members. The impact of HIV/AIDS is not limited to infection, but also about the tragedy of losing family members, like an HIV-positive orphan who loses both parents to HIV or a HIV-negative girl experiencing the death of her parents and siblings due to HIV. The narratives also represent the consequence (which is often HIV infection) of not listening to advice, whether it is advice from family, friend or doctor.

Most of the narratives (~80%) result in MTCT. Common themes among narratives resulting in MTCT include multiple sexual partners, partner infidelity, impact of HIV infection on family, children orphaned due to parents' HIV infection, testing, and travel or migration. Additionally, three of these narratives resulting in MTCT involve rape and five end with characters becoming involved in HIV/AIDS advocacy. The remaining narratives result in PMTCT and one narrative ends with a mother immediately starting treatment for PMTCT after she tests HIV-positive (2005, SN, 10-14, F). Testing is a theme present in all of these PMTCT narratives. Other common themes include support for an HIV-positive individual and counseling by a healthcare worker. One narrative involves rape.

Longitudinal

Understanding of MTCT and PMTCT

Across the years, the narratives depict different understandings of MTCT and PMTCT. The 1997 narratives only represent MTCT during pregnancy, whereas 2005 and 2014 narratives represent MTCT through other routes in addition to pregnancy and the possibility of PMTCT. The 1997 narratives that describe how MTCT can occur only address HIV being transmitted during pregnancy. This is understandable given that, according to a 1999 UNAIDS document, most PMTCT strategies at the time were focused on "[protecting] women of childbearing age from becoming infected with HIV in the first place" and in providing "family planning services, and pregnancy termination where this is legal, to enable women to avoid unwanted births" (UNAIDS, 1999, p. 6). Although early reports documenting the possibility of breastfeeding as an HIV transmission route date back to 1985 (WHO, UNAIDS, UNICEF, & UNFPA, 2007). Taverne notes in his study in Burkina Faso that in 1998 there was no health communication

messaging regarding breastfeeding as a route of MTCT (1999). One of these narratives provides a detailed biomedical description of how transmission occurs in the mother's womb by stating the child was infected through blood while in the amniotic sac (1997, SN, 15-19, M).

Narratives from 2005 address MTCT during pregnancy and childbirth, and through breastfeeding. For instance, in a Nigerian narrative, a couple is told by the pregnant woman's sister that they need "to take good care of their baby" when giving birth by having a C-section and that the mother should not breastfeed (2005, NG, 15-19, F). This author's inclusion of a C-section is interesting to note given that according to the 2004 WHO recommendations; "elective caesarean section is rarely carried out" in Africa (p. 7). Two Kenyan narratives discuss MTCT and PMTCT in relation to childbirth in medical facilities. A mother is described as deciding not to give birth with the assistance of a doctor and consequently the child is infected during birth (2005, KY, 20-24, M).

Among the 2014 narratives, the stories acknowledge that MTCT can occur during pregnancy and childbirth, and through breastfeeding. In a Kenyan narrative, a child is described as having "escaped the disease" because she was born before her parents were infected; her two younger siblings were born when the parents were infected so the virus was "passed to them through birth" (2014, KY, 15-19, F). A Nigerian narrative in 2014 presents the possibility of having a HIV-negative child because the mother had a C-section (2014, NG, 15-19, F). In a Kenyan narrative, MTCT is represented as occurring during childbirth and within the context of a mother's misconception about MTCT; the author describes the mother's misconception as "ignorance of the highest order" (2014, KY, 15-19, M). The husband insists that his wife needs to give birth at a hospital, but the wife thinks: "My child is in my stomach, I got HIV through sex, and so why must I go to hospital just to deliver, my child is not a ghost to have sex in my

stomach and with a ghost in my stomach for it to get HIV" (2014, KY, 15-19, M). The mother gives birth at home and consequently infects her baby during childbirth (2014, KY, 15-19, M). A Nigerian narrative describes a baby who was born HIV-negative, but becomes infected the moment a drop of blood from his HIV-positive mother's hand goes into his mouth (2014, NG, 15-19, F). The narratives also depict the possibility of PMTCT through biomedical drugs, receiving medical care, and not breastfeeding.

Biomedical drug terminology

The narratives utilize a variety of terms to refer to biomedical drugs used in relation to PMTCT. There is not a discernable longitudinal evolution in the terms used in the narratives; except for 1997 narratives using the broad term "treatment" ("traitement"), and 2005 and 2014 narratives utilizing the terms ARV and ART. The 1997 narratives do not reference any biomedical drugs for PMTCT; although ARV use for PMTCT was first introduced in 1994, the first WHO recommendations regarding this were not released until 2000 (WHO, 2004; WHO, 2010a). Of the ten 2005 narratives that reference biomedical drugs, nine are Francophone narratives and six are from Senegal. These Senegalese and Burkinabè narratives use the terminology treatments ("traitements"), medication ("médicaments") and anti-retroviral ("antiretroviro," "anti-rétroviraux," and "traitements antiretroviraux"). For instance, in a narrative where the mother is being counseled by a doctor, the doctors tells her she will prescribe her "des traitements" (*treatments*) for PMTCT (2005, SN, 10-14, F). In another narrative, a doctor explains to the pregnant woman that there are "des traitements" (*treatments*) for pregnant women that usually work to protect their children. The doctor further explains there is a chance the child will not be HIV-positive if the "traitement" (*treatment*) is started early (2005, SN, 20-

24, M). The two Senegalese narratives that use the terminology "anti-retroviral" also use the terminology "medication." The unborn child of an HIV-positive mother explains that his/her mother is taking "des anti-rétroviraux" (*anti-retroviral)* to protect her child. The narrator further says that his/her mother is taking "des medicaments" (*medications*) so that he/she can be healthy at birth (2005, SN, 10-14, M). One of the Burkinabè narratives associates antiretroviral with modern medicine. The narrator explains that if the husband had disclosed his status to his wife then the couple could have lived a long life with HIV-negative children because of "la médecine qui est développé" (*modern medicine*) and they would have taken "antrétroviraux" at precise hours as instructed by a doctor (2005, BF, 15-19, F). The one Anglophone narrative in 2005 that makes reference to biomedical drugs is from Kenya. In this story, the husband was taken to the hospital because he fell ill and is diagnosed with HIV. The doctor tells the pregnant wife she needs "special treatment" for PMTCT (2005, KY, 15-19, M). The narratives seem to use the various terms interchangeably to describe ARVs used for the purpose of prophylaxis or as part of a mother's treatment.

Four narratives from 2014 reference biomedical drugs. The Kenyan narrative utilizes "ARV's," the Nigerian narratives utilize "antiretroviral therapy (ART)" and "medication," and the Senegalese narrative utilizes "les traitments" (*treatments*). In the Nigerian narrative using the term "medication," the author seems to make a distinction between biomedical drugs specifically for the mother and those for PMTCT. It is described that a mother "herself didn't take any medication to treat herself, she took some medications while she was pregnant each time…" (2014, NG, 15-19, F). In the Senegalese narrative, the doctor advises a couple they should follow the treatments to live a long life and to save their future children (2014, SN, 10-14, M). The woman is not currently pregnant, but this seems to suggest she will be on ART.

Biomedical drugs and biomedicine for PMTCT

Both male and female-authored narratives make references to biomedical drugs used for PMTCT. Urban and rural authors and all age groups are represented among these. Within the 1997 narratives, there are references to the fact that HIV/AIDS cannot be cured. Many of the 2005 and 2014 narratives including a discussion of medication or treatment depict conversations between a pregnant woman and a doctor or between a couple and a doctor. Though different terminology is used to reference biomedical drugs, similar explanations are given by the doctors of why a mother should take or adhere to the medication or treatment. Doctors in the narratives say the biomedical drugs protect the child from infection, that it is for PMTCT, it protects the mother and child (perhaps a reference to ART), or it prevents infection during birth.

Three narratives mention how often a woman should take biomedical drugs for PMTCT; however, the narratives do not specify an exact timeline. WHO 2004 recommendations state that a mother "may receive ARV drugs during pregnancy as part of potent combination regimens used to treat their HIV infection or as prophylaxis to prevent HIV infection in infants" (p. 1). Revised WHO 2010 recommendations state that a mother can take lifelong ART to treat her HIV and it will reduce MTCT, or a mother not needing lifelong ART can take ARV prophylaxis for PMTCT during pregnancy, childbirth and breastfeeding period (WHO, 2010a). A 2005 Senegalese narrative has a scene in which the doctor tells the pregnant woman that she will be given ARVs to take "*regularly*" ("régulièrement") to protect her and her child, but specifically how often is unclear (2005, SN, 20-24, F). A Burkinabè narrative from the same year describes that, among other means, the couple could have prevented MTCT had they taken ARVs at precise hours ("…à des heures précises…"), but it is not described how often or for long the ARVs should be taken (2005, BF, 15-19, F). In a 2014 Kenya narrative, a mother is described as

giving birth to a HIV-negative child because she took ARVs every day (2014, KY, 10-14, F). Within these narratives, a clear distinction is not made between whether the biomedical drugs are being used specifically as prophylaxis or as part of lifelong ART.

Two Senegalese narratives from 2005 comment on the efficacy of biomedical drugs in being able to prevent MTCT. In a story narrated by an unborn child, the HIV-positive mother is described as taking ARVs to protect her child. The unborn child questions the efficacy of the ARVs and whether it will guarantee that he/she is born without HIV. The unborn child concludes that "*only God can protect against this [HIV] disease*" ("le seul protecteur contre cette maladie est Dieu"), states "*there is not yet a cure*" ("il n y a pas encore de remède") for HIV, and that he/she would rather not be born (2005, SN, 10-14, M). In another narrative, a doctor explains to a pregnant woman that there are treatments ("des traitements") for HIV-positive pregnant women to take to protect their babies and that the treatment is effective in most cases ("…dans la plupart des cas cela reussit") (2005, SN, 20-24, M).

A few narratives also discuss PMTCT measures that are not related to biomedical drugs. Three narratives from 2005 reference PMTCT in relation to receiving medical care. A Kenyan story is narrated by a child born to a HIV-positive mother who was raped. The child says he was born HIV-negative because his mother gave birth at a medical facility: "Health demanded that I be born in a hospital or face the grave consiquences. Hence I came to be a healthy baby boy without the infection of the H.I.V. my mother was harbouring after she had been raped…" (2005, KY, 20-24, M). In a Burkinabè narrative, a doctor explains to family members that the HIV-positive mother was able to give birth to a HIV-negative child because she received medical care throughout her pregnancy (2005, BF, 20-24, M).

Breastfeeding

Of the 47 narratives, only six reference breastfeeding or replacement feeding. The authors of these narratives include two males and four females, three authors are in the 15-19 age group and three are in the 20-24 age group. One narrative is from 1997, three are from 2005, and two are from 2014. Four of the narratives are written by rural authors and Kenya is the only country that does not have any narratives with reference to breastfeeding or replacement feeding.

Regardless of year or country, all six of the narratives indicate that a mother should not breastfeed the child. This is understandable for the 1997 and 2005 narratives given that WHO recommendations during that time encouraged replacement feeding (UNAIDS, 1999; WHO, 2004; WHO, 2010a). In 2010 WHO began encouraging exclusive breastfeeding even if ARVs were not available for the mother (WHO & UNICEF, 2016); yet, narratives from 2014 also portray that a child should not be breastfed.

A 2005 narrative from Swaziland mentions a specific replacement feeding called "Nun artificial milk" (2005, SW, 15-19, F). A narrative from 1997 and a narrative from 2005 describe bottle feeding (1997, SN, 20-24, M; 2005, BF, 20-24, M). The 1997 narrative describes bottle-feeding a child as a means to increase a child's chances of being saved ("sauver") from HIV (1997, SN, 20-24, M). The 2005 narrative relays that a child should be bottle-fed until he or she becomes older (2005, BF, 20-24, M). The authors of the 1997 and 2005 narratives do not depict any stigma associated with bottle-feeding. In contrast, stigma associated with not breastfeeding a child is a prominent theme in a 2014 Nigerian narrative. A mother is counseled by a doctor not to breastfeed her baby who was born HIV-negative as a result of a C-section (2014, NG, 15-19, F). The mother expresses that it will not be possible for her to not breastfeed her child because her "husband would suspect something" (2014, NG, 15-19, F). The husband is indeed suspicious

when he notices the child is not being breastfed: “For the last one month, Daniel noticed that gabriella wasn’t breast-feeding his child and from what he learnt while he was in school the mothers breast milk was the first stage to build up the child’s brain” (2014, NG, 15-19, F). The mother attempts to avoid giving a direct answer by saying their child is strong so she is giving him “natural food before” breastmilk and that she knows “what’s best” for their child, but the husband is not convinced by these explanations (2014, NG, 15-19, F). The husband’s suspicions eventually turn into a violent dispute between the couple (2014, NG, 15-19, F).

Mothers in the narratives are portrayed as receiving advice about not breastfeeding from both doctors and family members. In a 1997 narrative from Senegal, the doctor tells the pregnant woman that the child must be bottle-fed to increase the chances of PMTCT (1997, SN, 20-24, M). In a 2005 narrative from Swaziland, a mother recently tested HIV-positive and decides to seek counseling from a doctor because she does not want to transmit HIV to her baby (2005, SW, 15-19, F). The doctor lauds her for knowing her status particularly because she has an infant of breastfeeding age and asks the mother if she has been breastfeeding. The mother has been giving her baby replacement feeding. When family members give advice, mothers are explicitly told not to breastfeed. For instance, in a 2005 Nigerian narrative, the mother is told by her sister that in order “to take good care of” the baby she “should not brest feed the baby” (2005, NG, 15-19, F). Within the narratives, the action of not breastfeeding is portrayed as a means to increase a child’s chances of survival, as a way of taking “good care of” a child, and as an appropriate PMTCT method.

Barriers to PMTCT

Stigma

Three narratives from 2005 and 2014 represent stigma and fear of stigmatization as barriers to PMTCT. A 2005 Kenyan narrative depicts a couple that did not seek assistance because of pride. The husband was unfaithful and had sexual relations with a commercial sex worker. He contracted HIV and later infected his wife who became pregnant. The child was born HIV-positive because the couple "feared getting help because of their pride maintenance in the society…" (2005, KY, 15-19, R). The author recounts that the couple "opted to suffer in silence" and the child later died (2005, KY, 15-19, R).

Within the narratives, stigma is also represented graphically as mistreatment towards or lack of support for a HIV-positive mother and her HIV-positive child. The 1997 narratives do not portray this possibly due to the 1997 narratives not depicting the possibility of PMTCT other than in one story where a couple is told to bottle-feed their child to increase the child's chances of survival (1997, SN, 20-24, M). A Nigerian narrative describes a HIV-positive mother who gives birth to a HIV-positive child due to stigmatization by hospital workers. The hospital staff treats the mother "like a leper" by putting her in an unused room to give birth by herself. They only give her birth "instructions and materials through the window" (2005, NG 15-19, U). Not only is the child born HIV-positive, the child dies soon after birth.

Not knowing HIV status

Not being tested for HIV or not knowing one's HIV status is a barrier to PMTCT in four narratives from 2005. Three of the narratives were written by male authors and one by a female author, and three were written by rural authors. The authors do not solely focus on the HIV-

positive mother, but also describe how couples or husbands not being tested or not knowing their HIV status affects PMTCT. In a 2005 Swazi story, a wife knows her husband has had previous sexual partners so she suggests they get tested for HIV but he refuses. The wife gives birth, but the child becomes sick after 6 months. The wife later gives birth to a second child, but this time both she and the child become sick. The wife and two children are taken to the hospital, test HIV positive, and all three die a few months later (2005, SW, 15-19, F). The HIV-negative child narrating a 2005 Kenyan story says his younger sister could have been born HIV-negative if the nurses during his birth had told his mother she was HIV-positive, suggesting, that had the mother known she was HIV-positive she could have managed to prevent MTCT for her second child (2005, KY, 20-24, M).

Other barriers

The narratives also depict other barriers to PMTCT. Two Kenyan narratives, one from 2005 and one from 2014, depict birthing location as a barrier to PMTCT. In the 2005 narrative, the HIV-positive mother's first child was born in a hospital so was HIV-negative at birth. However, she did not give birth to her second child in a hospital and so the child was born HIV-positive (2005, KY, 20-24, M). In the 2014 narrative, birthing location is related to a mother's lack of knowledge about HIV/AIDS and MTCT/PMTCT. A mother tests HIV-positive during an antenatal visit at a clinic. However, she decides to have a home delivery "despite all she was told in the hospital" and the child is infected during child birth (2014, KY, 15-19, M).

A 1997 Senegalese narrative portrays lack of money as a barrier. A wife tells her husband that the doctor said they must bottle-feed the baby to increase the child's chances of survival. The husband remarks that a bottle is expensive (1997, SN, 10-14, F).

Disclosure

A woman's disclosure of her HIV status can affect her decision to seek PMTCT services or to uptake or adhere to PMTCT medication (Bwirire et al., 2008; Chinkonde et al., 2009; Gourlay et al., 2013; Tam et al., 2015). The decision to disclose HIV status is also related to the possibility of stigma and mistreatment. Within the narratives, both male and female authors write about HIV status disclosure in relation to MTCT/PMTCT. Most authors are either from the 15-19 or 20-24 age groups. Several disclosure situations are portrayed in the stories; including a mother choosing to disclose her status or decisions not to disclose HIV status. Disclosure of HIV status in the narratives is presented both as a barrier and facilitator to accessing PMTCT services, and is sometimes presented as not having an influence on PMTCT.

Four Francophone narratives, from each of the three time periods, depict ways in which a HIV-positive mother discloses her status to her male partner or husband. In three of the narratives, the HIV-positive mother discloses her status after a positive test result. For instance, a mother in a 1997 Senegalese narrative is pregnant and is told by the doctor she is HIV-positive. She then discloses to her husband that she is both pregnant and HIV-positive. The husband says she should have an abortion, but the wife says the doctor explained there is a possibility the child will be born HIV-negative and to bottle-feed the baby. The child is born HIV-negative (1997, SN, 20-24, M). A mother in a 2005 Senegalese narrative first tells her husband she heard that everyone should get tested, particularly pregnant women. The husband supports her decision to get tested. Upon her return from testing, the wife discloses to her husband she is HIV-positive and that they must follow the doctor's advice. The husband tells her he tested HIV-positive a while back ago, but did not know how to tell her. The narrative ends with the husband telling his wife they will go to see the doctor the next day about this (2005, SN, 20-24, F). In the 2014

Senegalese narrative, the HIV-positive mother finds out from a friend that her previous partner, Victor, has died of AIDS. She tells this to her husband and then discloses by answering affirmatively to her husband's question of whether she had unprotected sex with Victor. The married couple and children then all test HIV-positive. The couple receive counseling from the doctor about following "treatments" within the context of lifelong ART and to "save" their future children by PMTCT (2014, SN, 10-14, M).

One narrative depicts a combination of the HIV-positive mother disclosing her status to a family member and others then gossiping about her status. In this 2014 Nigerian narrative, the HIV-positive mother tells her sister-in-law she is an "a HIV carrier." When the mother starts showing "signs of AIDS," rumors start to spread around the town. As others start to find out about her status, she is described as "dwelling on her antiretroviral therapy (ART) as adviced by the doctor" (which seems to be related to ART in the context of lifelong ART), but takes PMTCT measures (e.g., not breastfeeding her children) and the children are HIV-negative (2014, NG, 20-24, F).

A 2005 Kenyan narrative describes a character actively choosing not to disclose HIV status. A couple's baby becomes sick at the age of 2 and later dies. The mother chooses not to disclose "the mystery behind the child's death" (2005, KY, 15-19, M).

Lastly, one narrative describes disclosure and confidentiality within the healthcare setting. In a 2005 Senegalese narrative, an engaged couple goes to the doctor for Ariane's test results; she received a pregnancy test and blood test. Ariane gives the doctor permission to disclose her status with her fiancé in the room. Ariane is diagnosed HIV-positive; Malik leaves the room and later decides to leave the relationship. Despite the disclosure of her status resulting in being left by Malik, she gives birth to a HIV-negative baby (2005, SN, 10-14, F).

Blame

The literature demonstrates that a woman's decision to disclose her status is also related to the possibility of a HIV-positive status resulting in blame (Chinkonde et al., 2009; Gourlay et al., 2013). Blame is not represented as a barrier to PMTCT within the narratives, but many narratives present instances of blame; for example, who is blamed for a mother's HIV/AIDS, who is being blamed for MTCT, and who is doing the blaming. Among the narratives, ten female authors and seven male authors discussed blame. Consistent with the literature, four narratives across the three time periods depict the HIV-positive mother or wife being blamed for her own HIV-infection and MTCT (Bwirire et al., 2008; Tam et al., 2015). At the end of a 1997 Senegalese narrative, the narrator blames the mother (Maimouna) for her infection, MTCT and eventual deaths of her and the child. Maimouna's friend told her to be careful around boys, but Maimouna does not believe AIDS exists. Maimouna becomes pregnant and finds out she is HIV-positive so her child is at risk for infection. The child dies three months after birth and Maimouna dies eight years later. The narrator concludes this all happened because Maimouna was hard headed and a dreamer (1997, SN 10-14, F). A 2005 Burkinabè narrative depicts a husband rejecting his wife and telling her to leave the household when she discloses her HIV-positive status. The husband thinks AIDS only infects husbands or wives who are unfaithful. Interestingly, this is one of the few narratives where there is an instance of forgiveness for blame; the husband asks for forgiveness from his wife once he learns that HIV/AIDS can affect anyone (2005, BF, 15-19, F). A 2014 Swazi text also depicts a husband blaming his wife for her infection and accusing her of being unfaithful despite the wife having been raped (2014, SW, 15-19, M).

Three narratives from 2005 and 2014 depict self-blame; that is, the HIV-positive mother blames herself. A HIV-positive mother in a 2005 Senegalese narrative expresses regret for her past actions or the "road" she took; she quit school and became involved in commercial sex work. She states she is responsible for her own death and her baby's death (2005, SN, 20-24, F). A 2005 Nigerian narrative portrays a mother (Ngozi) who wanted to abstain until marriage, but her partner insists on having sexual intercourse. The couple have sexual intercourse once, which results in the Ngozi becoming pregnant and she tests HIV-positive during an antenatal visit. Ngozi states, "I have sold my virginity for HIV & my innocent baby for HIV" (2005, NG, 20-24, F). A 2014 Kenyan narrative depicts a couple and their children affected by HIV. The husband became sick and died, and the wife became sick and tests HIV-positive. Shirley, the youngest child, also becomes sick. The wife blames herself for Shirley's condition because she knows she transmitted HIV to Shirley. The doctors later confirm that Shirley was infected during pregnancy (it is important to note that it is impossible to confirm the MTCT occurred during pregnancy as opposed to during childbirth or during breastfeeding) (2014, KY, 15-19, F).

The narratives also portray other individuals being blamed for a mother and child's HIV infection. Male partners/husbands are blamed by female partners/wives in three narratives, each from a different time point. The wife in a 1997 Senegalese narrative blames her HIV-positive husband for not listening to her and for having multiple sexual partners. She states that she is left with the consequences, yet she is the one who always stayed home (1997, SN, 15-19, F). The narrator of a 2005 Burkinabè narrative blames the husband for not telling his wife he tested HIV-positive when the couple went in for testing together. They had HIV-positive children. The narrator states the husband was "irresponsible" and did not think about their children (2005, BF,

15-19, F). A husband in a 2014 Kenyan narrative blames himself for his child dying of HIV/AIDS (2014, KY, 15-19, M).

Couples or parents are often blamed by the narrator for MTCT in 2005 and 2014 narratives. A 2005 Nigerian narrative portrays an unfaithful husband who has been in the U.S. for a few years. The husband infects his wife when he returns home. The couple tests positive and the wife finds out she is pregnant. The narrator blames the wife and husband by stating that they have "[already] made the mistake" and must now "take good care of their baby" (2005, NG, 15-19, F). The parents in a 2005 Kenyan narrative are blamed by their son for his sister's infection, for "spreading" the virus, and for "[l]eaving more orphans and more victims" of HIV (2005, KY, 20-24, M). A 2014 Swazi narrative portrays a couple blaming themselves for not getting tested for HIV before marriage. After their child's birth, the baby and mother became sick and later the couple had a second child who dies. They believe not having been tested was a mistake and reason for their child's death.

Parents or in-laws of the HIV-positive mother are also blamed in two 2005 narratives. For instance, a Burkinabè narrative portrays an unfaithful husband who blames his wife for his HIV-positive status. After the husband's death, the wife remarries her husband's younger brother. She gives birth to twins who do not survive. The wife blames her parents-in-law for the "disappearances" (deaths) of her husband and children (2005, BF, 15-19, M).

Facilitators

Though the narratives predominately portray MTCT, 16 narratives depict facilitators to PMTCT. Of these 16 narratives, 10 were written by male authors and 10 were written by urban authors. The most common facilitator presented across the three years was support from either

friends or family members. Friends and family members provide moral and monetary support, and support for the HIV infected mother to access health care for PMTCT. Only one 1997 narrative portrays any facilitator for PMTCT; in this Senegalese narrative, friend support is the only facilitator depicted. A couple recently finds out the wife is pregnant and are advised by a doctor to feed the baby with a bottle for PMTCT. The husband shares this information with a friend and states this will be hard. However, the friend provides monetary support by telling the husband they will pool their money because it will require money to bottle-feed (1997, SN, 20-24, M). This narrative illustrates the complexities discussed in early UNAIDS documents about recommending replacement feeding; policy-makers are told to consider whether replacement feeding is accessible and feasible within their country's context (UNAIDS, 1999). In the 2005 narratives, family support is typically from parents. In a Burkinabè narrative, a HIV-positive pregnant woman returns to her parents' home after her husband kicks her out of the household when she discloses her status. After the woman has a discussion with her parents, her parents are described as understanding and compassionate towards her. The mother assists her daughter in accessing health care for both herself and the unborn child. Her mother accompanies her to a health center to learn about AIDS and it is the mother who asks the doctor how MTCT can be prevented (2005, BF, 15-19, F). In a 2014 Kenyan narrative, a grandmother is described as providing moral support to her grand-daughter. Shiko was raped and is taken to the hospital by a "good Samaritan" (2014, KY, 10-14, F). At the hospital Shiko finds out she is both HIV-positive and pregnant. Shiko's grandmother comes to "stay with her until she recovered" and advises her "in all means" up until childbirth (2014, KY, 10-14, F). Shiko is able to take ARVs and her baby is born HIV-negative.

Testing and pregnant women knowing their HIV status are portrayed as common facilitators for PMTCT in the 2005 narratives, particularly in the Senegalese narratives. For instance, one narrative describes a pregnant woman as being tested during her third month of pregnancy. She is described as having taken ARVs to protect her child since the day she tested positive (2005, SN, 10-14, M). In another Senegalese narrative, a brother explains to his sister the importance of pregnant women getting tested for HIV. He explains that if a woman tests positive then she will be medically cared for until the child is not infected (2005, SN, 20-24, F).

Accessing and receiving proper medical care is another PMTCT facilitator. These facilitators are primarily portrayed in the 2005 narratives and in one 2014 narrative. In a 2005 Burkinabè narrative, family members of a woman who recently gave birth wonders how the child was born HIV-negative given that the mother is HIV-positive. The doctor explains to the family members that the child was born HIV-negative because the mother was taken care of and received medical care during her pregnancy (2005, BF, 20-24, M). A Nigerian narrative echoes a similar concept when describing that a mother had a HIV-negative child because she gave birth in a "well equiped hospital for HIV mothers" (2005, NG, 15-19, M).

Receiving counseling about HIV/AIDS from health professionals is depicted as a facilitator for PMTCT. This is consistent with the literature stating that lack of health education about HIV transmission and medication contributes to poor adherence of PMTCT measures (Gourlay et al., 2013; Mepham et al., 2011; Peltzer et al., 2010). In a 2014 Senegalese narrative a couple and their two children test HIV-positive. The doctor counsels them about treatment and preventing their future children from becoming infected. The couple previously thought HIV/AIDS was a death sentence. After counseling they understand there are other means and can still have HIV-negative children.

A mother's fear of transmitting HIV to her child is a facilitator to PMTCT in two narratives. A 2005 Swazi narrative describes a mother who recently tested HIV-positive and has a HIV-negative child. She seeks counseling from a doctor about how to nurse her child because she does not want to infect her child. She explains to the doctor she has been giving her child replacement feeding and wants to know how to take care of herself and her baby (2005, SW, 15-19, F). A 2014 Nigeria narrative describes a HIV-positive mother as "dwelling" on taking her ART, but she had a "fear of transmitting the disease to" her child so she "took appropriate medical care to prevent" MTCT and did not breastfeed (2014, NG, 20-24, F).

Positive Deviants

About 20% of the narratives in the study end in PMTCT and one ends with starting treatment for PMTCT. None of the positive deviant narratives are from 1997 (when PMTCT is not represented); most are from 2005 and two are from 2014. The narratives were written by five female authors, four male authors, five urban authors, and four rural authors. Most authors were either from the 15-19 or 20-24 age groups. Most of the 2005 positive deviants are Francophone narratives – three from Senegal and two from Burkina Faso. There is one 2005 narrative from Swaziland and one from Kenya. The 2014 narratives are from Kenya and Nigeria. Kenya is the only country with positive deviant narratives in both 2005 and 2014.

The positive deviant narratives present different scenarios, yet result in PMTCT. Scenarios include, for instance, husband infidelity, not getting HIV testing before marriage, rape, and disobeying parental advice. The narratives depict the possibility of accessing PMTCT despite the mother's situation or regardless of how a mother becomes HIV-positive.

Within the narratives, all of the mothers receive HIV-testing though testing occurs at different time periods. There are mothers who are tested when they test positive for a pregnancy, mothers who go back for testing after finding out they are pregnant, or mothers who are tested after receiving advice from others. A 2005 Burkinabè narrative explains that a mother did not heed her parents' advice and had multiple sexual partners. She was taken to the hospital when she became sick, and tested positive for a pregnancy and HIV. She felt hopeless because of her situation but her parents provided her moral support; she adhered to the ARV up through childbirth and bottle-fed her baby (2005, BF, 20-24, M). A 2005 Senegalese narrative describes a mother getting HIV tested later in her pregnancy during the sixth month. After the diagnosis, with the support of their parents, the mother and her husband "*fight the disease*" ("combattre la maladie") and the child is born HIV-negative (2005, SN, 20-24, M). Another 2005 Senegalese narrative describes a husband who recently tested HIV-positive and is advised by the doctor to have his pregnant wife get tested. With the help of a psychologist, the husband is able to convince the wife to get tested. Once the wife is diagnosed HIV-positive, the hospital begins the procedure for treatment ("la procedure de traitement") for PMTCT (2005, SN, 20-24, M).

The majority of the narratives portray mothers accessing PMTCT measures during pregnancy. However, one 2005 Swazi narrative describes the possibility of PMTCT even after pregnancy. A mother recently tested HIV-positive and her child HIV-negative. She takes initiative in seeking counseling from a doctor about how to take care of herself and her child, and how to nurse her child given that she is HIV-positive (2005, SW, 15-19, F).

A few of the positive deviant narratives depict mothers' resilience in accessing support and PMTCT measures. For instance, in a 2005 Burkinabè narrative, a wife tests HIV-positive during an antenatal visit, but she is afraid of her husband's reaction if she discloses her status.

She discloses her status to him, but he accuses her of infidelity and kicks her out of the household. The wife speaks to her parents about her status and the incident with her husband; they support her. Accompanied by her mother, the wife seeks counseling at a health center for PMTCT (2005, BF, 15-19, F). In a 2005 Senegalese narrative, Ariane finds out she is pregnant and is later accompanied by Malik to get her HIV-test results. Malik abandons Ariane when it is disclosed that she is HIV-positive. Ariane is devastated, but takes treatments ("des traitements") for PMTCT and gives birth to a HIV-negative child despite being left by Malik (2005, SN, 10-14, F).

DISCUSSION

This study looks longitudinally at social representations of MTCT/PMTCT and existing barriers in 47 narratives written by youth 10-24 years of age from Burkina Faso, Kenya, South-East Nigeria, Senegal, and Swaziland in 1997, 2005, and 2014 in the context of evolving PMTCT recommendations. The majority (~80%) of the narratives in the study result in MTCT. The 47 narratives share similar co-occurring themes, such as, partner infidelity (often a male partner), multiple sexual partners, and a family member's or friend's support for an HIV-positive individual. The narratives ending in PMTCT (~20%) present different scenarios (e.g., disobeying parental advice, rape), yet all include a mother receiving HIV-testing and accessing PMTCT.

The narratives present barriers to PMTCT including: stigma in the form of mistreatment and lack of support, not knowing one's HIV status, not accessing appropriate medical care during childbirth, lack of monetary means, and disclosure of HIV status. The narratives also describe facilitators to PMTCT including: support (e.g., moral, monetary) from family members and friends, HIV testing, pregnant woman knowing her HIV status, accessing and receiving proper medical care, receiving counseling about HIV/AIDS from health professionals, and mothers' fear of MTCT. There are also differences between PMTCT methods as presented in the narratives and the formal PMTCT recommendations of WHO and other international organizations during that time. For instance, only six of the 47 narratives reference breastfeeding or replacement feeding in relation to PMTCT. The six narratives are from different time periods, yet all six communicate that a HIV-positive mother should not breastfed her child. It is understandable for the 1997 and 2005 narratives to communicate not breastfeeding given that in 2010 WHO began to encourage exclusive breastfeeding even if ARVs were not available for the mother or child and to discourage sudden weaning (WHO & UNICEF, 2016).

International organizations like the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) and UNAIDS are working towards the elimination of pediatric AIDS and new HIV infections among children (EGPAF, 2017; UNAIDS, n.d.b). EGPAF currently works in 19 countries (15 of which are in sub-Saharan Africa) to "[expand] prevention of mother-to-child transmission of HIV (PMTCT) programs in countries hardest hit by the epidemic" (EGPAF, 2017, p. 1). EGPAF focuses on advocacy for "expand[ing] country-wide access to" PMTCT services, program implementation of "high-quality, evidence-based PMTCT services," working with communities to "[address] harmful social norms that prevent women from accessing health services," and PMTCT research (EGPAF, n.d.). UNAIDS and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) along with other partners are collaborating to work on "a super-fast-track framework for ending AIDS in children, adolescents and young women by 2020" called Start Free, Stay Free, AIDS Free (UNAIDS, n.d.b). To address PMTCT, the framework states that new HIV infections among women must be prevented, HIV-positive women need to be on lifelong ART, and breastfeeding mothers should receive health care during the breastfeeding period (UNAIDS, n.d.b). A recent UNAIDS document about the life-cycle approach to addressing HIV/AIDS identified the following as areas for "[c]losing the gaps" in relation to PMTCT: possibility of oral pre-exposure prophylaxis (PrEP) as a PMTCT option for pregnant and breastfeeding women; the need for a "simpler and cheaper diagnostic" tool for infant HIV testing (infants are not tested utilizing the antibody HIV test given that maternal HIV antibodies can be present in an infant's system for up to 18 months so an infant must undergo a virological test requiring laboratory technology); testing infants at birth and a few weeks after birth; ensuring "retention of mothers living with HIV and their babies" at heath facilities; and the

possibility of utilizing short message services (SMS) on mobile phones to remind mothers about postnatal appointments (UNAIDS, 2016d, p. 24-25; UNAIDS, 2016a).

The UNAIDS publication on the life-cycle approach to addressing HIV/AIDS states that the "progress made in reducing mother-to-child transmission of HIV is one of the remarkable success stories in global health" (UNAIDS, 2016d, p. 3). However, there were 150,000 new HIV infections among children in 2015 (UNAIDS, 2016c). EGPAF, UNAIDS and PEPFAR programs and goals to end MTCT and pediatric AIDS seem to be particularly focused on improving access to various PMTCT services. The findings from this study demonstrate it is not only about availability of PMTCT services like testing or biomedical drug provision, but also about how the social and situational context informs mothers' abilities to access PMTCT services. There is a need to prioritize social contextual issues around access to PMTCT services. As identified longitudinally in the narratives, if mothers/women face repercussions for HIV status disclosure, are blamed for HIV infections and MTCT, and do not receive family or friend support due to a HIV-positive status, then one cannot assure that a mother/woman will actively seek, access, and adhere to PMTCT methods. In the narratives, other individuals are also blamed for a mother/woman's and a child's HIV-positive status. Though mothers/women certainly need to have access to PMTCT services, family member, friends, and community members also need to be informed about PMTCT and how they can play a role in PMTCT. This highlights a need for continued and improved communication about PMTCT, especially given that PMTCT recommendations have changed over time (e.g., breastfeeding vs. not breastfeeding). Future research should consider how to improve PMTCT health communication for mothers and the wider community; and, should also consider how to improve and better inform health care workers, particularly those in rural locations, about PMTCT when recommendations change.

CONCLUSION

MTCT can occur during pregnancy, at childbirth, or through breastfeeding. Among the estimated 2.1 million people newly infected with HIV in 2015, 150,000 were in children (UNAIDS, 2016c). Most of these child infections were a result of MTCT and primarily occurred in sub-Saharan Africa (UNAIDS, 2016c). However, PMTCT methods do exist. Recommendations regarding breastfeeding and biomedical drugs (ARV prophylaxis and ART) have been the focus of PMTCT strategies since 1999 (UNAIDS, 1999). An estimated 1.6 million new child infections have been prevented since 1995 by providing pregnant women with ARV medications (UNAIDS, 2016b). However, information about MTCT and recommendations regarding PMTCT have been changing over time. ARV medication for PMTCT was first introduced in 1994 (WHO, 2001b) and WHO first released recommendations on ARV use in 2000 (WHO, 2004; WHO, 2010a). The recommendations have been updated and revised in 2004, 2006, 2010, 2013 and 2016 (McIntyre, n.d.; WHO & UNICEF, 2016). Recommendations regarding infant feeding and HIV were introduced by WHO and the UN in 2000 (WHO et al., 2007), and have since been updated and revised by WHO in 2010 and 2016 (WHO & UNICEF, 2016).

This study looks longitudinally at social representations of MTCT/PMTCT, related recommendations, and existing barriers in 47 narratives written by youth 10-24 years of age from Burkina Faso, Kenya, Nigeria, Senegal, and Swaziland in 1997, 2005, and 2014. The narratives present PMTCT barriers including: stigma in the form of mistreatment and lack of support, not knowing one's HIV status, not accessing appropriate medical care during childbirth, lack of monetary means, and disclosure of HIV status. PMTCT facilitators in the narratives include: support (e.g., moral, monetary) from family members and friends, HIV testing, a pregnant

woman knowing her HIV status, accessing and receiving proper medical care, receiving counseling about HIV/AIDS from health professionals, and mothers' fear of MTCT. An important discrepancy between PMTCT methods present in the narratives and PMTCT recommendations at the time is breastfeeding. 2014 narratives discussing breastfeeding state the HIV positive mother should not breastfeed, yet 2010 WHO recommendations encouraged exclusive breastfeeding even if ARVs were not available for "maternal health…and prevention of HIV transmission to infants" (WHO & UNICEF, 2016, p. 4).

International organizations like EGPAF, UNAIDS and PEPFAR seek to eliminate pediatric AIDS and new HIV infections among children (EGPAF, 2017; UNAIDS, n.d.b). The programs supported by these organizations are predominantly focused on improving access to PMTCT resources and methods. However, findings from this study demonstrate it is not only about access to PMTCT services (e.g., testing, biomedical drug provision), but also how individuals access PMTCT services. In addition to ensuring mothers'/women's access to PMTCT services, family members, friends, and community members should be informed about how they can contribute to PMTCT. There is a need to prioritize addressing social contextual issues that influence access to PMTCT services. Furthermore, there is a need for continued and improved health communication about PMTCT. Future research should consider how to improve PMTCT health communication for mothers and communities, and how to improve and better inform health care workers about PMTCT when recommendations change.

PUBLIC HEALTH IMPLICATIONS & RECOMMENDATIONS

The narratives from this study present barriers and facilitators to PMTCT over three distinct time periods. Lack of monetary means is represented as a barrier to PMTCT in 1997. Stigmatization and birthing location are represented as barriers to PMTCT in 2005 and 2014, and not knowing one's HIV status is a barrier in 2005 narratives. Only one 1997 narrative portrays a facilitator to PMTCT, which is support from a friend. Testing, mother's knowledge of HIV status, and accessing and receiving proper medical care are predominately represented as facilitators in 2005 narratives. 2005 and 2014 narratives also include family or friend support, receiving HIV/AIDS counseling and a mother's fear of transmission.

Findings from this study demonstrate that being able to successfully prevent MTCT is not only about mothers/women accessing PMTCT services, but also about how social and situational contexts influence mothers' abilities to access PMTCT services. International organizations like EGPAF, UNAIDS and PEPFAR that are focused on eliminating pediatric AIDS and new HIV infections among children should not only continue to focus on improving access to PMTCT services, but should also prioritize addressing social contextual issues around PMTCT. Family members, friends, and community members need to be informed of how they can play a role in PMTCT and how to support a mother/woman in seeking, accessing and adhering to PMTCT methods. 150,000 new HIV infections were in children in 2015 (UNAIDS, 2016c). Most of these child infections were a result of MTCT and primarily occurred in sub-Saharan Africa (UNAIDS, 2016c). Future research and programs should consider how to improve PMTCT health communication for mothers and communities, and consider how to improve and better inform health care workers about PMTCT recommendations when they change. Pediatric AIDS and new

HIV infections among children cannot be eliminated if mothers/women are not supported in accessing PMTCT services.

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