HIV and infant feeding: choices and decision-outcomes in the context of prevention of mother-to-child transmission among HIV-positive mothers in Zambia

by

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Declaration

In accordance with the regulations of the University of KwaZulu-Natal, I confirm that this thesis is my own work and that all published or other sources of material consulted have been acknowledged in notes to the text or the bibliography. I can confirm that this thesis has not been submitted for any other academic award anywhere else.

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Abstract

Mother-to-child transmission of HIV is one of the key drivers of the HIV pandemic in Zambia and impacts infant feeding for HIV-exposed infants. The aim of infant feeding counselling is to facilitate informed decision on method of feeding in relation to prevention of mother-to-child transmission of HIV. However, HIV-positive mothers are faced with uncertainty on how best to feed their infants. While exclusive breastfeeding has potential to contribute to a reduction in infant and under-five mortality, the practice is not widespread in resource-poor settings of sub-Saharan Africa. The overall aim of this study was to analyse choices and decision-outcomes on infant feeding in the context of prevention of mother-to-child transmission of HIV to enhance safer feeding practices during the first six months of the infant's life.

The study was conducted using qualitative triangulation through participant observations, focus group discussions and individual interviews. The study included HIV infected mothers (n=30), health care workers (n=6), HIV infected men (n=7) and community based volunteers (n=20). The field work was conducted from January to September 2014. Data were managed in QRS NVivo 10 and analysed using framework analysis.

While recognising promotion of exclusive breastfeeding as a public health approach in Zambia, the results showed that implementation was influenced by factors beyond the health care system. The findings highlight five thematic areas that explained and gave meaning to behavioural processes that determine decision-outcome on infant feeding in relation to prevention of mother-to-child transmission. Participants described breastfeeding as a cultural norm based on practices passed from generation to generation that impacted the understanding and behaviour change to practice exclusive breastfeeding for HIV-exposed infants. Therefore, choosing to exclusively breastfeed depended on how well mothers were counselled on infant feeding and prepared to practice exclusive breastfeeding in the first six months of the baby's life. Although, health care workers reported that they supported mothers to choose and practice exclusive breastfeeding, mothers in this study lacked the necessary skills needed to successfully feed their HIV-exposed infants.

Drawing on theories of behaviour change, the findings accordingly informed the development of a model that provides nurses, midwives and other front-line health care workers with simplified steps for consideration during infant feeding counselling of HIV-positive mothers.

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Dedication

I dedicate this PhD thesis to my children

Chilobe, Malonga, Hakasumo

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List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARVs	Antiretrovirals
CSO	Central Statistical Office
EBF	Exclusive Breastfeeding
FGDs	Focus Group Discussions
HCWs	Health Care Workers
HIV	Human Immuno Virus
MNCH	Maternal Neonatal and Child Health
MoH	Ministry of Health
MTCT	Mother-to-Child Transmission
PMTCT	Prevention of Mother-to-Child Transmission
SCT	Social Cognitive Theory
SMAGs	Safe Motherhood Action Groups
TBAs	Traditional Birth Attendants
TDRC	Tropical Disease Research Centre
UNAIDS	Joint United Nations Programme for AIDS
UNFPA	United Nations Population Fund
UNICEF	United Children's Population Fund
WHO	World Health Organization
AFASS	Acceptability, Feasibility, Availability, Sustainability, Safe
ANC	Antenatal Care
cART	Combination Antiretroviral Therapy
GHE	Group Health Education
NHSP	National Health Strategic Plan

Chapter 1

Introduction

Magnitude of the HIV pandemic

The global solidarity in the HIV and AIDS response during the past decades continues to generate extraordinary health gains, although the pandemic has remained one of the world's most serious health challenge. According to the joint United Nations Programme on HIV/AIDS (UNAIDS), at the end of 2013 an estimated 35 million people were living with HIV globally; of these 3.2 million were children younger than 15 years, while half of the adults were women. Of the 2.1 million new HIV infections reported, 240 000 were children younger than 15 years. Sub-Saharan Africa remains the region most heavily affected, accounting for 24.7 million adults and children living with HIV, with 150 000 newly infected. Of those infected, 12.8 million women aged above 15 years were living with HIV, and of infected children aged 15 years and younger, 210 000 were newly infected. In southern African countries neighbouring Zambia, the figures for children aged 0–14 years newly infected with HIV were 19 000 each for Mozambique and South Africa, 12 000 for Zimbabwe, 9 800 for Malawi and 1 800 for Namibia (UNAIDS, 2013).

The success has been recorded in bringing HIV programmes to scale, combined with the emergence of powerful new tools to prevent people from becoming infected and from dying from AIDS-related causes, holds out the prospect of an eventual end of AIDS. Despite the encouraging gains recorded, challenges nonetheless remain, especially in countries heavily affected by the pandemic, because national epidemics continue to expand in many parts of the world. Further declines in the numbers of children dying from AIDS-related causes and acquiring HIV infection have been recorded, although substantial efforts need to be accelerated to achieve global AIDS targets (UNAIDS, 2012).

Magnitude of HIV infection among women of reproductive age in Zambia

The prevalence of HIV among women aged 15–49 in Zambia is currently 15 per cent, compared to men at 11 per cent (CSO, MoH, & ICF, 2014), and mother-to-child transmission of HIV during pregnancy, delivery or breastfeeding is one of the key drivers of the epidemic. Thus, reducing the number of women newly infected with HIV can reduce HIV exposure for

their children. According to the Ministry of Health report, the number of women living with HIV who delivered in 2012 was 81 727, of whom 76 963 received antiretroviral drugs for prevention of mother-to-child transmission (PMTCT). These indicators showed a drop in the HIV transmission rate from mother-to-child from 24 per cent in 2009 to 12 per cent in 2012. However, the report also showed that 5 in 10 women or their infants did not receive antiretroviral drugs during breastfeeding to prevent mother-to-child transmission of HIV (MoH, 2014b). Therefore, the successes recorded were achieved against the backdrop of cultural, political and social economic challenges. Reaching the current global goal of eliminating new HIV infections among children by the end of 2015 will therefore require not only accelerated efforts to scale up services to prevent children from acquiring HIV infection but also steps to ensure that all programmatic elements are fully implemented (UNAIDS, 2012).

Prevention of mother-to-child transmission (PMTCT) of HIV

Prevention f mother-to-child transmission of HIV has been at the forefront of global HIV prevention activities since 1998, following the success of the short-course Zidovudine and single-dose Nevirapine clinical trials (Sperling et al., 1996). These interventions offered the promise of a relatively simple, low-cost intervention that could substantially reduce the risk of mother-to-child transmission (MTCT) of HIV. Research and programme experience over the past ten years has demonstrated newer and more effective ways to prevent new paediatric infections, particularly in high-burden, low-resource settings and significant progress has been made. However, it is still recognised that much work remains to be done because an estimated 430 000 children were newly infected with HIV in 2008, with a reduction recorded to 240 000 in 2013 and the vast majority of them through mother-to-child transmission. The global experts reiterated that even in countries with strong PMTCT programmes, there is no room for complacency (UNAIDS, 2013; WHO, 2010).

The PMTCT programme in Zambia was initiated in 1999 to address the burden of vertical transmission of HIV. This was in response to poor maternal health indicators in relation to HIV with a high antenatal HIV prevalence, estimated at 16.4 per cent in 2008. Given this background the approximately 80,000 infants born annually were at risk of acquiring HIV from their mothers. This prompted the Ministry of Health to integrate PMTCT into all maternal, newborn and child health (MNCH) services throughout the country with a view to

contribute to a significant reduction of transmission of HIV and subsequent child morbidity and mortality (CSO, MoH, TRDRC, UNZA, & MI, 2009).

The 2010 national infant feeding guidelines emphasised the introduction of more efficacious regimens and extended Nevirapine administration for the infant during the breastfeeding period as recommended by the World Health Organization (WHO) (MoH, 2010). In Zambia, more than 90 per cent of women attending antenatal care services are tested for HIV. The PMTCT programme was scaled up to include maintaining antenatal care (ANC) utilization above 90 per cent, increasing the percentage of women attending the first ANC by 14 weeks gestation, improving acceptance of testing to 100 per cent, improving adherence to antiretroviral therapy (ART) by HIV-positive women to 90 per cent, and increasing the proportion of women delivered by skilled health workers from 47 per cent to 70 per cent. All these operational programmes were intended to contribute to virtual elimination of mother-to-child transmission of HIV and provision of care and treatment for paediatric HIV infection that would reduce the transmission of MTCT of HIV to less than 5 per cent by 2015 (MoH, 2010). The country has equally benefited from research findings that inform policy changes to PMTCT interventions.

The 2013 Zambian consolidated guidelines were rolled out to provide comprehensive approaches for reducing new HIV infections, PMTCT, and provision of lifelong ART regardless of CD4 count for pregnant and breastfeeding women, for HIV-infected sexual partners of pregnant and breastfeeding women and for HIV-infected partners in serodiscordant couples (MoH, 2014a). All these efforts were in line with the international recommendations for prevention of HIV infection among children with a particular focus on treatment and infant feeding (WHO, UNICEF, UNAIDS, & UNFPA, 2012).

International infant feeding guidelines

A global consensus has emerged on the need for and feasibility of substantially reducing the number of children newly infected with HIV and improving the health of mothers and children to accelerate progress towards achieving the related Millennium Development Goals, including the Millennium Development Goal on HIV/AIDS. The updated 2010 WHO guidelines on antiretroviral medicine to treat pregnant women and prevent HIV infection among infants, combined with a renewed commitment to delivering comprehensive services

for PMTCT, spell out approaches that would considerably reduce the rates of HIV transmission, making eliminating MTCT an achievable goal even in resource-limited settings (WHO, UNAIDS, & UNICEF, 2011).

The 2010 WHO guidelines on the use of antiretroviral drugs for treating pregnant women and preventing HIV infection in infants are based on two key approaches: lifelong ART for for those who are treatment for their own health (which is also safe and highly effective in reducing MTCT), and new options for antiretroviral prophylaxis to prevent MTCT during pregnancy, delivery and breastfeeding for those who do not require treatment. For pregnant women living with HIV who are not on treatment, WHO recommends two efficacious antiretroviral regimen options for prophylaxis to reduce transmission during the perinatal period and while breastfeeding. For the first time, antiretroviral medicine for the mother or for the infant is recommended throughout the breastfeeding period, in settings where safe alternatives are not available (WHO, et al., 2012). The infant feeding guidelines have evolved over time and there is now much greater understanding of the risks associated with different types of infant feeding.

In 2001, the joint United Nations Program on HIV/AIDS (UNAIDS), World Health Organization (WHO) and United Nations Children's Fund (UNICEF) showed that HIV-positive mothers should avoid breast feeding in settings where safe alternatives were not available. The guidelines further showed that exclusive breastfeeding should be recommended during the first months of life, and that to minimize HIV transmission risk breastfeeding was to be discontinued as soon as feasible, taking into account the local circumstances, the individual woman's situation and the risks of replacement feeding (UNFPA, UNICEF, WHO, UNAIDS, & IATT, 2001). However, the guidelines emphasised that decision-makers were to be fully aware of the risks and benefits of all infant feeding options for HIV-positive women. It was therefore essential that all health care workers (HCWs) and counsellors be aware of, and able to implement, recommendations on Infant and Young Child Feeding (IYCF), including HIV and infant feeding, at various levels. Health care workers needed to select and propose appropriate infant feeding options to be discussed with HIV-positive pregnant women while further research was ongoing in different settings of the world (UNFPA, et al., 2001).

In 2010, the WHO released new guidelines on antiretroviral therapy for HIV infection in adults and adolescents. The recommendations dealing with breastfeeding changed quite radically from the previous guidelines released in 2006. In collaboration with UNAIDS, UNFPA and UNICEF, the WHO developed infant feeding guidelines based on significant programmatic experience and research evidence regarding HIV and infant feeding which had accumulated since recommendations on infant feeding in the context of HIV were last revised in 2006. This evidence had major implications for how women living with HIV might feed their infants, and how HCWs would counsel these mothers (WHO, 2010). The 2010 WHO infant feeding guidelines essentially recommended two infant feeding methods: exclusive breastfeeding for six months and then supplementary feeding and exclusive replacement feeding (WHO, UNAIDS, UNFPA, & UNICEF, 2010).

In 2012 the WHO released a revised framework for infant feeding guidelines that were practically the same as the 2010 guidelines regarding breastfeeding, but adding a recommendation that all pregnant mothers should take antiretroviral drugs (ARVs) for life (Option B+), coupled with an alternative recommendation for countries to choose (Option B) in which a mother could be tested for her eligibility for ARVs after the birth of her child. In both the 2010 infant feeding guidelines and the revised framework, exclusive breastfeeding for six months or beyond, followed by gradual weaning, was recommended (WHO, et al., 2012).

Exclusive formula feeding

According to the WHO infant feeding guidelines, mothers known to be HIV-infected should only give commercial infant formula milk as a replacement feed to their HIV-uninfected infants, or to infants who are of unknown HIV status, when the following specific conditions are met:

- safe water and sanitation are assured at the household level and in the community
- the mother, or other caregiver can reliably provide sufficient infant formula milk to support normal growth and development of the infant
- the mother or caregiver can prepare it cleanly and frequently enough so that it is safe and carries a low risk of diarrhoea and malnutrition
- the mother or caregiver can, in the first six months, exclusively give infant formula milk

- the family is supportive of this practice
- the mother or caregiver can access health care that offers comprehensive child health services

The above criteria carefully define the environmental conditions that make replacement feeding a safe (or unsafe) option for HIV-exposed infants to improve their HIV-free survival. It was considered that such language would better guide HCWs regarding what to assess, and help to communicate this to mothers who were considering if their home conditions would support safe replacement feeding (WHO, et al., 2010).

Exclusive breastfeeding (EBF)

The WHO infant feeding guidelines on breastfeeding recommend that mothers known to be HIV-infected (and whose infants are HIV-uninfected or of unknown HIV status) should exclusively breastfeed their infants for the first six months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS) for them and their infants. At six months, if replacement feeding is still not AFASS, continuation of breastfeeding with additional complementary foods is recommended, while the mother and baby continue to be regularly assessed and monitored. All breastfeeding should stop once a nutritionally adequate and safe diet without breast milk can be provided. Early cessation of exclusive breastfeeding (before six months) is no longer recommended, unless their situation changes and replacement feeding becomes AFASS (WHO, et al., 2010). For all these strategies, the implementation of infant feeding guidelines takes place in the communities where women live and work; hence quality counselling is fundamental for achievement of safer infant feeding among the affected populations in view of the known challenges (Leshabari, Blystad, de Paoli, & Moland, 2007; Levy, Webb, & Sellen, 2010).

HIV and infant feeding counselling

In the light of available evidence on PMTCT of HIV, the WHO guidelines recommend quality counselling for safer infant feeding practices. This is against the background that high-quality and timely HIV testing and counselling are essential to identify pregnant women living with HIV who can benefit from HIV care and interventions to reduce the risk of transmitting HIV from mother-to-child. In 2010, 35 per cent of an estimated 123 million pregnant women in low- and middle-income countries received an HIV test. The percentage

increased in almost all regions, growing around ten percentage points or more between 2009 and 2010 in eastern and southern Africa (52 to 61 percent). Although progress has been significant in almost all regions, nearly two-thirds of pregnant women still do not know their HIV status, including many pregnant women living with HIV who could benefit from further health interventions such as lifelong care for HIV and interventions to reduce the MTCT of HIV (WHO, et al., 2011). In Zambia, of pregnant women counselled and accessing care from public institutions who were tested, 15 per cent were found to be HIV-positive (CSO, et al., 2014).

Given programmatic experience and research, a package of interventions for PMTCT comprises potential contact of HIV-positive mothers with HCWs within a cascade of services that include antenatal clinic visits, the opt-out approach for HIV counselling and testing, ART, health facility-based deliveries, infant ARV prophylaxis and HIV testing, as well as postnatal care. Infant feeding recommended for HIV-positive mothers is either breastfeeding or formula feeding, and here too, counselling is prerequisite for safer infant feeding practices (MoH, 2010; WHO, et al., 2012).

The aim of infant feeding practices in the context of PMTCT is to ensure HIV-free survival among the exposed infants. As a public health approach in Zambia, all mothers are encouraged to exclusively breastfeed for six months regardless of their HIV status (MoH, 2014a; WHO, et al., 2012). Group health education, also used as group counselling, is the main means of giving information, education and communication in the Maternal, Neonatal and Child Health (MNCH) units and can be conducted by trained counsellors, students, volunteers and other appropriate service providers. Individual pre-test counselling, on the other hand, is reserved for those who have further issues to clarify, or, for those who have declined the test, to probe their possible reasons for declining the test, offer support and make arrangements for opportunities to test (MoH, 2010). However, to make an informed-decision on infant feeding, mothers must be able to make sense of the information provided during infant feeding counselling. In this regard, the HCWs play a significant role in guiding mothers in their decision making on infant feeding through giving quality counselling at every opportunity (MoH, 2010; WHO, et al., 2012).

Role of health care workers in PMTCT programmes in Zambia

Although it can be an added advantage, it is not essential that HCWs have formal training in PMTCT interventions in order to provide pregnant women and their families with information, care and support. Coupled with orientation and mentorship programmes, the PMTCT guidelines are used to equip programme managers and HCWs with knowledge and skills to ensure quality PMTCT service delivery. The role of HCWs, especially nurses and midwives, in the PMTCT programme is to provide counselling and testing services for pregnant mothers, and when found HIV-positive to counsel them on treatment option and infant feeding and/or refer for specialized care and/or administer medication as required at various stages of care. The HCWs link with the community and are supported by community-based volunteers (CBVs). Currently the CBVs, known collectively as Safe Motherhood Action Groups (SMAGs), comprising Traditional Birth Attendants (TBAs), Community Health Workers (CHWs), lay counsellors and others, serve as a liaison between the health care system and the community. They are trained by the Ministry of Health (MoH) at recognised HIV counselling institutions. The training is designed to equip them with skills in counselling and follow-up of clients in the community. They are recruited with support from the community leaders or influential people in the community. They work hand in hand with the health centre staff and their performance is monitored at that level. One of the responsibilities of SMAGs is to remind mothers recruited in the PMTCT treatment programmes and refer them to the health centre when there is a problem. The SMAGs and the nurses who are the contacts for the mothers therefore need to be guided on how to care for mothers and their infants during the first six months of infant feeding, because HIV-positive mothers may face a myriad of challenges during their infant feeding period.

Problem statement

In Zambia, the number of women living with HIV who delivered in 2012 was 81 727, of whom 76 963 received antiretroviral drugs for PMTCT. The MoH reported however that 5 in 10 women or their infants did not receive antiretroviral drugs for PMTCT during breastfeeding (MoH, 2014b). Breastfeeding has always been regarded as the best infant feeding method in most societies and is the most preferred choice by women regardless of their socioeconomic status (Leshabari, Blystad, & Moland, 2007; Oliver & Petty, 2012). However, infant feeding in the context of HIV has remained a controversial issue because

breast milk entails a 5 to 20 percent risk of HIV transmission even though it is still the safest source of nutrition for most infants. Given the socioeconomic challenges faced by mothers in resource-poor settings, breastfeeding protects infants against diarrhoea through reduced risk of bacteria from contaminated formula, other liquids and complementary foods, and, most importantly, transfer of maternal antibodies through breast milk creates some immunity in early childhood (UNICEF, 2010). Exclusive formula feeding, the safest option in terms of transmission of HIV, is associated with high rates of malnutrition, morbidity and mortality, especially in rural Africa. In such settings women generally lack resources to sustain the supply of formula and have poor water supply, among many other challenges (Matji et al., 2009). Available evidence shows that the risk of MTCT transmission of HIV is reduced with interventions in the form of lifelong ARVs coupled with safer infant feeding practices (WHO, et al., 2012).

The HIV pandemic and the risk of MTCT of HIV through breastfeeding thus pose unique challenges to the promotion of breastfeeding among the populations affected. In populations where mixed feeding is a cultural norm, mothers are faced with dilemmas on how best to feed their babies, notwithstanding evidence that supports breastfeeding and lifelong ARVs (Chinkonde, Hem, & Sundby, 2012; Madiba & Langa, 2014). To mitigate these challenges, quality infant feeding counselling has a bearing on whether HIV-positive mothers would implement a desired infant feeding choice. Informed-decision making on infant feeding is therefore dependent on adequate information on HIV as a disease, available infant feeding options and assessment of AFASS (WHO, et al., 2010). HIV-positive mothers must therefore be informed about such benefits as well as the risks of available infant feeding options, and should take these messages seriously when trying to balance the many factors that affect their decision on how best to feed their infants.

As a public health approach, mothers in Zambia are encouraged to exclusively breastfeed regardless of the HIV status. An informed-decision still applies, because mothers need to make sense of the information provided on exclusive breastfeeding in the context of HIV and PMTCT. Quality counselling is central to successful infant feeding practices and HCWs thus play an important role in helping mothers to decide what is the safest way to feed their infants (Dhandapany, Bethou, Arunagirinathan, & Ananthakrishnan, 2008; WHO, et al., 2012). Challenges in infant feeding counselling have nonetheless been reported in some settings and

they include lack of materials, low staffing levels, slow updates on infant feeding guidelines (Ferguson, 2013; Valley et al., 2013) and to a certain extent staff attitude.

Significance of the study

The ability of HIV-positive mothers to successfully achieve a desired feeding method is significantly influenced by the support provided through formal health services, social support systems and other community-based groups. This implies enhancing the mothers'ability to make decisions and choose exclusive breastfeeding (EBF) in their communities to reduce the risk of MTCT. Respecting the mothers' independence, would be to empower them with sufficient information about different options of infant feeding so that they can make an independent informed-decision and will know where to seek help and further information, if required.

Research questions

This research sought to answer the following questions:

1. How does the information provided in counselling on HIV and infant feeding assist mothers in making decisions for safer feeding practices for their infants?
2. What are the associated factors for serostatus disclosure among HIV-positive mothers?
3. What are the socio-cultural determinants of breastfeeding in Zambia?
4. How does the decision on infant feeding influence the outcome on exclusive breastfeeding practices for HIV-exposed infants?

Research aims and objectives

Overall aim of the study

To analyse choices and decision-outcomes about infant feeding in the context of prevention of mother-to-child transmission of HIV and enhance safer feeding practices during the first six months of the infants' life.

Specific objectives

1. Explore the serostatus disclosure among HIV-positive mothers accessing PMTCT services.
2. Explore sociocultural determinants of breastfeeding in Zambia.
3. Analyse how the information provided in counselling on HIV and infant feeding assists mothers in making decisions for safer feeding practices for exposed infants.
4. Describe the decision-making process in influencing the decision-outcome on infant feeding.

Definition of terms

- ***Breastfeeding*** is the normal way of providing newborn babies and young infants with the nutrients they need for healthy growth and development. Virtually all mothers can breastfeed, provided they have accurate information, and the support of their family, the health care system and society at large (UNICEF, 2010; WHO, 2010).
- ***Culture*** means emphases placed on aspects such as shared norms, beliefs and expectations, spoken language and behavioural customs (Coast, Jones, Portela, & Lattof, 2014).
- ***Choice*** is the act of selecting between or among more than one option or possibility (www.oxforddctionaries.com, 2015).
- ***Informed-decision*** is one where a reasoned choice is made by a reasonable individual using relevant information about the advantages and disadvantages of all the possible courses of action, in accord with the individual's beliefs (Bekker et al., 1999).
- ***Decision-outcome*** is the result that follows a particular action taken.
- ***Ethnography*** is the study of indigenous society and in the contex of this study it refers to a social scientific description of a people and the cultural basis of their being. It is also referred to as descriptive anthropology, and in its broadest sense is the science devoted to describing ways of humankind. The cultural group in this context are HIV-positive mothers who shared the infant-feeding experience (Denzin and Lincoln, 1998).
- ***Exclusive breastfeeding*** means that an infant receives only breast milk from his or her mother or a wet nurse, or expressed breast milk, and no other liquids or solids, not

even water, with the exception of oral rehydration solution, drops or syrups consisting of vitamins, mineral supplements or medicines if needed (WHO, 2012).

- ***Formula feeding*** is giving any non-human milk with the exclusion of all breast milk, with or without other liquids or solids (WHO, 2012).
- ***Mixed feeding*** is breastfeeding while the baby is also receiving water-based drinks, food-based fluid, semi-solid or solid food or non-human milk (also called partial breastfeeding) (WHO, 2012).
- ***Counselling*** is a professional relationship between a trained counsellor and a client designed to help the latter to understand and clarify their views of their life space and to learn to reach their self-determined goals through meaningful, well informed choices and the resolution of problems of an emotional nature (McLeod, 2013).
- In the context of HIV, ***serostatus disclosure*** is the act of informing any individual or organisation of the HIV status of an infected person, or to the effect that such information has been transmitted, by any means, by the person himself or herself, or by a third party, with or without consent. Except in exceptional circumstances, when disclosure to another person is required by law or ethical considerations, a person with HIV has the right to privacy and to exercise informed consent in all decisions about disclosure of his/her status (UNAIDS, 2000).

Methods and materials

This study was guided by theories from the social sciences and psychology. The intention was to bring together the socio-cultural environment and individual constructions of experiences that govern the choice of infant feeding method when a woman is found to be infected with HIV. In such an endeavour, it is important to map out the underlying circumstances in the life of the participant so that the reader gains an in-depth understanding of the localities, activities and constraints experienced in others' daily lives. For this study, ethnographic procedures were followed to gain a deeper understanding of the lived experiences of HIV-positive women through prolonged engagement in fieldwork.

The theoretical framework

Social constructivism, critical theory (feminist approaches) and social cognitive theory contributed to the design and methodology, analysis, and interpretation of the findings, thus

shedding light on potential issues for PMTCT policy and practice and for future research endeavours. I describe these theories in the following subsections.

Social constructivism

The constructivist perspective states that knowledge is socially and culturally constructed and proposes that reality cannot be discovered because it does not exist until it is created; in addition it states that we each create our own realities or truths based on a given experience. Constructivism has its roots in the fifth century B.C. in the Socratic Method of pursuing and acquiring knowledge. Despite its ancient roots, it was not until 2,400 years after the death of Socrates that constructivism evolved into a fully-fledged theory of knowledge construction through the independent works of Lev Vygotsky in Russia and Jean Piaget in the United States of America (Bann, 1990).

Constructivism, as presented by Guba and Lincoln, adopts relativist ontology, transactional epistemology, and a hermeneutic, dialectical methodology. The enquiry aims of this paradigm are oriented to the production of reconstructed understandings, where the traditional positivist criteria of internal and external validity are replaced by the terms *trustworthiness* and *authenticity*. The constructivist or interpretivist believes that to understand this world of meaning, one must interpret it. The inquirer must process the meaning and the construction, and clarify what and how they are embodied in the language and actions of social actors. Constructivists believe that knowledge and truth are created, not discovered by mind. In addition, knowledge and truth are apprehendable in the form of multiple, intangible mental constructions, socially and experientially based, local and specific in nature and dependent for their form and content on the individual persons or groups holding the constructions (Denzin & Lincoln, 1998).

In this worldview, individuals seek understanding of the world in which they live and work. They develop subjective meanings of their experiences – meanings directed toward certain objects or things. These meanings are varied and multiple, leading the researcher to look for the complexity of views rather than narrow the meanings into a few categories or ideas. The goal of research, then, is to rely as much as possible on the participants' views of the situation. Often these subjective meanings are negotiated socially and historically. In other words, they are not simply imprinted on individuals but are formed through interaction with

others and through historical and cultural norms that operate in the individuals' lives (Creswell, 2007; Lincoln & Guba, 2000).

The researchers recognise also that their own background shapes their interpretation, and they "position themselves" in the research to acknowledge how their interpretation flows from their own personal, cultural, and historical experiences. Thus the researchers make an interpretation of what they find, an interpretation shaped by their own experiences and background. The researcher's intent, then, is to make sense of (or interpret) the meanings which others attach to the world (Creswell, 2007).

According to Denzin and Lincoln (1998), the variable and personal nature of social constructions suggests that individual constructions can be elicited and refined only through interaction between and among investigator and respondents. These varying constructions are interpreted using conventional hermeneutical techniques and are compared and contrasted through a dialectical interchange. The aim is to have a consensus construction that is more informed. The constructivists' implications for data analysis and resulting discussions and conclusions are that there is no one truth. Themes derived from the texts are not proposed as truths. A constructivist researcher shows the various perspectives of the participants, provides possible explanations of their experiences and perceptions, and explains how the participants and the researcher constructed these perspectives (Denzin & Lincoln, 1998).

This study brought to light the social construction of breastfeeding in in the context of PMTCT of HIV. The meanings attached to breastfeeding have socio-cultural implications for PMTCT interventions and, in this perspective, are linked to the social responsibilities attached to birthing and motherhood – issues highlighted in the next section.

Critical theory

Critical theory refers to the theoretical tradition, based on neo-Marxist thinking, developed by the Frankfurt School (at the Frankfurt Institute of Social Research). The proponents of critical theory were Max Horkheimer, Theodor Adorno and Herbert Marcuse. Frustrated by forms of domination emerging from a post-enlightenment culture natured by capitalism, these scholars saw in critical theory a method of temporary freeing of academic work from these forms of power. They believed that injustice and subjugation shaped the lived world and analysed the forms of domination. Critical theory has a narrow and a broad meaning in philosophy and in

the history of the social sciences and is often used as an umbrella term for social theories that fundamentally critique existing social structures and that aim to change these structures and among others these are Marxism, post structuralism and feminism (Horkheimer, 1982). According to these theorists, a "critical" theory may be distinguished from a "traditional" theory according to a specific practical purpose: a theory is critical to the extent that it seeks human emancipation, "to liberate human beings from the circumstances that enslave them" (Horkheimer, 1982). In both the broad and the narrow senses, however, a critical theory based in social constructivist tradition provides the descriptive and normative bases for social enquiry aimed at decreasing domination and increasing freedom in all their forms. The different dimensions of critical theory include feminist research approaches (feminist social theory), critical race theory, disability theory, queer theory and indigenous research approaches. In critical theory gender has emerged as the most central concept and generally focused around the human concept of sex, a biological, physical division, that extends to a broad social construction; hence, neither masculinism nor feminism can be detached from issues relating to breastfeeding in particular and infant-feeding in general. Being liberated from the cultural submissive role may thus have a positive impact on child survival when a woman is empowered to feed her child on the basis of informed choice as provided in the infant feeding guidelines. A further analysis of feminist perspective is therefore provided below.

Feminist perspectives

According to Sally Slocum (Sheila, 1998), the perspective of women is in many ways foreign to an anthropology that has been developed and pursued by males. She asserts that there is a strong bias in the questions asked and the interpretations given and this draws attention to feminists' view that male bias limits women's knowledge by limiting the questions asked. Feminist researchers are discovering that most of the accepted theories in all traditional fields – even their methods of pursuing knowledge – are rife with prejudice and misunderstandings about women in particular and humanity in general, and ultimately compromise the generation of theories that have been used to understand women's experiences, realities and possibilities. Feminist theory is the extension of feminism into theoretical or philosophical discourse. It aims to understand the nature of gender bias and inequality. It examines women's social roles and experiences, together with feminist politics, in a variety of fields such as anthropology and sociology, communication, psychoanalysis, economics, literary,

education and philosophy. While generally providing a critique of social relations, much of feminist theory also focuses on analysing gender inequality and the promotion of women's rights, interests, and issues. Feminist researchers embrace two key tenets: (1) their research should focus on the condition of women in society, and (2) their research must be grounded in the assumption, that women generally experience subordination. Thus, feminist research rejects Weber's value-free orientation in favour of being overtly political – doing research in pursuit of gender equality (Brabeck & Brown, 1997).

In her contribution to feminist theory, Evelyn Fox Keller (1985) argues that the standards of objectivity and rationality that define traditional scientific perspective and practice are products of unrecognized value assumptions. She argues that these standards are masculine and that science might be different and probably truly objective if masculine values were neutralized. The single point at which all feminist scholarship has converged in the past has been the importance of recognising the social construction of gender and the deeply oppressive consequences of assuming that "men and women are born and not made". Feminist approaches to research therefore assume that knowledge about gender is socially constructed and that differences between genders are either exaggerated or trivialized in ways that legitimise and perpetuate the power relations between them. That is why gender relations have to be analysed in relation to their specific socio-cultural and historical contexts (Keller, 1985).

Using feminist perspectives for this study was one of the ways that a discourse was created in which HIV-positive mothers viewed their own realities of life and considered how the findings would contribute to empowering them in making informed-decisions on how best to feed their infants and take responsibility to account for the infant feeding practices and achieve HIV-free survival for the exposed infants. The assumption was that knowledge is empowering and that using feminist research as an empowering tool could address feminist interests and direct this research towards social change (Osmond & Thorne, 1993). The general assumption of this study was that all aspects of human interaction have a gender perspective, childbearing included. The complex issues of breastfeeding in the context of HIV and gender dimensions are interlinked. In societies where women are marginalized, understanding their experiences in decision making on the desired method of feeding cannot be dissociated from gender, as male domination is a visible feature in women's lives in this setting and it was assumed that this impacts on decision-outcomes on infant feeding in

relation to PMTCT. However, decision-outcomes cannot be dissociated from the ability of HIV-positive mothers to learn about their new HIV status and about infant feeding practices in the context of PMTCT – at which point it becomes relevant to consider the tenets of social cognitive theory.

Social cognitive theory

At the interpersonal level, theories of health behaviour assume that individuals exist within, and are influenced by, a social environment. The social environment includes family members, co-workers, friends, health professionals and others. Because it affects behaviour, the social environment also impacts health. Social cognitive theory (SCT) is one of the most frequently used and robust health behaviour theories. It explores the reciprocal interactions of people and their environments, and the psychosocial determinants of health behaviour (Rimer & Glanz, 2005); a particularly influential author on the application of SCT to health promotion has been Albert Bandura (1977, 1989, 1990, 1991, 2001). The theory describes a dynamic, ongoing process in which personal factors, environmental factors, and human behaviour exert influence upon each other to achieve an outcome. According to SCT, there are three main factors that affect the likelihood that a person will change a health behaviour: (1) self-efficacy, (2) goals, and (3) outcome expectancies (Figure 1-1).

Understanding of this interaction and the way in which modification of the environment can impact on behaviour offers an important insight into the way behaviour can be modified through health-promotion interventions. The core determinants include *knowledge* of health risks and benefits of different health practices, perceived *self-efficacy* that one can exercise control over one's health habits, *outcome expectations* about the expected costs and benefits of different health habits, the *health goals* that people set for themselves and the concrete plans and strategies for realizing them, and the *perceived facilitators* and social and structural *impediments* to the changes they seek (Bandura, 1989). In using SCT for social change, Bandura suggests that self-efficacy in combination with knowledge and environment influences choices people make and how they feel about facing a challenge. The assumption is that if an individual has a sense of personal agency or self-efficacy, they can change behaviours even when faced with obstacles. If they do not feel that they can exercise control over their health behaviour, they are not motivated to act, or to persist through challenges. However, as a person adopts new behaviours, this causes changes in both the environment

and in the person. Therefore, behaviour is not simply a product of the environment and the person, nor is the environment simply a product of the person and behaviour (Rimer & Glanz, 2005); the two have to complement each other because they determine the outcome.

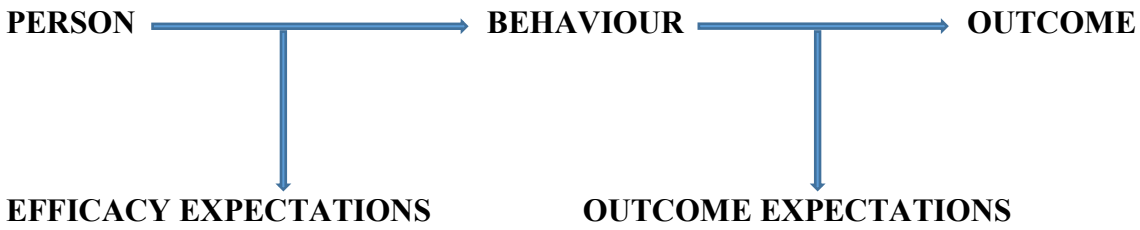

Figure 1-1 Efficacy expectations and outcome expectations

An *outcome expectancy* is defined as a person's estimate that a given behaviour will lead to certain outcomes. An *efficacy expectation* is the conviction that one can successfully execute the behaviour required to produce the outcomes. At this initial level, perceived self-efficacy influences choice of behavioural settings. People fear and tend to avoid threatening situations they believe exceed their coping skills, whereas they get involved in activities and behave assuredly when they judge themselves capable of handling situations that would otherwise be intimidating. Not only can perceived self-efficacy have directive influence on choice of activities and settings, but, through expectations of eventual success, it can affect coping efforts once they are initiated. While on the other hand *efficacy expectations* determine how much effort people will expend and how long they will persist in the face of obstacles and aversive experiences with stressful situations, given appropriate skills. Therefore, the stronger the perceived self-efficacy, the more active the efforts. However, expectation alone will not produce desired performance if the component capabilities are lacking. Moreover, there are many things that people can do with certainty of success that they do not perform since they have no incentives to do so because of their complex environment.

In a society where breastfeeding is a cultural practice, where health care delivery poses challenges in accessing and utilization of services, and where society dictates how women should be treated, this study sought to understand the cultural basis of breastfeeding in the context of prevention of mother-to-child transmission of HIV. To that effect, HIV-positive mothers were considered as a cultural group by applying the ethnographic context as I have described them in the next section of the thesis.

The ethnographic context

Ethnography refers to a social scientific description of a people and the cultural basis of their peoplehood. Ethnography is a subdiscipline also referred to as descriptive anthropology, and in its broadest sense is the science devoted to describing ways of humankind. In describing the origins of ethnography, Denzin and Lincoln (1998) show that it grew out of the interests of westerners in the origins of culture and civilization in the assumption that contemporary primitive peoples were in effect living replicas of the "great chain of being" that linked the Occident to its pre-historic beginnings. In the post-War period of the twentieth century, changed attitudes towards what happened in world history led the anthropologists to retool their approach as "ethnography" in studying primitive societies. In the recent past the methods of ethnography have become highly refined and diverse and the reasons for doing ethnography have multiplied, encompassing a variety of experiences in modern life. These methods of ethnography include confessional ethnography, life history, auto-ethnography, feminist ethnography, ethnographic novels, and the visual ethnography found in photography and video, and electronic media, in addition to critical ethnography (Denzin & Lincoln, 1998).

Critical Ethnography: Critical ethnography draws on cultural studies, neo-Marxist and feminist theories and research on critical pedagogy. The aim is to theorize social structural constraints and human agency in order to consider paths towards the empowerment of the researched. The overriding goal of critical ethnography is to free individuals from the sources of domination and oppression (Atkinson et al, 2001). Critical ethnography aims to change the culture, by analysing hidden agendas and "taken for granted" assumptions, and works towards disrupting the status quo by bringing to light systems of power and control. In essence, a critical ethnography underpinned by a post-colonial perspective allows for the bringing together of individual perspectives with group-based social histories in order "to understand how individuals are active in producing and shaping relations and are, in turn, shaped by these relations" (Reimer Kirkham & Anderson 2002). This process includes analysis of the influence of socially and historically situated elements in everyday life – elements that often contribute to power imbalances that lead to inequitable power relations and, potentially, marginalization. Critical ethnography shifts beyond traditional ethnography by being inherently including political, ethical and social issues together.

A critical ethnographer might, for example, address an inequity in society or some part of it and use the research to advocate and call for changes or empowerment. Rather than focusing on creating a description of the 'other', as in traditional ethnography, critical ethnography focuses on the development of a dialogical relationship between the researcher and participants with the ultimate aim of social transformation from sources of oppression (Brown & Dobrin 2004).

I used critical ethnography for this study to address the purpose and objectives of the study in order to engage with the HIV-positive mothers and unfold the realities of being seropositive and pregnant and of having to decide on safer infant feeding practices for the baby in societies where breastfeeding is a cultural event and where women are disempowered. The objectives and research questions centred on understanding HIV-positive women as a cultural group and the answers unveiled the realities of the lived world of these women (Creswell, 2007).

Design

The study had an exploratory research design that employed qualitative triangulation. Qualitative research is defined as "an inquiry process of understanding based on distinct methodological traditions of enquiry that explore a social or human problem. In this method the researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting" (Creswell, 2007). This allows the data to be analysed concurrently during the collection process.

There were two principal phases to the research.

The **first phase** included the following elements:

- sociocultural determinants of breastfeeding
- serostatus disclosure and associated factors
- infant feeding counselling; health care workers' and mothers' perspectives
- decision making on infant feeding in the context of promotion of exclusive breastfeeding
- experiences with infant feeding; the reality on the ground

The **second phase** comprised the design of a model for follow-up of HIV-positive mothers in the first six months of infant feeding. This conceptual framework was informed by the data that was generated in the first phase of the study.

Setting

Lusaka

Lusaka district is the capital city of Zambia, situated in Lusaka province. The study was conducted in an urban setting of Lusaka district using Chelstone and Ngombe health centres to recruit study participants who were accessing services for PMTCT of HIV. Both centres are sites for the Ministry of Health programmes on PMTCT of HIV and antiretroviral therapy (ART).

Figure 1-2 Map of Zambia showing Lusaka district

(Adapted from Google Maps)

The HIV disease burden and health care delivery in Zambia

According to the Ministry of Health (MoH) survey, the high disease burden in Zambia is compounded by the high prevalence of HIV, high poverty levels, and the poor macroeconomic situation. The government of the Republic of Zambia is committed to improving health care delivery through its restructured primary health care programme. The government is committed to providing efficient and cost-effective, quality basic health care services for common illnesses as close to the family as possible through implementation of the basic health care package at all levels of care based on an epidemiological analysis of diseases and conditions that cause the highest burden of morbidity and mortality. In its 2011–2015 National Health Strategic Plan (NHSP), the MoH aims to reduce the disease burden and accelerate attainment of the Millennium Development Goals (MDGs) and other national priorities. The NHSP places emphasis on addressing priorities such as fostering multisectoral responses for HIV/AIDS. Priority health objective include the following:

- To reduce under-5 mortality rate from the current 119 deaths per 1,000 live births to 63 deaths per 1,000 live births by 2015
- To reduce the maternal mortality ratio from the current 591 deaths per 100,000 live births to 159 deaths per 100,000 live births by 2015
- To reduce the population/doctor ratio from the current 17,589 to 10,000 by 2015
- To reduce the population/nurse ratio from the current 1,864 to 700 by 2015
- To increase the percentage of deliveries assisted by skilled health personnel from 45 percent in 2008 to 65 percent by 2015

Zambia, like many sub-Saharan countries, has been adversely affected by the HIV/AIDS pandemic. For the last three decades, the government has been committed to responding to the HIV/AIDS epidemic, in collaboration with national and international partners. In response to the high morbidity and mortality associated with HIV infection, the MoH embarked on the following measures:

- Distribution of free antiretroviral drugs in two major public health care facilities in 2005
- Distribution of highly effective ART has since been scaled up to include almost all of the districts in Zambia

- Expansion of quality services for PMTCT of HIV, voluntary HIV counselling and testing, ART, and other treatment and care services.

The 2011-2015 National HIV and AIDS Strategic Framework, launched in 2010, emphasises a multisectoral and decentralised response to the AIDS epidemic. Four national priorities for tackling the epidemic have been identified:

- To accelerate and intensify prevention in order to reduce annual rates of new HIV infections
- To accelerate universal access to comprehensive treatment, care and support for people living with HIV/AIDS, as well as their caregivers and families
- To mitigate the socioeconomic impact of HIV/AIDS
- To strengthen the capacity for a well-coordinated and sustainably managed multisectoral response to HIV/AIDS.

Target population

HIV-positive mothers

The focal population for this study was all HIV-positive pregnant women attending antenatal care (ANC) and who delivered in the selected health facilities and were residents of the catchment areas selected for this research. The estimated number of pregnant women in 2012 was 723,436. Of these, 688,060 (94%) attended ANC services at least once and were tested for HIV. The number of women living with HIV who delivered in 2012 was 81,727 out of which 76,963 received efficacious ARVs for PMTCT (Ministry of Health & National AIDS Council, 2014). During the last Zambia Demographic and Health Survey (ZDHS), the ANC attendance from a skilled health care provider was reported at 96 percent. The median duration of pregnancy at the first ANC visit was about 5 months. Skilled attendance at delivery was 64 percent and 63 percent of women received postnatal care (PNC). In urban areas such as Lusaka, mothers access ANC services from all the health facilties. For this study, 30 HIV-positive mothers accessing PMTCT services from the selected sites (Chelstone and Ngombe) were recruited to participate in the study. These participants were interviewed, subsequent to giving birth, at 6 days, 6 weeks, 12 weeks and 18 months during the first six

months of infant-feeding period. These contact periods are based on the prescribed schedules of visits for maternal health services including child growth monitoring and immunizations.

Health care workers (HCWs)

The number of public sector health care workers as of December 2009 was 0.93 per 1,000 population and these numbers are skewed towards the urban areas, which leaves the rural areas extremely vulnerable. This situation was further impacted by an employment freeze by government. These HCWs include medical doctors, nurses and midwives, clinical officers and other clinical care providers (Ministry of Health, 2011). For this study all HCWs in the PMTCT units of the selected health facilities were interviewed on the basis of their availability in the sites; they included nurses, midwives, nutritionists and clinical officers. On average there was only one nutritionist and clinical officer at each health facility.

Community-based volunteers

In order to alleviate the shortage of HCWs, the concept of Community Health Workers (CHWs) and Community Based Volunteers (CBVs) have been considered. The MoH has developed a CHW strategy, in order to standardise the training and certification of this cadre as well as to provide guidelines for the tasks and remunerations of this cadre and volunteers (Ministry of Health, 2011). For this study, all the CBVs working as lay counsellors and community health providers from each site participated in the focus group discussions (FGDs).

HIV-positive men accessing antiretroviral therapy

HIV-positive men accessing ART and whose spouses/partners had delivered within a past year prior to data collection were eligible to participate in the FGDs. During in-depth interviews with HIV-positive women, issues such as cultural practices of breastfeeding and serostatus disclosure emerged that needed to be verified with HIV-positive men. After giving consent, the men were invited to a central and convenient place for them to participate in the discussion.

Participant selection criteria

Recruitment of HIV-positive mothers started three months prior to commencement of data collection, using the health centre registers. All HIV-positive mothers were eligible to be recruited in the study. However, to be included in the study the mother needed to have attended pre-test and post-test counselling, have obtained the HIV test results, been placed on a treatment regimen, been counselled on infant feeding, have decided on the method of feeding, be willing, and have given written and signed consent to participate in the study.

Sampling technique

Purposive sampling techniques were employed to recruit participants for the study. To maintain a balance in age distribution for HIV-positive mothers, recruitment was done within the age ranges of 15 to 24, 25 to 34 and 35 to 40 years. Categories such as education level and social economic status were determined by employing judgmental sampling while maintaining flexibility as the themes emerged. However, to cater for loss to follow-up due to change of location, death of the baby or drop out from the study, an additional one participant for every four participants was recruited, giving a total of 30 HIV-positive mothers.

All HCWs in the PMTCT programme were interviewed on the basis of their availability in the programme. All community volunteers were recruited to participate in the FGDs.

Data collection procedures

Data were collected through participant observation, in-depth interviews and FGDs that were audio recorded after securing permission from the participants.

Participant observation

Participant observation was undertaken as a complementary method to prepare the interview situation both in terms of establishing rapport with study participants and in terms of discovering information to follow up during the subsequent interviews and observations. Observation in this case was essential in detecting meanings, feelings and experiences attached to infant feeding. The observations enabled me to describe activities or behaviours in terms of person, time and place, and to identify patterns of activity that were relevant for making conclusions. Through observation and informal conversations, I understood the

settings and contexts, the physical and social places, within which infant feeding took place. The observations were conducted during health education talks on infant feeding, during growth monitoring and immunizations programmes (children's clinic), during community orientation programmes on PMTCT, and during home visits for women who gave consent.

In-depth interviews

In-depth interviews are considered an appropriate tool because of the ability to effectively address complex and sensitive topics and to allow mothers to talk about personal feelings, opinions and experiences using their native language (Creswel, 2007).

Focus group discussions (FGD)

Focus group discussions complement in-depth interviews and can reveal not only the diversity within a population but also the potential change or modification of perceptions that takes place in group contexts. Focus group discussions were conducted with community volunteers and from HIV-positive men. Focus froup discussions with CBVs were conducted to elicit information on the community perspective of HIV and infant feeding because they were a liaison between the health facility and the community. Their scope of work focusses on working as lay counsellors and community support groups. They are also recruited to follow-up HIV-positive mother-baby paires. Therefore, their views on infant feeding in relation to promotion of exclusive breastfeeding were sought.

The FGDs with men was designed to enhance the information relating to serostatus disclosure, socio-cultural determinants of breastfeeding and their views on exclusive breastfeeding practices.

Data collection tool

A semi-structured interview guide was used to conduct the interviews. Although interviews were conducted with HIV-positive mothers, HCWs, HIV-positive men, and CBVs, the categories of questions remained the same but were contextualised and applied specifically to capture the diversity among the participants. These guides were hence presented as different tools for clarity during data collection for the the different groups. The tools were translated into a primary language commonly spoken by participants (Cinyanja). The research assistants were equally conversant with the language.

Field notes from observations were typed and saved on the computer immediately after they were generated.

Data management

All audio files from digital recorders were downloaded onto the computer. Recordings were transcribed verbatim from the primary language and then translated into English. All transcripts were checked for accuracy, quality and cleaned for anonymity by removing all identifiers. All field notes from observations were typed as soon as they were gathered. All the files were imported into QRS NVivo 10 for coding and analysis and a regular backup in the external drives was maintained throughout the project. All data will be kept safely locked and accessible only to the researcher for a period of 5 years from the time it was collected and thereafter destroyed.

Data analysis

Data were analysed using the framework analysis designed for health policy research (Richie & Lewis, 2003; Ritchie & Spencer, 2002). Data collection and analysis were carried out concurrently where data analysis commenced immediately after the first interview until there was no new information that came to the fore, thus saturation was achieved (Mason, 2010).

From the onset I actively listened to the all the recordings, which helped me to write the memos on the data emerging and giving the first impression. This process allowed me to get acquainted with the data as fieldwork proceeded. At this stage some questions were revised to focus directly on addressing research objectives based on what I found on the ground. This process also informed the conduct of FGDs because it allowed clarification of themes and this continued during writing and interpretation; in this way triangulation was achieved. This process was facilitated by using the NVivo software for open-coding similar information from different data sources on the same nodes (themes). The transcribed documents, field notes and audio analysis notes were read and re-read to understand content, and to proceed with open coding of themes that emerged. The open-coding process helped to identify key themes that formed the initial coding structure which was evolving as analysis progressed. After reviewing more data through open-coding, recoding, and categorizing, the final coding structure was developed. The integrated data on each theme was analysed for varying and

similar perspectives on each theme. This not only produced comprehensive findings on each theme but also provided a complex analysis of both similarities and differences in perspectives from different data sources, as shown in the papers/manuscripts that make up this thesis (chapters 3, 4, 5, 6, 7 and 8). These papers/manuscripts show how each theme evolved and how the different sources of information from different data collection methods was presented and compared to provide both common and unique perspectives on each theme. The major themes that emerged from the data are shown in Table 1-1 below.

Table 1-1 Themes and sub-themes that emerged from the study

Papers	Major themes	Sub-themes
Paper 1	Serostatus disclosure and associated factors	• Reasons for disclosure of serostatus • Non-disclosure of serostatus • Health care workers' perspective of serostatus disclosure in relation to prevention of mother-to-child transmission of HIV
Paper 2	Socio-cultural determinants of breastfeeding	• Knowledge of Mother-to-child transmission of HIV through breastmilk • Cultural understanding of breastfeeding • Mixed feeding as a cultural norm • Herbal use for mothers and babies • Perceived consequences for disregard of cultural practices
Paper 3	Infant feeding counselling	• Information on infant feeding counselling • The HIV-positive mothers' understanding of information on infant feeding • The mothers' decision to exclusively breastfeed • The mothers' risk in practicing mixed feeding
Paper 4	Promotion of exclusive breastfeeding	• Promotion of exclusive breastfeeding by health care workers • The mothers' understanding of information to exclusively breastfeed • The mothers' reasons for choosing to exclusively breastfeed • Decision making on infant feeding and behaviour change in relation to PMTCT
Paper 5	Experiences and decision-outcome on infant feeding	• Mother-to-child transmission of HIV; mothers' perspective of breast complications • Mothers' understanding of benefits of exclusive breastfeeding • Exclusive breastfeeding; reflections and narratives in relation to PMTCT • Challenges experienced during the first six months of infant feeding
Paper 6	Community perception of HIV and infant feeding	• Knowledge of mother-to-child transmission of HIV; the community perspective • Community based volunteers; a link to formal health care delivery • Cultural practices of breastfeeding; the community voices • Experience of HIV-positive mothers during the first six months of infant feeding; using the community lens

Ethical approval

Permission to conduct the research was obtained from the Ministry of Community Development, Mother and Child Health (MCDMCH). Ethical clearance was granted by the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal in South Africa (HSS/0104/013D) and the Biomedical Research Ethics Committee of the University of Zambia (Reference No. 016-11-13). Voluntary participation was accorded with written consent. No identifiers were used, to ensure confidentiality, and privacy was observed by conducting interviews at a place convenient to the participants. The participants were free to withdraw from the study and continuity of care was assured at all stages of the study.

Format and outline of the thesis

This research report is based on papers/manuscripts for scholarly publication focused in line with the research questions asked and the objectives of the study. Each paper builds on the overall theme of the study: *HIV and infant feeding: choices and decision-outcomes in the context of prevention of mother-to-child transmission among HIV-positive mothers in Zambia.* Each paper/manuscript highlights a theoretical and methodological triangulation that gave a rich and comprehensive description of infant feeding in the context of prevention of mother-to-child transmission of HIV. These are listed in Table 1-2 below.

Table 1-2 Outline of the papers/manuscripts in relation to the research questions and objectives

Paper/manuscript Number	Research question	Research objective	Research approach	Title of paper/manuscript	Contribution of the paper to the overall theme
Chapter 2 (Paper 1)	Global recommendations on infant feeding: what do they mean for the HIV-positive mothers in low-resource settings	Review of literature.	Review of empirical evidence	HIV and Infant feeding: the implementation of infant feeding guidelines in resource-poor settings: a review of literature.	The empirical evidence helped to refine the methods and conclusions of how the research fits into the debate and body of scientific knowledge.
Chapter 3 (Paper 2)	What are the associated factors for serostatus disclosure among HIV-positive mothers?	Explore the serostatus disclosure among HIV-positive mothers accessing PMTCT services.	Post-test exit interviews	HIV and infant feeding: Serostatus disclosure and associated risk factors among HIV-positive mothers in Lusaka, Zambia.	Serostatus disclosure has a direct link to the likelihood that the HIV-positive mother will choose and employ safe infant feeding practices. This has a bearing on decision-outcome on infant feeding.
Chapter 4 (Paper 3 published in the *Africa Journal of Nursing and Midwifery*)	What are the social-cultural determinants of breastfeeding in Zambia?	Explore socio-cultural determinants of breastfeeding.	Exploratory qualitative study	Social-cultural determinants of breastfeeding; lessons learnt from experiences of HIV-positive mothers in Lusaka.	Breastfeeding is a cultural practice in Zambia and should inform infant feeding counselling because these practices will always be past on from generation to generation.

Paper/manuscript Number	Research question	Research objective	Research approach	Title of paper/manuscript	Contribution of the paper to the overall theme
Chapter 5 (Paper 4 published in the ***Medical Journal of Zambia***)	How does the information provided in counselling on HIV and infant feeding assist mothers in making decisions for safer feeding practices for their infants?	Describe how the information provided in counselling on HIV and infant feeding assists mothers in making decisions for safer feeding practices for exposed infants.	Key informant and individual interviews	HIV-positive mothers' perception of infant feeding counselling in the context of prevention of mother-to-child transmission of HIV in Lusaka, Zambia	Infant feeding counselling is fundamental to PMTCT and should be the overriding focus of interventions.
Chapter 6 (Paper 5 published in the ***Internatioal Breastfeeding Journal***)	How does the decision on infant feeding influence the outcome to EBF for HIV-exposed infants?	Describe the decision-making process in influence the outcome on infant feeding among HIV-positive mothers.	Individual interviews and participant observations	Promotion of exclusive breastfeeding among HIV-positive mothers: An exploratory qualitative study.	Promotion of infant feeding options is informed by empirical evidence. This paper highlights that messages cannot be planned in the context of *'one size fits all'*.
Chapter 7 (Paper 6)		Describe the experiences with exclusive breastfeeding among HIV-positive mothers in the first six months of infant feeding.	Health facility and community-based qualitative study design	Exclusive breastfeeding: an exploratory qualitative analysis of experiences of HIV-positive mothers in Lusaka, Zambia.	This paper highlights many challenges faced by HIV-positive mothers to implement exclusive breastfeeding in a low-resource setting.

Paper/manuscript Number	Research question	Research objective	Research approach	Title of paper/manuscript	Contribution of the paper to the overall theme
Chapter 8 (Paper 7)	What does the community know about HIV and infant feeding?	Highlight the community perception of HIV and infant feeding	Focus Group Discussions (FGD)	Community perception of HIV and infant feeding	This chapter highlights the community percpectives of feeding HIV-exposed infants. This aspect was important to assist in establishing the community understanding because infant feeding takes place in the community where mothers live, interact, work and feed their infants.
Chapter 9 (Paper 7)	How can the HIV-positive mothers enhance their infant feeding practices in the context of PMTCT?	Design a model for follow-up of HIV-positive mothers in the first six months of infant feeding.	Grounded theory	Understanding the decision-outcome on infant feeding in the context of mother-to-child transmission of HIV: a conceptual framework.	This model is grounded in the data and is specific to the population studied but may be applied in similar settings. It is designed to enhance infant feeding practices and contribute to child health outcomes for the exposed infants.

Reference list

Atkinson, P., Coffey, SD., Lofland, J. and Lofland, L. (Editors) (2001) Handbook of Ethnography. London: Sage publication. p.12

Bandura, A. (1977). Self-efficacy: Toward a Unifying Theory of Behavioral Change. Psychological Review. 84:2:191-215.

Bandura, A. (1989). Social cognitive theory. In R. Vasta (Editor). Annals of child development. Six Theories of Childhood Development. Greenwich, CT: JAI Press.

Bandura, A. (1990). Perceived self-efficacy in the exercise of control over AIDS infection. Evaluation and Program Planning. 13:9-17.

Bandura, A. (1991). Social Cognitive Theory of Self Regulation. Organization Behaviour and Human decision Process. Academic Press Incorporated: 50:248-287.

Bandura, A. (2001). Social Cognitive Theory: An Agentic Perspective. Annual Review of Psychology. 52:1-26.

Bann, S. (1990). Tradition of Constructivism. Cambridge, MA: Da Capo Press.

Brabeck, M., & Brown, L. (1997). Feminist theory and psychological practice. In: Worell, J & Johnson, N. Editors: Shaping the future of feminist psychology: Education, research, and practice. Washington, D.C: American Psychological Association.

Chinkonde, J.R., Hem, M.H., & Sundby, J. (2012). HIV and infant-feedingin Malawi: public health simplicity in complex social and cultural contexts. BMC Public Health, 12, 700. doi: 10.1186/1471-2458-12-700

Creswell, J.W. (2007). Qualitatice inquiry and research design; choosing among five approaches. 2nd Edition. London Sage Publications, Incorporated.

CSO, MoH, & ICF. (2014). Zambia Demographic and Health Survey 2013-14. Rockville, Maryland, USA: Central Statistical Office.

CSO, MoH, TRDRC, UNZA, & MI. (2009). Zambia Demographic and Health Survey 2007. Maryland, USA: Central Statistics Office Macro International Incorprated.

Denzin, N., & Lincoln, Y. (1998). The Landscape of Qualitative Research: Theories and Issues United States of America: Sage Publications; Incorporated.

Dhandapany, G., Bethou, A., Arunagirinathan, A., & Ananthakrishnan, S. (2008). Antenatal counseling on breastfeeding -- is it adequate? A descriptive study from Pondicherry, India. Internationa Breastfeeding Journal. 3:5. doi: 10.1186/1746-4358-3-5

Ferguson, L. (2013). Women's experiences in services for preventing the mother to child transmission of HIV: a literature review. Geneva: World Health Organization.

Galel, N.K., Heath, H., Cameron, C., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Medical Research Methodology.13:117.

Guba, E. (1981). Criteria for Assessing the Trustiworthiness of Naturalistic Inquiries Educational Communication and Technology. 29:2;75-91.

Horkheimer, M. (1982). Critical Theory. New York: Seabury Press.

Keller, E. (1985). Reflections on Gender and Science. New Haven: Yale UP.

Leshabari, S.C., Blystad, A., de Paoli, M., & Moland, K. (2007). HIV and infant-feedingcounselling: challenges faced by nurse-counsellors in northern Tanzania. Human Resource for Health. 5:1-11. doi: 10.1186/1478-4491-5-18

Leshabari, S.C., Blystad, A., & Moland, K.M. (2007). Difficult choices: Infant-feedingexperiences of HIV positive mothers in northern Tanzania. Journal of social aspects of HIV/AIDS. 4:1.

Levy, J., Webb, A., & Sellen, D. (2010). "On our own, we can't manage": experiences with infant-feedingrecommendations among Malawian mothers living with HIV. International Breastfeeding Journal. 5:15. doi: 10.1186/1746-4358-5-15

Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. Newbury park, CA: Sage.

Madiba, S., & Langa, J. (2014). Cultural practices interfere with adherence to exclusive infant feeding: A qualitative study among HIV positive post-natal women in Hammanskraal, South Africa. African Journal for Physical, Health Education, Recreation and Dance (AJPHERD). 1;1:264-278.

Matji, J., Wittenberg, D., Makin, J., Jeffery, B., Maclntyre, U., & Forsyth, B. (2009). Factors affecting HIV-infected mothers' ability to adhere to antenatally intended infant-feedingchoice in Tshwane. South Africa Journal of Child Health. 3;1:20.

Ministry of Health. (2010). National Protocol Guidelines for Infant feeding; Integrated Prevention of Mother to Child Transmission of HIV/AIDS. Ministry of Health. Lusaka.

Ministry of Health. (2011). National health strategic plan 2011-2015 "Towards attainment of health related Millennium Development Goals and Other National Health Priorities in a clean, caring and Competent environment". Lusaka: Ministry of Health.

Ministry of Health. (2014a). Zambia Consolidated Guidelines for Treatment and Prevention of HIV infection. Ministry of Health. Lusaka:pp. 72.

Ministry of Health. (2014b). Zambia Country Report Monitoring the declaration of Commitment on HIV and AIDS and the Universal Access. Ministry of Health and National AIDS Council. Lusaka.

Oliver, S., & Petty, J. (2012). Breastfeeding and HIV transmission: An analysis of the factors influencing HIV positive mothers decision to breast-feed – A case study approach. Journal of Neonatal Nursing. 18:5;155-162. doi: http://dx.doi.org/10.1016/j.jnn.2012.07.013

Osmond, M., & Thorne, B. (1993). Feminist theories: The social construction of gender in families and society. In: P. G. Boss, W. J. Doherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.). Source book of family theories and methods: A contextual approach. New York: Plenum.

Richie, J., & Lewis, J. (2003). Qualitative research practicea: Guide for Social Science Students and Researchers. London: Sage publications

Rimer, B., & Glanz, K. (2005). Theory at a Glance; A Guide For Health Promotion Practice (2nd Edition): United States of America: National Institute of Health (NIH).

Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research: The Qualitative Researcher's Companion. London: Sage publications

Sheila, R. (1998). Issues in feminist: An Introduction to Women's Studies (4th ed.). London: Mayfield

Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. Education for Information; 22.

Smith, J., & Firth, J. (2011). Qualitative data analysis: the framework approach. Nurse Researcher. 18:2.

Sperling , R., Shapiro, D., Coombs , R., Todd , J., Herman, S., Mcsherry, G., . . . GROUP, S. (1996). Maternal Viral Load, Zidovudine treatment, and the Risk of Transmission of Human Immunodeficiency Virus Type 1 from mother to infant. The New England Journal of Medicine. 335:22.

UNAIDS. (2012). Global report: UNAIDS report on the global AIDS epidemic Switzerland UNAIDS.

UNAIDS. (2013). UN estimates with uncertainty abounds. Retrieved 7th November, 2014, from http://www.unaids.org/en/resources/documents/2014/HIV estimates with uncertainty bounds 1990-2013.

UNFPA, UNICEF, WHO, UNAIDS, & IATT. (2001). New Data on the Prevention of Mother-to-child Transmission of HIV and their Policy Implications: WHO Technical Consultation. Geneva Department of Reproductive Health and Research. Family and Community Health. Geneva: World Health Organization.

UNICEF. (2010). Improving Exclusive Breastfeed Practices by using Communication for Development in Infant and Young Child Feeding Programmes. pp. 41.

Valley, L., Kelly, A., Kupul, M., Neo, R., Fiya, V., Kaldor, J., . . . Worth, H. (2013). Infant-feedingin the context of HIV: a qualitative study of health care workers' knowledge of recommended infant-feedingoptions in Papua New Guinea. International Breastfeeding Journal. 8:8.

WHO. (2010). PMTCT strategic vision 2010-2015: Preventing mother-to-child transmission of HIV to reach the UNGASS and Millenium Development Goals. Geneva: WHO.

WHO, UNAIDS, UNFPA, & UNICEF. (2010). HIV and Infant-feeding Guidelines, Principles and recommendations for infant-feedingin the context of HIV and a summary of evidence. Geneva: WHO.

WHO, UNAIDS, & UNICEF. (2011). Global HIV/AIDS response: Epidemic update and health sector progress towards universal access. Geneva: World Health Organization

WHO, UNICEF, UNAIDS, & UNFPA. (2012). The 2010 WHO Guidelines on HIV and Infant Feeding: An updated framework for priority action. Geneva: World Health Organization

Chapter 2

HIV and infant feeding: implementation of infant feeding guidelines in resource-poor settings: a review of literature

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Abstract

Sub-Saharan Africa continues to be the region most severely affected by the HIV and AIDS pandemic, and babies born to HIV-positive women in this setting continue to have added risks of acquiring infection and dying from it before their fifth birthdays if no interventions are employed. Hence, the World Health Organization has continued to advise countries to prepare adequately for the dynamic and rapidly changing field of prevention of mother-to-child transmission of HIV to enable mothers and their infants to benefit fully from the package of interventions. This review brings to the fore the gaps that have continued to plague PMTCT programmes despite the gains achieved in treatment and prevention strategies. If not adequately addressed, poor quality counselling without regard to the principle of informed decision, coupled with continued cultural distance between the originators of standards and HIV-positive mothers' contextual environment in which breastfeeding takes place, has the potential to impede the global goal of virtual elimination of mother-to-child transmission of HIV.

Keywords: *Breastfeeding, culture, HIV, infant-feeding counselling, infant feeding guidelines, informed decision, prevention of mother-to-child transmission (PMTCT)*

Introduction

The global solidarity in the HIV and AIDS response during the past decade continues to generate extraordinary health gains although the pandemic has remained one of the world's most serious health challenge. Despite the declines recorded in the numbers of children dying from AIDS-related causes and acquiring HIV infection, substantial efforts are still needed to accelerate the achievement of global targets (UNAIDS, 2012). In the implementation of interventions, the efforts are directed at national health services to guide HIV-mothers, especially in resource-poor settings, on how best to feed their HIV-exposed infants and contribute towards the elimination of mother-to-child transmission (MTCT) (WHO, UNICEF, UNAIDS, & UNFPA, 2012). Prevention of mother-to-child transmission (PMTCT) of HIV has attracted a lot of debate on a number of issues such as ethical dilemmas surrounding the infant feeding choices, the poor applicability of infant feeding guidelines to the local context, and social drivers of HIV and AIDS (Auerbach, Parkhurst, & Caceres, 2011; Blystad et al., 2010; Fletcher, Ndebele, & Lelly, 2008). The focus of this debate is mothers in resource-poor settings. A number of thematic areas will be described before making a conclusion on the applicability of the infant feeding guidelines to the local contexts.

Magnitude of HIV among women and children in sub-Saharan Africa

Despite the gains achieved in prevention and treatment strategies, the world has continued to record new infections among women in the reproductive age and children aged 0-14 years. Out of an estimated 35 000 000 people living with HIV globally, 16 900 000 were women aged 15 years and above and 3 500 000 were children aged 0-14 years. Of the 1 400 000 new HIV infections reported in sub-Saharan Africa, 250 000 were children up to 14 years of age. With no interventions, babies born to HIV-positive women in sub-Saharan Africa will continue to have added risks of acquiring HIV infection and dying from it before their fifth birthdays. In estimates for children newly infected in southern African countries, the figures recorded for Mozambique and South Africa were 19 000 in each case, for Zimbabwe, 12 000, for Namibia, 1 800, for Malawi, 9 800, and for Zambia, 15 000 (UNAIDS, 2013). In Zambia, the prevalence of HIV among women aged 15-49 is currently 15 per cent (CSO, MoH, &

ICF, 2014), and the number of women living with HIV who delivered in 2012 was 81 727 (MoH, 2014b).

Although hese indicators continue to paint a gloomy picture of the fight against the HIV and AIDS pandemic as it continues to ravage sub-Saharan Africa, a lot of progress has been recorded in the prevention of paediatric new infections through PMTCT interventions.

Prevention of mother-to-child transmission of HIV

In research that has been conducted in some resource-poor settings, MTCT of HIV emerges as one of the key drivers of the HIV pandemic (Chinkonde, Sundby, de Paoli, & Thorsen, 2010; L. Kuhn et al., 2007; Leshabari, Koniz-Booher, Burkhalter, Hoffman, & Jennings, 2007; Rollins et al.). Since 1998, PMTCT has therefore been at the forefront of regional and global HIV prevention activities, following the success of the short-course Zidovudine and single-dose Nevirapine clinical trials which offered the promise of a relatively simple, low-cost intervention that could substantially reduce the risk of MTCT of HIV (UNAIDS & WHO, 2009). Research and programme experience has shown still newer and more effective ways to prevent MTCT, particularly in high-burden, low-resource settings, and significant progress has been made. However, work remains to be done because of new infections being recorded among children aged 0-14 years and hence there is no room for complacency (UNAIDS, 2013; WHO, 2010).

This background attests to the fact that PMTCT of HIV has remained a dynamic and rapidly changing field (Moland et al., 2010). The past decades have seen the emergence of new data to support treatment regimens and data on the safety of different modes of infant feeding to reduce postnatal transmission of HIV from the infected mother to her child (Coovadia et al., 2007; Iliffa et al., 2005; Sperling et al., 1996). Currently, the World Health Organization PMTCT antiretroviral (ARV) guidelines on treating pregnant women and preventing infection in infants encourages provision of two short-term ARV prophylaxis options (Option A and Option B) or of lifelong ART to all HIV-infected pregnant women, regardless of CD4 cell count (Option B+), and a number of countries are already adopting or considering the latter approach (MoH, 2014a; WHO, 2012). The responsibility for effectively implementing the infant feeding guidelines rests with national health care systems in populations with high HIV prevalence among women in the reproductive age. The next theme explores experiences

with contextualising the infant feeding guidelines in resource-poor settings and lessons learnt for the future.

Global infant feeding guidelines

The current 2010 infant feeding guidelines reflect the significant new evidence and knowledge regarding antiretroviral therapy (ART) and breastfeeding. In this regard, the World Health Organization (WHO) recommended that national health authorities should endorse either breastfeeding while receiving antiretroviral drugs (ARVs) (to the mother or infant), or avoidance of all breastfeeding (UNFPA, UNICEF, WHO, UNAIDS, & IATT, 2001; WHO et al., 2012). While formula feeding offers the safest postnatal prevention of HIV infection, its implementation in resource-poor settings poses risks of survival due to mixed feeding and contamination (Chisenga, Siame, Baisley, Kasonka, & Filteau, 2011; L Kuhn & Aldrovandi, 2010; Ladzani, Peltzer, Mlambo, & Phaweni, 2011), lack of resources to appropriately feed the baby (Manuela de Paoli, Manongi, & Klepp, 2003; Matji et al., 2009), and stigma coupled with guilty feelings (Doherty, Chopra, Nkonki, Jackson, & Greiner, 2006; Lakshman, Ogilvie, & Ong, 2009). However, in settings where formula feeding has been implemented, it was strongly associated with quality counselling and demonstration on preparation of feed, together with follow-up, serostatus disclosure, male-partner involvement and support (Odongkaraa, Kigulib, & Edison, 2013). On the other hand, breastfeeding, especially early initiation and exclusive breastfeeding in the first six months, offers protection from postnatal HIV infection (Coovadia et al., 2007; Iliffa et al., 2005; Kuhn et al., 2007). The 2010 WHO infant feeding guidelines recommend exclusive breastfeeding for the first six months of infant feeding and beyond while the mother gets lifelong ART (WHO et al., 2012). The guidelines continue to highlight the importance of avoiding mixed feeding, to reduce the risk of HIV transmission and to avoid diarrhoea and malnutrition.

At six months, if replacement feeding is still not AFASS-compliant, continuation of breastfeeding with additional complementary foods is recommended, while the mother and baby continue to be regularly assessed and monitored. All breastfeeding should stop once a nutritionally adequate and safe diet without breast milk can be provided (WHO, UNAIDS, UNFPA, & UNICEF, 2010).

In all these strategies, the implementation of infant feeding guidelines takes place in the communities where women live and work, hence quality counselling is fundamental to achieve safer infant feeding among the affected populations in view of the known challenges (Leshabari, Blystad, de Paoli, & Moland, 2007; Levy, Webb, & Sellen, 2010). Although the current infant feeding guidelines offer the hope of eliminating vertical transmission of HIV from mother-to-child, the recommendations do not give practical advice on how to guide the mother to choose and practice safer infant feeding while there is ongoing research for treatment.

However, regardless of the options available, success hinges on each mother's good intentions in choosing and practising safer infant feeding and on avoiding the risk of portraying a cosmetic picture of feeding as recommended while failing to cope with societal pressure and cultural demands.

Infant feeding counselling: local contextualisation in resource-poor settings

Burks and Stefflre describe counselling as a professional relationship between a trained counsellor and a client designed to help the latter to understand and clarify their views of their life space and to learn to reach their self-determined goals through meaningful, well informed choices and the resolution of problems of an emotional nature (McLeod, 2013). When applied to the principle of informed decision for infant feeding in the context of PMTCT, the process allows for a therapeutic engagement in which HIV-positive mothers are advised on safer infant feeding practices given the risks involved.

Evidence regarding infant feeding counselling shows that challenges arise in assisting HIV-positive mothers to choose and practice safer infant feeding. These challenges relate to infrastructure, communication skills among health care workers, low staffing levels, slow updates on infant feeding guidelines, and, to a certain extent, poor staff attitudes (Fadnes et al., 2010; Gourlay et al., 2014; Israel-Ballard, Waithaka, & Greiner, 2014; Leshabari, Blystad, de Paoli, et al., 2007; Sagoe-Moses, Mwinga, Habimana, Toure, & Ketsela, 2012). For instance, health care worker behaviours observed in some settings include their personal beliefs towards infant feeding, conveying contradictory messages on PMTCT, exhibiting directive counselling styles, and lack of practical strategies to offer mothers, often leading to improvised counselling approaches (Fadnes et al., 2010; Tuthill, Chan, & Butler, 2015).

In some settings, health care workers have attributed such factors to poor compliance by mothers and passive resistance resulting in stress, depression and burnout (Buskens & Jaffe, 2008). These factors have a multiplier effect on HIV-positive mothers, who have been observed to feel obliged to hide their feeding practices (Kalu et al., 2014; Lazarus, Struthers, & Violari, 2013), thereby risking the lives of their HIV-exposed infants.

Variations in counselling practices have also been reported and include prescriptive models where one option is proposed for all women, based on the mother's economic status, whereas mothers are concerned with social issues related to the risk of being stigmatized as a bad mother or as being HIV-positive when making a decision (Desclaux & Alfieri, 2009). Other researchers have observed that counsellors frequently framed counselling sessions as health education programmes and instruction, where mothers are subjected to 'advising and giving of information' – a style rooted in a didactic and instructive model and consequently unable to create an environment where choice could become an option (Buskens & Jaffe, 2008; Oladokun, Brown, & Osinusi, 2010). These deficiencies have led to recommendations that counselling messages should critically align infant feeding with local context and making use of counselling cards (Katepa-Bwalya, Kankasa, Babaniyi, & Siziya, 2011; Leshabari, Koniz-Booher, Astrom, de Paoli, & Moland, 2006). An environment that better enables mothers to understand the information on national guidelines and make informed decisions should thus be available, taking heed of lessons learnt in similar settings (Odongkaraa et al., 2013).

Prevalence of breastfeeding and exclusive breastfeeding

While WHO infant feeding guidelines emphasise that exclusive breastfeeding (EBF) for six months is protected, promoted and supported (WHO et al., 2012), evidence shows that the prevalence of EBF remains low in the developing world, despite considerable coverage of PMTCT services (Cai, Wardlaw, & Brown, 2012; Katepa-Bwalya et al., 2015). Exclusive breastfeeding for the first six months is known to reduce the risk of postnatal vertical transmission of HIV infection from mother-to-child (Coovadia et al., 2007; Iliffa et al., 2005; Thomas et al., 2011), but despite the known health and economic benefits of breastfeeding, several obstacles to exclusive breastfeeding remain, with mothers in most settings showing a preference for mixed feeding (Leshabari, Blystad, & Moland, 2007; Nor et al., 2012).

A number of factors have been cited for the failure by HIV-positive mothers to practise EBF. In some societies, for instance, mixed feeding is considered a normal practice and this information is passed from generation to generation (Laar, Ampofo, Tuakli, & Quakyi, 2009; Madiba & Langa, 2014). In some settings, EBF is hindered by difficulties such as breast health problems, poor nutrition of mothers, lack of knowledge about EBF practices and lack of psychosocial support (Maman et al., 2012; Matji et al., 2009; Matovu, Kirunda, Rugamba-Kabagambe, Tumwesigye, & Nuwaha, 2008).

Breastfeeding, a cultural practice in sub-Saharan Africa: what women know

In regard to breastfeeding, what do women already know? Research in different settings in sub-Saharan Africa has brought to light the deep-seated conceptualization of breastfeeding as a customary way of feeding newborn babies. In these settings, mothers have always regarded breastfeeding as a way of fulfilling motherhood and have therefore found it difficult to adhere to the scientifically recommended infant feeding guidelines in the context of PMTCT while simultaneously trying to maintain cultural practices (Chinkonde, Hem, & Sundby, 2012; Fadnes et al., 2009; Leshabari, Blystad, & Moland, 2007; Madiba & Langa, 2014; Maman et al., 2012). Among the cultural practices related to breastfeeding are early introduction of fluids (a practice of introducing the baby to foods), mixed feeding associated with milk insufficiency, and use of herbs to cleanse the intestines of the newborn baby – practices which are run counter to the facts related to MTCT of HIV (Engebretsen et al., 2010; Fjeld et al., 2008; Levy et al., 2010). On the other hand, beliefs about the quality of breast milk, especially in relation to colostrum, highlight the role of culture in women's decisions and behaviours affecting infant feeding practice (Katepa-Bwalya et al., 2015; Thairu, Pelto, Rollins, Bland, & Ntshangase, 2005).

In the overall context of culture and breastfeeding, discrepancies have been observed in health worker attitudes, cultural beliefs, and counselling messages relating to existing recommendations on HIV and infant feeding (Piwoz et al., 2006). This requires attention because of the tendency to look down on what women strongly believe rather than empowering them with decisions on how to modify their practices.

Change in the mindset of recipients requires attention because identifying cultural practices that influence breastfeeding and infant feeding in general is a move in the right direction that

would directly influence uptake of PMTCT interventions. Quality counselling plays an important in helping mothers make such decisions for the benefit of their HIV-exposed infants. But what does infant feeding counselling mean in resource-poor settings?

Informed-decision; a way to successful infant feeding

Studies relating to HIV and infant feeding often associate informed-decision with choice between breastfeeding and formula feeding for HIV-exposed infants (Laar et al., 2009; Lawani, Onyebuchi, Iyoke, Conoh, & Nkwo, 2014; Leshabari, Blystad, & Moland, 2007). But in regard to the question, "*What is informed-decision in the context of prevention of mother-to-child transmission of HIV?*" there is in fact no agreed definition for *informed-decision* because it is seen as dependent on the theoretical predisposition of the investigator of the phenomena. A compromise definition by Bekker and others (1999), cited by O'Connor and others (2003) suggests that informed-decision is where a reasoned choice is made by a reasonable individual, using relevant information about the advantages and disadvantages of all the possible courses of action, in accord with the individual's beliefs. Applying this definition to a local context would thus entail that an informed decision is where an infant feeding choice is made by a counselled and empowered HIV-positive mother, using relevant and context-appropriate infant feeding counselling messages with full knowledge about the advantages and disadvantages of all the possible feeding options based on individual circumstances.

Whereas participation in decision making is fundamental for client participation in prevention and health care and is the guiding principle for infant feeding counselling (Elwyn et al., 2003), the principle of informed-decision on infant feeding has been applied differently in some resource-poor settings. It is important to note that what is common among HIV-positive mothers is their desire to make the best choice for themselves and their infants, but it has been observed that what varies are their levels of support, the environments within which infant-feeding takes place, and their personal voices as they express their concerns, aspirations and approaches to facing their future living with HIV (Piwoz & Bentley, 2005).

Among the conditions highlighted as necessary for informed-decision is serostatus disclosure – an issue which has been poorly handled in various settings, with mothers feeling coerced to take the HIV test which in turn makes it difficult for them to freely utilize PMTCT services

(Hardon et al., 2012). Quality counselling entails making sure that women clearly understand HIV infection in the context of MTCT, although this may be associated with prescriptive models of counselling where health care workers educate the clients instead of guiding them along the pathway of knowledge acquisition (Gourlay et al., 2014). In some settings where gaps have been identified in infant feeding counselling, use of counselling cards has had success in enhancing communication, while in others development of culturally sensitive guidelines have improved uptake of PMTCT services (Katepa-Bwalya et al., 2011; Leshabari, Koniz-Booher, et al., 2007).

While recognising the importance of infant-feeding counselling and promotion of exclusive breastfeeding for HIV-positive mothers with lifelong ART in resource-poor settings (WHO et al., 2012), evidence suggests the need for objective counselling that assesses the suitability of the different feeding options for each mother and the importance of providing information that will empower them make informed-decisions about a feasible and sustainable feeding option (Frizelle & Solomon, 2009). Quality counselling will enable HIV-positive mothers to identify opportunities and possible limitations that would hinder uptake of PMTCT services and adequately prepare them to deal with such challenges. Some of the known obstacles to uptake of PMTCT services are described in reation to the next theme of this review.

Obstacles to uptake of services for PMTCT in resource-poor settings

According to WHO, there are a number of inequities that can affect access to PMTCT services, relating to location, income and other socio-economic factors. Although PMTCT interventions can be highly successful in reducing the risk of HIV transmission, access to and utilization of PMTCT services is still limited in many parts of sub-Saharan Africa owing to a variety of structural-contextual factors. For instance, in countries with generalized epidemics, rural and/or poor women often have difficulty in accessing the services (Adedimeji, Abboud, Merdekios, & Shiferaw, 2012; Kendall & Danel, 2014; WHO, 2010). Factors that have been identified as potentially discouraging HIV-positive women from participating in the PMTCT programmes include fear of knowing one's own HIV status, stigma, socio-cultural aspects of pregnancy and childbirth, lack of support and negative attitudes of health care workers. Although HIV and AIDS stigma has been documented in numerous settings as an obstacle to uptake of HIV testing and treatment services, particularly in resource-limited countries, efforts to reduce it are not given priority in intervention programmes. One primary reason

which is often cited in seeking to explain the limited response to HIV/AIDS-related stigma is the complexity of this pervasive phenomenon (Mahajan et al., 2008), but for as long as women remain unprotected from stigmatization it will continue to hinder progress in uptake of PMTCT services in resource-poor settings. One entry point for reducing stigmatization is facilitating disclosure of serostatus. Serostatus disclosure is significantly associated with EBF (Onono, Cohen, Jerop, Bukusi, & Turan, 2014) but the belief that disclosure causes divorce, abuse or is unimportant contributes to nondisclosure in some settings (Mucheto et al., 2011). In settings where the issue had been adequately addressed, HIV-positive women who had disclosed their serostatus were nearly three times more likely to EBF than women who were HIV-negative or did not know their status. High rates of anticipated male-partner stigma, on the other hand, and fear of negative male-partner reactions, including intimate partner violence during pregnancy and postpartum, are associated with lack of disclosure of serostatus (Onono et al., 2014), negatively affecting uptake of PMTCT services. As earlier indicated, social support networks and individual factors have a bearing on how best HIV-positive mothers should feed their infants. These factors are known to facilitate or hinder uptake of services at various levels of health care delivery (Betancour, Abrams, McBain, & Fawzi, 2010). Maternal health services such as antenatal care coverage, access to facility birth, distance to health facility and staffing, if not adequately addressed, could hinder uptake of PMTCT services because they are integrated in maternal, neonatal and child health services in some settings of sub-Saharan Africa (Adedimeji et al., 2012; MoH, 2010). For instance, increasing access to health facility delivery coverage could raise the numbers of mother-child pairs who are getting PMTCT interventions (Lerebo, Callens, Jackson, Zarowsky, & Temmerman, 2014).

Theoretical perspective to HIV and infant feeding

Mother-to-child transmission of HIV has changed the landscape of infant feeding in resource-poor settings, and even in countries with strong PMTCT programmes there is no room for complacency (WHO, 2010). This raises the need for modification in the way of feeding babies, calling for the kind of change that is always difficult to adapt to, and requires learning if it is to be achieved. Among the core determinants for behaviour change are knowledge and self-efficacy, and the higher the self-efficacy, the more likely it is that women will be able to exert the necessary effort and perseverance for behaviour to change (Rimer & Glanz, 2005).

Some scholars have recommended that general messages and top-down directives are not enough to change entrenched normative views within communities, among both HIV-positive mothers and health workers, about appropriate feeding practices for HIV-exposed infants (Lazarus et al., 2013). This highlights the point that every human experience or event is socially and culturally constructed, gendered, and subject to meaning-making processes that transform it into a social practice even if it is rooted in the normal function of the body (Creswell, 2007). While acknowledging the importance of the emphasis in the revised 2010 WHO infant feeding guidelines on EBF in resource-poor settings, some scholars have argued that merely changing guidelines is not sufficient to change practice, particularly with regard to culturally sanctioned forms of feeding, such as mixed feeding, because of the existing structural, social and contextual obstacles to effective implementation of the guidelines (Lazarus et al., 2013). Different approaches have been tested with encouraging results for improvement in uptake of PMTCT services.

Family-centred approaches to care and support have been seen to increase spousal communication on risks of HIV infection that was associated with increased HIV testing in male partners (Betancour et al., 2010). Provider–patient relations were associated with PMTCT services, and, in settings where this was tested, led to shared-decision making for infant feeding, although power imbalance in favour of providers was reported. Also identified in this regard were gaps in service provision where there was potential for optimising provider–patient relations to improve ART adherence and uptake of maternal health services more broadly (Gourlay et al., 2014).

Adapting WHO infant feeding guidelines to the local context thus requires assessment of gaps and opportunities in the settings by means of intervention mapping. Where this has been applied, it has been possible to develop culturally sensitive infant feeding guidelines because identification of obstacles and facilitators for change assisted in the development of key counselling messages and graphics that reflect the socio-economic reality, cultural beliefs and norms of mothers and their significant others (Leshabari et al., 2006). This approach has been recommended in settings where EBF was regarded as impossible because it ran counter to the culturally traditional way of feeding newborn babies (Engebretsen et al., 2010).

In another setting, a multi-stage content development approach to text messaging that was informed by behavioural theory resulted in message content that was consistent and was

assumed to improve postpartum PMTCT retention and infant HIV testing in a randomized trial (Odeny et al., 2014). Health care systems need to acknowledge that implementation of infant-feeding guidelines takes place in communities were women live and work. Strategies for successful implementation therefore need to be considered in line with the community dynamics.

Conclusion

This review highlights what still needs to happen for HIV-positive mothers as they strive to choose and practice safer infant feeding within their challenging environments. The gaps identified may continue to plague PMTCT interventions if not adequately addressed because of their potential to derail programmes for virtual elimination of MTCT of HIV. In settings where breastfeeding is a cultural practice, it is particularly important for infant feeding counselling to be informed by the way breastfeeding in particular and infant feeding in general are conceptualized by HIV-positive mothers. In such a context, attempting to generalize what works to all settings can potentially obstruct evidence-based practice, with negative consequences. Counselling on infant feeding should be tailored towards ensuring optimal PMTCT practices that are sensitive to particular settings. Feeding options that provide optimal survival of HIV-exposed infants need to be clearly explained to mothers without ambushing them to do so. The principle of informed-decision needs to be guided by relevant information about the known scientifically proven options, while allowing mothers to conduct an informed self-assessment of safer options for feeding their infants.

List of references

Adedimeji, A., Abboud, N., Merdekios, B., & Shiferaw, M. (2012). A Qualitative Study of Barriers to Effectiveness of Interventions to Prevent Mother-to-Child Transmission of HIV in Arba Minch, Ethiopia. International Journal of Population Research. 2012:1-7. doi: 10.1155/2012/532154.

Auerbach, J. D., Parkhurst, J. O., & Caceres, C. F. (2011). Addressing social drivers of HIV/AIDS for the long-term response: conceptual and methodological considerations. Global Public Health. 6 Supplement. 2011:3;S293-309. doi: 10.1080/17441692.2011.594451

Bekker, H., Lilleyman, J., Thornton, J., MacIntosh, M., Airey, C., Maule, A., . . . MB, R. (1999). Informed decision making: an annotated bibliography and systematic review. Health Technology Assessment. 3:1.

Betancour, T., Abrams, E., McBain, R., & Fawzi, M. (2010). Family-centred approaches to the prevention of mother to child transmission of HIV. Journal of International AIDS Society. 13:2.

Blystad, A., van Esterik, P., de Paoli, M. M., Sellen, D. W., Leshabari, S. C., & Moland, K. M. (2010). Reflections on global policy documents and the WHO's infant-feedingguidelines: lessons learnt. International Breastfeeding Journal. 5:18. doi: 10.1186/1746-4358-5-18.

Buskens, I., & Jaffe, A. (2008). Demotivating infant-feeding counselling encounters in southern Africa: do counsellors need more or different training? AIDS Care. 20:3;337-345. doi: 10.1080/09540120701660346

Cai, X., Wardlaw, T., & Brown, D. (2012). Global trends in exclusive breast feeding. International Breastfeeding Journal. 7:12.

Chinkonde, J. R., Hem, M. H., & Sundby, J. (2012). HIV and infant-feeding in Malawi: public health simplicity in complex social and cultural contexts. BMC Public Health. 12:700. doi: 10.1186/1471-2458-12-700.

Chinkonde, J. R., Sundby, J., de Paoli, M., & Thorsen, V. C. (2010). The difficulty with responding to policy changes for HIV and infant-feedingin Malawi. International Breastfeeding Journal. 5:11. doi: 10.1186/1746-4358-5-11.

Chisenga, M., Siame, J., Baisley, K., Kasonka, L., & Filteau, S. (2011). Determinants of infant-feeding choices by Zambian mothers: a mixed quantitative and qualitative study. Maternal and Child Nutrition. 7:2;148-159. doi: 10.1111/j.1740-8709.2010.00264.x.

Coovadia, H.M., Rollins, N.C., Bland, R.M., Little, K., Coutsoudis, A., Bennish, M., & Newell, M. (2007). Mother-to-child transmission of HIV-1 infection during exclusive breastfeeding in the first 6 months of life: an intervention cohort study. The Lancet:369, 9567, 1107.

Creswell, J.W. (2007). Qualitatice inquiry and research design; choosing among five approaches (2nd Edition). London: Sage Publications.

CSO, MoH, & ICF. (2014). Zambia Demographic and Health Survey 2013-14. Rockville, Maryland, USA: Central Statistical Office.

Desclaux, A., & Alfieri, C. (2009). Counseling and choosing between infant-feeding options: overall limits and local interpretations by health care providers and women living with HIV in resource-poor countries (Burkina Faso, Cambodia, Cameroon). Social Science and Medicine. 69:6;821-829. doi: 10.1016/j.socscimed.2009.06.007

Doherty, T., Chopra, M., Nkonki, L., Jackson, D., & Greiner, T. (2006). Effect of the HIV epidemic on infant-feeding in South Africa:"When they see me coming with the tins they laugh at me" Bulletin of the World Health Organization (Vol. 84).

Elwyn, G., Edwards, A., Wensing, M., Hood, K., Atwell, C., & Grol, R. (2003). Shared decision making: developing the OPTION scale for measuring patient involvement. Quality and Safe Health Care. 12:93-99.

Engebretsen, I. M.S, Moland, K. M., Nankunda, J., Karamagi, C. A., Tylleskar, T., & Tumwine, J. K. (2010). Gendered perceptions on infant-feeding in Eastern Uganda: continued need for exclusive breastfeeding support. International Breastfeeding Journal. 5:13. doi: 10.1186/1746-4358-5-13.

Fadnes, L.T., Engebretsen, I.M.S., Moland, K.M., Nankunda, J., Tumwine, J.K., & Tylleskar, T. (2010). Infant-feeding counselling in Uganda in a changing environment with focus on the general population and HIV-positive mothers - a mixed method approach. BMC Health Services Research. 10:260. doi: 10.1186/1472-6963-10-260

Fadnes, L.T., Engebretsen, I.M.S., Wamani, H., Semiyaga, N., Tylleskar, T., & Tumwine, J.K. (2009). Infant-feeding among HIV-positive mothers and the general population mothers: comparison of two cross-sectional surveys in Eastern Uganda. BMC Public Health. 9:124. doi: 10.1186/1471-2458-9-124.

Fjeld, E., Siziya, S., Katepa-Bwalya, M., Kankasa, C., Moland, K. M., Tylleskar, T., & Group, P.-E. S. (2008). 'No sister, the breast alone is not enough for my baby' a qualitative assessment of potentials and barriers in the promotion of exclusive breastfeeding in southern Zambia. International Breastfeeding Journal. 3:26. doi: 10.1186/1746-4358-3-26.

Fletcher, F., Ndebele, P., & Lelly, M. (2008). Infant-feeding and HIV in sub-Saharan Africa: What lies beneath the dilemma. Theor Med Bioeth. doi: DOI 10.1007/s11017-008-9083-z.

Frizelle, K., & Solomon, V. (2009). Strengthening PMTCT through communication: A review of literature. UNICEF. South Africa.

Gourlay, A., Wringe, A., Birdthistle, S., Mshana, G., Michael, D., & Urassa, M. (2014). ‘‘It Is Like That, We Didn’t Understand Each Other’’: Exploring the Influence of Patient-Provider Interactions on Prevention of Mother-To-Child Transmission of HIV Service Use in rural Tanzania. PLoS ONE. 9:9. doi: 10.1371/journal.pone.0106325.g001.

Hardon, A., Vernooij, E., Bongololo-Mbera, G., Cherutich, P., Desclaux, A., Kyaddondo, D., . . . Obermeyer, C. (2012). Women’s views on consent, counseling and confidentiality in PMTCT: a mixed-methods study in four African countries. BMC Public Health. 12:26. doi: 10.1186/1471-2458-12-26.

Iliffa, P., Piwozb, E., Tavengwaa, N., Zunguzac, C., Marindaa, E., Nathood, K., . . . Humphreya, J. (2005). Early exclusive breastfeeding reduces the risk of postnatal HIV-1 transmission and increases HIV-free survival. AIDS. 19:699–708. doi: 10.1016/j.qad.2004.09.015.

Israel-Ballard, K., Waithaka, M., & Greiner, T. (2014). Infant-feeding counselling of HIV-infected women in two areas in Kenya in 2008. International Journal of STD and AIDS. 25:13;921-928. doi: 10.1177/0956462414526574.

Kalu, S., Reynolds, F., Petra, G., Ikechebelu, J., Dada, M., Oluboyo, B., & Igwegbe, A. (2014). Infant-feeding Choices Practiced among HIV-Positive Mothers Attending a Prevention of Mother to Child Transmission (PMTCT) of HIV Program in Nnewi, Nigeria. Journal of AIDS & Clinical Research. 5:5;6. doi: 10.4172/2155-6113.1000300.

Katepa-Bwalya, M., Kankasa, C., Babaniyi, O., & Siziya, S. (2011). Effect of using HIV and infant-feeding counselling cards on the quality of counselling provided to HIV positive mothers: a cluster randomized controlled trial. International Breastfeeding Journal. 6:13. doi: 10.1186/1746-4358-6-13.

Katepa-Bwalya, M., Mukonka, V., Kankasa, C., Masaninga, F., Babaniyi, O., & Siziya, S. (2015). Infants and young children feeding practices and nutritional status in two districts of Zambia. International Breastfeeding Journal. 10:1. doi: 10.1186/s13006-015-0033-x.

Kendall, T., & Danel, I. (2014). Research and Evaluation Agenda for HIV and Maternal Health in sub-Saharan Africa: Women and Health Initiative Working Paper No. 1. Boston MA: Havard School of Public Health.

Kuhn, L., & Aldrovandi, G. (2010). Survival and health benefits of breastfeeding versus artificial feeding in infants of HIV-infected women: developing versus developed world. Clinical Perinatol. 37:4;843-862. doi: 10.1016/j.clp.2010.08.011x

Kuhn, L., Sinkala, M., Kankasa, C., Semrau, K., Kasonde, P., Scott, N., . . . Thea, D. M. (2007). High uptake of exclusive breastfeeding and reduced early post-natal HIV transmission. PLoS ONE. 2:12;e1363. doi: 10.1371/journal.pone.0001363.

Laar, A., Ampofo, W., Tuakli, J., & Quakyi, I. (2009). Infant-feeding choices and experiences of HIV-positive mothers from two Ghanian districts. Journal of AIDS and HIV Research. 1:2;023-033.

Ladzani, R., Peltzer, K., Mlambo, M. G., & Phaweni, K. (2011). Infant-feeding practices and associated factors of HIV-positive mothers at Gert Sibande, South Africa. Acta Paediatrica. 100:4;538-542. doi: 10.1111/j.1651-2227.2010.02080.x.

Lakshman, R., Ogilvie, D., & Ong, K. K. (2009). Mothers' experiences of bottle-feeding: a systematic review of qualitative and quantitative studies. Arch Dis Child. 94;8:596-601. doi: 10.1136/adc.2008.151910.

Lawani, L. O., Onyebuchi, A. K., Iyoke, C. A., Conoh, R., & Nkwo, P. O. (2014). The challenges of adherence to infant-feeding choices in prevention of mother-to-child transmission of HIV infections in South East Nigeria. Patient Preference & Adherence. 8:377-381. doi: 10.2147/PPA.S61796.

Lazarus, R., Struthers, H., & Violari, A. (2013). Promoting safe infant-feeding practices - the importance of structural, social and contextual factors in Southern Africa. Journal of International AIDS Society. 16:18037. doi: 10.7448/IAS.16.1.18037.

Lerebo, W., Callens, S., Jackson, D., Zarowsky, C., & Temmerman, M. (2014). Identifying factors associated with the uptake of prevention of mother to child HIV transmission programme in Tigray region, Ethiopia: a multilevel modeling approach. BMC Health Service Research. 14:181. doi: 10.1186/1472-6963-14-181.

Leshabari, S.C., Blystad, A., de Paoli, M., & Moland, K.M. (2007). HIV and infant-feeding counselling: challenges faced by nurse-counsellors in northern Tanzania. Human Resource for Health. 5:1-11. doi: 10.1186/1478-4491-5-18.

Leshabari, S.C., Blystad, A., & Moland, K.M. (2007). Difficult choices: Infant-feeding experiences of HIV positive mothers in northern Tanzania. Journal of social aspects of HIV/AIDS. 4:1.

Leshabari, SC., Koniz-Booher, P., Astrom, A., de Paoli, M., & Moland, K. (2006). Translating global recommendations on HIV and infant-feeding to the local context: the development of culturally sensitive counselling tools in the Kilimanjaro Region, Tanzania. Implementation Science. 1:22. doi: 10.1186/1748-5908-1-22.

Leshabari, S., Koniz-Booher, P., Burkhalter, B., Hoffman, M., & Jennings, L. (2007). Testing a PMTCT Infant-feeding Counseling Program in Tanzania. Operations Research Results.

Levy, J., Webb, A., & Sellen, D. (2010). "On our own, we can't manage": experiences with infant-feeding recommendations among Malawian mothers living with HIV. International Breastfeeding Journal. 5:15. doi: 10.1186/1746-4358-5-15.

Madiba, S., & Langa, J. (2014). Cultural practices interfere with adherence to exclusive infant feeding: A qualitative study among HIV positive post natal women in Hammanskraal, South Africa. African Journal for Physical, Health Education, Recreation and Dance (AJPHERD). 1:1;264-278.

Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Sawires, S. R., Ortiz, D. J., . . . Coates, T. J. (2008). Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. AIDS. 22:Suppemlent 2;S67-79. doi: 10.1097/01.aids.0000327438.13291.62.

Maman, S., Cathcart, R., Burkhardt, G., Omba, S., Thompson, D., & Behets, F. (2012). The infant-feeding choices and experiences of women living with HIV in Kinshasa, Democratic Republic of Congo. AIDS Care. 24:2;259-265. doi: 10.1080/09540121.2011.597708.

Manuela de Paoli, M., Manongi, R., & Klepp, K.-l. (2003). Are infant-feeding options that are recommended for mothers with HIV acceptable, feasible, affordable, sustainable and safe? Pregnant women's perspective. Public Health Nutrition. 7:5;611-619. doi: 10.1079/PHN2003596.

Matji, J., Wittenberg, D., Makin, J., Jeffery, B., Maclntyre, U., & Forsyth, B. (2009). Factors affecting HIV-infected mothers' ability to adhere to antenatally intended infant-feeding choice in Tshwane. South Africa Journal of Child Health. 3:1;20.

Matovu, A., Kirunda, B., Rugamba-Kabagambe, G., Tumwesigye, N., & Nuwaha, F. (2008). Factors influencing adherence to exclusive breastfeeding among HIV positive mothers in Kabarole District, Uganda. East African Medical Journal. 85:4;162-117.

McLeod, J. (2013). An Introduction to Counselling, 5E: McGraw-Hill International.

MoH. (2010). National Protocol Guidelines for Infant feeding; Integrated Prevention of Mother to Child Transmission of HIV/AIDS. Lusaka: Ministry of Health.

MoH. (2014a). Zambia Consolidated Guidelines for Treatment and Prevention of HIV infection. Lusaka: Ministry of Health.

MoH. (2014b). Zambia Country Report Monitoring the declaration of Commitment on HIV and AIDS and the Universal Access. Lusaka: Ministry of Health and National AIDS Council.

Moland, K.M., de Paoli, M., Sellen, D.W., van Esterik, P., Leshabari, S.C., & Blystad, A. (2010). Breastfeeding and HIV: experiences from a decade of prevention of postnatal HIV transmission in sub-Saharan Africa. International Breastfeeding Journal. 5:10-16. doi: 10.1186/1746-4358-5-10.

Mucheto, P., Chadambuka, A., Shambira, G., Tshimanga, M., Notion, G., & Nyamayaro, W. (2011). Determinants of nondisclosure of HIV status among women attending the prevention of mother to child transmission programme, Makonde district, Zimbabwe, 2009. Pan African Medical Journal. 8:51.

Nor, B., Ahlberg, B. M., Doherty, T., Zembe, Y., Jackson, D., Ekstrom, E. C., & Group, P.-E. S. (2012). Mother's perceptions and experiences of infant-feeding within a community-based peer counselling intervention in South Africa. Maternal and Child Nutrition. 8:4;448-458. doi: 10.1111/j.1740-8709.2011.00332.x.

O'Connor, A., Stacey, D., Entwistle, V., Llewellyn-Thomas, H., Rovner, D., Holmes-Rovner, M., . . . J, J. (2003). Decision aids for people facing health treatment or screening decisions. doi: 10.1002/14651858.CD001431). Retrieved 26/02/2015, from Cochrane Database of Systematic Reviews 2003.

Odeny, T., Newman, M., Bukusi, E., McVlelland, R., Cohen, C., & Camlin, C. (2014). Developing Content for mHealth Intervention to Promote Postpartum Retention in Prevention of Mother to Child Transmission HIV Programs and Early Infant Diagnosis of HIV: A qualitative study. PLoS ONE. 9:9. doi: 10.1371/journal.pone

Odongkaraa, B., Kigulib, S., & Edison, M. (2013). Factors influencing replacement feeding practices among HIV -positive mothers attending the PMTCT program at Uganda. Journal of Pediatric Infectious Diseases. 8:7-17. doi: 10.3233/jpi-130376.

Oladokun, R. E., Brown, B. J., & Osinusi, K. (2010). Infant-feeding pattern of HIV-positive women in a prevention of mother-to-child transmission (PMTCT) programme. AIDS Care. 22:9;1108-1114. doi: 10.1080/09540120903511008.

Onono, M., Cohen, C., Jerop, M., Bukusi, E.A., & Turan, J.M. (2014). HIV serostatus and disclosure: implications for infant-feeding practice in rural south Nyanza, Kenya. BMC Public Health. 14:390. doi: 10.1186/1471-2458-14-390

Piwoz, E., & Bentley, E. (2005). Women's voices, Women's choices: The Challenge of Nutrition and HIV/AIDS. The Journal of Nutrition. 135:4;933.

Piwoz, E.G, Ferguson, Y.O., Bentley, M.E., Corneli, A.L, Moses, A., Nkhoma, J., . . . BAN, U. P. (2006). Differences between international recommendations on breastfeeding in the presence of HIV and the attitudes and counselling messages of health workers in Lilongwe, Malawi. International Breastfeeding Journal. 1:2. doi: 10.1186/1746-4358-1-2

Rimer, B., & Glanz, K. (2005). Theory at a Glance; A Guide For Health Promotion Practice (2nd Edition): National Institute of Health (NIH).

Rollins, N., Becquet, R., Bland, R., Coutsoudis, A., Coovadia, H., & Newell, M. Infant feeding, HIV infection and mortality at 18 months: the need for appropriate choices by mothers and prioritization within programmes.

Sagoe-Moses, C., Mwinga, K., Habimana, P., Toure, I., & Ketsela, T. (2012). Implementation of the new who recommendations on HIV and infant feeding: challenges and the way forward. African Journal of Food, Agriculture, Nutrition and Development. 12:4.

Sperling , R., Shapiro, D., Coombs , R., Todd , J., Herman, S., Mcsherry, G., . . . GROUP, S. (1996). Maternal Viral Load, Zidovudine treatment, and the Risk of Transmission of Human Immunodeficiency Virus Type 1 from mother to infant. The New England Journal of Medicine. 335:22.

Thairu, L., Pelto, G., Rollins, N., Bland, R., & Ntshangase, N. (2005). Sociocultural influences on infant-feeding decisions among HIV infected women in rural Kwa_Zulu Natal, South Africa. Maternal and Child Nutrition. 1:2-10.

Thomas, T., Masaba, R., Borkowf, C., Ndivo, R., Zeh, C., Misore, A., . . . Ki, B. S. S. T. (2011). Triple-antiretroviral prophylaxis to prevent mother-to-child HIV transmission through breastfeeding--the Kisumu Breastfeeding Study, Kenya: a clinical trial. PLoS Medicine. 8:3;e1001015. doi: 10.1371/journal.pmed.1001015.

Tuthill, E. L., Chan, J., & Butler, L. M. (2015). Challenges faced by health-care providers offering infant-feeding counseling to HIV-positive women in sub-Saharan Africa: a

review of current research. AIDS Care. 27:1;17-24. doi: 10.1080/09540121.2014.951310

UNAIDS. (2012). Global report: UNAIDS report on the global AIDS epidemic. Switzerland: UNAIDS.

UNAIDS. (2013). UN estimates with uncertainty abounds Retrieved 7th November, 2014, from http://www.unaids.org/en/resources/documents/2014/HIV estimates with uncertainty abounds 1990-2013.

UNAIDS, & WHO. (2009). AIDS epidemic update Switzerland WHO.

UNFPA, UNICEF, WHO, UNAIDS, & IATT. (2001). New Data on the Prevention of Mother-to-child Transmission of HIV and Their Policy Implications: WHO Technical Consultation. Geneva Department of Reproductive Health and Research, Family and Community Health. Geneva: World Health Organization.

WHO. (2010). PMTCT strategic vision 2010-2015. Preventing mother to child transmission of HIV to reach the UNGASS and Millennium Development Goals. Geneva WHO.

WHO. (2012). Use of antiretroviral drugs for treating pregnant women and preventing hiv infection in infants HIV/AIDS Program update. Geneva: WHO.

WHO, UNAIDS, UNFPA, & UNICEF. (2010). HIV and Infant-feeding Guidelines, Principles and recommendations for infant-feedingin the context of HIV and a summary of evidence. Geneva: WHO.

WHO, UNICEF, UNAIDS, & UNFPA. (2012). 2010 WHO Guidelines on HIV and Infant-feedingAn updated framework for priority action. Geneva: WHO

Chapter 3

HIV and infant feeding: Serostatus disclosure and associated risk factors among HIV-positive mothers in Lusaka, Zambia

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Abstract

As a public health approach in Zambia, all mothers, regardless of their HIV status, are encouraged to exclusively breastfeed for the first six months of infant feeding. This study is linked to the Ministry of Health's effort to encourage breastfeeding among HIV-positive

mothers. Health care workers must offer women counselling, guidance and support to practice exclusive breastfeeding. However, there are challenges faced in counselling HIV-positive mothers to practice exclusive breastfeeding. The aim of this study was to explore serostatus disclosure and associated risk factors in the context of exclusive breastfeeding among HIV-positive mothers accessing PMTCT services.

This research was part of the larger study to analyse choices and decision outcomes on infant feeding in the context of prevention of mother-to-child transmission of HIV. This was a health facility and community-based study that was designed to follow HIV-positive mothers for six months after delivery. The design was a case study utilizing in-depth interviews with 30 HIV-positive mothers and six key informants. A semi-structured instrument was used to conduct interviews which were digitally recorded, simultaneously transcribed and all files imported into QRS NVivo 10 version for coding and analysis.

Our findings revealed that although HIV-positive mothers were aware of the risks of mother-to-child transmission of HIV through breast milk, the pattern of serostatus disclosure varied according to individual circumstances. Some mothers disclosed their serostatus to someone, but reasons for disclosure leaned towards social aspects to their lives rather than to issues of protecting the method of feeding chosen. Mixed feeding was predominant with some mothers not practising exclusive breastfeeding. Nondisclosure was associated with fear of victimization, fear of family and community gossip. We conclude that in seeking to achieve exclusive breastfeeding practices for HIV-exposed infants there needs to be an emphasis in the PMTCT programme on quality counselling that translates to disclosure.

Keywords: Disclosure, exclusive breastfeeding, infant feeding, Lusaka, nondisclosure, risks, Zambia.

Introduction

The global solidarity in the HIV and AIDS response during the past decades continues to generate extraordinary health gains, although the pandemic has remained one of the world's most serious health challenges. Despite the gains achieved in prevention and treatment strategies, the world has continued to record new infections among women in the reproductive age and children younger than 15 years. With no interventions, babies born to

HIV-positive women in sub-Saharan Africa will continue to have added risks of acquiring HIV infection and dying before their fifth birthdays (UNAIDS, 2013).

In Zambia, the prevalence of HIV among women aged 15–49 is currently 15 per cent (CSO, MoH, & ICF, 2014), women living with HIV who delivered in 2012 totalled 81 727 (MoH, 2014b), and 15 000 new infections were reported among children less than 15 years old (UNAIDS, 2013) and mostly through mother-to-child transmission (MTCT). Mother-to-child transmission of HIV is one of the key drivers of the HIV pandemic in resource-poor settings. Prevention of mother-to-child transmission (PMTCT) of HIV has therefore been at the forefront of regional and global HIV prevention activities since 1998.

Research and PMTCT programme experience has demonstrated newer and more effective ways to prevent MTCT, particularly in high-burden, low-resource settings, and significant progress has been made (UNAIDS, 2013; WHO, 2010). Prevention of MTCT of HIV nonetheless continues to be a dynamic and rapidly changing field (Moland et al., 2010). Recent decades have seen an emergence of evidence for establishing treatment regimens and for the safety of different modes of infant feeding to reduce postnatal transmission of HIV from the infected mother to her child (Coovadia et al., 2007; Iliffa et al., 2005; Sperling et al., 1996).

In settings with a high burden of HIV infection, the current World Health Organization (WHO) PMTCT antiretroviral (ARV) guidelines on treating pregnant women and preventing infection in infants encourage provision of two short-term ARV prophylaxis options (Option A and Option B) or of lifelong antiretroviral therapy (ART) to all HIV-infected pregnant women regardless of CD4 cell count (Option B+). Some countries, like Zambia, already adopted the latter approach (MoH, 2014a; WHO, 2012) while implementing infant feeding guidelines provided by WHO (WHO, UNAIDS, UNFPA, & UNICEF, 2010).

The national authorities may decide either breastfeeding with an antiretroviral intervention to reduce transmission or avoidance of all breastfeeding (WHO, UNICEF, UNAIDS, & UNFPA, 2012). Breastfeeding without antiretroviral intervention carries a risk of HIV transmission, while not breastfeeding represents a considerable risk to infant survival in low-income countries. Exclusive breastfeeding – which involves feeding the baby only breast milk plus any minerals, vitamins and prescribed medicines, if needed, for the first six months after birth – reduces the risk of transmission of HIV among the exposed infants (Coovadia, et

al., 2007; Iliffa, et al., 2005; Thomas et al., 2011), while non-exclusive breastfeeding more than doubles the risk of postnatal HIV transmission (Kuhn et al., 2007; Young et al., 2010; Young et al., 2011). But despite the recognised importance of exclusive breastfeeding, the practice is not widespread in the developing world (Cai, Wardlaw, & Brown, 2012; Seid, Yesuf, & Koye, 2013; Shapiro et al., 2003). To achieve exclusive breastfeeding, quality counselling on infant feeding, disclosure of serostatus, access to comprehensive PMTCT services and a supportive environment are thus crucial and necessary elements of the PMTCT programme interventions.

Breastfeeding is a customary way of feeding babies in most countries of the sub-Saharan Africa, and to practice exclusive breastfeeding, HIV-positive mothers may have to go against family and community norms that support early introduction of fluids and mixed feeding (Chinkonde, Hem, & Sundby, 2012; Leshabari, Blystad, & Moland, 2007; Madiba & Langa, 2014). The PMTCT programme interventions in these settings are thus faced with social and programmatic challenges.

There are known factors for poor uptake of PMTCT interventions in low-resource settings, inter alia gender inequalities and stigma, lack of partner support, and fear of serostatus disclosure (Fletcher, Ndebele, & Kelly, 2008; Gourlay, Birdthistle, Mburu, Iorpenda, & Wringe, 2013; Medley, Garcia-Moreno, McGill, & Maman, 2015; MoH, 2014b). Serostatus disclosure is significantly associated with exclusive breastfeeding in some settings (le Roux et al., 2013; Madiba & Letsoalo, 2013; Onono, Cohen, Jerop, Bukusi, & Turan, 2014), although the belief that disclosure causes divorce or abuse, or is unimportant, contributed to nondisclosure in a study conducted in Zimbabwe (Mucheto et al., 2011) or was associated with intimate partner violence in the same setting (Shamu, Zarowsky, Shefer, Temmerman, & Abrahams, 2014).

According to the national infant feeding guidelines for Zambia, serostatus disclosure is encouraged among HIV-positive mothers accessing services for HIV counselling and testing in maternal and child health programm (MoH, 2010). We explored serostatus disclosure and associated risk factors in the context of exclusive breastfeeding among HIV-positive mothers accessing PMTCT services in selected sites.

Materials and methods

The design

This study was part of a research that was conducted to analyse choices and decision-outcomes on infant feeding in the context of prevention of mother-to-child transmission of HIV in Zambia. The larger study was aimed to enhance safer infant-feeding practices during the first six months of the infants' life. This was a health facility and community-based case study where mothers were interviewed after delivery (Bless, Higson-Smith, & Sithole, 2013; Creswell, 2007). The study was conducted from January to September 2014.

Participant selection criteria

30 HIV-positive mothers accessing PMTCT services from the health facilities were recruited. Using a health facility register, recruitment of mothers commenced two months prior to fieldwork. To be included in the study the mother needed to have attended HIV pre-test and post-test counselling, have obtained the test results, have been placed on treatment regimen, have received infant feeding counselling, been willing and have given written and signed consent to participate in the study.

All the health care workers were included in the study after giving written and signed consent to participate.

Sampling technique

Purposive sampling techniques were employed to recruit participants for the study. To maintain a balance in age distribution, recruitment was done within the age ranges of 15–24, 25–34 and 35-45 years. Categories such as education level and socio-economic status were determined by employing judgmental sampling while maintaining flexibility. However, to cater for loss to follow-up due to change of location, death of the baby or drop-out from the study, an additional one participant for every four was recruited, bringing a total to 30 HIV-positive mothers.

Data collection procedures

The first author and two research assistants collected the data through in-depth interviews that were audio recorded after securing permission with the participants. During interviews

participants spoke openly using their primary language, about their serostatus and disclosure. With permission, some interviews were conducted at the homes of participants and issues of privacy and confidentiality were respected.

Data collection instrument

A semi-structured interview guide was used to conduct interviews. The questions we asked for this sub-study were: 1) Tell me if you told someone about your HIV test results. 2) Please explain your relationship with the person you shared the HIV test results with. 3) What did it mean for you to share the results with someone? 4) What did the person you shared the results with say or do afterwards?

Data management

All audio files from digital recorders were downloaded onto the computer. Recordings were transcribed verbatim from the primay language and then translated into English. All transcripts were checked for accuracy, quality and cleaned for anonymity by removing all identifiers. All the files were imported into QRS NVivo 10 version for coding and analysis and a regular backup in the external drives was maintained throughout the project.

Data analysis

Data collection and analysis were carried out concurrently and we used the framework analysis to understand the patterns of disclosure of serostatus (Richie & Lewis, 2003; Ritchie & Spencer, 2002). In the initial coding phase, codes relevant to disclosure and nondisclosure of serostatus were identified and categorised. Once the coded data were merged a second level of coding tested the themes and their relationships leading to further refining of the codes and themes and quotes of participants' actual words were linked to the descriptions (Galel, Heath, Cameron, Rashid, & Redwood, 2013).

Findings

This section of the article will describe the complexity of serostatus disclosure and provide an indepth understanding of reasons that motivate mothers to share their HIV test results. While recognising the mothers' perceived risks of serostatus disclosure, this study will highlight the

implications to exclusive breastfeeding. We conclude this section by describing the health care workers' perspective of serostatus disclosure and how it impacts PMTCT interventions.

Characteristics of HIV-positive mothers

The 30 HIV-positive mothers recruited in the study were aged between 15-45 years. They self-reported as being single, married or widowed. These participants were either first-time mothers or had delivered more than two children and in some cases more than once with the sero-positive status. All had attended HIV pre and post-test counselling and were on treatment regimen. All had experienced the birth of a mature infant who had a normal birth weight.

Reasons for disclosure of serostatus

Regarding reasons for serostatus disclosure, some mothers reported telling someone about their HIV test results sighting fear to infect the baby with HIV. In addition, being infected with HIV was perceived to lead to immediate death and hence some mothers felt that they needed family support. For a 35 year old mother of 4 children, telling her spouse that she tested positive enabled to choose formula feeding as opposed to breastfeeding. She explained: *"I told my husband because he was supposed to know. I also did not want to breastfeed because I feared that my baby may be infected with HIV through breastmilk. I decided to give formula instead"*. [35 years, 4 children]

During counselling and testing, mothers are encouraged to share their results with their spouses and for this study, some mothers were particularly concerned about their spouses testing for HIV as well. The following were some of the responses:

> *"I went for VCT (voluntary counselling and testing) alone and after I got the results I went home and showed my husband and he said he would also go to have a test"*. [29 years, 3 children]
>
> *"I told my husband because I wanted him to go and get tested also but he didn't get tested and up to this time he doesn't know his status… no"*. [23 years, 3 children].

Families by nature are expected to provide emotional support and care, and some mothers naturally disclosed their serostatus to at least a member of the family. Family members

included mothers, sisters and for some mothers the whole family was informed. The reason for telling the family members was to gain their support. Typical responses were:

> *"I told my family that I have been found with HIV. My relatives said that it's good I started treatment early than when I am finished".* [25 years, 1 child]

> *"I told my mother first because I wanted to hear what advice she would give me".* [23 years, 3children]

> *"I told my sister because she is the one who started encouraging me to be strong and a friend of mine strengthened me otherwise I would have died".* [22 years, 2 children]

> *"I told my mother and my aunt that is all. My aunt is the eldest in my family and she looks after me so I could not hide".* [23 years, 3 children]

> *"I shared my results with my whole family. I wanted them to know and it made me feel free knowing that I shared the information and will be open with them to live positively. The first thing is to accept on my own then it will become easy to live positively".* [26 years, 2 children]

Given individual circumstances, sometimes disclosure of an HIV-positive test result could be overwhelming. For one mother, fear of death led to disclose to a known HIV-positive friend who motivated her to seek and access PMTCT services. She explained. *"I told my friend who is also HIV-positive because I got scared and thought that this was just a death sentence. But then my friend said no, it isn't a death sentence because the nurses at the clinic know how they do it to protect the babies to remain fat and healthy".* [24 years, 2 children]

Non-disclosure of serostatus

Some mothers did not disclose when they believed that they would be victimized, would be a centre of gossip, would cause emotional pain to the family or did not feel obliged to do so. This theme describes what they perceived as risks to disclosure.

In societies where women are marginalized, they tend to express fear of partner violence. This may be a case with experiences of an emotional nature such as being found HIV-positive during pregnancy and at first visit for antenatal care. A mother explained: *"I did not tell my husband because I was scared of how he will react and be angry with me. Yes even now he doesn't know, no, he doesn't know"*. [20 years, 2 children].

For some mothers, fear of family and community gossip was overwhelmimg. Typical responses were:

> *"Some of the ones that we live with like my step mother is a gossip she can go all around telling everyone"*. [23 years, 1 child].
>
> *"I did not tell anyone, to be honest, people in the compound where we live have bad talk such that you can even hang yourself"*. [29 years, 4 children]
>
> *"I did not tell anyone about my HIV status and no one knows. Just kept it to myself"*. [18 years, 1 child].

In a similar perspective, a mother who was on separation with her sexual partner did not feel obliged to tell any one. She explained: *"No I did not tell my partner because we separated and he was a married man, it was a mistake that I had a child with him. So no one knows"*. [33yrs, 3 children].

A young first time mother did not disclose to anyone because she did not want to disappoint her family. She explained: *"I did not tell my family because the pregnancy issues, the education issue, the status issue were just too much for them"*. [22 years, 1 child]

Health care workers' perspective of serostatus disclosure by mothers

While HIV-positive mothers were more focused on the social aspect of serostatus disclosure to their lives, the next section presents the perspectives of the HCWs. In the context of PMTCT, the HCWs noted that disclosure of serostatus was associated with either exclusive breastfeeding or formula feeding because it was easy for mothers to get family support. The following were their responses:

"If the mother fails to disclose her serostatus it is very difficult for her to practice exclusive breastfeeding or to be supported to make a good decision on infant feeding". [nutritionist, 4 years in PMTCT]

"If the mother did not disclose her serostatus to her spouse during pregnancy and after delivery, it would be very difficult to get the baby off the breast to give formula because she would have no answers to provide to the spouse as to why she is not breastfeeding or why she removed the baby from the breast…". [midwife, 10 years in PMTCT]

When women did not disclose their serostatus to someone, HCWs found it difficult to provide comprehensive care. The difficulties experienced by HCWs in guiding and supporting such mothers in accessing PMTCT services and practice the infant feeding of choice were highlighted by another key informant: *"If a mother doesn't disclose her serostatus to her partner, close relatives and friends she would not expect any help from them… it is quite difficult. Only those that open up to their relatives, partners and friends are easy to manage in the PMTCT programme"*. [clinical officer, 2 years in PMTCT].

However, with continued health education, motivation and support HCWs were hopeful that mothers would find it easy to tell someone their HIV test results: *"Women in the community use feeding practices that negatively impact on child health outcomes. These practices are behaviour change related including serostatus disclosure and this can only be achieved in stages. So our role is to educate the mothers, give them information, motivate and support them when they choose a method of feeding despite the challenges they may face in the community. We know that when we do that women will stop the practices that negatively impact infant feeding"*. [nutritionist, 4 years in PMTC]

Discussion

This study focused on serostatus disclosure and associated risk factors in the context of mother-to-child transmission of HIV. Our finding that some participants disclosed their serostatus to partners, someone in the family or friends was in line with national indicators for the last Zambia Demographic and Health Survey that showed that 97 per cent of women who were tested during antenatal clinic and knew their test results shared their results with someone (CSO, et al., 2014). This trend is similar to some settings of the sub-Saharan Africa

(Hardon et al., 2012; Madiba & Letsoalo, 2013; Visser, Neufeld, de Villiers, Makin, & Forsyth, 2008). The positive disposition by mothers towards serostatus disclosure implied that they did not generally experience difficulties in selecting an appropriate infant feeding method such as breastfeeding including other strategies in the PMTCT intervention. Undoubtedly, this position is consistent with the recommendations provided in the WHO infant feeding guidelines and the HCWs in this study were supportive of its fundamental role in the implementation of the PMTCT interventions in Zambia (MoH, 2010; WHO et al., 2012). However, reasons for serostatus disclosure leaned towards the social aspect to mothers' lives as opposed to protecting infant feeding practice.

Contrary to these findings, a study conducted in Kenya showed that HIV-positive mothers who had disclosed their serostatus were nearly three times more likely to exclusively breastfeed than women who were HIV-negative or did not know their serostatus (Onono, et al., 2014). These findings were comparable with results in Nigeria (Lawani, Onyebuchi, Iyoke, Conoh, & Nkwo, 2014) and South Africa (Madiba & Letsoalo, 2013). Clearly serostatus disclosure may not always translate into safer infant feeding practices and would require additional strategies to support mothers that disclose to their partners, relatives and friends. Taking advantage of the fact that some mothers did not find it difficult to disclose their serostatus, HCWs would use this opportunity to promote safer infant feeding such as exclusive breastfeeding in the first six months and beyond while the mother adhered to anteretrovial therapy. The social support network for HIV-positive mothers such as family and friends need to be brought on board for the successeful implementation of PMTCT strategies especially at community level.

On the other hand, a significant number of mothers did not disclose their serostatus to anyone, an indication that there could have been gaps in the HIV counselling and testing process. Perceived risks for disclosure such as fear of victimization, fear of family and community gossip were reported for this study and in other similar settings (Mucheto, et al., 2011; Onono, et al., 2014) and generally observed in low-resource settings (Medley, et al., 2015). Even though mothers in the current study were not asked directly how their refusal to disclose to partners and family affected their adherence to safer infant feeding practice such as exclusive breastfeeding, the voices of HCWs in this regard needs to be taken into cognizance; that such mothers would consequently find it more problematic to exercise the choice of breastfeeding and practice exclusive breastfeeding for their babies. For instance,

going against community norms of feeding leads to questions about the mother's HIV status, fear of stigma and violence from partner, family, the community including unwanted disclosure, and thus mothers may avoid participating in PMTCT programmes as reported in Malawi (Chinkonde, et al., 2012), Tanzania (Leshabari, et al., 2007) and Zimbabwe (Shamu, et al., 2014).

These results highlight the fact that infant feeding guidelines are implemented in the community where women, live, work and feed their babies. Therefore, strategies to promote appropriate infant feeding methods such as exclusive breastfeeding should utilize community-based approaches and use exisiting structures to support mothers. As some health care workers intimated, there is still hope in reaching out to women in the communities and achieve behaviour change in the implementation of appropriate infant feeding methods to the benefit of all infants and those exposed to HIV to contribute towards the national and global goal of elimination of mother-to-child transmission of HIV (MoH, 2010, 2014a; WHO, et al., 2012).

Conclusion

We conclude that serostatus disclosure remains a problematic and stressful event that has a bearing on infant feeding such as exclusive breastfeeding among HIV-positive mothers accessing PMTCT services in Zambia. The results highlight the importance of quality and effective counselling that would translate into serostatus disclosure on the basis of protecting breastfeeding and practice exclusive breastfeeding for HIV-exposed infants. The role of HCWs is therefore broader in reality than currently practiced and requires redesigning to ensure that women with potential risk of nondisclosure are identified and supported with alternative options to do so (Medley, et al., 2015) and women who disclose are encouraged to engage their families during infant feeding.

Recommendations

1. Integrate community approaches in PMTCT programmes has been associated with improvements in uptake of services (Betancour, Abrams, McBain, & Fawzi, 2010; Busza et al., 2012) and these can be tested in the settings studied and at national level.

2. HIV-positive buddies have been reported to be an effective source of infant-feeding support for HIV-positive women in South Africa, however, its full impact needs further testing for the similar populations (Andreson et al., 2013) such as Zambia.
3. Intensify Voluntary Counselling and Testing (VCT) among couples and encourage mutual serostatus disclosure needs strengthening at community level as opposed to health facility-based activities in order to reduce stigma related to VCT and PMTCT practices.

Ethical approval

Ethical approval was granted by the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal in South Africa (HSS/0104/013D) and the Biomedical Research Ethics Committee of the University of Zambia (Reference No. 016-11-13). Voluntary participation was accorded with written consent.

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Limitations

1. One serious limitation of the study was that we did not probe how non-disclosing mothers dealt with the challenge of feeding their babies and this is future research consideration.
2. Lack of empirical evidence on prevalence of exclusive breastfeeding in the settings studied had a bearing on conclusions made on exclusive breastfeeding practices. However, evidence from similar settings provided grounds for making comparisons and recommendations for future research.
3. We recognised lack of generalization of the findings beyond the group studied, however, this did not weigh down the value of research findings to inform interventions and improve infant feeding practices among HIV-positive mothers.
4. There is need for a follow-up interventional research on exclusive breastfeeding for HIV-positive mothers accessing PMTCT services in Zambia. This should be followed

by a research to assess the relationship between nondisclosure of serostatus and the difficulties in implementing exclusive breastfeeding as a strategy.

Competing interest

There were no competing interests declared by all the authors.

List of references

Betancour, T.S., Abrams, E.J., McBain, R., & Fawzi, M.C.S. (2010). Family-centred approaches to the prevention of mother to child transmission of HIV. Journal of International AIDS Society. 13:2.

Bless, C., Higson-Smith, C., & Sithole, S. (2013). Fundamentals of Social Research Methods: An African Perspective: Juta.

Busza, J., Walker, D., Hairston, A., Gable, A., Pitter, C., Lee, S., . . . Mpofu, D. (2012). Community-based approaches for prevention of mother to child transmission in resource-poor settings: a social ecological review. Journal of International AIDS Society. 15:Suppl 2; 17373. doi: 10.7448/IAS.15.4.17373.

Cai, X., Wardlaw, T., & Brown, D.W. (2012). Global trends in exclusive breastfeeding. International Breastfeeding Journal. 7:12.

Chinkonde, J.R., Hem, M.H, & Sundby, J. (2012). HIV and infant-feeding in Malawi: public health simplicity in complex social and cultural contexts. BMC Public Health.12:700. doi: 10.1186/1471-2458-12-700.

Coovadia, H.M., Rollins, N.C., Bland, R.M., Little, K., Coutsoudis, A., Bennish, M., & Newell, M. (2007). Mother-to-child transmission of HIV-1 infection during exclusive breastfeeding in the first 6 months of life: an intervention cohort study. The Lancet:369;9567, 1107.

Creswell, J.W. (2007). Qualitatice inquiry and research design; choosing among five approaches (2nd Edition). London Sage Publications.

CSO, MoH, & ICF. (2014). Zambia Demographic and Health Survey 2013-14. Rockville, Maryland, USA: Central Statistical Office.

CSO, MoH, TRDRC, UNZA, & MI. (2009). Zambia Demographic and Health Survey 2007. Maryland, USA: Central Statistics Office. Macro International Incyclopedia

Fletcher, F., Ndebele, P., & Kelly, M. (2008). Infant-feedingand HIV in sub-Saharan Africa: What lies beneath the dilemma. Theor Med Bioeth. doi: DOI 10.1007/s11017-008-9083-z

Galel, N.K., Heath, H., Cameron, C., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Medical Research Methodology. 13:117.

Gourlay, A., Birdthistle, I., Mburu, G., Iorpenda, K., & Wringe, A. (2013). Barriers and facilitating factors to the uptake of antiretroviral drugs for prevention of mother-to-child transmission of HIV in sub-Saharan Africa: a systematic review. Journal of International AIDS Society. 16:1;18588. doi: 10.7448/IAS.16.1.18588.

Hardon, A., Vernooij, E., Bongololo-Mbera, G., Cherutich, P., Desclaux, A., Kyaddondo, D., . . . Obermeyer, C. (2012). Women's views on consent, counseling and confidentiality in PMTCT: a mixed-methods study in four African countries. BMC Public Health. 12:26. doi: 10.1186/1471-2458-12-26.

Iliffa, P.J., Piwozb, E.G., Tavengwaa, N.V., Zunguzac, C.D., Marindaa, E.T., Nathood, K.J., . . . Humphreya, J.H (2005). Early exclusive breastfeeding reduces the risk of postnatal HIV-1 transmission and increases HIV-free survival. Aids. 19:699–708. doi: 10.1016/j.qad.2004.09.015

Kuhn, L., Sinkala, M., Kankasa, C., Semrau, K., Kasonde, P., Scott, N., . . . Thea, D. M. (2007). High uptake of exclusive breastfeeding and reduced early post-natal HIV transmission. PLoS ONE. 2:12;e1363. doi: 10.1371/journal.pone.0001363

Lawani, L. O., Onyebuchi, A. K., Iyoke, C. A., Conoh, R., & Nkwo, P. O. (2014). The challenges of adherence to infant-feeding choices in prevention of mother-to-child transmission of HIV infections in South East Nigeria. [Article]. Patient Preference & Adherence. 8:377-381. doi: 10.2147/PPA.S61796.

le Roux, I. M., Tomlinson, M., Harwood, J. M., O'Connor, M. J., Worthman, C. M., Mbewu, N., . . . Rotheram-Borus, M. J. (2013). Outcomes of home visits for pregnant mothers and their infants: a cluster randomized controlled trial. Aids. 27:9;1461-1471. doi: 10.1097/QAD.0b013e3283601b53.

Leshabari, SC., Blystad, A., & Moland, K.M. (2007). Difficult choices: Infant-feeding experiences of HIV positive mothers in northern Tanzania. Journal of social aspects of HIV/AIDS. 4:1.

Madiba, S., & Langa, J. (2014). Cultural practices interfere with adherence to exclusive infant feeding: A qualitative study among HIV positive post natal women in Hammanskraal, South Africa. African Journal for Physical, Health Education, Recreation and Dance (AJPHERD). 1:1;264-278.

Madiba, S., & Letsoalo, R. (2013). HIV disclosure to partners and family among women enrolled in prevention of mother to child transmission of HIV program: implications for infant-feeding in poor resourced communities in South Africa. Global Journal of Health Science. 5:4;1-13. doi: 10.5539/gjhs.v5n4p1.

Medley, A., Garcia-Moreno, C., McGill, S., & Maman, S. (2015). Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. Bulletin of the World Health Organization. 82:4.

MoH. (2010). National Protocol Guidelines for Infant feeding; Integrated Prevention of Mother to Child Transmission of HIV/AIDS. Lusaka: Ministry of Health.

MoH. (2014a). Zambia Consolidated Guidelines for Treatment and Prevention of HIV infection. Lusaka: Ministry of Health.

MoH. (2014b). Zambia Country Report Monitoring the declaration of Commitment on HIV and AIDS and the Universal Access. Lusaka: Ministry of Health and National AIDS Council.

Moland, K.M.I., de Paoli, M.M., Sellen, D.W., van Esterik, P., Leshabari, S.C, & Blystad, A. (2010). Breastfeeding and HIV: experiences from a decade of prevention of postnatal HIV transmission in sub-Saharan Africa. International Breastfeeding Journal. 5:10-16. doi: 10.1186/1746-4358-5-10.

Mucheto, P., Chadambuka, A., Shambira, G., Tshimanga, M., Notion, G., & Nyamayaro, W. (2011). Determinants of nondisclosure of HIV status among women attending the prevention of mother to child transmission programme, Makonde district, Zimbabwe, 2009. PanAfrican Medical Journal. 8:51.

Onono, M.A., Cohen, C.R., Jerop, M., Bukusi, E.M., & Turan, J.M. (2014). HIV serostatus and disclosure: implications for infant-feeding practice in rural south Nyanza, Kenya. BMC Health Health. 14:390. doi: 10.1186/1471-2458-14-390.

Richie, J., & Lewis, J. (2003). Qualitative research practicea: Guide for Social Science Students and Researchers. London: Sage publication.

Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research: The qualitative researcher's companion. London: Sage Publications.

Seid, A.M., Yesuf, M.E., & Koye, D.N. (2013). Prevalence of Exclusive Breastfeeding Practices and associated factors among mothers in Bahir Dar city, Northwest Ethiopia: a community based cross-sectional study. International Breastfeeding Journal. 8:1;14. doi: 10.1186/1746-4358-8-14.

Shamu, S., Zarowsky, C., Shefer, T., Temmerman, M., & Abrahams, N. (2014). Intimate Partner Violence after Disclosure of HIV Test Results among Pregnant Women in Harare, Zimbabwe. PLoS ONE. 9:10;e109447. doi: 10.1371/journal.pone.0109447

Shapiro, R.L., Lockman, S., Thior, I., Stocking, L., Kebaabetswe, P., Wester, C., . . . Heymann, S.J. (2003). Low adeherence to recommended infant-feeding strategies among HIV infected women: Results from the pilot phase of a Randomized Trial to prevent mother-to-child transmission in Botswana. AIDS Education and Prevention. 15:3;221-230.

Sperling , R.S., Shapiro, D.E., Coombs , R.W., Todd , J.A., Herman, S.A., McSherry, G.D., . . . GROUP, S. (1996). Maternal Viral Load, Zidovudine treatment, and the Risk of Transmission of Human Immunodeficiency Virus Type 1 from mother to infant. The New England Journal of Medicine. 335:22.

Thomas, T.K., Masaba, R., Borkowf, C.B., Ndivo, R., Zeh, C., Misore, A., . . . Ki, B. S. S. T. (2011). Triple-antiretroviral prophylaxis to prevent mother-to-child HIV transmission through breastfeeding--the Kisumu Breastfeeding Study, Kenya: a clinical trial. PLoS Medicine. 8:3;e1001015. doi: 10.1371/journal.pmed.1001015.

UNAIDS. (2013). UN estimates with uncertainty abounds Retrieved 7th November, 2014, from http://www.unaids.org/en/resources/documents/2014/HIV estimates with uncertainty abound 1990-2013.

Visser, M. J., Neufeld, S., de Villiers, A., Makin, J. D., & Forsyth, B. W. (2008). To tell or not to tell: South African women's disclosure of HIV status during pregnancy. AIDS Care. 20:9;1138-1145. doi: 10.1080/09540120701842779.

WHO. (2010). PMTCT strategic vision 2010-2015 Preventing mother to child transmission of HIV to reach the UNGASS and Millenium Development Goals. Geneva WHO.

WHO. (2012). Use of antiretroviral drugs for treating pregnant women and preventing HIV infection in infants HIV/AIDS Program update. Geneva: WHO.

WHO, UNAIDS, UNFPA, & UNICEF. (2010). HIV and Infant-feeding Guidelines, Principles and recommendations for infant-feeding in the context of HIV and a summary of evidence. Geneva: WHO.

WHO, UNICEF, UNAIDS, & UNFPA. (2012). 2010 WHO Guidelines on HIV and Infant-feeding: An updated framework for priority action. Geneva: World Health Organization.

Young, S. L., Israel-Ballard, K. A., Dantzer, E. A., Ngonyani, M. M., Nyambo, M. T., Ash, D. M., & Chantry, C. J. (2010). Infant-feeding practices among HIV-positive women in Dar-es-Salaam, Tanzania, indicate a need for more intensive infant-feeding counselling. Public Health Nutrition. 13:12;2027-2033. doi: 10.1017/S1368980010001539.

Young, S. L., Mbuya, M. N., Chantry, C. J., Geubbels, E. P., Israel-Ballard, K., Cohan, D., . . . Latham, M. C. (2011). Current knowledge and future research on infant-feeding in the context of HIV: basic, clinical, behavioral, and programmatic perspectives. Advances in Nutrition. 2:3;225-243. doi: 10.3945/an.110.000224.

Chapter 4

Sociocultural determinants of exclusive breastfeeding: lessons learnt from experiences of HIV-positive mothers in Lusaka, Zambia. (Published article)

SOCIO-CULTURAL DETERMINANTS OF EXCLUSIVE BREASTFEEDING: LESSONS LEARNT FROM EXPERIENCES OF HIV-POSITIVE MOTHERS IN LUSAKA, ZAMBIA

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ABSTRACT

Breastfeeding is a culturally accepted way of feeding a baby despite the risk of HIV transmission. In the context of HIV, it is especially important to protect, promote and support exclusive breastfeeding for the first six months of life. The aim of this study was to explore socio-cultural determinants of exclusive breastfeeding to inform interventions on prevention of mother-to-child transmission of HIV among HIV-

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positive mothers in Lusaka, Zambia. We utilised ethnographic approaches and a triangulation of focus group discussions; in-depth individual interviews, participant observations and field notes to collect data. Thirty HIV-positive mothers were followed at 6 days, 6 weeks, 12 weeks and 18 weeks after delivery. Inadequate knowledge of exclusive breastfeeding was pronounced. Predominantly, mixed feeding was practised as a cultural norm and to compensate for the delay in initiation of breastfeeding for HIV-exposed infants. Use of herbs was reported for reasons varying from medication to treat abdominal pains and protection of the baby from childhood illnesses. We conclude that breastfeeding is the customary way of feeding new-born babies; however, the recommended exclusive breastfeeding for all mothers is alien in populations driven by culture. Therefore, developing culturally appropriate counselling tools that address known practices has potential to improve breastfeeding in the context of prevention of mother-to-child transmission of HIV.

Keywords: exclusive breastfeeding, HIV-exposed infants, HIV-positive mothers, mixed feeding, social-culture, ethnographic research, Zambia

INTRODUCTION AND BACKGROUND INFORMATION

According to the joint United Nations Programme on HIV/AIDS (UNAIDS), at the end of 2013 an estimated 35 million people were living with HIV globally. Of these, 3.2 million were children less than 15 years, while half of the adults were women. Of the 2.1 million new HIV infections reported, 240 000 were children less than 15 years of age (UNAIDS, 2013). According to the Ministry of Health (MoH) in Zambia, the number of women living with HIV who delivered in 2012 was 81 727, from which 76 963 received efficacious antiretroviral drugs for prevention of mother-to-child transmission. These indicators showed a drop in the HIV transmission rate from mother-to-child from 24% in 2009 to 12% in 2012. However, the report showed that 5 in 10 women or their infants did not receive antiretroviral drugs during breastfeeding to prevent mother-to-child transmission of HIV (MoH, 2014). The successes recorded were achieved against the backdrop of cultural, political and social economic challenges. Therefore, reaching the current global goal of eliminating new HIV infections among children by 2015 will require not only accelerated efforts to bring services to prevent children from acquiring HIV infection to scale up, but also steps to ensure that all programmatic elements are fully implemented (UNAIDS, 2012).

In the current 2010 infant feeding guidelines, the World Health Organization (WHO) emphasised that breastfeeding, and especially early and exclusive breastfeeding, is one of the most valuable interventions for improving child survival, and it also confers many benefits in addition to reducing the risk of child morbidity and mortality (WHO, 2010). However, the customary patterns of breastfeeding that support early introduction of fluids and foods have been reported in some settings (Moland, De Paoli, Sellen, Van Esterik, Leshabari & Blystad 2010), thus posing an increased risk of HIV transmission.

Zambia is a multicultural country with minimal variations in cultural practices within the regions. To aid in achieving the country goal of virtual elimination of mother-to-child transmission of HIV, informed decisions based on country context research that focuses on social-cultural determinants of breastfeeding and lessons learnt from the region are required (Shirunga, 2010).

STATEMENT OF THE RESEARCH PROBLEM

The success of prevention of mother-to-child transmission of HIV depends on the ability of HIV-positive mothers to implement safer infant feeding practices such as exclusive breastfeeding. In societies rooted in the cultural feeding practices, adherence to exclusive breasting is a challenge for mothers to implement.

PURPOSE OF THE STUDY

The aim of this research was to explore the socio-cultural determinants of exclusive breastfeeding to inform interventions on prevention of mother-to-child transmission of HIV among HIV-positive mothers in Lusaka, Zambia.

RESEARCH QUESTION

What are the socio-cultural determinants of exclusive breastfeeding in Lusaka, Zambia?

Definitions of key concepts

Exclusive breastfeeding is feeding the baby only breast milk and any minerals, vitamins and prescribed medicines if needed for the first six months of life.
Herbs are traditional medicines prepared from local wild plants.
HIV-exposed infants are babies born from HIV-positive mothers.
Mixed feeding is giving an infant solids and fluids with breast milk.
Social culture is shared values and beliefs by a group.

RESEARCH METHODOLOGY

The design

This study was designed as part of the research to develop a model for follow up of HIV-positive mothers during the first six months of infant feeding. This exploratory descriptive qualitative study utilising ethnographic procedures was based on field work conducted in Lusaka from January to September 2014. To strengthen the credibility of results, triangulation was achieved through participant observation and in-depth

interviews with HIV-positive mothers. In-depth interviews conducted with each mother were at four different intervals during the first six months of infant feeding and we achieved individual validation of data. Key informant interviews with nurses, midwives, clinical officers and nutritionists strengthened the quality of information as themes emerged in the research. Focus group discussions were held with Community-Based Volunteers (CBDs) trained as lay counsellors and men accessing antiretroviral therapy.

Research site

The research was conducted in urban settings of Lusaka using Chelstone and Ngombe Health Centers to recruit the participants. These are sites for government programmes on prevention of mother-to-child transmission of HIV and Antiretroviral therapy.

Study population

The focal population studied was HIV-positive mothers and key informants working in the prevention of mother-to-child transmission of HIV programmes. Interviews were also held with community volunteers and men accessing antiretroviral therapy.

Sample

Thirty (30) HIV-positive mothers accessing services for prevention of mother-to-child transmission of HIV (PMTCT) and meeting the selection criteria were recruited and followed for six months. During recruitment, saturation was achieved when there was no longer a variation and diversity in participant characteristics of interest.

All the six (6) health care workers in the PMTCT departments from Chelstone and Ngombe Health Centers were interviewed.

One focus group discussion (FGD) comprising 10 participants was conducted with all the community-based volunteers for Chelstone. One FGD was conducted with all the 10 community-based volunteers for Ngombe.

One FGD was conducted with 15 men accessing antiretroviral therapy and whose spouses had delivered a live baby within the past year prior to this research.

Sampling techniques

Purposive sampling was used to select all the participants in the study. To maintain a balance in age distribution among the HIV-positive mothers, recruitment was in age ranges of 18–28, 29–39 and 40+ years. Categories such as education level and social economic status were determined by employing judgmental sampling while maintaining flexibility as the themes emerged. The carefully selected study sites catered for women of different social economic status and education (Creswell, 2007:126–129a). To be selected, the mother should have attended pre-test and post-test counselling; obtained

the HIV-test results; placed on a treatment regime, counselled on infant feeding; having chosen a method of infant feeding; willing, giving written and signed consent to participate and during follow-up, the mother should have had a live baby.

Data collection procedures

Qualitative triangulation was achieved through the use of participant observations, in-depth interviews and focus group discussions (Creswell, 2007:117–145c). A team comprising the principal investigator (PI), who is the first author, and two midwives were involved in data collection. The midwives, who were conversant in speaking Cibemba and Cinyanja and trained in counselling and prevention of mother-to-child interventions, were enrolled and trained as research assistants. They underwent a one-week training and orientation to the tools, procedures for recruitment of participants, observations and interviewing techniques, use of digital recorders and transfer of the recordings to the computers. This was followed by a one-week field orientation to the sites to test the tools, which were subsequently finalised.

In-depth interviews were conducted to address complex and sensitive topics and to allow mothers to talk about personal feelings, opinions and experiences on breastfeeding. Interviews were conducted in local languages (Cinyanja and Cibemba) depending on which one the participant was conversant with, although some were conducted in English. The interviews were conducted with each mother at 6 days, 6 weeks, 12 weeks and 18 weeks and we achieved individual validation. These participants each typically generated a large amount of information when nothing new came out of the interviews, and a total of 120 transcripts were produced. The interviews were conducted either at home for mothers, who gave permission, or at a place convenient to the mother.

Participant observation was essential for detecting meanings, feelings and experiences attached to infant feeding and to describe and identify patterns of breastfeeding relevant for making conclusions. These observations were conducted during health education talks at the health facilities, during the mothers' visits at the health facilities for growth monitoring and immunisations or at their homes as the situation dictated.

Focus group discussions to complement in-depth interviews with mothers and health care workers were conducted to explore the diversity within a population on culture and breastfeeding. Two were conducted with community-based volunteers and one with HIV-positive men.

Throughout the field work, close supervision was maintained with research assistants through regular meetings and active communication by the principal investigator.

Data collection tools

A semi-structured interview guide was used to conduct in-depth interviews and focus group discussions to explore the social-cultural determinants to breastfeeding. This was done to enable the participants to tell their stories in their own way. During each stage of

breastfeeding, mothers were expected to observe known cultural practices and the tool was designed to explore these as the study progressed. At 6 days, the questions focused on known cultural practices of breastfeeding, and at 6 and 12 weeks we verified which practices were observed. At the time of exit from the study (18 weeks), the interviews explored the mothers' experiences of breastfeeding in the context of prevention of mother-to-child transmission of HIV.

In addition to interviews, field notes compiled by the researcher focused on breastfeeding practices when mothers visited the health centres and how they interacted with health care workers. For mothers who were visited at their homes, the observations included the general surroundings, presence of any family members for support and any aspects that had a bearing on breastfeeding practices.

Data management

All audio files from digital recorders were downloaded on the computer and transcribed verbatim from local languages into English. All transcripts were checked for accuracy, quality and cleaned for anonymity by removing all identifiers. All field notes from observations, informal interviews were typed as soon as they were gathered. All the files were imported into the QRS Nvivo 10 version for coding and analysis, and a regular backup in the external drives was maintained throughout the project.

Data analysis

Data were analysed using a conceptual framework analysis designed for health policy research. Data collection and analysis were conducted concurrently (Ritchie and Spencer, 2002:305–329). After data were sorted and coded, five major themes emerged: 1) knowledge of HIV transmission through breastfeeding; 2) cultural value of breastfeeding; 3) mixed feeding as a cultural norm; 4) herbal use for babies and mothers; and 5) perceived consequences of disregard of cultural practices. These common themes were highlighted to select quotes that either supported or refuted them.

Trustworthiness

Accepted as the general standard for establishing trustworthiness for this research, we used the Lincoln and Guba's (1985) criteria of credibility, transferability, dependability, and conformability. Credibility was achieved through reflexivity and thick description of exclusive breastfeeding as a phenomenon. To establish the context of the research, we provided comprehensive description of the methods, results and ideas that can be replicated in another context. Dependability was done through a triangulation process, coding and recoding procedures as well as sifting the data to determine the themes. Confirmability was used to appraise the integrity of the results through reflexivity,

statement of researchers' beliefs and assumptions, while recognising the limitations of the study (Creswell, 2007:45–90b).

Ethical consideration

Permission to conduct the research was obtained from the Ministry of Community Development, Mother and Child Health. Ethical clearance was granted by the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal in South Africa (HSS/0104/013D) and the Biomedical Research Ethics Committee of the University of Zambia (Reference No. 016-11-13). Voluntary participation was accorded with written consent. No identifiers were used to ensure confidentiality and privacy was observed by conducting interviews at a place convenient to the participant. The participants were free to withdraw from the study at any stage and continuity of care was assured.

FINDINGS

Characteristics of study participants

Thirty (30) mothers recruited were aged between 20–40 years old and were single or married, employed or unemployed. The HIV-positive men were aged 37–47 years and were either small business entrepreneurs or in formal employment, while the community-based volunteers aged 30–58 years were fully attached to the health centres as lay counsellors.

Knowledge of HIV transmission through breastfeeding

Participants understood that HIV could be transmitted through breast milk and that the risk was higher when the mother was not on treatment for the prevention of mother-to-child transmission of HIV. They were aware that exclusive breastfeeding for the first six months reduced the risk of transmission.

> … HIV transmission can be at delivery and during breastfeeding. During breastfeeding if you did not prevent then the baby can be infected (Mother, 35years).

The mothers' understanding of the role of breast milk in HIV transmission influenced their perception of the cultural practices performed to their babies and themselves during breastfeeding as described in the next section of the article.

Cultural understanding of the value of breastfeeding

While participants were able to describe the value of breast milk, there were varied statements in the way they understood its components. Typical narratives were:

> … all the foods are in the breast milk, and even if there is no food at home you can't worry because the baby has the breast milk … (Mother, 22 years).

> The milk which comes out first (colostrum) is the one which has vitamins, after that then there is nothing that you're, giving the baby and you will punish the child (Mother, 25 years).

> … before breastfeeding the baby, first the dirt, the first milk (colostrum) has to come out so that it is clean that is when you breastfeed the baby the good milk (Man, 42 years)

Participants understood breast milk as food for the baby, however, their knowledge on the value of the different compositions such as colostrum had implications on the way the babies were fed. Therefore, despite infant feeding counselling, mothers practised the cultural norm of mixed feeding.

Mixed feeding as a cultural norm

Mothers believed that the baby remains hungry on breast milk only and mixed the feeding with orange juice, cow's milk and light maize meal porridge as described by the nurse:

> Yes our mothers practice mixed feeding because they feel the baby is not having enough milk from the breast, so they'd want to start giving the baby cow's milk meanwhile they're also breastfeeding …(Registered Nurse).

Participants agreed that the babies cry of abdominal pain and hunger, forcing them to mix the feed.

> In the community they say that you have to make the baby stop crying, mine stopped at three months after I started to give it porridge (Mother, 25 years).

The link between what was discussed during infant feeding counselling and the community knowledge posed challenges for mothers to adhere to exclusive breastfeeding. One participant had the following to say:

> … it depends on whether the baby is still hungry even with the breast milk because sometimes some breasts produce more milk others do not. If the baby cries of hunger after you give the breast milk you start giving soft, soft porridge just like that (Mother, 22 years).

Mixed feeding was reported to commence as early as two weeks when elders advised younger women to do so, resulting in the practice being passed from generation to generation. Referring to their own babies, some participants said:

The elders want to start feeding him after he has turned two weeks or one month (Mother, 35 years).

> … yes, elderly women say that the baby does not get satisfied with breast milk unless you give him porridge. The elderly ones, even now they talk about it (Mother, 32 years).

The results revealed that mothers were more concerned about the immediate needs of their babies than the risks of mixed feeding.

Herbal use for babies and mothers

Herbal use was reported for reasons varying from use as medication, bathing and cleansing the breasts of the mother after the death of a previous baby to ward off evil spirits.

Herbal use for medication

Herbal medication was reportedly given to the baby to drink as a performing ritual to ward off ghosts. Health care workers were aware of this practice among HIV-positive mothers.

> … when the baby is discharged and they go back home the older women will tell the mothers to breastfeed but they also give herbs to the baby to drink perceived to clear the stomach (Registered Nurse).

A man in a focus group discussion added:

> … in line with tradition when the child is born the grandmother comes, or I will look for someone, even pay so that they find medicine for the baby to drink and bath. Then they will tie in the waist or the neck of the baby to protect it from chibele (diarrhea). It is an old tradition that has been there before clinics came into existence (Man, 45 years).

In some cases, herbs were used to treat signs of dehydration, fever and oral thrush. A nurse had this to say:

> … some of them rub the palates of the newborn baby with herbs thinking that there is an abnormality (chapamutu and chamukamwa) thus bruising the palate and definitely while breastfeeding the baby is going to get infected with HIV (Registered Nurse).

A participant confirmed the practice and identified the source of the herbs.

> … the herbal medicine is taken from a 'mukuyu' tree to give the baby to drink in order to stop vomiting and diarrhea and then the baby will be fine (Mother, 32 years).

Herbal use was also reported for tattoos perceived to ward off the evil spirits of the previous dead baby.

> Others get a razor blade to give traditional tattoos to prevent the spirit of the dead child to follow the new born (Mother, 23 years).

It was observed that mothers did not breastfeed immediately in the labour ward because they expected to wash the breasts with herbal medicine.

Herbal use to wash the mother's breasts

When the mother lost the previous baby through death, she was expected to wash the breasts before breastfeeding the new born baby. The practice was associated with cleansing the breasts of bad spirits and was perceived to prevent mixing breast milk of the dead child with that of the new born baby. This practice delayed the initiation of breastfeeding after delivery. The mother who lost her children said:

> … the way my children died … this time before I breast fed, I washed my breasts with herbs because the baby may start having fits because of the spirits of the children that passed away. (Mother, 32 years).

Perceived consequences of disregard of cultural practices

Fear and insecurity led mothers to adhere to cultural practices that were in conflict with the messages from the health facilities. The consequences of failure to observe the culturally defined norms varied from the baby contracting a childhood disease and death.

Chibele (Diarrhea)

Chibele (diarrhea) was perceived to be induced by breastfeeding a baby in public where other babies were assumed to be protected with *chithumwa* (herbs) worn around the neck or waist of the baby or the mother.

> … if your baby hasn't got the herbs (chithumwa) in the waist and then you meet with the baby who has, then yours will be infected with chibele (Mother, 32 years).

A community volunteer in a Focus Group Discussion said:

> … mothers cannot breastfeed their babies in public when they come to the clinic for fear that their babies may get infected with chibele (diarhoea) and other diseases (Female, Community volunteer).

Mililo/midulo (Chest infections)

This article further reveals practices that were perceived to protect the baby from chest infections and included *kupeleka mwana kumpasa,* a practice done at the first sexual

intercourse about 6 weeks to 6 months post-delivery. After sexual intercourse, the semen would be smeared on the baby's back, joints and chest.

> The elders teach us that after a baby is born and when a couple wants to resume sexual intercourse, after the act, you get the semen and smear on the baby's back, joint and chest (Mother, 29 years).

The value attached to the cultural norms and practices was based on respect for tradition that is passed from generation to generation.

DISCUSSION

Infant feeding when a mother has HIV infection is complex in settings known to be deeply driven by culture and where mixed feeding is a norm. Mothers have to adhere to exclusive breastfeeding, which is one of the fundamental strategies in the PMTCT programmes. However, this research brings to the fore the realities faced by mothers as they choose safer feeding practices for their new born babies.

The conflicting views on the value of breast milk and especially the disregard for the significance of colostrum unveil the gaps in infant feeding counselling. Lack of knowledge of the proven nutritional value of colostrum, which contains antibodies, vitamin A, less fat and carbohydrates, thus conferring the first immunisation the baby requires the first few days after birth and essential for HIV-exposed infants, needs to be addressed (WHO, 2003; WHO, UNICEF, UNAIDS & UNFPA, 2012). Similar findings have been reported in Zambia, showing a deep rooted cultural belief that the first milk is dirty and might make the baby sick (Fjeld, Siziya, Katepa-Bwalya, Kankasa, Moland, Tylleskar & PE Group, 2008), leading to delays in initiating breastfeeding. Delays in immidiate initiation of lactation undermine efforts to prevent HIV infection in the post-natal period and the success of breastfeeding. Given these findings, we assumed that mixed feeding commenced earlier than reported. Mixed feeding with cow's milk, light maize meal porridge and orange juice is known to erode the stomach mucus lining of the infant, thus predisposing it to HIV and other infections (MoH, 2014; WHO et al., 2012). A knowledge gap on how to care for new born babies by mothers, where they generally perceived crying to mean hunger and abdominal pains, led to their own interpretation of the phenomenon and the subsequent use of traditional herbs to treat diarhoea (*chibele*), chest infections (*midulo/milio),* dehydration (*chapamutu)* and oral thrush *(chamukamwa).* The dosages and frequency of the herbs were not established as mothers indicated that they these were given to them by the elders and the effects of these herbs on HIV-exposed infants are not documented in Zambia. Our assumption was that women used herbs due to anxiety and the vulnerability created by lack of knowledge of common causes of childhood illnesses. The existing guidelines on management of childhood diseases should be part of the messages and materials to use during infant feeding counselling (WHO, 2005). We observed that the health facilities did not have the charts to illustrate common childhood ailments that could draw the

mothers' attention during antenatal clinics, children's clinics and counselling sessions. Therefore, the focus for both individual counselling and group health education should be broadened beyond infant feeding methods, to cover a variety of subjects that have a bearing on child survival among the HIV-exposed infants.

Group health education is the main method of teaching in the maternal, neonatal and child health departments. This is meant for mothers to clarify any issues related to maternal and child health, including prevention of mother-to-child transmission, and serves as a group pre-test counselling session (MoH, 2010). However, the health care workers adopted a traditional approach that leaned towards instructive and prescriptive models, while assuming the position of authority to tell mothers to exclusively breastfeed, thus creating a distance between themselves and the mothers. Critics of global policy guidelines on infant feeding and HIV have highlighted that the social and cultural distance between the producers and implementers of the infant feeding guidelines with its many recipients has generated a sense of helplessness, confusion, guilt and fear among the ones involved in the intervention (Koricho, Moland & Blystad, 2010; WHO, UNAIDS, UNFPA & UNICEF, 2010). Issues of infant feeding should be emphasised during individual infant feeding counselling to avoid group dynamics observed in this research where mothers systematically detached themselves from voices that seemed to undo health education messages.

RECOMMENDATIONS

The following recommendations were made by the authors:

4. Intensify promotion of exclusive breastfeeding among all mothers.
5. Develop culturally appropriate counselling tools that address the known cultural practices of the populations affected.
6. Design strategies to facilitate integration of spouses, family (in-laws, mothers, grandmothers) in care to facilitate accountability of behavioural practices of breastfeeding.
7. Strengthen skills in effective communication and provide frequent updates on infant feeding guidelines among health care workers to avoid distorted information trickling down to the mothers and the community.

LIMITATIONS OF THE STUDY

We recognised lack of generalisation of the findings beyond the group studied. However, this did not weigh down the value of research findings to inform interventions and improve breastfeeding practices among HIV-positive mothers.

CONCLUSIONS

We conclude that a mix of cultural norms of breastfeeding is known and is holding up against current prevention of mother-to-child transmission of HIV interventions among the population studied and similar settings (Chinkonde, Hem & Sundby, 2012; Madiba and Langa, 2014). The magnitude of the HIV pandemic is a big challenge in resource-constrained countries of sub-Saharan Africa where cultural norms are rooted in the way of lives of people. We reiterate that prevention of mother-to-child transmission of HIV programmes will vary in effectiveness in different contexts unless they fundamentally respond to socio-cultural norms as lived out in communities they intend to serve (Blystad, Van Esterik, De Paoli, Sellen, Leshabari & Moland, 2010). The health care system should critically analyse available opportunities to improve breastfeeding practices among all mothers accessing maternal, neonatal and child health services.

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REFERENCE LIST

Blystad, A., Van Esterik, P., De Paoli, M. M., Sellen, D. W., Leshabari, S. C. & Moland, K. M. 2010. Reflections on global policy documents and the WHO's infant feeding guidelines: lessons learnt. *International Breastfeeding Journal* 5:18.

Chinkonde, J. R., Hem, M. H. & Sundby, J. 2012. *HIV and infant feeding in Malawi: public health simplicity in complex social and cultural contexts. BMC Public Health,* 12**,** 700.

Creswell, J. 2007. *Qualitative inquiry and research design.* 2nd Edition. London: Sage Publications.

Fjeld, E., Siziya, S., Katepa-Bwalya, M., Kankasa, C., Moland, K. M., Tylleskar, T. & Group, P. E. S. 2008. 'No sister, the breast alone is not enough for my baby': a qualitative assessment of potentials and barriers in the promotion of exclusive breastfeeding in southern Zambia. *International Breastfeeding Journal* 3:26.

Koricho, A. T., Moland, K. M. & Blystad, A. 2010. Poisonous milk and sinful mothers: the changing meaning of breastfeeding in the wake of the HIV epidemic in Addis Ababa, Ethiopia. *International Breastfeeding Journal* 5:12.

Madiba, S. & Langa, J. 2014. Cultural practices interfere with adherence to exclusive infant feeding: a qualitative study among HIV positive post natal women in Hammanskraal, South Africa. *African Journal for Physical, Health Education, Recreation and Dance (AJPHERD)* 1:264–278.

Ministry of Health. 2010. *National Protocol Guidelines for Infant feeding; Integrated Prevention of Mother to Child Transmission of HIV/AIDS. Lusaka*: Ministry of Health.

Ministry of Health. 2014. *Zambia Country Report; Monitoring the declaration of Commitment on HIV and AIDS and the Universal Access.* Lusaka: Ministry of Health and National AIDS Council.

Moland, K., De Paoli, M., Sellen, D., van Esterik, P., Leshabari, S. & Blystad, A. 2010. Breastfeeding and HIV: experiences from a decade of prevention of postnatal HIV transmission in sub-Saharan Africa. *International Breastfeeding Journal* 5:10–16.

Ritchie, J. & Spencer, L. 2002. Qualitative data analysis for applied policy research. In Huberman, A.M. & Miles, M.B., *The qualitative researcher's companion*, pp305-329. London: Sage Publications

Shirunga, M. 2010. Cultural and social factors impacting on the programme to prevent-mother-to-child-transmission (PMTCT) of HIV in Namibia: a case study of the kavango region. Unpublished Master's of Medical Anthropology Research, University of Western Cape, Bellville, South Africa.

United Nations Programme on HIV/AIDS. 2012. *Global report: UNAIDS report on the global AIDS epidemic*. Geneva: United Nations AIDS programme.

United Nations Programme on HIV/AIDS. 2013. *UN estimates with uncertainty abound*. http://www.unaids.org/en/resources/documents/2014/HIV_estimates_with_uncertainty_bounds_1990-2013 (Accessed 07 November 2014).

World Health Organization. 2003. *Global strategy for infant and young child feeding*. Geneva: World Health Organization.

World Health Organization 2005. *Handbook IMCI: integrated management of childhood illness, World Health Organization*. Geneva: World Health Organization.

World Health Organization, United Nations Programme on HIV/AIDS, United Nations Population Fund & United Nations Children's Fund. 2010. *HIV and infant feeding guidelines, principles and recommendations for infant feeding in the context of HIV and a summary of evidence.* Geneva: World Health Organization.

World Health Organization, United Nations Programme on HIV/AIDS, United Nations Population Fund & United Nations Children's Fund. 2012. *2010 WHO Guidelines on HIV and infant feeding: an updated framework for priority action.* Geneva: World Health Organization.

Chapter 5

Mothers' Perception of Infant Feeding Counselling in the Context of Prevention of Mother-to-Child Transmission of HIV in Lusaka, Zambia. (Published article)

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ORIGINAL ARTICLE

Mothers' Perception of Infant Feeding Counselling in The Context of Prevention of Mother-to-child Transmission of HIV in Lusaka, Zambia

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ABSTRACT

Background: The aim of infant-feeding counselling is to facilitate informed decision on method of feeding in the context of prevention of mother-to-child transmission of HIV. However, HIV-positive mothers are faced with uncertainty on how best to feed their infants. The question we asked for this research was: how does the information provided in counselling on HIV and infant-feeding assist mothers in making decisions for safer feeding practices for their infants?

Methods: This sub-study was part of the larger study conducted on: HIV and infant feeding; choices and decision outcomes in the context of PMTCT among HIV-positive mothers in Zambia. Data were collected through key-informant interviews with health care workers (HCWs) and individual interviews with 30 HIV-positive mothers. Data were collected from January to September 2014. The interviews were digitally recorded and transcribed verbatim. The QRS NVivo 10 version was used for data coding and analysis.

Results: The role of health care workers in PMTCT was to provide information on infant feeding and facilitate informed decision on feeding HIV-exposed infants. Concerning the decision on infant feeding, mothers reported that they chose to practice exclusive breastfeeding because it was an optimal choice for their exposed infants. However, there appeared to be other factors that influenced the decision on how to feed HIV-exposed infants: maternal instinct to protect the baby from getting infected with HIV; the perception that a breastfed baby is health; and the cost of formula. Potentially, mothers may have risked to practice mixed feeding due to: late initiation of breastfeeding in respect of cultural norms; the belief that the baby can just stop breastfeeding on its own; and pressure from family and community to practice mixed feeding.

Conclusion: While EBF is now recommended for HIV-exposed infants, challenges remain on how to promote EBF and tailor information on infant feeding counselling and assist mothers make an informed decision in settings where formula feeding would not be recommended. Therefore, quality and objective infant feeding counselling should be practiced by HCWs to enhance safer feeding practices.

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INTRODUCTION

The aim of infant-feeding counselling in the context of prevention of mother-to-child transmission (PMTCT) of HIV is to facilitate informed decision on method of infant feeding. Mothers infected with HIV in resource-poor

Keywords: *Exclusive breastfeeding, Formula feeding, Infant feeding counselling, Health promotion, Informed decision, Lusaka, Zambia.*

settings are faced with a myriad of challenges and uncertainties on how best to feed their infants. A package of interventions for PMTCT in maternal, neonatal and child health (MNCH) programmes includes antenatal clinic visits, the opt-out approach for HIV counselling and testing, antiretroviral therapy (ART), health facility-based deliveries, infant ARV prophylaxis and HIV testing, in addition to postnatal care. Infant feeding recommended for HIV-positive mothers in Zambia is exclusive breastfeeding for the first six months and beyond, with lifelong ARVs for the mother; here too, counselling is a prerequisite for safer infant-feeding practices [1,2]. Given the socioeconomic challenges faced by mothers in low-resource settings, breastfeeding protects infants against diarrhoea through reduced risk of bacteria from contaminated formula, other liquids and complementary foods, and most importantly the transfer of maternal antibodies through breastmilk renders some immunity in early childhood [3].

Counselling is a professional relationship that is adopted by a trained counsellor and a client for the purpose of making an informed decision [4]. This is a process intended to allow health care workers to advise HIV-positive mothers on safer infant feeding practices while recognising their limitations. However, research findings regarding infant feeding counselling shows that challenges arise in assisting HIV-positive mothers to choose and practice safer infant feeding. These challenges relate to infrastructure, communication skills among healthcare workers, low staffing levels, slow updates on infant feeding guidelines, and, to a certain extent, poor staff attitudes[5-9]. For instance, healthcare worker behaviours observed in some settings include their personal beliefs towards infant feeding, conveying contradictory messages on PMTCT, exhibiting directive counselling styles, and lack of practical strategies to offer mothers, often leading to improvised counselling approaches [10]. In some settings, healthcare workers have attributed challenges faced in counselling mothers to poor compliance by mothers and passive resistance resulting in stress, depression and burnout [11]. These factors have a multiplier effect on HIV-positive mothers, who have been observed to feel obliged to hide their feeding practices[12, 13], thereby risking the lives of their HIV-exposed infants.

Variations in counselling practices have also been reported and include prescriptive models where one option is proposed for all women, based on the mother's economic status, whereas mothers are concerned with social issues related to the risk of being stigmatized as a bad mother or as being HIV-positive when making a decision[14]. Other researchers have observed that counsellors frequently framed counselling sessions as health education programmes and instruction, where mothers are subjected to 'advising and giving of information' – a style rooted in a didactic and instructive model and consequently unable to create an environment where choice could become an option [11, 15]. These deficiencies have led to recommendations that counselling messages should critically align infant feeding with local context and making use of counselling cards[16, 17]. An environment that better enables mothers to follow national guidelines and make informed decisions should thus be available, taking heed of lessons learnt in similar settings [18]. Therefore, the question we asked for this study was: how does the information provided in counselling on HIV and infant-feeding assist mothers in making decisions for safer feeding practices for their exposed infants?

MATERIALS AND METHODS

Design and setting

This sub-study was part of the larger study conducted on: HIV and infant feeding; choices and decision outcomes in the context of PMTCT among HIV-positive mothers in Zambia. Data were collected through participant observation and in-depth interviews between January and September 2014. Participants were recruited from two health facilities that are part of national PMTCT and ART programme in Lusaka. Apart from curative services, these health facilities provide MNCH services in the district.

Participant and sampling

30 HIV-positive mothers were recruited in the study. Six health care workers were selected from the PMTCT programme as key informants. All participants were purposively sampled. The HCWs were selected based on their availability in the PMTCT programme at the time of data collection. The selection criteria for mothers were that they needed to have attended group health education apart from testing for HIV, placed on treatment regimen (ARVs) and counselled on infant feeding.

Data collection and techniques

The first author and two research assistants collected all data. A semi-structured guide was used to conduct interviews. The main interview question for health care workers was: how is the information provided on HIV and infant feeding assist mothers in making a decision for safer feeding practices for their exposed infants? The main question for the HIV-positive mothers was: how did the information on infant feeding counselling assist you to make a decision on how to feed your HIV-exposed infant from birth?

Key-informant interviews

Key informant interviews were conducted with two nurses, two nutritionists and two clinical officers. The HCWs' interviews were meant to establish how the health facilities planned and implemented infant feeding counselling for HIV-positive mothers. The nurses were key providers of MNCH services, nutritionists were actively involved in counselling for infant and young child feeding (IYCF) while the clinical officers conducted screening, diagnosis and prescribing treatment and all were trained in PMTCT interventions. There were no pre-determined guides on how observations were assessed because of variations within health facilities across the sites.

Individual interviews

Individual interviews were held with mothers who had attended group health education and infant feeding counselling. This was considered an appropriate tool to effectively gain understanding of the complex and sensitive emerging issues and to allow mothers to express their opinions in their native language and share their experiences on how they decided to feed their HIV-exposed infants.

Data management and analysis

The tape recorded interviews were transcribed verbatim from a primary language into English by four trained research assistants. The transcripts were checked for accuracy, quality and cleaned for anonymity by the first author. When no discrepancies were identified, the files were imported into QRS NVivo 10 version for coding and analysis by the first author and one research assistant coded the data to allow for comparisons as themes emerged. The method of analysis was interpretive descriptive analysis to gain insight into infant feeding counselling as a phenomena from the participants' perspective [19]. At the initial stage the content of the data files were read to identify the nature of the phenomenon or the major thematic areas. The main task was to display data in a way that was conceptual in order to make distinctions that were meaningful and provide content that illuminated the phenomena. There are three key steps involved in interpretive descriptive analysis that were used for this study. Detection involved identifying and assigning the substantive content and dimensions of infant feeding counselling. These dimensions included the three major themes: The information that HCWs presented to HIV-positive mothers during infant feeding counselling; how HIV-positive mothers understood information on infant feeding in the context of PMTCT; how mothers decided to breastfeed; how mothers potentially risked to practice mixed feeding. This process was followed by identifying categories that were refined and were then assigned to classes or groups that hold true the data that described the phenomena to exclusively breastfeed.

RESULTS

Mothers frequently self-reported as married (27) and there were younger mothers (15-24 years) with primary level education (0-7).

Table 1 Demographic characteristics of HIV-positive

Characteristic	Categories	Frequency
Age	15-24	10
	25-34	16
	35>	4
Marital status	Single	2
	Married	27
	Widowed	1
Education (Grades)	0-7	14
	8 & 9	11
	10-12	2
	College education	2
Employment	None	28
	Employed	2
Children	1-3	21
	4-6	9
TOTAL		30

The information that HCWs presented to HIV-positive mothers during infant feeding counselling

Infant feeding counselling in the context of PMTCT of HIV is based on national guidelines and applied at every level of health care delivery. One of the elements of infant feeding counselling is for HCWs to communicate to mothers the competitive advantages of breastfeeding and other available feeding options for HIV-exposed infants. For this research, HCWs described their role in PMTCT as providing information on infant feeding and to facilitate informed decision on feeding HIV-exposed infants. A key informant explained: *"Our role is to educate the mothers, give them information, motivate them and support them especially when they choose an option of infant feeding. For some mothers, as long as we give them information and motivate them, there is going to be behaviour change especially in the community"*. [nutritionist, 4 years in PMTCT]. In the same perspective, another key informant added: *"We emphasise to them to feed their babies on breastmilk exclusively without any other foods until the baby is six months"*. [midwife, over 10 years in PMTCT]. The same midwife explained: *"As they come we teach them as a group, but even when they come to deliver, we talk more on infant feeding because during group health talks it may be difficult for some women to disclose whatever they may have wanted to share secretly. During one on one before the woman delivers we talk to them again to ensure the baby is put to the breast immediately"*.

Emphasing exclusive breastfeeding while a mother is on ARVs was further explained in the context of making sure the guidelines were followed: *"Initially what we are trying to counsel mothers is to adhere to treatment including their babies because chances of mother-to-child transmission of HIV is reduced. We emphasise these things during counselling so that the risks are reduced further when the mother starts to breastfeed"*. [nutritionist, 25years, 4 years in PMTCT]

How HIV-positive mothers understood information on infant feeding in relation to PMTCT

In order to make an informed decision, mothers needed to understand the principles that guide infant feeding in the context of exclusive breastfeeding, which in this case was a default choice promoted by HCWs. Overall, mothers explained that they chose to practice exclusive breastfeeding because it was optimal for their HIV-exposed infants and themselves. According to a mother of two children, information from the clinic helped her to make such a decision: *"The information I got from the clinic helped me a lot. So at the moment, I am breastfeeding my baby and he is very healthy. At six months I will start giving him other foods such as porridge and water to drink, then I will wean him off"*. [mother, 32years, 2 children]. Another participant added: *"We get help from the clinic on how to breastfeed our babies. For me I will be doing what I have been told by the nurses. They told me not to give the baby food or water,*

but only breast milk. When the time comes to give the baby other foods then I will do that". [mother, 25years, 1 child]

However, for some participants, group health education and infant feeding counselling were: *"just the usual talk that goes on at the clinic. Not necessarily the information that I needed to help me choose the method of infant feeding".* [Mother, 26years, 2 children]. This description may have been related to the routine health talks that were conducted in the MNCH units for pregnant mothers attending antenatal clinic and other services. The perspective to lack of information on infant feeding was also expressed by other participants in the following responses:

> *"Unless I am told by the nurses, the thing is that I do not know much, if I was told to stop breastfeeding him, yes I could do it".* [Mother, 26years, 2 children]

> *"I don't have much information, although we were told that we will be taught how to feed the baby but the teaching was not done in details. I just know that I have to breastfeed the baby as advised... things like that".* [Mother, 22years, 1 child]

How mothers decided to breastfeed

Although mothers reported lack of information to enable them choose a method of feeding, choosing to breastfeed was influenced by maternal instinct to protect the baby from HIV infection; the perception that a breastfed baby is healthier; and the cost of formula. This section of the article highlights these factors individually.

To protect the baby from getting infected with HIV

The key informants explained that mothers were told that exclusive breastfeeding while on ARVs reduced the risk of the mother infecting her baby with HIV through breast milk. These messages appeared to be understood by mothers. One participant illustrated how she chose to breastfeed so that she could protect her baby from HIV infection: *"I am breastfeeding so that my baby should not get infected with HIV".* [Mother, 26years, 2 children]. In the same perspective, another participant added: *"I want to protect the baby from HIV because I am on medication (ARVs) and I can breastfeed. I will not miss the medicines so that the baby is protected and grows healthy".* [mother, 25years, 1 child].

The perception that a breastfed baby is healthy

The perception of the healthy baby as a breastfed baby was supported by the understanding that with ARVs the risk of the mother infecting her baby with HIV through breastmilk is reduced: *"They said I should exclusively breastfeed and they gave me medicine (ARVs) for protection. I learnt that breastfeeding is healthier for the bay than formula feeding".* [mother, 33years, 3 children]. Similarly, another participant added: *"I chose to exclusively breast feed because I want to see my daughter grow healthy. I was encouraged that if I breastfeed my baby there will be no problems and that is what I want to see".* [mother, 33years, 5 children]. The perception of a healthy baby was supported by a young mother of two children who illustrated further that breastmilk does not compare with any other food for the baby: *"There are no other foods that you can give a new-born baby apart from breast milk".* [mother, 26years, 2 children]

The cost of formula

While participants decided to breastfeed their HIV-exposed infants, their understanding of the cost of formula was considered a barrier to choose a safer feeding option for their infants. They understood that they would not be able to initiate and sustain formula feeding. Typical responses were:

> *"Sometimes you know that you do not have money, like for me my husband died and if the money that he left for me finishes I will suffer to buy milk. The money that I was supposed to use to buy milk, I use it to buy food for the rest of the family to eat and the baby eats from the breast".* [mother, 34years, 3 children]

> *"Yes money is hard to find. If I chose formula it was going to be difficult to have enough milk for the baby every day. For example one tin can finish in four days, and then you need some more money, it is difficult you see. So it was better that I chose to breastfeed".* [mother, 25years, 1 child]

How mothers potentially risked practicing mixed feeding

Despite the messages on the benefits of breastfeeding and especially exclusive breastfeeding, this section of the article highlights factors that promote mixed feeding among selected populations. They include: late initiation of breastfeeding; pressure from family and community to practice mixed feeding; breast complications; and the perceived breast milk insufficiency.

Late initiation of breastfeeding

The difficulty reported by mothers to achieve early initiation of breastfeeding in the midst of social expectations was based on the understanding of the values attached to cultural practices of breastfeeding. In settings driven by culture, certain customs are performed as a ritual before initiation of breastfeeding. The rituals among others may include: washing the breast before the new-born baby is put to the breast in the event that the mother lost the last baby. The herbal medicine is perceived to ward off the spirits of the dead baby and is practiced before putting the new-born baby to the breast after birth. This practice potentially led to delay to initiate breastfeeding as mothers had to wait for the ritual to be performed. Without undue discomfort to share her experience, a mother who lost her two children before the current baby explained: *"I lost my last two children so I had to use the traditional medicine so that this baby should not be seeing his dead siblings. I used the herbs which the elders brought for me and rubbed on my breasts and I also used it to bath the baby. This was done before I breastfed him. After I rubbed the breasts with herbs that's when I breastfed him"*. [mother, 26years, 1 child]. These practices impacted early initiation of breastfeeding and the well being of new-born babies. Without making direct reference to herself, a 28year old mother of three children described the difficulty experienced when one delivered in a health facility: *"It depends on where you come from and how the people are. After delivery there are situations when the baby would be crying but as a mother you have to wait for the elders to prepare the herbs to use before breastfeeding. As a mother you would make the baby suck the finger. When asked by the nurses you just tell them the baby has breastfed"*. [mother, 28years, 3 children]

The above experiences were also illustrated in the following responses:

> *"In my culture, the breasts are washed before the baby starts breastfeeding or touches the breast"*. [mother, 35years, 4 children]

> *"If I had a baby that passed on, I need to take some herbs so that the new baby will not have the spirit of the dead sibling"*. [mother, 24years, 1 child]

The belief that the baby can just stop breast feeding on its own

The belief that sometimes the baby can wean off from the breast abruptly because the breastmilk is not enough was illustrated by a 22 year old mother of two children. She explained: *"I breastfed my baby for five months but the baby just stopped breastfeeding because my breasts don't produce a lot of milk. So that is how the baby stopped breastfeeding and I started giving him formula and Super shake (Cow's milk)"*. In situations where the mothers informed the nurses about their perceived milk insufficiency, a mother described how she was encouraged to continue to put the baby to the breast in order to have sufficient flow of breastmilk. She explained: *"When at the clinic and the baby cries the nurses tell us to continue breastfeeding saying that is when the milk will be coming out more. Even when you say the milk is not coming out the nurses insist that the baby will pull until the milk comes out"*. [mother, 25years, 1 child]

Pressure from the family and community to practice mixed feeding

Although the health-promotion messages on exclusive breastfeeding appeared to be understood as only feeding the baby with breast milk, mothers were anxious about pressure from the family and community to practice

mixed feeding. This anticipated challenge influenced their capacity to resist mixed feeding. A young first-time mother explained: *"When the baby is born you are advised to only breastfeed by the nurses, but people say that for the baby's stomach to relax you need to give orange juice"*. [mother, 24years, 1 child]. In the same perspective, a mother of five children added: *"Sometimes, you can make a mistake and give the baby water and then you breastfeed him"*. [mother, 31years, 5 children]. Therefore, mothers had to deal with pressure to mix the feed with other fluids and porridge: *"I just used to listen when people are talking in the community. Yes, others were saying that the baby should be given milk (formula), others were saying Super shake (cow milk based product), others Delite and Cerelac porridge"*. [mother, 18years, 1 child].

DISCUSSION

Our findings indicate that regardless of the method of feeding proposed for HIV-exposed infants in resource-poor settings, mothers are capable of understanding the risks and optimal benefits to their infants and themselves if appropriately counselled. The mothers' perception of messages on infant feeding were understood in the context of how they were presented by HCWs. However, we also found evidence of factors that either promote exclusive breastfeeding or mixed feeding that HIV-positive mothers had to consider when choosing how to feed their exposed infants.

In this study, we found evidence that all mothers were encouraged to exclusively breastfeed. According to the HIV consolidated guidelines for treatment and prevention, Zambia adopted option B^+ where HIV-positive mothers are initiated on combination antiretroviral therapy [cART] during pregnancy and breastfeeding regardless of CD4 count. The strategy is aimed at reducing the rate of mother-to-child transmission of HIV among the exposed infants. Replacement feeding especially with formula would only be considered if acceptable, feasible, affordable, sustainable and safe (AFASS) (MoH, 2014a). However, in order to achieve exclusive breastfeeding, client and healthcare worker decision-making interactions on infant feeding should be encouraged and supported to increase uptake of messages on the method of feeding [5,9].

Awareness of messages to exclusively breastfeed in the context of PMTCT was nearly universal among the mothers studied. Therefore, when appropriately addressed, infant feeding counselling would provide an opportunity for mothers to clarify issues relating to the method of feeding and avoid pitfalls in behavioural change that is required for optimal uptake of EBF. As reported in a similar study, HCWs especially nurses and midwives are the common source of information on breastfeeding and HIV and are required to be more knowledgeable and have the skills to communicate to mothers in an effective way [16]. This includes identifying factors that would promote exclusive breastfeeding based on individual circumstances because mothers generally perceive instructions from HCWs as binding – a belief also shared by mothers in similar settings [5]. This is therefore, an added advantage to the process of ensuring that HCWs identify individual factors that may present barriers to EBF during infant feeding counselling. We provide evidence that factors such as the desire to protect the baby from HIV infection, the perception that a breastfed baby is healthier and the cost of formula impacted on how mothers chose to feed their infants in the context of PMTCT.

Mothers' understanding that exclusive breastfeeding and ARVs would protect the baby from getting infected with HIV should be used to strengthen the promotion of EBF in selected populations. Although this study included more women with primary level of education, they showed potential to understand EBF as a PMTCT strategy. Studies in similar settings have however, reported that educated mothers were more likely to head health education messages and comply with advice than non-educated women [20]. This study has shown that added efforts by HCWs in promoting EBF would lead to mothers retaining messages that they understand to be important to the survival of their HIV-exposed infants.

This is more so because they perceived that a breastfed baby is healthier than a formula fed baby. In this context researchers have reported the associated benefits of breastfeeding and especially exclusive breastfeeding among the HIV-exposed infants (Coovadia et al., 2007; Iliffa et al., 2005). The associated benefits and the perception that a breastfed baby is healthy is also a practice that is rooted in the way of feeding new-born babies in settings rooted in their culture. However, in these settings, mixed feeding is a norm [21] and therefore, there is need for intensive health-promotion messages in order to empower mothers to protect EBF to the benefit of their exposed infants. Hence HCWs need to spend more time to explain to mothers the fundamental elements that guide exclusive breastfeeding because this cannot be achieved through a once-off infant feeding counselling encounter that is common in the settings where mothers were recruited from. This is so especially given low literacy levels and socioeconomic status that is common among some selected populations of Lusaka. This aspect should be considered seriously in PMTCT programme because the cost of other alternative feeding options such as formula is considered a barrier to choice of feeding. Participants in this study echoed that if they had the financial means they would have opted to formula feed in order to protect their infants from HIV infection through breastmilk. The WHO infant feeding guidelines recommend the promotion of EBF combined with ARVs for HIV-positive mothers in settings where formula feeding is not acceptable, feasible, affordable, sustainable and safe [AFASS] [3]. There are also a lot of factors that need to be considered before choosing to formula feeding such as water supply, sanitation and consistent supply of formula among others. Even in settings where free formula has been implemented, challenges abound with serious consequences to underfeeding [22]. When poorly implemented, such strategies pose serious infant and child health outcomes. Therefore, clear health-promotion messages on EBF are critical so that HIV-positive mothers may be aware and avoid factors that potentially lead to mixed feeding such as late initiation of breastfeeding perceived milk insufficiency and pressure to practice mixed feeding from family and friends.

Our finding about the difficulty reported by mothers to achieve early initiation of breastfeeding in the midst of social expectations was based on the understanding of the values attached to cultural practices of breastfeeding. Washing of the breast after giving birth and before the new-born baby is put to the breast was reportedly practiced in the event that the mother lost the last baby to ward off the spirits of the dead baby. This practice potentially led to delay to initiate breastfeeding as mothers had to wait for the ritual to be performed by an elderly member of the family or in the community. We did not find research that has reported this practice in similar settings. However, late initiation of breastfeeding has been associated with poor milk flow and poor feeding of the new-born babies. This practice may have influenced the perception of breastmilk insufficiency when mothers believed that babies can just stop breastfeeding on their own when the mother's breasts did not produce enough breastmilk. This may have been compounded with anxiety to deal with pressure to mix the feed from family and the community. This perception could have been due to poor understanding or even lack of skills on how to achieve breastfeeding by use of techniques that have been proven to work [23].

We conclude that the aim of infant feeding counselling is to facilitate informed decision on method of feeding for HIV-exposed infants. While exclusive breastfeeding is now recommended, challenges remain on how to assist mothers make an informed decision to choose and practice safer infant feeding in settings where formula feeding would not be recommended.

Ethical approval

The study was approved by the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal (HSS/0104/013D) and the Biomedical Research Ethics Committee of the University of Zambia (No. 016-11-13). Voluntary participation was accorded with written and signed consent.

Limitations of the study

Purposive sampling procedures were followed, however, adjustments were made when attendance was low. We also recognised researcher impact on the study participants and a lack of generalization of the findings beyond the group studied.

Competing interests

The authors declare that they have no competing interests

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REFERENCES

1. Ministry of Health. National Protocol Guidelines for Infant feeding; Integrated Prevention of Mother-to-Child Transmission of HIV/AIDS. Lusaka: Ministry of Health; 2010. p. 1-60.
2. Ministry of Health. Zambia Consolidated Guidelines for Treatment and Prevention of HIV infection. Lusaka: Ministry of Health; 2014. p. 72.
3. WHO, UNICEF, UNAIDS, UNFPA. 2010 WHO Guidelines on HIV and Infant Feeding. An updated framework for priority action. Geneva: World Health Organization 2012.
4. McLeod J. An Introduction To Counselling, 5E: McGraw-Hill International; 2013.
5. Leshabari S, Blystad A, de Paoli M, Moland K. HIV and infant feeding counselling: challenges faced by nurse-counsellors in northern Tanzania. Human resources for health. 2007; 5:1-11.
6. Fadnes L, Engebretsen I, Moland K, Nankunda J, Tumwine J, Tylleskar T. Infant feeding counselling in Uganda in a changing environment with focus on the general population and HIV-positive mothers - a mixed method approach. BMC Health Services Research. 2010; 10:260.
7. Israel-Ballard K, Waithaka M, Greiner T. Infant feeding counselling of HIV-infected women in two areas in Kenya in 2008. International journal of STD & AIDS. 2014; 25:921-8.
8. Sagoe-Moses C, Mwinga K, Habimana P, Toure I, Ketsela T. Implementation of the new who recommendations on HIV and infant feeding: challenges and the way forward African Journal of Food, Agriculture, Nutrition and Develpment. 2012; 12.
9. Gourlay A, Wringe A, Birdthistle S, Mshana G, Michael D, Urassa M. "It Is Like That, We Didn't Understand Each Other": Exploring the Influence of Patient-Provider Interactions on Prevention of Mother-To-Child Transmission of HIV Service Use in Rural Tanzania. PLoS ONE. 2014; 9.
10. Tuthill EL, Chan J, Butler LM. Challenges faced by health-care providers offering infant-feeding counseling to HIV-positive women in sub-Saharan Africa: a review of current research. AIDS care. 2015; 27:17-24.
11. Buskens I, Jaffe A. Demotivating infant feeding counselling encounters in southern Africa: do counsellors need more or different training? AIDS care. 2008; 20:337-45.
12. Kalu S, Reynolds F, Petra G, Ikechebelu J, Dada M, Oluboyo B, et al. Infant Feeding Choices Practiced among HIV Positive Mothers Attending a Prevention of Mother to Child Transmission (PMTCT) of HIV Program in Nnewi, Nigeria. Journal of AIDS & Clinical Research. 2014; 05:6.
13. Lazarus R, Struthers H, Violari A. Promoting safe infant feeding practices - the importance of structural, social and contextual factors in Southern Africa. Journal of the International AIDS Society. 2013; 16:18037.
14. Desclaux A, Alfieri C. Counseling and choosing between infant-feeding options: overall limits and local interpretations by health care providers and women living with HIV in resource-poor countries (Burkina Faso, Cambodia, Cameroon). Social Science and Medicine. 2009; 69:821-9.

15. Oladokun RE, Brown BJ, Osinusi K. Infant-feeding pattern of HIV-positive women in a prevention of mother-to-child transmission (PMTCT) programme. AIDS care. 2010; 22:1108-14.
16. Katepa-Bwalya M, Kankasa C, Babaniyi O, Siziya S. Effect of using HIV and infant feeding counselling cards on the quality of counselling provided to HIV positive mothers: a cluster randomized controlled trial. International Breastfeeding Journal. 2011; 6:13.
17. Leshabari S, Koniz-Booher P, Burkhalter B, Hoffman M, Jennings L. Testing a PMTCT Infant-feeding Counseling Program in Tanzania. Operations Research Results.2007.
18. Odongkaraa B, Kigulib S, Edison M. Factors influencing replacement feeding practices among HIV -positive mothers attending the PMTCT program at Uganda. Journal of Pediatric Infectious Diseases. 2013; 8.
19. Ritchie J, Lewis J, editors. Qualitative research practice London, Thousand Oaks, New Delhi: Sage Publications; 2003.
20. Matovu A, Kirunda B, Rugamba-Kabagambe G, Tumwesigye N, Nuwaha F. Factors influencing adherence to exclusive breastfeeding among HIV positive mothers in Kabarole District, Uganda. East African Medical Journal. 2008; 85:162-17-.
21. Hazemba A, Ncama B, Yusuf A. Socio-cultural determinants of exclusive breastfeeding: Lessons learnt from experiences of HIV-positive mothers in lusaka, zambia. Africa Journal of Nursing and Midwifery. 2015; 17:104-17.
22. Doherty T, Sanders D, Goga A, Jackson D. Implications of the new WHO guidelines on HIV and infant feeding for child survival in South Africa. Bulletin of the World Health Organization. 2011; 89:62-7.
23. Dykes F. Twenty-five years of breast-feeding research in Midwifery. Midwifery. 2011; 27:8-14.

Chapter 6

Promotion of exclusive breastfeeding among HIV-positive mothers: An exploratory qualitative study. (Published article)

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Promotion of exclusive breastfeeding among HIV-positive mothers: an exploratory qualitative study

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Abstract

Background: Exclusive breastfeeding has the potential to reduce infant and under-five mortality, but research shows the practice is not widespread in resource-poor settings of sub-Saharan Africa. We explored factors influencing the decision to exclusively breastfeed among HIV-positive mothers accessing interventions for prevention of mother-to-child transmission of HIV in selected sites of Zambia.

Methods: This exploratory qualitative study was embedded in research conducted on: HIV and infant feeding; choices and decision-outcomes in the context of prevention of mother-to-child transmission among HIV-positive mothers in Zambia. Thirty HIV-positive mothers and six key informants were recruited from two health facilities providing mother-to-child HIV transmission prevention services. A semi-structured guide was used to conduct interviews, which were digitally recorded and simultaneously transcribed. Data coding and analysis was done with the support of QRS Nvivo 10 version software.

Results: Despite the known benefits of exclusive breastfeeding, gaps in understanding and potential for behaviour change remained. We found that information promoting exclusive breastfeeding may have been understood by mothers as instructions from the health care workers indicating how to feed their HIV-exposed babies rather than as an option for the mothers' own informed-decision. This understanding influenced a mother's perceptions of breast milk safety while on antiretroviral medicine, of the formula feeding option, and of the baby crying after breastfeeding. The meanings mothers attached to exclusive breastfeeding thus influenced their understanding of breast milk insufficiency, abrupt weaning and mixed feeding in the context of preventing mother-to-child transmission of HIV.

Conclusion: In order to enhance feeding practices for HIV-exposed infants, our study suggests a broader health campaign supporting all mothers to exclusively breastfeed.

Keywords: Exclusive breastfeeding, Formula feeding, Promotion, HIV-positive, Informed-decision, Zambia

Background

Breastfeeding is a way of providing ideal food for the healthy growth and development of infants and in some settings of the sub-Saharan Africa it is a customary way of feeding new-born babies [1, 2]. However, mothers known to be infected with HIV risk transmitting the virus to their babies through breast milk, which has changed the landscape of infant feeding in sub-Saharan Africa [3]. Research has shown that breastfeeding – especially exclusive breastfeeding, limited to breast milk only, plus any minerals, vitamins and prescribed medicines that may be needed – for the first six months after birth reduces the risk of postpartum transmission of HIV from an infected mother to her baby [4–7]. Non-exclusive breastfeeding, on the other hand, more than doubles the risk of vertical transmission of HIV [8–10]. Despite the recognized importance of exclusive breastfeeding, the practice is not widespread in the developing world [11–13]. To practice exclusive breastfeeding, HIV-positive mothers may have to go against cultural norms

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that support early introduction of fluids and mixed feeding [1, 14, 15].

In Zambia, the prevalence of HIV among women aged between 15 and 49 is currently 15 per cent [16]. According to the Ministry of Health (MoH) report, a decline was recorded in the number of new HIV infections among children younger than 15 years from 19,000 in 2009 to 9500 in 2012 [17]. Reductions have also been recorded in the HIV transmission rate from mother-to-child, during breastfeeding, from 24 per cent in 2009 to 12 per cent in 2012, representing a 51 per cent decrease in the number of new HIV infections among children [17]. The MoH further states, however, that 5 in 10 HIV-positive women or their infants did not receive antiretroviral drugs during breastfeeding to prevent mother-to-child transmission of HIV [17].

Without stepping up interventions, babies born to HIV-positive women will continue to have added risk of acquiring HIV infection and dying from it before their fifth birthdays [18]. As a public health approach, all mothers in Zambia are encouraged to practice exclusive breastfeeding for 6 months regardless of their HIV status [17, 19]. Additional interventions addressed in the roll-out of the 2013 Zambian consolidated guidelines for mothers infected with HIV were prevention of mother-to-child transmission (PMTCT) and provision of life-long combination antiretroviral therapy (ART) regardless of CD4 count (Option B^+) for pregnant and breastfeeding mothers [20].

Coupled with promotion of exclusive breastfeeding and life-long ART for HIV-positive mothers is the need for objective counselling which assesses the suitability of the different feeding options for each mother and gives her the information she needs to make a genuinely informed-decision about how she will feed her HIV-exposed baby [21] – a point which is emphasised in the World Health Organization (WHO) infant feeding guidelines [2]. The aim of this sub-study was to explore factors that influence the decision to exclusively breastfeed in the context of preventing mother-to-child transmission of HIV.

Methods

Design

This exploratory qualitative study formed part of a research project titled "HIV and infant feeding; choices and decision-outcomes in the context of prevention of mother-to-child transmission (PMTCT) among HIV-positive mothers in Zambia". The study aimed to analyse infant feeding choices and decision-outcomes in the context of PMTCT and enhance safer infant feeding practices during the first six months of the infant's life. Data collection occured through individual interviews with mothers and key informants. Attendance at individual infant feeding counselling sessions was not part of the scope of this study. After giving birth, mothers were interviewed at six days, six weeks, twelve weeks and eighteen weeks. This paper addresses the theme: promotion of exclusive breastfeeding among HIV-positive mothers accessing PMTCT services.

Setting

The study was conducted in an urban setting of Lusaka district using two health facilities to recruit study participants. The health facilities are sites for Ministry of Health (MoH) PMTCT and ART programmes integrated in maternal, neonatal and child health (MNCH) services. The fieldwork was conducted from January to September 2014.

Participants and sampling

The main study focussed on a group of 30 HIV-positive mothers, selected by purposive sampling, who were accessing PMTCT services. In addition, six key informants were selected from the PMTCT programme.

For the group of HIV-positive mothers, selection criteria were: a mother should have attended health promotion talks on infant feeding, been tested for HIV, been placed on treatment regimen (Antiretroviral medicines), been counselled on infant feeding, opted to exclusively breastfeed, and have a normal vaginal delivery of a live full-term baby. Categories such as education level and socio-economic status were considered during sampling as themes emerged because the study sites catered to women of differing socio-economic background.

Data collection

A team, composed of the principal investigator, who is the first author, and two research assistants (RAs) who were qualified and practicing midwives conducted data collection. The RAs were conversant in the primary language spoken by mothers, trained in counselling and PMTCT interventions. The first author planned and conducted training of the RAs regarding the use of a data collection guide, procedures for recruitment of participants, management of consent and issues of confidentiality, interviewing techniques, and management of audio recordings.

A semi-structured interview schedule was used to collect data. The main interview question for health care workers (HCWs) was: "how have you been presenting the messages on promotion of exclusive breastfeeding?" The main interview questions for HIV-positive mothers were: "tell me what you know about exclusive breastfeeding" and "tell me why you chose to exclusively breastfeed your baby, and how have you fed your baby since giving birth?"

Key informant interviews

Key informant interviews were conducted with two nurses, two nutritionists and two clinical officers. These

interviews were conducted one time at the beginning of data collection to develop the questions to be asked of the HIV-positive mothers. These HCWs provided the information, ideas and insights in the promotion of exclusive breastfeeding in relation to PMTCT.

Participant observation

Participant observations were undertaken as a complementary method and were essential in detecting meanings and feelings attached to breastfeeding [22]. Situations that provided an opportunity for participant observations included health education sessions where HCWs informed mothers about exclusive breastfeeding and its benefits to infants regardless of the HIV status of the mother. These health education sessions were part of routine activities in the MNCH units at the health facilities. The observations were extended to homes with permission from mothers who preferred to be interviewed from their home environments.

Individual interviews

Individual interviews were considered an appropriate method because they made it possible to effectively address complex and sensitive topics and allowed mothers to talk about personal feelings, opinions and experiences using their primary language.

Data management

All audio recordings were transcribed verbatim from primary language into English. All transcripts were checked for accuracy and quality. All identifiers were removed to insure anonymity and all the files were imported into QRS Nvivo 10 version for coding and analysis.

Ethics

Ethical approval was granted by the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal in South Africa (HSS/0104/013D) and the Biomedical Research Ethics Committee of the University of Zambia (Reference No. 016-11-13). All participating women and key informants gave written and signed consent.

Data analysis

Using framework analysis, data analysis proceeded alongside data collection [23, 24] and emerging themes were followed up in subsequent interviews. Interpretation of the results was guided by social constructivism, a theory of knowledge construction articulated by Schwandt [25] in which the basic tenets are that knowledge is formed by people in their daily interaction with one another and that knowledge is a social product. Mothers in this study constructed their own knowledge, based on their understanding of information on exclusive breastfeeding presented by HCWs. We thus relied as much as possible on the mothers' views and understanding of exclusive breastfeeding formed through interactions with HCWs, although our interpretations of the mothers' understanding and behaviour in relation to PMTCT of HIV were also shaped by our own background and experience with HIV/AIDS interventions. We formed a consensus construction that was largely based on the perspectives of mothers and of the researchers [25].

At inception of data collection, the analytical memos in the initial coding phase were used to identify codes relevant to exclusive breastfeeding in the context of PMTCT. The meanings that mothers attached to exclusive breastfeeding were diverse. This led us to look for the complexity of views rather than narrow the meanings into a few categories or ideas. The integrated data on major themes were further analysed for varying and similar perspectives in order to develop sub-themes as appropriate. In all the themes, quotes (constructs) of the mothers' actual words were linked to the descriptions [26].

Results

The analysis identified four major themes that related to factors influencing the decision to exclusively breastfeed in the context of PMTCT as: (i) promotion of exclusive breastfeeding by HCWs; (ii) the mothers' understanding of information to exclusively breastfeed; (iii) the mothers' reasons for choosing to exclusively breastfeed; and (iv) decision making on infant feeding and behaviour change in relation to PMTCT. These themes are described in detail in the next section of the article.

Demographic characteristics of mothers interviewed

The mothers accessing PMTCT services and who were our target group from the selected sites, self-reported as married; two reported as single and one reported as a widow. Nearly all had lower primary education and were unemployed (Table 1).

Key informants interviewed

Six HCWs were recruited for the study. The nurses (n = 2) were key providers of MNCH services, the nutritionists (n = 2) were involved in counselling for infant and young child feeding, and the clinical officers (n = 2) provided screening, diagnosis and treatment services. All the HCWs in the selected sites were orientated to PMTCT interventions and trained in HIV counselling and testing. The key informant interviews were conducted at the inception of the fieldwork to clarify the questions to be used during interviews with HIV-positive mothers. When it became apparent that emerging themes from individual interviews with mothers needed clarification, these key informants were interviewed to shed more light on the subject under investigation. This

Table 1 Demographic characteristics of mothers interviewed

Characteristic	Categories	Frequency
Age	15–24	10
	25–34	16
	≥35	4
Marital status	Single	2
	Married	27
	Widowed	1
Education (Grades)	0–7	14
	8 & 9	12
	10–12	2
	College education	2
Employment	None	28
	Employed	2
Number of children	1–3	21
	4–6	9

was done until the interviews reached saturation stage where new information could not be generated.

Promotion of exclusive breastfeeding by Health Care Workers

According to the 2010 Ministry of Health national infant feeding guidelines for Zambia, all mothers are encouraged to exclusively breastfeed their babies for the first six months of life [19]. In this study, we observed that group health education was conducted during antenatal care to encourage all attending pregnant women to practice exclusive breastfeeding regardless of their serostatus. Group health education was the first activity in the counselling process for HIV-positive mothers. This activity was conducted before mothers could be provided with other pertinent and more specific services such as HIV counselling and testing, infant feeding counselling as well as other antenatal care (ANC) services. Therefore, all mothers attending ANC for the first time (antenatal booking) and through subsequent visits had an opportunity to listen to these counselling talks. HIV-positive mothers were additionally given individual training on infant feeding.

Although information was given to HIV-positive mothers during individual counselling sessions about the other available infant feeding option (formula feeding) for HIV-exposed infants, the HCWs interviewed reported encouraging mothers to practice exclusive breastfeeding as a policy directive from the Ministry of Health. This led us to conclude that mothers were not given an opportunity to weigh the pros and cons of other feeding options thus denying them the opportunity to make an informed-decision in total disregard of their socio-economic situation which would not have allowed them to initiate and sustain formula feeding. The HCWs understood the promotion of exclusive breastfeeding in this context as a matter of prescribing in an effectively top-down approach. In the words of a key informant with two years of experience in PMTCT: *"We tell HIV-positive mothers from the scientific point of view on what is expected. We encourage them to follow national guidelines on infant feeding regardless of what their families or people in the community expect of them. We emphasise what is supposed to be followed and if they exactly follow this (instructions), there won't be any problems".*

Despite the WHO recommendation/s and Ministry of Health guidelines to assess acceptability, feasibility, affordability, sustainability and safety (AFASS) when discussing formula feeding, the responses by key informants were confined only to determining whether the mother could afford the formula. Asked whether mothers were informed about formula feeding or other available infant feeding options, a key informant explained, for instance, that although formula feeding was discussed, the emphasis was to assist mothers to exclusively breastfeed: *"We explain to mothers that because of their HIV-positive status, they have two choices on how to feed their babies. That is, either to breastfeed exclusively or to give formula. If they can manage and afford to buy formula for the first six months of the baby's life then they can choose formula. But we emphasise that if they exclusively breastfeed and adhere to medication (ARVs), the risk of the baby getting infected with HIV through breast milk are very, very slim".*

Although the PMTCT intervention allows mothers to make an informed-decision on infant feeding and the process is clearly defined in the national and WHO guidelines, mothers in this study reported that they were not assisted step by step in making their decision on how to feed their babies. Consequently, mothers were reported as doubting the risk of mother-to-child transmission (MTCT) would be reduced while they were on ARVs and exclusively breastfeeding. This was highlighted in another key informant interview:

> *"HIV-positive mothers make an informed-decision on infant feeding although sometimes they don't believe that if they continue breastfeeding exclusively while they are taking their medication (ARVs) the possibility of them passing the HIV virus to the baby through breast milk is reduced. They think that the baby can still easily get infected".*

These disclosures led us to conclude that HCWs seeking to discourage formula feeding, needed nonetheless to give a clear explanation of exclusive breastfeeding practice in relation to the AFASS criteria of acceptability, feasibility, acceptability, sustainability and safety. Although

HCWs recognised the importance of informing mothers about the advantages and disadvantages of exclusive breastfeeding and formula feeding, their perspectives leaned more towards promotion of exclusive breastfeeding only, and comments were made such as *'we are not giving them options', 'options are not discussed'*, and *'at the moment we are left with exclusive breastfeeding'*. Such comments were highlighted in the following responses:

> *"We are not giving options because mothers are following the national guidelines. All babies despite their mothers' HIV status are to be exclusively breastfed from zero up to six months. We also offer support to mothers to exclusively breastfeed".* [nutritionist, 5 months in PMTCT]

> *"The options on infant feeding are not discussed because we fear that we may discourage a mother that would really want to breastfeed. This is how we talk to them even on a one-to-one basis. During one-to-one counselling sessions, we give mothers information about the benefits and disadvantages of breastfeeding to the baby and the mother. We emphasise that Zambia is promoting exclusive breastfeeding regardless of the HIV status of the mother, but the mother will finally make a decision on how to feed her own baby".* [nutritionist, 4 years in PMTCT]

> *"We are talking to all mothers during group health education (group counseling) and individual counselling sessions on infant feeding but as far as choices are concerned, at the moment we encourage exclusive breastfeeding for the first 6 months regardless of the HIV status of the mother. This is the way we've gone".* [nurse, 15 years in PMTCT]

To adequately provide individual infant feeding counselling, the mothers need appropriate health facilities that provide adequate space and trained HCWs. A nutritionist key informant who had worked for four years providing counselling on infant and young child feeding commented that a conducive environment was needed for promoting exclusive breastfeeding, such as scheduling counselling sessions at the health facility at times that would encourage seropositive mothers to meet, and see for themselves, other mothers breastfeeding their babies who are in the same situation:

> *"The health facility itself needs to have a schedule in place for teaching HIV-positive mothers to promote exclusive breastfeeding and to support mothers during infant feeding. Mothers need to be motivated to protect their decisions to exclusively breastfeed and they should find a friendly environment where they will see their fellow women breastfeeding as well. This will serve as a motivation despite their serostatus. They'll also learn from their friends' experiences on breastfeeding".*

Key informants reported that it was also useful to have health education materials such as brochures in primary languages spoken by mothers available as carry-home materials to read and to conduct demonstrations on breastfeeding:

> *"When we have them, we give mothers brochures so that they can read in their primary languages. We show mothers some materials with the actual pictures of mothers feeding their babies. We also conduct demonstrations on breastfeeding right here at the health facility".*

The mothers' understanding of information to exclusively breastfeed

The aim of promotion of exclusive breastfeeding is to improve child survival for the HIV-exposed babies. In this study, mothers appeared to understand that the ARVs they were taking reduced the risk of MTCT of HIV through breast milk and hence recognized its benefits for their exposed babies. This understanding was in line with what was reported by key informants. Typical responses by mothers were:

> *"The medicine [ARVs] that I am taking is helping me to exclusively breastfeed and the baby also needs to take the medicine (ARVs) which we get from the clinic".* [mother, 23 years, 1 child]

> *"The risk of infecting the baby with HIV is reduced if the baby is breastfed only and as long as I am taking the medicine [ARVs] as instructed by the nurses".* [mother, 34 years, 4 children]

Although the HCWs declared that promotion of exclusive breastfeeding was meant to assist mothers to make an informed-decision on how best to feed their babies, it seems likely that mothers took the information they received in the counselling sessions as directive rather than informative from which they were free to make their own decisions. Promotion of exclusive breastfeeding in the context of informed-decision implies that the choice is made by a counselled (informed) HIV-positive mother, assisted by relevant and context-appropriate health-promotion messages, with full knowledge about the advantages and disadvantages of the possible feeding options being promoted. However, the word 'just' was used frequently by mothers when referring to the decision to exclusively breastfeed as shown in the following responses:

"I just had to exclusively breastfeed because the nurses are the ones to tell me everything because I am not educated". [mother, 25 years, 1 child]

"I just decided based on what they taught us at the clinic. To give the baby breast milk only for six months". [mother, 33 years, 4 children]

"I don't have much information, because I just know that I have to breastfeed the baby without giving him anything else as advised by the nurses, things like that". [mother, 22 years, 1 child]

"At the clinic, they just said that the baby should be breastfed for six months without giving him any other foods, only breast milk". [mother, 32 years, 2 children]

Frequent use of the word 'just' by mothers signifies the absence of choice in feeding their babies. It drives home the fact that the approach adopted and provided by HCWs was more prescriptive rather than encouraging choice of options.

The mothers' reasons for choosing to exclusively breastfeed

Besides the information on promotion of exclusive breastfeeding for HIV-exposed infants, there appeared to be other factors influencing mothers' decision to exclusively breastfeed. Factors that came into consideration for the mothers were understanding of breast milk safety versus formula for their HIV-exposed babies, perception of baby's crying after breastfeeding, and their ability to meet and sustain the cost of formula. The following subthemes describe each of the highlighted factors with corresponding responses.

The mothers' understanding of the safety of breast milk versus formula

The HCWs in this study reported emphasising to mothers that exclusive breastfeeding while adhering to ARV protocol reduced the risk of MTCT through breast milk. Despite this emphasis, some mothers doubted the safety of breast milk for their HIV-exposed babies even when taking ARVs, while others regarded it as a safer option given their individual circumstances. These two divergent perspectives on the part of mothers may have arisen from inadequate information and lack of understanding of exclusive breastfeeding practice in the context of PMTCT of HIV.

These perspectives were apparent when mothers were asked about what their decision to exclusively breastfeed meant to them and their babies. A 35 year-old mother of four children feared that through breast milk, she may infect her baby with HIV: *"... just not wanting to breastfeed due to fear that the baby may be infected with HIV through breast milk".* Other mothers, who could afford formula, were aware of the risks of waterborne diseases suggesting that women are considering risks associated with formula when making their decisions. A mother explained: *"I made a choice to breastfeed my baby because my other babies who I gave formula passed on. The formula used to give them diarrhoea till they died, and for this reason, I decided to breastfeed this baby exclusively without giving him any other fluids or food"* [mother, 32 years, 1 child]. Even when the cost of formula was not a deterrent, a 32-year-old mother of 4 children, employed as a teacher, weighed formula feeding against the protective effect of breast milk for her new-born baby: *"Of course I can manage to buy the formula. It's not because of money, I chose to exclusively breastfeed in order to protect my baby from other diseases".*

The mothers' ability to meet and sustain the cost of formula

Whereas breastfeeding was thought to be cheap and always available on demand, mothers were also aware of the risks of mixed feeding of formula and breast milk. A 26-year-old mother of two children explained: *"I chose to breastfeed because it is cheap and I was not scared after being given the information that the baby cannot get sick if it is exclusively breastfed. I was more scared to kill my baby with hunger because I may not have enough money to buy formula".* She added: *"I can't also be changing from giving my baby formula today, and then tomorrow if the formula finishes I give the baby breast milk. That is why I chose to exclusively breastfeed".*

The following responses confirmed that the cost of formula was a deterrent to choosing exclusive breastfeeding:

"I decided to breastfeed the baby because we [with spouse] did not have enough money to buy formula, and there was nothing else I could do". [mother, 31 years, 5 children]

"If I could manage to buy formula, I would have chosen to give formula and not breastfeed". [mother, 26 years, 4 children]

"If I had money, I would buy formula and not breastfeed". [mother, 35 years, 4 children]

Decision making on infant feeding and behavior change in relation to PMTCT

According to the HCWs, promotion of exclusive breastfeeding is not confined to teaching and needs to include support for mothers during the infant feeding period, especially the first six months after giving birth. When we interviewed mothers to explore how messages promoting

exclusive breastfeeding contributed to their understanding and behaviour in relation to PMTCT during the first six months of infant feeding, additional hindrances to exclusive breastfeeding practice emerged. These included perceived breast milk insufficiency when the baby cried after breastfeeding, mixed feeding and potential for abrupt weaning due to breast complications.

Perceived breast milk insufficiency

Despite the promotion of exclusive breastfeeding for HIV-exposed infants, there emerged other factors that influenced the way mothers regarded exclusive breastfeeding practice. The perception by some mothers that babies cry of hunger because the breastmilk is sometimes not enough influenced how they interpreted the baby crying even after breastfeeding. This perception, along with limited understanding of how to manage infants with childhood ailments, could potentially induce mothers to mix the feed with light porridge, as explained by a 25-year-old mother of one child: *"Sometimes you know how the devil is, the baby is crying and maybe it is hungry, you sense the temptation to make some light porridge and give the baby so that it can stop crying. But at the same time you know the instructions from the clinic, where they said the baby should only be given food and water after six months".* Another mother added: *"When the baby cries a lot, it can force you to give it anything. You can make the baby drink anything available so that it stops crying, because sometimes you don't know why it is crying... maybe it is hunger. You can be forced to do something for the baby".* [mother, 21 years, 2 children]

Asked how they were feeding their babies, some mothers reported giving their babies other fluids apart from breast milk. A young first-time mother explained: *"Yes I am breastfeeding her but if I have gone very far, she takes Bonita milk (Cow's milk). I give her from the cup. The breast milk is not enough that is why I mix with Bonita".* [24 years, 1 child]. Another mother added: *"I give orange juice to the baby and something for the stomach apart from breastfeeding".* [mother 22 years, 2 children]

Potential for abrupt weaning from exclusive breastfeeding due to breast complications

It also emerged from the interviews with mothers, that they were unclear about weaning practices and under what circumstances weaning might be appropriate. In the event that sores developed on the breasts of the mother, this potentially altered their capacity to exclusively breastfeed and as a consequence, abrupt weaning from exclusive breastfeeding was planned or initiated. Typical responses were:

"Sometimes I think that I may have a sore on my nipples which I may not be aware of. But the nurses said that there should not be any sores on the breast when breastfeeding. So I get worried that the baby may get infected with HIV". [mother, 26 years, 2 children]

"I usually think about weaning my baby from breastfeeding, since the nurses said that at times there can be sores on the mother's nipples". [mother, 32 years, 4 children]

"The nurses said that I should breastfeed the baby and if sores develop on my breasts, I should not breastfeed him. They said I need to go back to the clinic to inform them". [mother, 26 years, 4 children]

The lack of understanding of weaning practice was further highlighted by a young mother who explained that being bitten on the nipples by the baby would warrant giving formula until the sores healed. She explained: *"When the baby starts teething and during breastfeeding it bites you on the nipples then you need to stop giving the baby breast milk and give formula until that sore heals".* [mother, 23years, 2 children]

Discussion

The study revealed that despite information promoting exclusive breastfeeding for HIV-exposed infants, problems remained among HIV-positive mothers in their understanding of the information impacting their willingness to change behavior. Exclusive breastfeeding for the first six months is known to reduce the risk of postnatal vertical transmission of HIV (infection) from mother-to-child [4, 5, 7]. Although mothers reported that they were aware that exclusive breastfeeding while on ARVs reduced the risk of MTCT of HIV through breast milk, we found that the messages promoting exclusive breastfeeding may have been understood simply as instructions from the HCWs indicating how to feed HIV-exposed infants rather than knowledge imparted to enable an informed-decision. This was evident when mothers doubted the safety of breast milk while on ARVs and their limited understanding of the formula feeding option.

According to the WHO infant feeding guidelines, mothers known to be HIV-infected should be informed of the infant feeding practice recommended by the national authority, both in order to improve HIV-free survival of exposed infants and so that the mothers are aware of alternatives they might wish to adopt [2, 19, 20]. Although clearly defined, counselling on methods of infant feeding in PMTCT programmes have shown practical and theoretical variations by sites [27–29]. In this study, both HCWs and mothers used expressions that

implied direct instruction to exclusively breastfeed rather than imparting knowledge about exclusive breastfeeding as recommended in the current national infant feeding guidelines. This indicates that HCWs need to be fully orientated to PMTCT interventions, be equipped with appropriate communication skills, spend time with mothers focusing on individual needs, and help them to make a genuinely informed-decision to practice exclusive breastfeeding.

Promotion of exclusive breastfeeding is aimed at child survival in Zambia, where infant and under-five mortality is high, 45 and 75 per 1000 live births respectively [16]. In developed countries, mothers that are infected with HIV will more likely choose formula. But for their poorer counterparts, such as the women who were interviewed for this study and others in similar settings, exclusive breastfeeding becomes appropriate in view of poor sanitary conditions and the probability of inappropriate use of formula that can lead to diarrhoea and dehydration; the major causes of infant mortality globally [3, 18]. It is in this context, therefore, that health promotion messages for HIV-positive mothers to practice exclusive breastfeeding need to be understood. Studies in various settings of sub-Saharan Africa have shown that more is needed than just one session promoting exclusive breastfeeding if the recommendations are to achieve their intended goal [30, 31]. Addressing national authorities, Lazarus, Struthers and Violari [32] argued strongly that a top-down instructive approach is not enough to bring about necessary behaviour change in the way HIV-exposed infants are fed in resource-poor settings. They recommended an open and sustained engagement facilitating dialogue about infant feeding with HIV-positive mothers, their families, communities and even HCWs. Despite the known benefits of exclusive breastfeeding while the mother is on ARVs, mothers in this study did not have a sustained engagement with HCWs on infant feeding counselling in order to fully understand and practice exclusive breastfeeding because they only had two sessions. As observed in similar settings, it is crucial for infant feeding counselling messages to be specifically aligned not only to local context [33], but also with an environment that enables mothers to understand the recommended infant feeding options for HIV-exposed infants so that informed-decision can be made [34–36].

Challenges thus remain on how to ensure that HIV-positive mothers understand exclusive breastfeeding practice in the context of PMTCT and are adequately prepared to manage problems that may arise during infant feeding period. Considering that almost all participating mothers had primary and lower secondary education and in view of the country's high illiteracy levels [16], more women accessing PMTCT services in Zambia will need a schedule of activities that will address challenges faced during exclusive breastfeeding. However, like other countries in sub-Saharan Africa, poor staffing levels, lack of infrastructure and inaccessible health promotion materials pose challenges to adequately provide infant feeding counselling and support; especially where exclusive breastfeeding is concerned [37–39].

Knowledge gaps due to inadequate infant feeding counselling may have contributed to the mothers' perceived breast milk insufficiency associated with the baby crying even after breastfeeding. This finding is consistent with research in similar settings such as Uganda [40], Malawi [41], Swaziland [42], and was found to be a persistent feature in Zambia [43]. The perception that some breasts produce more milk than others could thus, potentially, be thought to justify mixed feeding of breast milk with other fluids and foods. Although we did not find any strong research to support the theory about some breasts producing more milk than others in similar settings, some scholars suggest that mothers should be taught how to effectively position and attach their infants to the breast to optimise breastfeeding and counter perceptions of milk insufficiency. This is on the basis that unrestricted exclusive breastfeeding results in ample milk production [44]. Although, HCWs reported that they supported mothers to choose and practice exclusive breastfeeding, mothers in this study lacked the necessary skills needed to successfully feed their infants as recommended. As reported in other settings, this could have been due to low staffing levels, inadequate infrastructure, lack of communication skills among HCWs, slow updates on infant feeding guidelines and to a certain extent poor staff attitudes [29, 40, 45, 46]. To address some of these challenges, HCWs in the current study reported that they used demonstrations to teach mothers how to put the baby to the breast but may not have had time to supervise each of them and make sure that they had acquired the skills which they needed to apply in their home settings. The low staffing levels in health facilities in Zambia could thus impede these efforts [47].

We recognise that even though it is a natural act, breastfeeding has also been described as a learned behaviour [48] and that mothers need to be equipped with information and skills to feed their infants and wean them appropriately. Regarding cessation of breastfeeding, the WHO infant feeding guidelines advise that mothers known to be HIV-infected should stop gradually over the course of a month, while continuing to receive support and treatment, and that mixed feeding should be discouraged [2]. This research showed that some mothers are not understanding the risks of mixed feeding and in this society, it is considered a cultural norm [43] and has been reported in similar settings of sub-Saharan Africa [14, 15, 49–51]. Provided they have accurate information, mothers in this and similar settings need to be supported by the health care system and by

family and community in initiating and practicing exclusive breastfeeding [48, 52, 53] for their HIV-exposed infants.

Conclusion

Although it does not attempt to generalize the findings to a larger population, our study suggests a broader health promotion campaign supporting all mothers to exclusively breastfeed. More effort is needed to improve communication skills among HCWs to enable them provide objective infant feeding counselling regardless of the method of feeding promoted for HIV-positive mothers.

Abbreviations

AFASS: acceptable, feasible, affordable, sustainable, safe; AIDS: acquired immune deficiency syndrome; ANC: antenatal care; ART: antiretroviral therapy; ARVs: antiretroviral; HCWs: Health Care Workers; HIV: human immune virus; MNCH: maternal neonatal and child health; MoH: Ministry of Health; MTCT: mother-to-child transmission; PMTCT: prevention of mother-to-child transmission; RAs: research assistants; WHO: World Health Organization.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

ANH conceived the study and was the principal investigator and hence made a substantial contribution to its conception, design, data collection, analysis and interpretation. ANH contributed to the draft of the manuscript, revised it for its intellectual content and approved the final version to be published, and is accountable for all the aspects of the article submitted for publication. BPN was involved in the conception of the research and was involved in the development of the protocol to its completion. BPN contributed substantially to drafting of the manuscript, revised it for its intellectual content and approved the final version submitted for publication. SLS contributed substantially to the intellectual content of the manuscript and provided the theoretical understanding of the social aspect of the study. All authors read and approved the final draft of the manuscript.

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References

1. Leshabari SC, Blystad A, Moland KM. Difficult choices: Infant feeding experiences of HIV positive mothers in northern Tanzania. J Soc Asp HIV/AIDS. 2007;4:1.
2. WHO, UNAIDS, UNFPA, UNICEF. HIV and infant feeding guidelines: principles and recommendations for infant feeding in the context of HIV and a summary of evidence. Geneva: WHO; 2010.
3. WHO, UNAIDS, UNFPA, UNICEF. 2010 WHO guidelines on HIV and infant feeding; an updated framework for priority action. Geneva: WHO; 2012.
4. Coovadia HM, Rollins NC, Bland RM, Little K, Coutsoudis A, Bennish ML, et al. Mother-to-child transmission of HIV-1 infection during exclusive breastfeeding in the first 6 months of life: an intervention cohort study. Lancet. 2007;369(9567):1107–16.
5. Iliffa PJ, Piwoz EG, Tavengwa NV, Zunguza CD, Marinda ET, Nathoo KJ, et al. Early exclusive breastfeeding reduces the risk of postnatal HIV-1 transmission and increases HIV-free survival. AIDS. 2005;19:699–708.
6. Sperling RS, Shapiro DE, Coombs RW, Todd JA, Herman SA, McSherry GD, Protocol 076 study group. Maternal viral load, Zidovudine treatment, and the risk of transmission of Human Immunodeficiency Virus type 1 from mother to infant. N Engl J Med. 1996;335:22.
7. Thomas TK, Masaba R, Borkowf CB, Ndivo R, Zeh C, Misore A, KiBS study team. Triple-antiretroviral prophylaxis to prevent mother-to-child HIV transmission through breastfeeding-the Kisumu Breastfeeding Study, Kenya: a clinical trial. PLoS Med. 2011;8(3):e1001015.
8. Kuhn L, Sinkala M, Kankasa C, Semrau K, Kasonde P, Scott N, et al. High uptake of exclusive breastfeeding and reduced early post-natal HIV transmission. PLoS ONE. 2007;2(12):e1363.
9. Young SL, Israel-Ballard KA, Dantzer EA, Ngonyani MM, Nyambo MT, Ash DM, et al. Infant feeding practices among HIV-positive women in Dar es Salaam, Tanzania, indicate a need for more intensive infant feeding counselling. Public Health Nutr. 2010;13(12):2027–33.
10. Young SL, Mbuya MNN, Chantry CJ, Geubbels EP, Israel-Ballard K, Cohan D, et al. Current knowledge and future research on infant feeding in the context of HIV: basic, clinical, behavioral, and programmatic perspectives. Adv Nutr. 2011;2:225–43.
11. Cai X, Wardlaw T, Brown DW. Global trends in exclusive breast feeding. Int Breastfeed J. 2012;7:12.
12. Seid AM, Yesuf ME, Koye DN. Prevalence of exclusive breastfeeding practices and associated factors among mothers in Bahir Dar city, northwest Ethiopia: a community based cross-sectional study. Int Breastfeed J. 2013;8:14.
13. Shapiro RL, Lockman S, Thior I, Stocking L, Kebaabetswe P, Wester C, et al. Low adeherence to recommended infant feeding strategies among HIV infected women: Results from the pilot phase of a Randomized Trial to prevent mother-to-child transmission in Botswana. AIDS Educ Prev. 2003; 15(3):221–30.
14. Chinkonde JR, Hem MH, Sundby J. HIV and infant feeding in Malawi: public health simplicity in complex social and cultural contexts. BMC Public Health. 2012;12:700.
15. Madiba S, Langa J. Cultural practices interfere with adherence to exclusive infant feeding: A qualitative study among HIV positive post natal women in Hammanskraal, South Africa. Af J Phys Health Educ Recreat Dance. 2014;1(1): 264–78.
16. Central Statistical Office, Ministry of Health, ICF International. Zambia Demographic and Health Survey (ZDHS) 2013–14. Rockville: Central Statistical Office, Ministry of Health, ICF International; 2014.
17. Ministry of Health, National AIDS Council. Zambia country report; monitoring the declaration of commitment on HIV and AIDS and the universal access. Lusaka: MoH, NAC; 2014.
18. UNICEF. Improving exclusive breastfeeding practices by using communication for development in Infant and Young Child Feeding programmes. New York: UNICEF; 2010. p. 16.
19. Ministry of Health. National protocol guidelines for infant feeding; integrated prevention of mother-to-child transmission of HIV/AIDS. Lusaka: Ministry of Health; 2010.
20. Ministry of Health. Zambia consolidated guidelines for treatment and prevention of HIV infection. Lusaka: Ministry of Health; 2014.
21. Frizelle K, Solomon V. Strengthening PMTCT through communication: A review of literature. 2009. http://www.unicef.org/southafrica/SAF_resources_pmtctcommunication.pdf. Accessed 11 Jul 2014.
22. Creswell JW. Data collection. In: Creswell JW, editor. Qualitative Inquiry and Research Design: Choosing among Five Approaches. 2nd ed. London: Sage Publications; 2007. p. 117–45.
23. Spencer L, Ritchie J, O'Connor W. Carrying out qualitative analysis. In: Ritchie J, Lewis J, editors. Qualitative Research Practice: A Guide for Social Science Students and Researchers. London: Sage Publications; 2003. p. 219–62.

24. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Huberman AM, Miles MB, editors. The Qualitative Researcher's Companion. London: Sage Publications; 2002. p. 305–29.
25. Schwandt TA. Constructivist, interpretivist approaches to human inquiry. In: Denzin NK, Lincoln YS, editors. The Landscape of Qualitative Research: Theories and Issues. London: Sage Publications; 1998. p. 221–59.
26. Galel NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013;13:117.
27. Desclaux A. After the withdrawal of 'informed choice': the meanings and social effects of mothers' choice for HIV prevention in Senegal. Anthropol Med. 2014;21(2):113–24.
28. Desclaux A, Alfieri C. Counseling and choosing between infant-feeding options: overall limits and local interpretations by health care providers and women living with HIV in resource-poor countries (Burkina Faso, Cambodia, Cameroon). Soc Sci Med. 2009;69(6):821–9.
29. Leshabari SC, Blystad A, de Paoli M, Moland KM. HIV and infant feeding counselling: challenges faced by nurse-counsellors in northern Tanzania. Hum Resour Health. 2007;5:1–11.
30. Leshabari S, Koniz-Booher P, Burkhalter B, Hoffman M, Jennings L. Testing a PMTCT Infant-feeding Counseling Program in Tanzania. Operations Research Results. 2007. Published for the U.S. Agency for International Development (USAID) by QAP.
31. Ndubuka J, Ndubuka N, Li Y, Marshall CM, Ehiri J. Knowledge, attitudes and practices regarding infant feeding among HIV-infected pregnant women in Gaborone, Botswana: a cross-sectional survey. BMJ Open. 2013;3(11): e003749.
32. Lazarus R, Struthers H, Violari A. Promoting safe infant feeding practices - the importance of structural, social and contextual factors in southern Africa. J Int AIDS Soc. 2013;16:18037.
33. Leshabari SC, Koniz-Booher P, Åstrom AN, de Paoli MM, Moland KM. Translating global recommendations on HIV and infant feeding to the local context: the development of culturally sensitive counselling tools in the Kilimanjaro Region, Tanzania. Implement Sci. 2006;1:22.
34. Buskens I, Jaffe A. Demotivating infant feeding counselling encounters in southern Africa: do counsellors need more or different training? AIDS Care. 2008;20(3):337–45.
35. Odongkaraa BM, Kiguli S, Edison MA. Factors influencing replacement feeding practices among HIV -positive mothers attending the PMTCT program at Uganda. J Pediatr Infect Dis. 2013;8:7–17.
36. Oladokun RE, Brown BJ, Osinusi K. Infant-feeding pattern of HIV-positive women in a prevention of mother-to-child transmission (PMTCT) programme. AIDS Care. 2010;22(9):1108–14.
37. Chinkonde JR, Sundby J, de Paoli M, Thorsen VC. The difficulty with responding to policy changes for HIV and infant feeding in Malawi. Int Breastfeed J. 2010;5:11.
38. Fadnes LT, Engebretsen IMS, Moland KM, Nankunda J, Tumwine JK, Tylleskär T. Infant feeding counselling in Uganda in a changing environment with focus on the general population and HIV-positive mothers - a mixed method approach. BMC Health Serv Res. 2010;10:260.
39. Gourlay A, Birdthistle I, Mburu G, Iorpenda K, Wringe A. Barriers and facilitating factors to the uptake of antiretroviral drugs for prevention of mother-to-child transmission of HIV in sub-Saharan Africa: a systematic review. J Int AIDS Soc. 2013;16(1):18588.
40. Engebretsen IMS, Moland KM, Nankunda J, Karamagi CA, Tylleskär T, Tumwine JK. Gendered perceptions on infant feeding in Eastern Uganda: continued need for exclusive breastfeeding support. Int Breastfeed J. 2010;5:13.
41. Levy JM, Webb AL, Sellen DW. "On our own, we can't manage": experiences with infant feeding recommendations among Malawian mothers living with HIV. Int Breastfeed J. 2010;5:15.
42. Shongwe MC, Mkhonta NR. The experiences of HIV positive mothers breastfeeding exclusively in Swaziland. Afr J Food Agric Nutr Dev. 2014;14:5.
43. Fjeld E, Siziya S, Katepa-Bwalya M, Kankasa C, Moland KM, Tylleskär T, Promise-EBF-study. 'No sister, the breast alone is not enough for my baby' a qualitative assessment of potentials and barriers in the promotion of exclusive breastfeeding in southern Zambia. Int Breastfeed J. 2008;3:26.
44. Ingram J, Johnson D, Greenwood R. Breastfeeding in Bristol: teaching good positioning, and the support from fathers and families. Midwifery. 2002;18:87–101.
45. Israel-Ballard K, Waithaka M, Greiner T. Infant feeding counselling of HIV-infected women in two areas in Kenya in 2008. Int J STD AIDS. 2014;25(13):921–8.
46. Sagoe-Moses C, Mwinga K, Habimana P, Toure ID, Ketsela T. Implementation of the new WHO recommendations on HIV and infant feeding: challenges and the way forward. Afr J Food Agric Nutr Dev. 2012;12:4.
47. Ministry of Health. National health strategic plan 2011–2015: Towards attainment of health related Millennium Development Goals (MDGs) and other national health priorities in a clean, caring and competent environment. Lusaka: Ministry of Health; 2011.
48. World Health Organization. Global strategy for Infant and Young Child Feeding. Geneva: WHO; 2003.
49. Fadnes LT, Engebretsen IMS, Wamani H, Semiyaga NB, Tylleskär T, Tumwine JK. Infant feeding among HIV-positive mothers and the general population mothers: comparison of two cross-sectional surveys in Eastern Uganda. BMC Public Health. 2009;9:124.
50. Laar SA, Govender V. Factors influencing the choices of infant feeding of HIV-positive mothers in Southern Ghana: The role of counsellors, mothers, families and socio-economic status. J AIDS HIV Res. 2011;3(7):129–37.
51. Maman S, Cathcart R, Burkhardt G, Omba S, Thompson D, Behets F. The infant feeding choices and experiences of women living with HIV in Kinshasa, Democratic Republic of Congo. AIDS Care. 2012;24(2):259–65.
52. Betancour TS, Abrams EJ, McBain R, Fawzi MCS. Family-centred approaches to the prevention of mother to child transmission of HIV. J Int AIDS Soc. 2010;13 Suppl 2:S2.
53. Busza J, Walker D, Hairston A, Gable A, Pitter C, Lee S, et al. Community-based approaches for prevention of mother to child transmission in resource-poor settings: a social ecological review. J Int AIDS Soc. 2012;15 Suppl 2:17373.

Chapter 7

HIV and infant feeding: an exploratory qualitative analysis of experiences with exclusive breastfeeding among HIV-positive mothers in Lusaka, Zambia

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Abstract

Exclusive breastfeeding (EBF) in the first six months, offers protection from postnatal HIV infection but remains low in resource-poor settings. We asked HIV-positive mothers to share their experience with exclusive breastfeeding in the first six months of the infant's life. A health facility and community-based qualitative study was conducted among 30 HIV-positive mothers practising EBF and meeting the selection criteria. In-depth interviews were conducted 4 time but within the first six months after giving birth. Interviews were transcribed verbatim and files imported into QRS NVivo 10 version for coding and analysis.

Exclusive breastfeeding was difficult to achieve because of individual circumstances. We found that mothers had a basic understanding of the risks of mother-to-child transmission of HIV through breast milk and were aware of benefits of breastfeeding and especially EBF to their exposed babies. However, they were particularly concerned about achieving HIV-free survival because they lacked information about the HIV status of their exposed infants. Although they reported being supported by the families, poor health while caring for their infant's wellbeing was a concern.

We conclude that PMTCT programmes that adopt a once-off infant feeding counselling do not achieve adequate preparation of mothers to practice EBF. Follow-up care and support is

therefore required in order to provide a continuum of infant feeding experience in the first six months of the infant's life.

Keywords: Counselling; Exclusive breastfeeding; Experiences; Infant feeding,

Introduction

HIV and infant feeding remains a global public health challenge despite advances in biomedical research. While recognising the gains achieved in treatment and prevention strategies, prevention of mother-to-child transmission (PMTCT) of HIV continues to be a dynamic and rapidly changing field. The current 2010 infant feeding guidelines reflect the significant new evidence and knowledge regarding antiretroviral therapy (ART) and breastfeeding. While formula feeding offers the safest postnatal prevention of HIV infection, its implementation in resource-poor settings poses risks of survival among children born from mothers infected with HIV. Breastfeeding, especially early initiation and exclusive breastfeeding in the first six months, offers protection from postnatal HIV infection (Coovadia et al., 2007).

In 2012 the WHO released a revised framework for infant feeding guidelines that were practically the same as the 2010 guidelines regarding breastfeeding, but adding a recommendation that all pregnant mothers should take antiretroviral drugs (ARVs) for life (Option B+), coupled with an alternative recommendation for countries to choose (Option B) in which a mother could be tested for her eligibility for ARVs after the birth of her child. In both the 2010 infant feeding guidelines and the revised framework, exclusive breastfeeding for six months or beyond, followed by gradual weaning, was recommended. The guidelines continue to highlight the importance of avoiding mixed feeding to reduce the risk of HIV transmission and to avoid diarrhoea and malnutrition. There is recognition by WHO of settings where replacement feeding may remain the best strategy to promote HIV-free survival for HIV-exposed infants (WHO et al., 2012).

Mother-to-child transmission (MTCT) of HIV during pregnancy, delivery or breastfeeding is one of the key drivers of the epidemic in Zambia. Currently, the prevalence of HIV among women in the reproductive age 15–49 years is 15 per cent (Central Statistical Office et al., 2014). Efforts to reduce mother-to-child transmission (MTCT) have shown improvements in rate of transmission from 24 per cent in 2009 to 12 per cent in 2012 (Ministry of Health & National AIDS Council, 2014). The Zambia national PMTCT programme uses an opt-out

approach which makes HIV testing part of the routine laboratory processes undertaken during all pregnancies (Ministry of Health, 2010). In addition, the 2013 Zambian consolidated guidelines were rolled out to provide comprehensive approaches for reducing new HIV infections, PMTCT, and provision of lifelong ART regardless of CD4 count for pregnant and breastfeeding women, for HIV-infected sexual partners of pregnant and breastfeeding women and for HIV-infected partners in sero-discordant couples (MoH, 2014a).

All these efforts were in line with the international recommendations for prevention of HIV infection among children with a particular focus on treatment and infant feeding (WHO, UNICEF, UNAIDS, & UNFPA, 2012). This emphasises the retention of HIV-positive mothers in the PMTCT programme by preventing loss to follow-up during the infant feeding period. Hence, the question we asked for this sub-study was: What are the experiences of HIV-positive mothers regarding exclusive breastfeeding in the first six months of the infant's life?

Design and setting

This health facility and community-based longitudinal qualitative study was part of a larger study that was aimed to enhance safer infant feeding practices during the first six months of the infants' life. Individual interviews were conducted with 30 HIV-positive women. The study consisted four contacts with the participants after giving birth at 6 days, 6 weeks, 12 weeks and 18 weeks. The settings from which the mothers were selected were urban that had water and sanitation services supplied by the local municipalities. Access to the health centres providing PMTCT services for mothers was within walking distance of 30 minutes to an hour and a half.

Participants and selection criteria

30 HIV-positive mothers met the selection criteria to be included in the study. To be included in the study, a mother should have opted to exclusively breastfeed for the first six months of the infant's life. Infant feeding counselling was a prerequisite for recruitment of the participants. All the participants had given birth at full term to babies with normal birth weights. At the 4th contact the mother and her infant disengaged from the study and continued receiving care and other services at selected health facilities.

Purposive sampling was used to select all mothers and to obtain the required sample we recruited mothers aged 15-24, 25-34 and 35+ years while remaining cognisant of the consenting age.

Data collection procedures

Data were collected through individual interviews and this was appropriate to gain an understanding of personal experiences with exclusive breastfeeding practice in the context of PMTCT. Where mothers gave consent, interviews were conducted at their homes or a place convenient to the mother. The other activities that provided an opportunity to have contacts with mothers were times when they reported at the health facilities for child growth monitoring and immunization and resupply of ARVs. These contacts provided an opportunity to observe participants interact with health care workers, family and friends. Observations were also used as a complementary method to prepare the next interview and establish rapport in terms of discovering issues to follow-up during the subsequent individual interviews.

Data collection tool

Data were collected using a semi-structured interview guide that enabled participants to tell their stories in their own way using their primary language. The main questions we asked for this paper were: (i) how did you choose to feed your baby, (ii) why did you choose to feed your baby in this way, (iii) how are you feeding your baby now, (iv) what can you tell me about the benefits you derived from how you have been feeding your baby, (v) please share your strengths and challenges of feeding your baby from the time you gave birth until now?

Data management and analysis

Interviews were tape recorded, fully transcribed, and field notes of reflexive observations generated were recorded in a research diary. All audio files from digital recorders were downloaded on the computer and transcribed verbatim. All transcripts were checked by the first author for accuracy, quality and cleaned for anonymity and were imported into QRS NVivo 10 version for coding and analysis.

In the initial coding phase, codes relevant to experience with infant feeding were identified. The major themes for this sub-study were: mother-to-child transmission of HIV; the mothers' perspective, the mothers' understanding of benefits of exclusive breastfeeding, exclusive

breastfeeding; reflections and narratives in relation to PMTCT, and challenges experienced during the first six months of the infant's life.

Findings

This section of the paper will highlight the HIV-positive mothers' perspective of mother-to-child transmission of HIV and the understanding of benefits to exclusive breastfeeding, reflections and narratives on exclusive breastfeeding in the context of PMTCT as well as the challenges experienced during the first six months of infant feeding.

Participant information

The participants who met the selection criteria were aged 15 to 45 years. We interviewed both first-time mothers and those that had had delivered more than two times. Some participants reported loss of previous babies, however, for this study we did not explore the causes of their death although some mothers were able to give additional information. In some instances some mothers reported having delivered more than once during their HIV-positive serostatus.

Participant information

Participant reference #	Age at recruitment	No. of pregnancies	No. of surviving children
1	35	4	4
2	27	2	1
3	21	3	2
4	21	2	2
5	33	3	3
6	22	2	2
7	18	1	1
8	23	3	3
9	26	3	1
10	31	3	3
11	34	3	3
12	23	3	3
13	33	6	4
14	24	2	1
15	30	3	3
16	20	1	1
17	32	5	5
18	26	4	4
19	26	2	2
20	28	3	3
21	32	4	4
22	24	3	1
23	36	2	2
24	31	5	5
25	26	4	2
26	33	4	4
27	33	5	5
28	35	4	4
29	22	1	1
30	29	4	4

Mother-to-child transmission of HIV; the mothers' perspective

In settings where the participants were recruited from, health care workers conducted health education talks on various topics including HIV infection, mother-to-child transmission of HIV, infant feeding as well as exclusive breastfeeding. In order to contextualize the experiences with exclusive breastfeeding, we asked mothers what they understood about mother-to-child transmission of HIV and the following quotes give an indication of the scope of their knowledge:

If you have sores on the nipples and the baby has sores in the mouth while breastfeeding, it is very easy for the baby to get infected with HIV. [participant # 12*]*

If I introduce solid food early the baby can have sores in the stomach and when I breastfeed the baby, he can get infected with HIV. [participant # 30*]*

In another interview, a participant gave a more extended description of the risks associated with blood contact while breastfeeding, however, according to her, the risk warranted abrupt cessation of breastfeeding. She explained: *"when I am breastfeeding, I need to ensure that there are no cracks or sores on the nipples. If there are sores on the nipples, then, blood will be coming out when the baby is breastfeeding and the blood is the one which carries the HIV virus. So, if I have sores I can stop breastfeeding the baby because the baby will suck blood"*. [participant # 25]

The mothers' understanding of the benefits exclusive breastfeeding to their babies

While this sub-study focussed on experiences with exclusive breastfeeding, it was imperative to explore how participants understood the known benefits of both breastfeeding and exclusive breastfeeding for HIV-exposed infants. We found that mothers knew that breastmilk had essential elements for the healthy growth of their infants. However, they categorically referred exclusive breastfeeding to a teaching conducted by health care workers as opposed to information received to enable them feed their babies in a way that reduced the risk of mother-to-child transmission of HIV through breast milk. A participant explained: "*exclusive breastfeeding is based on what we were taught at the clinic so that I can take care of the baby's life and mine"*. [participant # 2]. Another mother added: *"The nurses were teaching us at the clinic that the baby should be breastfed exclusively for six months without giving him any other foods, only breast milk"*. [participant # 21].

In these communities where participants lived, mixed feeding is a normal practice. To practice exclusive breastfeeding mothers were required to change their behaviour and hence we explored whether they understood its benefits to their HIV-exposed exposed infants. Predominantly, women knew the benefits of exclusive breastfeeding in relation to PMTCT. One participant related breastmilk to healthy growth and as food readily available for the new-born baby and her goal was to ensure HIV free survival for her exposed infant. She explained: *"I am breastfeeding only and the baby does not have any health problems, even*

myself I do not have any pressure to look for food for the baby. I want my baby to be found HIV-negative". [participant # 8]. Another participant added: "A*ll the nutrients needed for the baby up to six months are there in the breast milk, including water".* [participant # 11]. The same mother added that breastmilk was always available on demand: "*There are many benefits of breastmilk and one is that it is not scarce and at any time you can give the baby and it is not expensive".* [participant # 11]

Exclusive breastfeeding; reflections and narratives in relation to PMTCT

For this sub-study, we described the infant feeding experience in three sub-themes: (1) the concern about whether the baby was already born with HIV, (2) the concern about achieving HIV-free survival for the exposed infants, and (3) social support during infant feeding.

The concern about whether the baby was born with HIV

Despite the understanding of the known benefits of breastfeeding and EBF, some mothers were particularly concerned that their babies may have been born with HIV. Typical responses were:

> *I am just taking chances to breastfeed…there are times when I think… what if the baby was born with HIV…I am just taking chances*. [participant # 6]

> *The fears of infecting the baby with HIV through breastmilk is there, but again the baby may have contracted HIV through other ways, maybe in the womb, maybe she could have contracted the virus at birth or any other time".* [participant # 18]
> W*e were given the drugs to protect the baby from HIV infection but it can also happen that the baby may have already been born with HIV and then you breastfeed him. Again if he is not found with HIV, he may have it in future so I start to think that I should just stop breastfeeding and start bottle feeding with formula".* [participant # 23]

> *Sometimes I worry that my baby can have a problem in future because she could have been born with HIV… or can get infected with HIV through breastmilk. But there is nothing I can do because I have already chosen to breastfeed. Whatever will happen I will just continue giving my baby the medicine".* [participant # 24]

The desire to achieve HIV-free survival for the exposed infant

During infant feeding counselling, the HCWs encourage mothers to take their medicine (ARVs) and continue to exclusively breastfeed for the first six months of the infant's life. However, doubts lingered in the minds of the mothers as to whether their infants were protected with the medicine (ARVs) and what a negative test result would mean for their babies: *"I usually have thoughts like if they test him and find that he is negative, will I stop breastfeeding or will I introduce him to formula? It is hard"*. [participant # 24]. Another mother expressed deep emotion about how she did not want her baby to end up like her. She explained: "Y*es like my HIV-positive status, I do not want my baby to be the way I am. So I want to follow the instructions I was told at the clinic so that I see whether they will help me or not*". [participant # 30].

Mothers were even more concerned when sores appeared in the mouth of the baby. Out of desperation, one mother planned to express and spill the milk because she did not know what to do. She explained: "…f*or instance, she has sores with blood in the mouth so I was thinking of first expressing and spilling some milk before putting the baby to the breast. I was confused and thinking about different ways of protecting my baby like going to consult the doctor"*. [participant # 27]

Social support during the first six months of infant feeding

Having someone at the time of giving birth and the first few months of infant feeding was described as a source of support and encouragement. Predominantly, mothers reported having someone around for support such as husbands, partners, sisters, mothers and fellow HIV-positive mothers. The following were some of the responses:

> *I have the support especially from my husband and from my mother's side and they encourage me so much and that is why my heart feels as though I am not HIV-positive"*. [participant # 26]
>
> *My family has been very supportive and they ask how the baby is doing and whether I am giving her the medication".* [participant # 18]
>
> *Previously, I used to get scared but now we meet with different mothers at the clinic when we are getting the drugs and most of them are breastfeeding and so it encourages me to keep breastfeeding my baby.* [participant # 21]

Challenges experienced during the first six months of the infant's life

Despite the efforts by mothers to follow the instructions on infant feeding in relation to PMTCT, challenges were experienced. The decision to practice EBF was complex to achieve given individual circumstances. There were concerns with the health of the mother and the baby as well as the need to maintain a healthy diet for the mother as described in the following sub-themes.

The concerns about the health of the mother and baby

The general wellbeing of mothers and babies was reported to be a challenge. A mother complained of signs of malaria with loss of appetite: *"I have a problem with malaria and it was quite serious and I could not even eat"*. While her own health was a concern, the same mother reported that her baby was sick as well: "*The baby has diarrhoea, coughing and sneezing. I have so much fear that the virus that I have may also go to my baby, because he is usually sick of diarrhoea, it doesn't finish for a month and a week now. Even in the night he can have diarrhoea five times and it is greenish in colour"*. [participant # 29]. Similarly another mother explained: *"The baby had rash and when I went to the hospital the baby was given medicine but I think the rash is developing again… so I stopped giving her the medication (ARVs)*. [participant # 27]

Maternal nutrition; challenges to access food

Women infected with HIV in settings with high levels of poverty and food insecurity, may be at risk during pregnancy and breastfeeding. To achieve successful breastfeeding, mothers require a good nutrition. Generally, mothers in this study were economically not empowered and they expressed the difficulties faced in ensuring that they had enough food for themselves: *"Yes the demand is there because as a mother you need to ensure that the baby is well-fed but I also need to eat well but sometimes when there is no food I just drink water and it affects the flow of milk"*. [participant # 11]. Another mother added: *"There are times when things are hard. I get dried maize seeds, I roast them and eat and then I drink water. Luckily milk comes out a lot. There is nothing I can do"*. [participant # 27]. However, there were also reports of mothers who managed to have three meals in a day: *"We have three meals per day, for breakfast we have tea with bread and avocado, for lunch we have nshima (maize meal) with either meat or vegetables, and then snacks in between. I also eat supper"*. [participant # 17]

Discussion

Our findings demonstrate that exclusive breastfeeding is difficult to achieve for mothers in selected populations because of individual circumstances that border on their own wellbeing and that of their babies. Research has shown that breastfeeding, especially early initiation and exclusive breastfeeding, is one of the most critical interventions for improving child health-outcomes for HIV-exposed infants (Coovadia et al., 2007; Thomas et al., 2011; WHO et al., 2012). Breastfeeding compared to lack of breastfeeding has been shown to protect children by significantly reducing the risk of malnutrition and serious infectious diseases, especially in the first year of life. On the other hand, not breastfeeding during the first two months of life is associated with a six-fold increase in mortality due to infectious diseases in resource-poor countries (United Nations Childrens' Fund, 2010; WHO, 2000).

Although the current study did not determine prevalence of exclusive breastfeeding among HIV-positive mothers accessing PMTCT services in selected sites, we conclude that there were gaps in the way mothers were counselled and prepared to practice exclusive breastfeeding that led to challenges experienced in the first six months of infant feeding. Mothers' understanding of the risks of mother-to-child transmission of HIV was limited to the presence of sores on the mothers' nipples and that the risk was higher when the baby developed sores in the mouth. Their concerns were valid because more is needed to enable mothers understand all the risks involved while being cognisant of the current knowledge regarding reduced risk of mother-to-child transmission of HIV with adherence to lifelong ARVs (Option B+). In this case, mothers needed to know how to manage complications while insuring that their babies were not deprived of feeding in the event that sores developed on the mothers' nipples. A study conducted in Malawi suggested that breast complications such as mastitis, a condition with generally low morbidity could pose a risk of mother-to-child transmission of HIV-1, because it is associated with an opening of paracellular pathways with an increase in inflammatory cells and plasma-derived components that could contain HIV-1 and might have serious consequences for exposed infants (John et al., 2001) and similar findings were reported in Nairobi (Embree et al., 2000).

The complexity of their concerns were more evident because they wondered whether their babies were already infected with HIV during pregnancy or at birth. This showed that they needed the support of health care workers to insure that Polymerase Chain reaction (PCR) tests were done as required and results communicated immediately for them to deal with their

individual circumstances and to allay anxiety. Where appropriate, arrangements for further support of mothers whose babies tested positive could have been made. In similar settings, and where mothers experienced challenges during the first six months of infant feeding, researchers recommended support of mothers during the postnatal period in order to assist them overcome the pitfalls experienced (Babakazo et al., 2015).

For this study mothers appeared to be less stressed in the presence of their social support networks such as husbands, sisters, mothers and friends. Family structures have been known to provide opportunities for support that could translate into improved uptake of PMTCT services (Betancour et al., 2010; Busza et al., 2012). The social support network in this case, could have been utilised to ensure that the nutritional needs of mothers were met because the mother's wellbeing is important for successful infant feeding experience. In similar settings, researchers reported that healthy mothers are an essential element to the wellbeing of their children (Izugbara & Ngilangwa, 2010), prompting some researchers to recommend involving family members in infant feeding counselling and education, especially on exclusive breastfeeding practice (Matovu et al., 2008). Social support is possible in societies where extended families are closely knit and may easily be integrated into PMTCT within the limits of national guidelines to improve uptake of exclusive breastfeeding among all mothers regardless of their serostatus.

Given the findings about the concerns reported regarding the wellbeing of babies and where persistent diarrhoea was reported, mothers need to be informed about the importance of seeking health care early enough to avoid further complications. Babies exposed to HIV infection require constant monitoring and care for improved child health outcomes. In settings where mixed feeding is a norm (Hazemba et al., 2015), there was a likelihood that mothers may have been mixing breastfeeding with other fluids or solid foods which could have predisposed their babies to infections leading to diarhoea. The WHO infant feeding guidelines discourage mixed feeding (WHO et al., 2010; WHO et al., 2012).

We conclude that exclusive breastfeeding is difficult to implement in low-resource settings. Among others, additional training for frontline health care workers on how to support and follow up mothers during the infant feeding period is needed. However, improved staffing levels in this and similar settings is imperative to allow health care workers to provide individualized, unbiased, accurate information on exclusive breastfeeding and enhance safer

infant feeding practices for PMTCT interventions to impact child health outcomes for HIV-exposed infants.

Limitations

Although we cannot generalize these findings to a larger cohort, the study nevertheless provides evidence that can inform PMTCT interventions and improve exclusive breastfeeding practices and follow-up of HIV-positive mothers. The interviews for this research were conducted in the primary languages of the participants and all data were translated into English for analysis however, we acknowledge that nuances of meaning may have been lost during the translation process despite the fact that the first author verified the translation with the research assistants.

Ethical consideration

Approval to conduct this study was granted by the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal in South Africa (HSS/0104/013D) and the Biomedical Research Ethics Committee of the University of Zambia (Reference No. 016-11-13). Voluntary participation was accorded with written consent.

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Reference list

Babakazo, P., Donnen, P., Akilimali, P., Ali, N., & Okitolonda, E. (2015). Predictors of discontinuing exclusive breastfeeding before six months among mothers in Kinshasa: a prospective study. International Breastfeeding Journal. 10:1. doi: 10.1186/s13006-015-0044-7.

Betancour, T., Abrams, E., McBain, R., & Fawzi, M. (2010). Family-centred approaches to the prevention of mother to child transmission of HIV. Journal of International AIDS Society. 13:2.

Busza, J., Walker, D., Hairston, A., Gable, A., Pitter, C., Lee, S., . . . Mpofu, D. (2012). Community-based approaches for prevention of mother to child transmission in resource-poor settings: a social ecological review. Journal of International AIDS Society. 15 Suppl 2:17373. doi: 10.7448/IAS.15.4.17373

Central Statistical Office, Ministry of Health, & ICF International. (2014). Zambia Demographic and Health Survey 2013-14. Rockville, Maryland, USA: Central Statistical Office.

Coovadia, H., Rollins, N., Bland, R., Little, K., Coutsoudis, A., Bennish, M., & Newell, M. (2007). Mother-to-child transmission of HIV-1 infection during exclusive breastfeeding in the first 6 months of life: an intervention cohort study. The Lancet. 369;9567:1107.

Embree, J., Njenga, S., Datta, P., Nagelkerke, N., Ndinya-Acholac, J., Mohammed, Z., . . . Plummer, F. (2000). Risk factors for postnatal mother±child transmission of HIV-1. Aids. 14:2535-2541.

Hazemba, A., Ncama, B., & Yusuf, A. (2015). Socio-cultural determinants of exclusive breastfeeding: Lessons learnt from experiences of HIV-positive mothers in Lusaka, Zambia. Africa Journal of Nursing and Midwifery.17;1:104-117.

Izugbara, C., & Ngilangwa, D. (2010). Women, poverty and adverse maternal outcomes in Nairobi, Kenya. BMC Womens Health. 10:33. doi: 10.1186/1472-6874-10-33

John, G., Nduati, R., Mbori-Ngacha, D., Richardson, B., Panteleeff, D., Mwatha, A., . . . Kreiss, J. (2001). Correlates of Mother-to-Child Human Immunodeficiency Virus Type 1 (HIV-1) Transmission: Association with Maternal Plasma HIV-1 RNA Load, Genital HIV-1 DNA Shedding, and Breast Infections. Journal of Infectious Diseases. 183:206-212.

Matovu, A., Kirunda, B., Rugamba-Kabagambe, G., Tumwesigye, N., & Nuwaha, F. (2008). Factors influencing adherence to exclusive breastfeeding among HIV positive mothers in Kabarole District, Uganda. East African Medical Journal. 85;4:162-117-.

Ministry of Health. (2010). National Protocol Guidelines for Infant feeding; Integrated Prevention of Mother to Child Transmission of HIV/AIDS. Lusaka: Ministry of Health.

Ministry of Health, & National AIDS Council. (2014). Zambia Country Report Monitoring the declaration of Commitment on HIV and AIDS and the Universal Access. Lusaka: Ministry of Health and National AIDS Council.

Thomas, T., Masaba, R., Borkowf, C., Ndivo, R., Zeh, C., Misore, A., . . . Ki, B. S. S. T. (2011). Triple-antiretroviral prophylaxis to prevent mother-to-child HIV transmission through breastfeeding--the Kisumu Breastfeeding Study, Kenya: a clinical trial. PLoS Medicine. 8:3. doi: 10.1371/journal.pmed.1001015

United Nations Childrens' Fund. (2010). Improving Exclusive Breastfeed Practices by using Communication for Development in Infant and Young Child Feeding Programmes (pp. 41).

WHO. (2000). The Role of Breastfeeding on the Prevention of Infant Mortality. Effect of breastfeeding on infant and child mortality due to infectious diseases in less developed countries: A pooled analysis. The Lancet. 2000; 355:451–5.

WHO, UNAIDS, UNFPA, & UNICEF. (2010). HIV and Infant Feeding Guidelines, Principles and recommendations for infant feeding in the context of HIV and a summary of evidence. Geneva: WHO.

WHO, UNICEF, UNAIDS, & UNFPA. (2012). 2010 WHO Guidelines on HIV and Infant Feeding An updated framework for priority action. Geneva: World Health Organization

Chapter 8

Community perception of HIV and infant feeding

Introduction

HIV-positive mothers practice infant feeding in communities where they live and work. Programmes aimed at improving uptake of PMTCT services should therefore embrace community structures because they have been known to provide a much-needed platform for improved health care delivery in low-resource settings of sub-Saharan Africa (Betancour, Abrams, McBain, & Fawzi, 2010). For this study, *HIV and infant feeding: choices and decision-outcomes in the context of prevention of mother-to-child transmission among HIV-positive mothers in Zambia,* I explored the community perspective on HIV and infant feeding to gain a broader perspective on implementation of infant-feeding for HIV-exposed infants. The questions I asked were: 1) what does the community know about HIV and infant feeding? 2) What is the role of the community in PMTCT service delivery?

Design

For this study I interviewed HIV-positive mothers and HCWs in order to understand the choices and decision outcomes on infant feeding and as it relates to prevention of mother-to-child transmission of HIV. For triangulation purposes and to investigate the community perspective on HIV and infant feeding, three Focus Group Discussions (FGDs) were held. FGDs was used to explore the views of the participants while at the same time learning from their experiences living with HIV-positive mothers in the community. During FGDs, participants listened, reflected and then considered their own standpoint on the subject under discussion (Ritchie & Lewis, 2003).

Interview guide

A semi-structured focus group guide was used to conduct the discussions. The major issues of focus were social-cultural determinants of breastfeeding, serostatus disclosure, and methods of infant-feeding based on the available options and their views and experiences on HIV and infant feeding.

Participants

One FGD from each site was held with community-based volunteers (CBVs) comprising lay counsellors, members of the neighbourhood health committees and community health workers. The categories of CBVs are defined according to the Ministry of Health description. The CBVs work as liaison between the health facilities and the community. For each site, all eight of the CBVs participated in the discussions.

In addition, men accessing ART from one site participated in a FGD to provide an understanding of their experiences with infant-feeding given that their spouses had given birth a year prior to data collection. The FGDs were held at the health facilities because this was convenient for all the participants. During the discussions refreshments were provided and at the end of the session all participants were reimbursed transport money to go back home (K50.00 each [USD 6]).

Table 8-1 Particulars of participants – Community based volunteers

ID no.	Sex	Age	Marital status	Occupation	Education
CH1	F	35	Married	Counsellor	G12
CH2	F	45	Married	Community health provider	Tertiary
CH3	F	30	Single	Community health provider	G11
CH4	F	52	Widow	Community health provider	Form 3
CH5	M	58	Married	Community health provider	G8
CH6	M	45	Married	Community health provider	G12
CH7	F	49	Single	Community health provider	G7
CH8	F	37	Married	Community health provider	G8
CH9	M	40	Married	Community health provider	Tertiary
CH10	F	35	Married	Community health provider	G6
NG1	F	33	Married	Counsellor	G9
NG2	F	47	Married	Counsellor	G10
NG3	F	49	Married	Counsellor	G7
NG4	F	47	Married	Counsellor	G9
NG5	M	39	Single	Counsellor	G11
NG6	F	40	Widow	Counsellor	G9
NG7	M	43	Married	Counsellor	G12
NG8	F	48	Married	Counsellor	G10
NG9	F	44	Married	Counsellor	G7
NG10	M	69	Married	Counsellor	Form 2

CH-Chelstone Health Facility; NG-Ngombe Health Facility

Table 8-2 Particulars of FGD participants – HIV-positive men accessing ART

ID no.	SEX	Age	Marital status	Primary occupation	Educational level
1	M	40	Married	Business entrepreneur	Grade 12
2	M	45	Married	Unemployed	Grade 9
3	M	37	Married	Employed	Grade 12
4	M	39	Married	Employed	Grade 12
5	M	39	Divorced	Unemployed	Grade 7
6	M	47	Married	Business entrepreneur	Grade 12
7	M	42	Married	Employed	Grade 4

Results

Six thematic areas emerged from this study: participant description of PMTCT; CBVs as a liaison between health centres and the community; known cultural practices of breastfeeding; perceived challenges faced by HIV-positive mothers during infant feeding; and challenges faced by CBVs during the PMTCT community work.

Description of mother-to-child transmission of HIV

This sub-theme describes the participant understanding of mother-to-child transmission of HIV. As stated in the other chapters, infant feeding takes place in the communities were mothers live and work. This subtheme highlights what the community understands about HIV and infant feeding in the context of PMTCT. An HIV-positive man explaines: *"If my wife is pregnant there will come a time when she will deliver and the baby will have to breastfeed, if me, as a father and the mother have HIV we need to protect the baby from contracting HIV. The baby should breastfeed from birth up to five months. In the sixth month, the mother should remove the baby from the breast".* [HIV-positive man, 45 years]

The information that an HIV-infected mother could transmit the HIV virus to her infant through breastmilk was widespread among the discussants. Typical responses were:

> *What I know is that the baby can get HIV from the mothers' milk during breastfeeding. It happens if in the first six months the baby is given other*

foods before the intestines become strong the baby will have sores and when breastfeeding the virus in the milk can easily infect the baby. [NG: man, 58 years]

When the baby is breastfeeding and gets sores in the mouth and the mother is HIV-positive the baby can get the HIV virus through the breast milk. [NG: woman, 52 years]

If a mother has sores on her breasts and the baby is breastfeeding, the baby can get infected with HIV. [NG: woman, 37 years]

The breastfeeding mother who has sores on her breast and is HIV-positive and breastfeeds, the baby can contract the virus. [CH: woman, 37 years]

When the expectant mother does not register the pregnancy at the health facility, the baby can be HIV-positive through breastfeeding but when they come for antenatal care they are registered and tested they will be given the medicines even after delivery they will be given but if not, they risk chances of the baby getting infected with HIV. [NG: woman: 35 years]

Community Based Volunteers: a liaison between the health facilities and the community

The CBVs were asked to describe how they worked with the health care workers in the health facilities. Generally, their activities involved identifying clients and referring them to the health facilities and follow-up care:

We work with nurses because we refer clients to them from the community. [CH: man, 45 years]

We work as a team for the community wellbeing to improve. [CH: woman, 35 years]

We go in the community and identify clients. Then we come to the nurses and seek advice. They either tell us to bring the clients to the clinic or the follow up care. [CH: woman, 45 years]

For follow-up of mothers, we get guidelines from the nurses because they are the ones having the information in their register. They are the ones who

tell us who is not coming for review and then we follow them and bring them to the health facility. [CH: man, 45 years]

After our door to door visits in the community, we give the nurses feedback on types of clients we find, what we have told them, the problems they face and those who have promised to come to the health facilities. [CH: woman, 45 years]

However, despite their self-reported role in health care delivery, it was apparent that they felt unrecognised by the health facility staff: *"As volunteers we have many ideas to contribute to PMTCT program but what we need is recognition at the health centres".* [NG: woman, 47 years]. Another participant added: *For the program to run smoothly in the community there is need for transport and lunch allowances and this will encourage more people to participate in voluntary work.* [CH: woman, 45 years]. This issue was brought out because some mothers did not want to visit the health facilities for one reason or another. One participant described such mothers as being lazy. He explained: *Through outreaches programmes we get mothers that are lazy to come to the clinic for under 5 and then we capture them to get results for HIV testing for their babies and give immunizations.* [CH: man, 45 years].

In relation to HIV and infant feeding, the following sub-themes reflect ways in which the CBVs described how they were involved in the PMTCT programme. They assisted with facilitating serostatus disclosure when mothers tested for HIV, they participated in health promotion campaigns on infant feeding and supported mothers during breastfeeding.

Facilitating serostatus disclosure

Serostatus disclosure was understood as involving spouses in antenatal. This was described in the following response:

We assist mothers to involve their husbands during antenatal. They will know how to prevent the baby from contracting the HIV virus by reminding their wives to take the medicine (ARVs), and will know for how long the mother should breastfeed the baby. [CH: woman, 30 years]

Perceived risk for serostatus disclosure

However, the CBVs described the consequences of serostatus disclosure and they recognised the difficulties women faced because in some intances, spouses threatened to end marriages:

> *When a husband discovers that the spouse is HIV-positive they decide on ending the marriage. Therefore, the other partner's life becomes a misery and even the growth of the baby is affected.* [CH: woman, 45 years].

In some instances mothers failed to convince their spouses about safer infant feeding. A man explained: *Men are difficult and we need sensitization because sometimes a mother can have information when to stop the breastfeeding because of HIV but the husband can stop and start asking questions as to why she would want to stop breastfeeding. As a result she will continue and infect the baby since she cannot make the husband understand.* [CH: man, 58 years].

Regarding practicing safer infant feeding, some family members raised questions about why mothers fed their babies differently: A man in a FGD explained: *Some family and friends question mothers who stop breastfeeding their babies at 6 months and those taking ARVs in the community.* [CH: man, 45 years]. Another participant added: *In the community family and friends are the ones bringing confusion because they say that the mother can prayed for and fasted and can be cured. This has discouraged many from taking ARVs.* [CH: woman, 35 years].

Health-promotion activities on infant feeding

The CBVs described their health-promotion activities as teaching and advising mothers on exclusive breastfeeding practice. Typical responses were:

> *We advise mothers to breastfeed their babies within 24 hours of giving birth. They are supposed to breastfeed the baby for 6 months without giving any other fluids or foods. Even when the mother is HIV-positive, she should breastfeed the baby for 6 months. After 6 months is over, they are advised to give the baby the local food that we normally eat in the community.* [NG: woman, 45 years]

We are teaching mothers and most of them have known that there are benefits in breastfeeding their children when they are just born and especially for the first 6 months without giving any other fluids and foods. We teach them to follow up with complimentary feeding after 6 months. [NG: woman, 49 years]

Yes when we have health talks for antenatal mothers we talk about how a mother should protect herself and the baby. We talk about exclusive breastfeeding from 0 to 6 months, we talk about children who are HIV-positive and negative so if a mother delivers, she will know what to choose, and how she should take care of her baby.[NG: woman, 44 years]

We first discus and let them say what they desire. Then we tell them about the other methods and ask them what they think. They definitely agree and say that breastfeeding is cheap and decide to try it but we ensure that they bring their babies for under-five clinic for growth monitoring and immunization. [CH: woman 45 years]

Participants emphasised that the comparative advantages of formula and breastfeeding are discussed with mothers before they make a choice on how best to feed their infants. However, they were aware that breastmilk gives the baby its essential nutrition and the first immunization. A man explained: *The choice to exclusively breastfeed is not because of money. We tell mothers the benefits that are found in breastmilk compared with the formula. When we talk about breastmilk, the disadvantages are few unlike formula which are plenty. Colostrum, the first milk, which is like the first immunization for the child is not there in the formula. Which means when the baby is breastfeeding before BCG it is like the first injection has already been given through breastfeeding to protect the child from TB. So mothers will choose the breast whether they have money or not because they will see that this one is good and makes sense.* [NG: man, 43 years].

Their health-promotion activities included further education for mothers who choose to formula feed especially regarding preparation and hygiene. A participant explained: "*For those who choose formula and work, we also let them know that the bottle is not safe because when they are not at home they don't know how the bottles are kept or if they are washed properly. The bottles have a way of being washed by using brushes and washing in clean*

water. Sometimes the housemaid may not be managing to do everything properly. Then the baby may continue having diarrhoea because of how the bottle is being kept. If they can manage to express the milk from the breast, they can teach their maid or a relative the one who has a heart to keep the baby using feeder cups because they are easy to keep and wash because breastmilk is cheap and a mother walks with it. If I mother is eating enough good food the milk is enough and she can express and leave for the baby. She will not have the headache of how much money she will need in a day to buy formula because she readily has the breastmilk". [NG: woman, 49 years]. Another participant added: "*We teach mothers about two options: exclusive breastfeeding and formula method of feeding and let them choose the method they desire. But if they choose to formula feed they are supposed to prepare according to the measurements. Wrong measurements may affect the baby's growth. So to avoid this we ask them whether or not they can afford to buy formula at K45/tin ($ 4) per week for 6 months. In addition we tell them that hygiene is also required to wash their hands after coming from toilets, before preparing the milk and cleaning the bottle. Failure to do this, the milk becomes contaminated and the baby may suffer from diarrhoea and may die. If the mother cannot manage this method, then we suggest breastfeeding and explain to them how it is done".* [CH: woman, 30 years]. Another participant's comment emphasised time to prepare a formula feed as a factor in ensuring the baby was fed on time: "*Giving formula you need time for preparation before giving the baby, time will pass and the baby will cry and get tired. Keeping the utensils used to feed the baby and the washing may be difficult. As for the breasts, a woman knows how to bath so the breasts are ready and at the right temperature but the formula a mother has to keep warming and it will take time".* [NG: man, 35 years]

Helping mothers to breastfeed

For mothers who choose to breastfeed, the CBVs provided support mothers during early stages of infant feeding. The CBVs were aware that some mothers do not want to breastfeed because of fear to infect their babies with HIV. A participant with experience in PMTCT explained: "*In the past if the mother is positive she would refuse to breastfeed the baby for fear that the baby might get HIV and children used to die. So we help mothers by teaching them to breastfeed until the baby is 24 months and for protection there is medicine (ARVs) that is used to protect the baby. We help them to exclusively breastfeed and when the baby turns 6 months, they introduce other foods to help the baby to grow, prevent disease and give strength".* [NG: woman, 69 years]. Another participant added: *"We encourage exclusive*

breastfeeding from zero to six months for a woman who is positive or negative to breastfeed without mixing with other foods until the baby turns six months". [NG: woman, 52 years]. They participants reported teaching mothers on the technique of breastfeeding: *"Another thing is we help them on how to hold the breast when breastfeeding the baby because some hold breasts like a scissors and they squeeze the breast for the milk to come out. But we help them on how to hold the breast and when the mother breastfeeds and the baby finishes the milk then she moves to the other breast. If the mother breastfeeds the baby like that the nipple cannot have sores and the baby can be protected"*. [NG: woman, 69 years].

In addition, they advised mothers to exclusively breastfeeding and bring babies to the health facilities for testing. A man explained: *"When a mother is found HIV-positive during pregnancy and is given medicine (ARVs), we encourage them to breastfeed without mixing with any other foods or liquids because everything is in the milk unless the doctor says you give medicine. While the baby is on treatment with the mother, at six weeks the baby is brought to be tested at the hospital. Then the test is repeated at six months, at one year and again at one year six months. When the baby is not found to have HIV at one year six months, then the child is safe. When they come to wean the child at two years and they stop breastfeeding we encourage them to give the medicine for a whole week before they stop giving medicine"*. [NG: man, 43 years]

Known cultural practices of breastfeeding

During the discussions, known cultural practices were highlighted. The following sub-themes describe what the participants knew and to a certain extent practiced and supported.

Not breastfeeding in the presence of other breastfeeding mothers

In the society where the participants come from, mothers breastfeed on demand and anywhere. For participants in this study, they reported that mothers would not breastfeed in the company of other breastfeeding mothers because the practice was associated with the baby contracting diarrhoea. Participants explained giving examples of mothers who believed strongly in this practice: *"When mothers come for BCG and the baby starts to cry, they leave the group to hide and breastfeed. So mothers do not breastfeed in the presence of other mothers because they fear 'chibele' (diarrhoea)"*. [CH: woman, 30 years]. Another participant added: *"Another reason why mothers do not want to breastfeed in public is that*

some women wear traditional medicine in their waists or on the baby's writ to protect the baby from diarrhoea (chibele) and the baby may die if the mother has not protected her child". [CH: woman, 49 years]

The first milk is dirt

Colostrum, the first milk that comes out on initiation of breastfeed is regarded to be unclean and not suitable for the baby. A man explained: *"The first milk is dirty, yes, and if the mother's breastmilk stays for a long time it goes bad and the mother may start giving the child gripe water (off the counter medicine) to clean the stomach"*. [CH: man, 58 years]

Abrupt ceasation of breastfeeding

The participants supported abrupt ceasation of breastfeeding, pointing out that it is practiced when the mother realises that she is pregnant. A participant explained: *"The other thing is that if a woman is breastfeeding and suddenly finds out that she is pregnant, she will have to remove the baby from the breast immediately. The fear is that the baby in the womb will share the milk with the breastfeeding baby, and the baby will have diarrhoea and vomiting, or even die"*. [CH: woman, 52 years]

Late initiation of breastfeeding

Late initiation of breastfeeding is practiced when a mother lost her previous baby to allow her to wash the breasts with traditional medicine. A participant explained: *"When a woman has a miscarriage for the previous pregnancy, when she delivers she does not breastfeed until she washes the breasts in traditional herbs otherwise the new-born baby will also die"*. [CH: woman, 45 years]. This practice is passed from one generation to the other by elders in the family: *"When their mothers or grandmothers or in-laws tell them that when this child is born, they should not breastfeed at the clinic, she will not breastfeed but will give other liquids to the child. Mothers do it even when the baby is only one month"*. [CH: woman, 35 years].

In situations where there was delay in milk coming out at initiation of breastfeeding, participants reported that it was due to spells and witchcraft and this could could lead to mixed feeding. Men living with HIV explained in the following responses:

When a woman has delivered then it is time to breastfeed, and the milk is not coming out, what can you do? You go and buy formula and use it to feed the baby. If you try and force it what will the baby breastfeed? It is better you buy formula while you wait for the milk to come out, that is what I know. [HIV-positive man, 42 years].

When a woman delivers and milk is not coming out it means someone has put a spell or has tied the milk flow with medicine. So as a family you look for traditional medicine so that the milk should start coming out. If it fails completely then you buy formula. So when you buy formula sometimes the child does not have strength, because they are not sucking on the mother's blood, they will not have strength and sometimes they even die. That is why they look for traditional medicine. Sometimes the mother has to drink the traditional medicine so that the breasts can become soft. [HIV-positive man, 47 years]

In a different perspective, washing of the breasts with herbs is believed to ward off the dead baby's spirits: *"When a baby is born and breastfeeds shortly and then dies and the mother gets pregnant again she has to wash the breasts with traditional medicine before breastfeeding a newborn baby. So the elders will prepare the medicine to wash the breasts and ward off the spirits of the dead baby and protect the newborn baby".* [HIV-positive man, 37 years]

The practice of making a baby strong

Another known cultural practice is the perception of making a newborn baby strong. A male respondent gave a long explanation of this practice and seemed convinced about its value to the baby. He explained: *"There is a tradition where after 3 or 6 months following the birth of the baby, a couple has to resume sexual relations. After sexual intercourse the semen has be rubbed on the baby's back and legs. So you will find that the woman will ask to use the condoms and the husband will say that traditionally the condom use will not make the baby strong. You cannot remove the semen from the condom. So that brings friction between couples".* [HIV-positive man, 45 years]

Wet nursing

In some communities, wet nursing is still being practiced in the event that the mother of the newborn baby dies. A participant explained: *"When a woman dies leaving a small baby, in the community the sister breastfeeds the child, together with her child. It happens but it is*

wrong because you don't know the baby's HIV status and that of the woman who has gotten the baby, and even the status of the mother who died. It is better we sit as a community and relatives and find a way of buying formula instead of feeding from the breasts like we are still in the past". [HIV-positive man, 45 years]

Despite all these beliefs, participants nonetheless reported that breastfeeding helps to bond the baby and the mother: *"Breastfeeding is good because it brings a close relationship between the mother and the baby. That is one way a baby reaffirms that this is my mother because the baby breastfed straight from the mother's. A baby that is fed on formula is like a baby taken care by other people other than the mothers".* [HIV-positive man, 40 years]

Perceived challenges faced by mothers during infant feeding; the community perspective

The CBVs recognised that mothers could choose a method of feeding that they understood to be safe. However, the cost of formula, family and community pressure to practice mixed feeding, storage facilities for milk, and stigma were perceived as problems for infant feeding.

Cost of formula

The cost of formula determined whether a mother would breastfeed or not. Participants expressed affordability in the following responses:

> *Economic empowerment determines whether the mother can use either breastfeeding or formula. If they are doing well financially they can go for formula feeding, if not they opt for exclusive breastfeeding.* [CH: man, 40 years].

> *Some women choose to formula feed and we don't know why. But maybe they can afford to buy formula throughout. But babies that are breastfed from 0 to 6 months are healthier than those who are not. There are situations where a mother would start with formula and then notices that the baby is unhealthy and is losing weight then she decides to switch to breastfeeding the baby again.* [CH: woman, 45 years].

For this reason they said they made it clear that breastfeeding should be priority whether or not a mother was working:

> *Whether a mother is working or not we encourage them to take food that can increase breast milk so that they can express in the cup and can be stored for 24 hrs. When the mother is away from the baby the milk can be used to feed the baby using a cup and spoon.* [CH: woman, 30 years]

Therefore, the CBVs expressed that breastfeeding was a cheaper alternative to feeding HIV-exposed infants: *"We advise mothers to exclusively breastfeed from 0 to 6 months because it is cheap than formula feeding. Breast milk contains all essential nutrients for the baby".* [CH, Man, 45 years]. Another participant added: We advise mothers not to introduce foods that are expensive but foods that they can afford to buy and are always available in the home. And we also teach them methods of preparing these nutritional foods and stages when to introduce them to their children. [CH: woman, 45 years].

Community pressure

Whatever the method of feeding, family and community questioned why babies were being fed differently. An HIV-positive man shared his experience and explained: *"There is pressure in the family and community. Like me and my wife we are HIV-positive and we have a child. I remember when I had my last child my relatives who knew our status would tell us not to breastfeed saying the child will get the HIV and they asked us to just buy formula but we were told at the clinic what to do".* [HIV-positive man, 37 years]

Storage facilities for formula and expressed breastmilk

Whether a mother chooses to breastfeed or give formula, in each situation mothers need refrigerators to store both expressed breastmilk and formula before the next feed and the following alternative methods were highlighted by participants: *"It's not a matter of having the fridge because our parents never had fridges and their food never went bad. A mother should just get cool water in the dish and put under the room temperature with the cup of milk and it will not go bad".* [CH: woman, 30 years]. Another participant added: *I know that milk cannot just go bad the moment you store it. It can stay for about 5 to 12 hours before it goes bad/sour and the baby can be fed.* [CH: man, 58 years]. A man added: *"Storing milk becomes critical for others who don't have fridges and eventually milk can go bad".* [CH: man, 40 years].

Stigma

An HIV-positive man described how stigma affects the way an HIV-exposed infant is fed: *"Stigma is very common because people in the community talk. If they see you buying formula and giving the baby they become suspicious. When your wife stops breastfeeding people come to conclusions because they see that maybe the woman is not working and stays home, why is she giving the formula? For me I have made some people become very close to me even some neighbours so that I am not stigmatized".* [HIV-positive man, 37 years]

Challenges and recommendations for PMTCT programme; the community perspective

Loss to follow-up

Working at the community level, the CBVs sometimes encountered difficulties in following up the mothers on their registers because mothers gave wrong addresses. A participant explained: *"Most of the time we emphasise when the baby is born after six weeks the baby should be tested for HIV and if after one month the results are not collected, we tell the mother to go and get the results. Also the under 5 card shows how the baby is being fed and we tick. Previously we used to do follow-ups on the mothers who did not collect the results because the register showed information for us to check".* [CH: man, 45 years]. This led to some clients being completely abandoned: *"The reasons why we stopped is because people give us wrong addresses and it is very difficult to locate them".* [CH: woman, 30 years]

Defaulting

Some mothers defaulted completely: *"Sometimes we have defaulters who give wrong contact address and when we go there you find that it is another person or they don't have anyone who delivered. So we encourage them to give the correct house numbers or the correct phone numbers. Sometimes when you call the number it's a wrong phone number".* [CH: woman, 59 years]

Failure to help the community to fully understand the health promotion messages on infant feeding

In some instances the community did not appear to comprehend the health-promotion messages, hence variations were proposed such as use of drama: *"The understanding level of people in the community differs. Some understand through word to word but some it's*

through sketches and drama. There is need that once in a while we go in the community to conduct drama so that people become fully acquainted to PMTCT". [CH: woman, 30 years]

Conclusion

This section of the thesis highlights the importance of integrating community-based structures in promotion of breastfeeding and exclusive breastfeeding among HIV-positive mothers. The barriers that hinder uptake of PMTCT services occur at community level where mothers live and feed their infants. In some settings of sub-Saharan Africa, community support has been identified as a major factor in the uptake of PMTCT services (Gourlay, Birdthistle, Mburu, Iorpenda, & Wringe, 2013) leading to successful treatment outcomes for some populations affected (Busza et al., 2012).

The finding that CBVs were willing to work as a liaison between the health facilities and the community shows that the PMTCT programme may be well received by mothers and the community but caution needs to be exercised because of the potential for stigmatization of mothers by the CBVs themselves and the community if not well monitored.

However, in low resource settings staffing levels are generally low (Frizelle & Solomon, 2009). The employment freeze which has been in effect for the past three years in Zambia (Ministry of Health, 2010) has impacted negatively on health care delivery. Therefore, the CBVs could be trained, supported and monitored to facilitate uptake of PMTCT services at community level and enhance breastfeeding practices among HIV-positive mothers if well integrated.

Reference list

Busza, J., Walker, D., Hairston, A., Gable, A., Pitter, C., Lee, S., . . . Mpofu, D. (2012). Community-based approaches for prevention of mother to child transmission in resource-poor settings: a social ecological review. Journal of International AIDS Society. 15:Suppl 2;17373. doi: 10.7448/IAS.15.4.17373.

Betancour, T.S., Abrams, E.J., McBain, R., & Fawzi, M.C.S. (2010). Family-centred approaches to the prevention of mother to child transmission of HIV. Journal of International AIDS Society. 13:2.

Frizelle, K., & Solomon, V. (2009). Strengthening PMTCT through communication: A review of literature. South Africa: UNICEF.

Gourlay, A., Birdthistle, I., Mburu, G., Iorpenda, K., & Wringe, A. (2013). Barriers and facilitating factors to the uptake of antiretroviral drugs for prevention of mother-to-child transmission of HIV in sub-Saharan Africa: a systematic review. Journal of International AIDS Society. 16:1;18588. doi: 10.7448/IAS.16.1.18588.

Ministry of Health. (2010). Ministry of Health (2010) National Strategic Plan for 2011-2015. Lusaka: Ministry of Health.

Spencer L, Ritchie J, O'Connor W. (2003). Carrying out qualitative analysis. In: Ritchie J, Lewis J, editors. Qualitative Research Practice: A Guide for Social Science Students and Researchers. London: Sage Publications.

Chapter 9

Understanding the decision-outcome on infant feeding in the context of mother-to-child transmission of HIV: a conceptual framework

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Abstract

Introduction

Breastfeeding is the most desirable choice to feed new-born babies but poses a risk of mother-to-child transmission of HIV. We analysed choices and decision-outcomes on infant feeding in the context of prevention of mother-to-child transmission (PMTCT) of HIV.

Methods

This grounded theory study included HIV-positive mothers (n=30), health workers (n=6), HIV-positive men (n=7) community volunteers (n=20). Field work was conducted in Lusaka from January-September, 2014. Purposive sampling was used at inception while theoretical sampling determined next participants. Interviews were transcribed verbatim, cleaned and transported into QRS NVivo 10 for analysis.

Results

Participants acknowledged the risk of mother-to-child transmission of HIV through breastmilk and identified areas impacting infant feeding: Social-cultural determinants of exclusive breastfeeding (EBF), serostatus disclosure versus EBF, infant feeding counselling and experience with EBF; opportunities and challenges. These categories formed a basis for the emerging model to understand barriers and facilitators for behaviour change and enhance infant feeding practices. Using axial and selective coding, we developed propositions: Contextual environments for HIV-positive mothers, infant feeding options for HIV-exposed babies, health care factors in PMTCT interventions, and decision-outcome on infant feeding.

Discussion

Regardless of the infant feeding option recommended for HIV-exposed infants, this model provides health care workers with simplified steps for consideration to enhance infant-feeding practices.

Key words: *HIV-exposed infants, Exclusive breastfeeding, Social-culture, behaviour change, decision-outcome*

Introduction

The HIV and AIDS pandemic has changed the landscape of infant feeding among the affected populations because of the risk of mother-to-child transmission through breastmilk. Health services worldwide are developing and implementing interventions to respond to the pandemic and specifically to include antiretroviral therapy and safer infant feeding practices (WHO, UNICEF, UNAIDS, & UNFPA, 2012). The initiatives increase the efforts to understand the overall mortality risks associated with different infant feeding strategies under different conditions. However, various factors influence uptake and retention of prevention of mother-to-child transmission of HIV (PMTCT) services. In order to benefit from the interventions, HIV-positive mothers need to be counselled, assisted and supported to make decisions to seek and benefit from PMTCT interventions. Successful implementation of PMTCT interventions are complicated however, and influenced by factors beyond the health facilities (Laar & Govender, 2011; Matji et al., 2009; Matovu, Kirunda, Rugamba-Kabagambe, Tumwesigye, & Nuwaha, 2008; Odongkaraa, Kigulib, & Edison, 2013). A more integrated approach to safer infant-feeding could therefore play an important role in improving uptake and retention of PMTCT services, provided that the implementation of such interventions takes place in the communities where women live and work and where varying circumstances such as family support may influence the decision-outcome for safer infant feeding practices (Betancour, Abrams, McBain, & Fawzi, 2010).

In Zambia, all mothers are encouraged to exclusively breastfeed, regardless of their HIV status (MoH, 2010, 2014), but the difficulty in making a decision for infant feeding affects uptake of PMTCT services and child health-outcomes. The purpose of this grounded theory study was to analyse choices and decision-outcomes in the context PMTCT among HIV-positive mothers in Lusaka in order to enhance the infant feeding practices in the first six months of the infants's life.

Design and setting

This study was conducted in urban setting of Lusaka using two health facilties to recruit participants and both are sites for government programmes on PMTCT and antiretroviral therapy. Grounded theory was the qualitative design used and according to Glasser and Strauss (2006), a theory or model should be informed by the data. Therefore, the theoretical framework for this study was concerned with actions, interactions, and social processes

shared by HIV-positive mothers that are depicted in categories comprising the theoretical guidelines (Charmaz, 2008 ; Creswell, 2007; Glaser & Strauss, 2006).

Participants

Purposive sampling guided the selection of participants at inception. As themes emerged theoretical sampling determined next participants and the questions to be asked. Thirty HIV-positive mothers, aged between 20 and 35> years, accessing PMTCT services and meeting the selection criteria, were recruited at inception of the study and were interviewed at 6 days, 6 weeks, 12 weeks and 18 weeks after delivery. All had experienced the birth of a mature infant who had a normal birth weight. All six of the health care workers in the PMTCT programme from the selected health facilities were interviewed. When it became apparent that some issues needed clarification, community-based volunteers from the two sites were recruited to participate in focus group discussions.

Critical issues regarding infant feeding decision-making emerged and these raised questions that needed clarification with HIV-positive men that experienced a birth. A total of seven men aged between 37 and 47 years accessing antiretroviral therapy, and whose spouses had delivered a live baby within the year prior to this research were invited to participate in a focus group discussion.

Data collection procedure

This process started with ethical approval granted by the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal (HSS/0104/013D) and the Biomedical Research Ethics Committee of the University of Zambia (Reference No. 016-11-13). Voluntary participation was accorded with written consent. The first author with two research assistants recruited all the participants using health facility registers.

The interview guide

A semi-structured interview guide was used to interview all the participants. At the inception of the study all the participants were asked the same questions. However, as the interview process progressed probes were individualized based on the participants' circumstances. Mothers were interviewed at 6 days, 6 weeks, 12 weeks and exit interviews were conducted

at 18 weeks. Figure 9-1 below depicts the age of the infants at the time the mothers were interviewed.

At the inception of the study mothers were asked how they decided to feed their HIV-exposed infants. The first interview provided an opportunity to explore socio-cultural practices of breastfeeding. It was also significant at this stage to establish whether mothers had disclosed their serostatus to someone in the family or their partners. Further, to gain insight into the infant feeding counselling we established how the information mothers received during infant feeding counselling assited them to make an informed-decision on how to feed their infants.

In follow-up interviews at 12 weeks and 18 weeks, we focused on coping strategies, challenges faced, support received and continuity of care for the mother-baby pair.

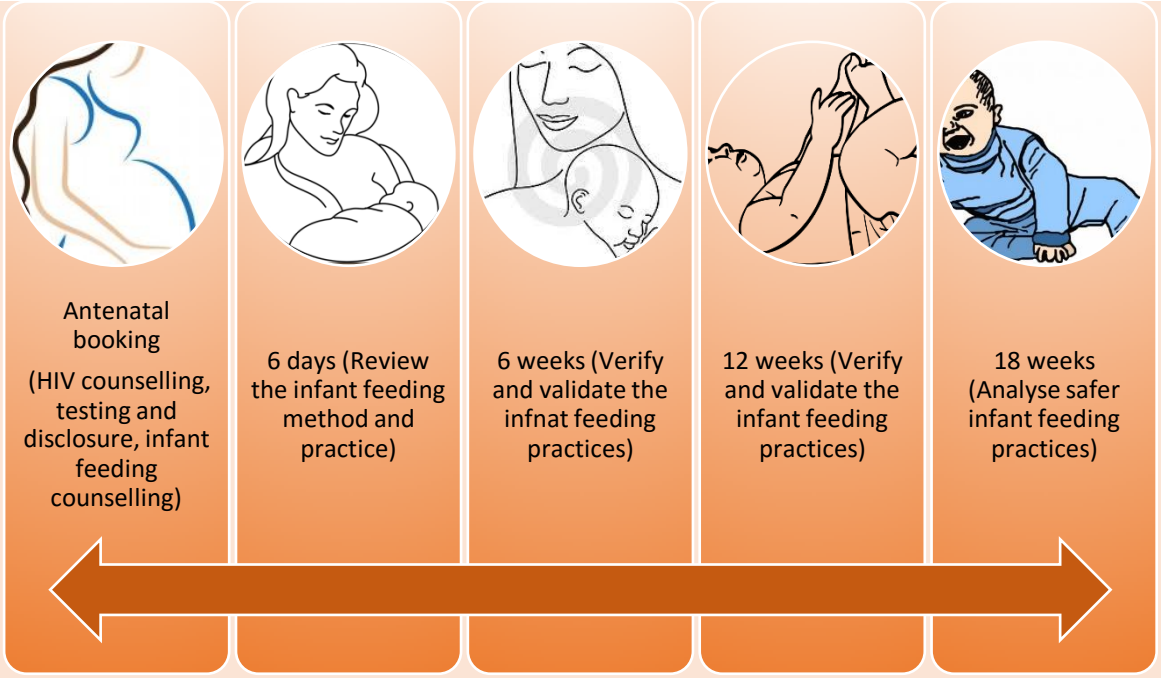


Figure 9-1 Contact phases during data collection: opportunities and challenges

Data Management and analysis

All interviews were transcribed verbatim and analysed using QRS NVivo 10 version. Transcribed data were analysed using the procedures described by Glasser and Strauss (2006) which involved open, axial and selective coding.

In open coding, the first author read all the transcripts to categorize the major themes, which were compared exhaustively to the central phenomenon (exclusive breastfeeding) that was identified and this was the central component of the theory. This process was followed by axial coding to create relationships between the categories and as they related with the central theme. Selective coding, which was the final stage of coding, was done by writing statements or the narrative of the model in order to contextualise the categories according to the findings of the study (Glaser & Strauss, 2006).

Findings

We identified five thematic areas that explained and gave meaning to behavioural processes that determined decision-making on infant feeding in relation to PMTCT. The concepts were then developed from the themes and were labelled and organised into categories, consistent with open-coding procedures [see Table 9-1] (Rimer & Glanz, 2005). The major categories were:

1. Sociocultural determinants of breastfeeding
2. Disclosure of serostatus
3. Infant feeding counselling
4. Promotion of exclusive breastfeeding
5. Experience with infant feeding during the first six months after giving birth

The table below (Table 9-1) describes the results of the study using the categories mentioned above. The texts were derived from quotes of participants. The table further shows the proposed strategies to enhance infant-feeding for the HIV-exposed infants.

Table 9-1 Themes that informed the model and their related texts with proposed strategies

Thematic areas	Texts from key findings	Proposed strategies to enhance safer feeding for HIV-exposed infants	Propositions
Serostatus disclosure	Disclosure of serostatus was reported **Reasons for disclosure of serostatus** • Fear to infect the baby with HIV • Fear of death • To get family support • For the partner/husband to test also **Nondisclosure of serostatus** • Fear of family and community gossip **Health care workers' perspective** • Lack of serostatus disclosure associated with poor uptake of PMTCT services	• Facilitate disclosure of serostatus in the context of exclusive breastfeeding practices • Intensify voluntary counselling and testing (VCT) among couples and encourage mutual serostatus disclosure at community level as opposed to health facility based activities in order to reduce stigma related to attendance of VCT and PMTCT services • Integrate HIV-positive buddies for social support	• Contextual environments for HIV-positive mothers
Social-cultural practices of breastfeeding	**Cultural understanding of breastfeeding** • Breastfeeding is a cultural norm • Colostrum is considered as dirt and is discarded before initiation of lactation • Breast milk is not enough food for the baby **Cultural practices and associated risks to exclusive breastfeeding** • Early introduction of fluids and solids to compensate for delay in the initiation of breastfeeding	• Integrate culture in infant feeding counselling • Design culturally sensitive counselling tools to enhance uptake of PMTCT services • Continue to promote exclusive breastfeeding	• Contextual environments for HIV-positive mothers

Thematic areas	Texts from key findings	Proposed strategies to enhance safer feeding for HIV-exposed infants	Propositions
	• Mixed feeding as a cultural norm • Washing of breasts with traditional herbs before breastfeeding if the previous baby died • Use of herbs for the baby to ward off bad spirits • Use of herbs for treating abdominal pains for the baby		
Infant feeding counselling	**Infant feeding counselling** • Mothers encouraged to practice exclusive breastfeeding • Mothers chose exclusive breastfeeding **The mothers' decision to practice EBF** • To protect the baby from HIV infection • A breastfed baby is healthy • The difficult to initiate sustain formula feeding **Potential to practice mixed feeding** • Late initiation of breastfeeding • The belief that the baby can stop breastfeeding on its own • Pressure from family and friends to practice mixed feeding • Potential for abrupt weaning from exclusive breastfeeding and breastfeeding	• Strengthen group health education on PMTCT • Facilitate objective infant feeding counselling • Implement HIV-positive buddies • Provide take home materials on breastfeeding and exclusive breastfeeding • Display posters on various topics on pregnancy, childbirth and care of infants	• Infant feeding options for HIV-exposed babies • Health care factors in PMTCT interventions

Thematic areas	Texts from key findings	Proposed strategies to enhance safer feeding for HIV-exposed infants	Propositions
Promotion of exclusive breastfeeding	**Promotion of exclusive breastfeeding** • All mothers encouraged to exclusively breastfeed **Mothers' understanding of information to exclusively breastfeed** • ARVs reduced the risk of MTCT of HIV • Information received in the counselling sessions was perceived as directives rather than informative from which they were free to make their own decisions. **Mothers reasons for choosing to exclusively breastfeed** • Perception of safety of breastmilk • Perception of baby crying after breastfeeding • Perception of the cost of formula as a barrier to choose formula feeding **Decision on infant feeding and behaviour change** • Perception of breastmilk insufficiency • Potential for abrupt weaning	• Use bottom-up approach to promotion of exclusive breastfeeding • Provide quality and objective infant feeding counselling • Design and adopt exclusive breastfeeding plans for individual mothers • Link mothers to social support networks	• Health care factors in PMTCT interventions

Thematic areas	Texts from key findings	Proposed strategies to enhance safer feeding for HIV-exposed infants	Propositions
Experience with exclusive breastfeeding in the first six months of infant feeding	**The mothers' perspective of MTCT of HIV** • Sores on the nipples and sores in the mouth of the baby poses a risk of MTCT through breast milk **Exclusive breastfeeding; reflections and narratives in relation to PMTCT** • Concerns about whether the baby was born with HIV infection • Concerns about survival of HIV-exposed infants • Social support networks **Challenges faced in the first six months of feeding** • Concerns about the mothers' wellbeing and the health of the infant • Maternal nutrition	• Encourage and support mothers to adhere to treatment and care • Encourage mothers to protect breastfeeding • Link mothers to socioeconomic empowerment programs • Design and promote use of mobile phones for call-backs to communicate and enquire on complications that arise during infant feeding in the first six months or beyond • Reinforce ongoing infant and young child feeding counselling • Strengthen child growth monitoring and immunizations	• Decision-outcome on infant feeding.

Adopted from the Social Cognitive Theory(Rimer & Glanz, 2005)

Discussion

The results of this study presented a pattern of events that culminated into steps for consideration in PMTCT interventions. The discussion is based on a schematic presentation using the proposed steps by Hugh, Majda and Fiona (Figure 9-2) (Hugh, Majda, & Fiona, 2014).

Overview of the model

The findings of this research were described within the defined categories and shows how the major themes informed the concepts of the conceptual framework and how the phenomena is centred on exlusive breastfeeding. Six interlinked concepts reflect that decision-outcome on infant-feeding can only be achieved with serious consideration of: Contextual environments for HIV-positive mothers, infant feeding options for HIV-exposed babies, health care factors in PMTCT interventions, and decision-outcome on infant feeding. Application of this framework in the PMTCT programme has potential to facilitate implementation of the WHO infant feeding guidelines within the local context (MoH, 2010, 2014; WHO et al., 2012).

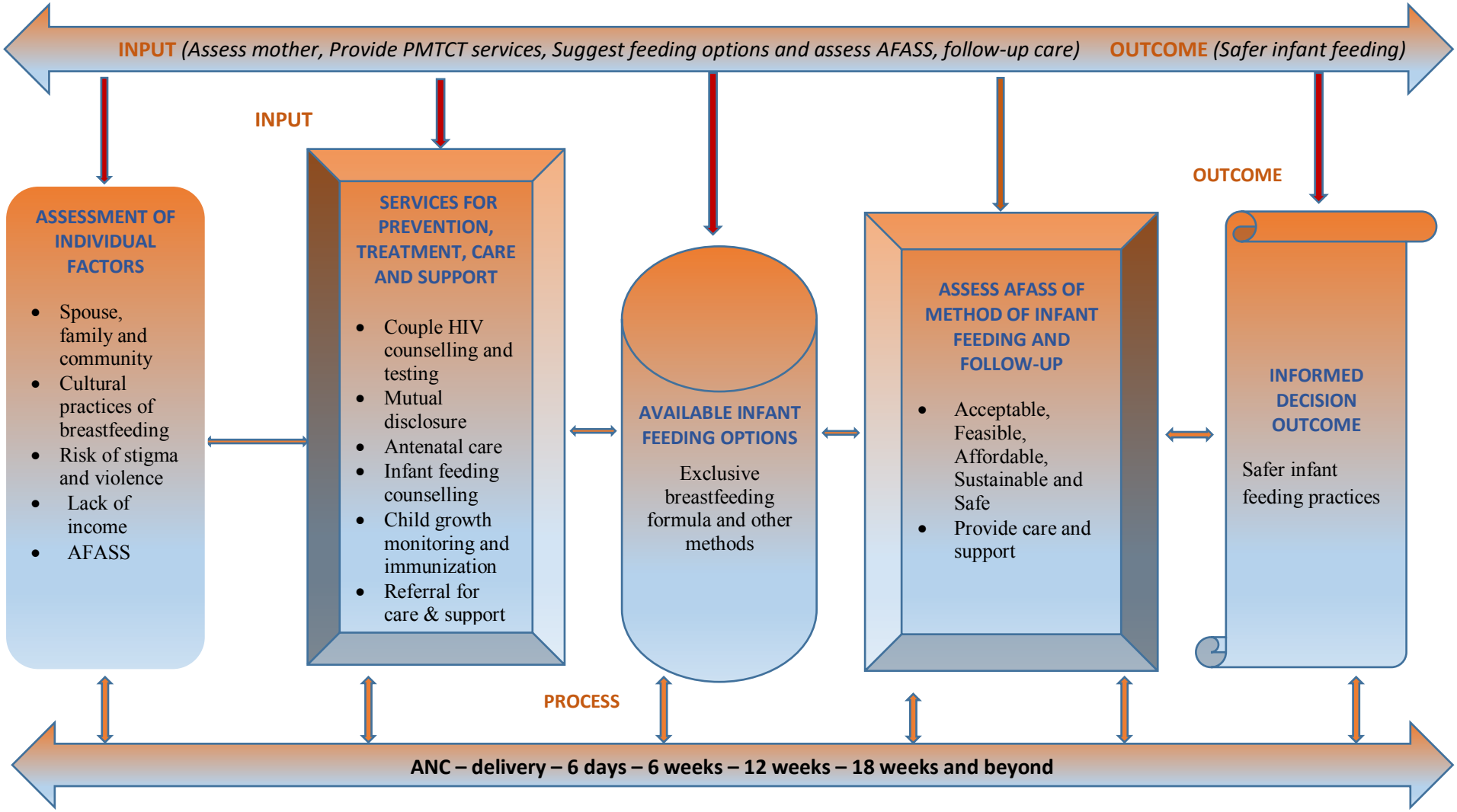


Figure 9-2. Conceptual framework for follow up of HIV-positive mothers during infant feeding

Elements of the model

The context

Regardless of the options available to HIV-positive mothers, infant feeding takes place in a complex community where they live and work. While recognising that outcomes of health interventions are increasingly being shaped less by individual behaviour and more by the wider environments in which HIV-positive mothers live and make decisions, using an integrated bottom-up approach to the promotion of exclusive breastfeeding will enable mothers to make informed decisions on how best to feed their infants (Matji et al., 2009). The model provides a clear understanding of facilitators and limitations in the implementation of infant feeding practices within the local context.

The target

The target for this model is HIV-positive mothers to facilitate decision-outcomes on safer infant feeding practices. The model links the HIV-positive mothers to their community and health care system, thus encompassing a multidimensional context directed towards a common goal of virtual elimination of mother-to-child transmission of HIV.

Objectives of the model

The overall aim of the model is to enhance infant feeding practices in the first six months of the HIV-exposed infant's life.

The objectives of the model are as follows:

1. Assess individual factors and contextual environment for HIV-positive mothers in order to identify opportunities and limitations for infant feeding.
2. Explore access to available services for PMTCT.
3. Apply the AFASS criteria regardless of the method of infant feeding promoted for mothers infected with HIV.
4. Monitor, support and provide follow-up and continuum of care for safer infant feeding for HIV-exposed infants.

Provisions of the model

The model provides an integrated approach to achieving a continuum for safer infant feeding practices among HIV-positive mothers and their exposed infants. It is a simple but unique model that provides an opportunity for policy makers and other stakeholders to adapt the WHO infant feeding guidelines to the local context to the benefit of exposed infants. Given the interplay proposed, the model guides the HIV-positive mothers along the continuum of infant feeding experience that translates into safer infant feeding practices.

Structure of the model

The model fits into the existing antenatal and postnatal care strategies for all mothers in the child bearing age. It is intended to be applied at all health care delivery levels but with emphasis on a multidimensional bottom-up approach that will preserve the principle of informed-decision. In implementing the model, the stakeholders will include the HIV-positive mothers, the health care workers and the community-based volunteers. The health care workers will report to the district health office which is part of the national health care system, the community-based volunteers will give feedback to the health facilities, and HIV-positive mothers will have a direct link to the community-based volunteers and the health care workers. The structure thus shows an interlinking continuum of infant feeding and is accountable to the decision-outcomes that are well informed by all stakeholders.

Propositions of the model

The strength of the model lies in its applicability within the existing MNCH services of the health care delivery system. Table 9-1 shows the proposed strategies which are directly linked to the results from this research. However, a multidimensional bottom-up approach will thus achieve the following objectives for HIV-positive mothers:

1. Facilitated disclosure of serostatus to allow HIV-positive mothers to achieve a more dynamic interaction with their environment where they live, work and where they practice infant feeding.
2. Quality counselling that will ensure that HIV-positive mothers are empowered and supported to make an informed-decision on infant feeding because knowledge is

experiential and contextual and grounded in a particular life context, in individuals, families, communities, culture and over time.

3. Quality counselling that will ensure that HIV-positive mothers plan and anticipate their decision-outcomes through adherence to treatment and safe infant feeding practices.
4. Quality counselling that will enhance identification of facilitators and limitations for infant feeding thus creating confidence in the mother's ability to implement preventive measures and overcome any anticipated barriers and take action to overcome them.
5. Applying the AFASS criteria that will facilitate accountability for feeding practices and decrease the likelihood of failure associated with poor infant feeding outcomes.
6. Implement a structured follow-up programme that is rooted in the community but with links to the health care system.

Expected outcomes of the model

The expected outcome will be enhanced infant feeding practices and achieve HIV-free survival among the exposed infants.

Purposes and uses of the model

The current WHO recommended infant feeding guidelines are the basis for implementation of the strategies for PMTCT (WHO et al., 2012). The complexity of the implementation of infant feeding guidelines in resource-poor settings requires modelling of strategies within applicable contexts because there is nothing atheoretical in clinical practice (Hugh et al., 2014). Hence, the purpose of the model is to enhance infant feeding practices among HIV-positive mothers within their own settings.

Essentials of the model

The period of implementation is designed to commence at antenatal booking through to the first six months of infant feeding. The conceptual framework provides specific activities designed for planning and re-planning as the situation dictates and according to varying individual demands and circumstances. When all the steps in the model are considered

individually and accounted for, the HIV-positive mothers will apply safer infant feeding practices.

Concepts of the model

Contextualisation of individual and environmental factors

In line with the WHO recommendations, the first step in the PMTCT programme in Zambia is for all pregnant women to know their HIV status, using an opt-out approach. As HIV testing is part of the routine laboratory processes undertaken during all pregnancies, the women do not have to sign a consent form but only need to be fully informed of the test. Disclosure of HIV serostatus is known to be one of the most significant determining factors for exclusive breastfeeding but its complexity can erode the intentions to disclose (Onono, Cohen, Jerop, Bukusi, & Turan, 2014). Proposed measures to facilitate disclosure that have been tested include HIV testing and counselling for couples and home-based couples-based HIV counselling and testing, an acceptable strategy that would support mutual HIV serostatus disclosure and provide an opportunity to increase uptake of antenatal HIV testing and increase men's involvement in PMTCT, all of which could collectively work to reduce vertical and horizontal HIV transmission (Engebretsen et al., 2010; Walcott, Hatcher, Kwena, & Turan, 2013). This model therefore provides an opportunity to test these measures for mothers infected with HIV and living in settings where men are a dominant feature in their lives, and could be a fundamental strategy for improving uptake of PMTCT services.

The environment in which infant feeding takes place is not static and includes a range of individual factors that are best understood through application of social and behavioural theories that take account of differing experiences (Fletcher, Ndebele, & Lelly, 2008; Matji et al., 2009). The participants in this research (and the target for this model) each created their own realities based on their complex experience with infant feeding within their environments that included, family, friends, community, their culture and the health care system, and each had unique experiences that provided either negative or positive vibes regarding infant feeding (Laar & Govender, 2011). The contextual environment exposed mothers to potential risks with stigma and violence, to available traditional health practitioners and to other community-based influences. These factors had potential to facilitate uptake or present as obstacles to accessing services in the PMTCT (Parker &

Aggleton, 2002). This model links the contextual environment to the health care system because access to treatment and care for HIV-positive mothers is influenced by these varying circumstances and they need to be taken on board in planning prevention, treatment and support for HIV-positive mothers.

Access to services for prevention, treatment, care and support during infant feeding

A comprehensive package of care and support is recommended for HIV-positive mothers and their exposed infants. Included in the package should be: good referral networks for mother and infant to access prophylactic treatment; antiretroviral therapy for the mother and the baby; prompt screening, treatment and management of opportunistic infections for the mother-infant pair; psychosocial support to mothers and their families and referrals to community-based groups such as people living with HIV (PLHIV); and continued education and counselling of mothers and their partners on vital aspects of PMTCT (MoH, 2010, 2014; WHO et al., 2012).

Available infant feeding options

In the 2010 infant feeding guidelines the WHO encouraged national authorities to decide which infant feeding practice to promote for HIV-positive mothers. The choice was essentially between breastfeeding with an antiretroviral intervention or avoidance of all forms of breastfeeding. Where ARVs are available, mothers known to be HIV-infected are encouraged to exclusively breastfeed for six months and beyond. The recommendation that replacement feeding should not be used unless it is acceptable, feasible, affordable, sustainable and safe (AFASS) should therefore be applied for mothers to make an informed-decision (WHO, UNAIDS, UNFPA, & UNICEF, 2010).

Affordability, feasibility, availability, sustainability and safety (AFASS) of infant feeding option

What was common among the participants in the current study, and supported by literature, was their desire to make the best choice for infant feeding for themselves and their babies, but what varied were their levels of support, the environments within which infant feeding took place, and their personal voices as they expressed their concerns, aspirations and approaches to facing their future living with HIV (Piwoz & Bentley, 2005). To address these

discrepancies the model emphasises the need to apply the AFASS criteria in assessing the mother's ability to carry out any method of infant-feeding proposed and chosen.

Responsibility for the AFASS assessent rests with the health care workers during counselling. An AFASS assessment tool has been developed (with validated content) that could be used for infant feeding counselling in sub-Saharan Africa (Adegbehingbe, Paul-Ebhohimhen & Marais, 2012). This model provides an opportunity to test the tool on mothers who either choose breastfeeding or formula feeding because in both contexts safer infant feeding practices need to be accounted for.

Informed decision-outcome on infant feeding

The aim of infant feeding counselling is to enable an informed decision on safer infant feeding, but a wide range of factors that impede access to prevention, treatment and support put infants born to women infected with HIV at risk of acquiring infection. In the final analysis, the linking of the different concepts in this model will ensure that HIV-positive mothers and the health care workers take account of safer infant feeding practices. All stakeholders in the PMTCT intervention programme should invest in safer infant feeding that translates into HIV-free survival for the exposed infants.

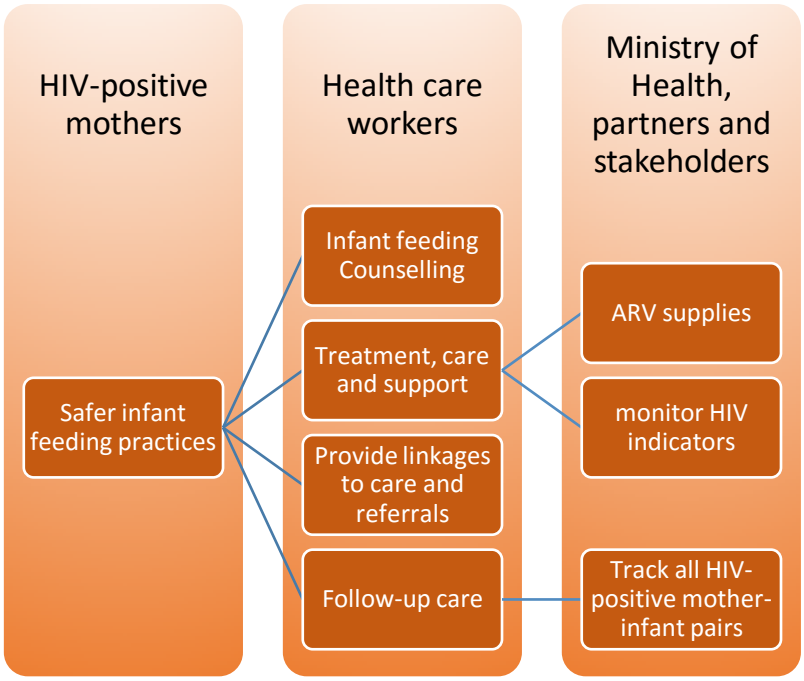


Figure 9-3 Accountability for HIV-free survival for exposed infants

Boundaries of the model

Application of the model falls within the existing health care delivery structures, with the central focus being the HIV-positive mothers who require support from all stakeholders.

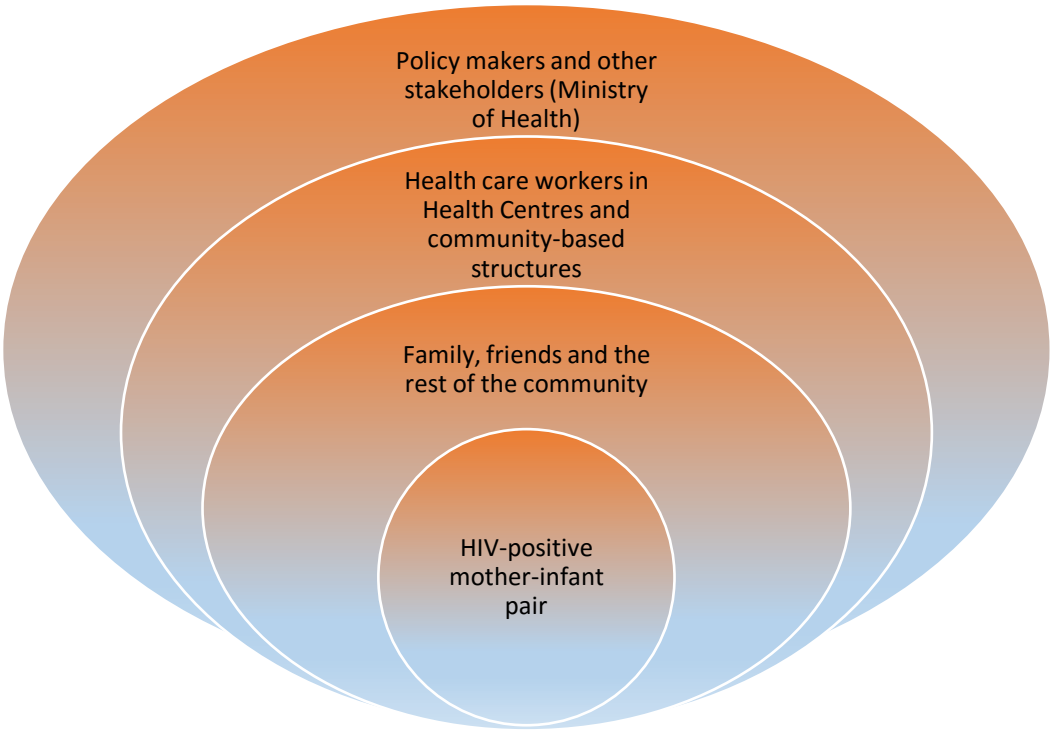


Figure 9-4 Boundaries of the model

General contributions of this research

The aim of the WHO infant feeding guidelines is to create and sustain an environment that encourages appropriate feeding practices for all infants while scaling-up interventions to reduce HIV transmission. There is now adequate knowledge of appropriate programme responses to support HIV-positive mothers and their exposed children in PMTCT (WHO et al., 2010). This research brought to light evidence that can inform the way infant-feeding guidelines are operationalised.

Unique contributions of this research

The current model provides opportunities for collaboration within and among the stakeholders in the PMTCT programme. At each step of the model, the HIV-positive mother is an active participant surrounded by her own contextual environment and the health care system to help her make an informed decision and account for safer feeding.

Conclusion

When all stakeholders, including HIV-positive mothers, invest in safer infant feeding, it will contribute to the global goal of eliminating mother-to-child transmission of HIV (WHO et al., 2012).

Reference list

Adegbehingbe, S., Paul-Ebhohimhen, V., & Marais, D. (2012). Development of an AFASS assessment and screening tool towards the prevention of mother-to-child HIV transmission (PMTCT) in sub-Saharan Africa - A Delphi survey. BMC Public Health. 12:402.

Bandura, A. (1990). Perceived self-efficacy in the exercise of control over AIDS infection. Evaluation and Program Planning. 13:9-17.

Bandura, A. (1991). Social Cognitive Theory of Self Regulation. Organization Behaviour and Human Decision Process. 50:248-287.

Bandura, A. (2001). Social Cognitive Theory: An Agentic Perspective. Annual Review of Psychology. 52:1-26.

Bekker, H., Lilleyman, J., Thornton, J., MacIntosh, M., Airey, C., Maule, A., . . . MB, R. (1999). Informed decision making: an annotated bibliography and systematic review. Health Technology Assessment. 3:1.

Betancour, T., Abrams, E., McBain, R., & Fawzi, M. (2010). Family-centred approaches to the prevention of mother to child transmission of HIV. Journal of International AIDS Society. 13:2.

Cames, C., Saher, A., Ayassou, K. A., Cournil, A., Meda, N., & Simondon, K. B. (2010). Acceptability and feasibility of infant-feeding options: experiences of HIV-infected mothers in the World Health Organization Kesho Bora mother-to-child transmission prevention (PMTCT) trial in Burkina Faso. Maternal and Child Nutrition. 6;3:253-265. doi: 10.1111/j.1740-8709.2009.00201.x.

Charmaz, K. (2008). Constructionism and the Grounded Theory Method. In: Holstein, J & Gubrium, J. (Editors). Handbook of Constructionist Research. New York: The Guiford Press. pp. 397-412.

Chinkonde, J. R., Hem, M. H., & Sundby, J. (2012). HIV and infant-feeding in Malawi: public health simplicity in complex social and cultural contexts. BMC Public Health. 12:700. doi: 10.1186/1471-2458-12-700.

Creswell, J.W. (2007). Qualitatice inquiry and research design; choosing among five approaches (2nd Edition). London: Sage Publications

Desclaux, A., & Alfieri, C. (2009). Counseling and choosing between infant-feeding options: overall limits and local interpretations by health care providers and women living with HIV in resource-poor countries (Burkina Faso, Cambodia, Cameroon). Social Science and Medicine. 69;6:821-829. doi: 10.1016/j.socscimed.2009.06.007.

Engebretsen, I. M., Moland, K. M., Nankunda, J., Karamagi, C. A., Tylleskar, T., & Tumwine, J. K. (2010). Gendered perceptions on infant-feeding in Eastern Uganda: continued need for exclusive breastfeeding support. International Breastfeeding Journal. 5:13. doi: 10.1186/1746-4358-5-13.

Fletcher, F., Ndebele, P., & Lelly, M. (2008). Infant-feeding and HIV in sub-Saharan Africa: What lies beneath the dilemma. Theor Med Bioeth. doi: DOI 10.1007/s11017-008-9083-z.

Frizelle, K., & Solomon, V. (2009). Strengthening PMTCT through communication: A review of literature (Vol. 2009, pp. 54). South Africa: UNICEF.

Glaser, B., & Strauss, A. (2006). The discovery of grounded theory: Strategies for qualitative research. London: Aldine Transaction.

Hugh, P., Majda, P., & Fiona, A. (2014). Fundamentals of Nursing Models, Theories and Practice, Second Edition. (2nd Edition): John Wiley & Sons Ltd.

Katepa-Bwalya, M., Kankasa, C., Babaniyi, O., & Siziya, S. (2011). Effect of using HIV and infant-feeding counselling cards on the quality of counselling provided to HIV positive mothers: a cluster randomized controlled trial. International Breastfeeding Journal. 6:13. doi: 10.1186/1746-4358-6-13.

Laar, S., & Govender, V. (2011). Factors influencing the choices of infant-feeding of HIV-positive mothers in Southern Ghana: The role of counsellors, mothers, families and socio-economic status. Journal of AIDS and HIV Research. 3;7:129-137.

Leshabari, S.C., Blystad, A., de Paoli, M., & Moland, M.K. (2007). HIV and infant-feeding counselling: challenges faced by nurse-counsellors in northern Tanzania. Human Resource for Health. 5:1-11. doi: 10.1186/1478-4491-5-18.

Madiba, S., & Langa, J. (2014). Cultural practices interfere with adherence to exclusive infant feeding: A qualitative study among HIV positive post natal women in Hammanskraal, South Africa. African Journal for Physical, Health Education, Recreation and Dance (AJPHERD). 1;1:264-278.

Manuela de Paoli, M., Manongi, R., & Klepp, K.-l. (2003). Are infant-feeding options that are recommended for mothers with HIV acceptable, feasible, affordable, sustainable and safe? Pregnant women's perspective. Public Health Nutrition. 7;5:611-619. doi: 10.1079/PHN2003596.

Matji, J., Wittenberg, D., Makin, J., Jeffery, B., Maclntyre, U., & Forsyth, B. (2009). Factors affecting HIV-infected mothers' ability to adhere to antenatally intended infant-feeding choice in Tshwane. South Africa Journal of Child Health. 3;1:20.

Matovu, A., Kirunda, B., Rugamba-Kabagambe, G., Tumwesigye, N., & Nuwaha, F. (2008). Factors influencing adherence to exclusive breastfeeding among HIV positive mothers in Kabarole District, Uganda. East African Medical Journal. 85;4:162-117-.

MoH. (2010). National Protocol Guidelines for Infant feeding; Integrated Prevention of Mother to Child Transmission of HIV/AIDS (pp. 1-60). Lusaka: Ministry of Health.

MoH. (2014). Zambia Consolidated Guidelines for Treatment and Prevention of HIV infection. Lusaka: Ministry of Health.

O'Connor, A., Stacey, D., Entwistle, V., Llewellyn-Thomas, H., Rovner, D., Holmes-Rovner, M., . . . J, J. (2003). Decision aids for people facing health treatment or screening decisions (Review). DOI: 10.1002/14651858.CD001431). Retrieved 26/02/2015, from Cochrane Database of Systematic Reviews 2003.

Odongkaraa, B., Kigulib, S., & Edison, M. (2013). Factors influencing replacement feeding practices among HIV -positive mothers attending the PMTCT program at Uganda. Journal of Pediatric Infectious Diseases. 8:7-17. doi: 10.3233/jpi-130376.

Onono, M. A., Cohen, C. R., Jerop, M., Bukusi, E. A., & Turan, J. M. (2014). HIV serostatus and disclosure: implications for infant-feeding practice in rural south Nyanza, Kenya. BMC Public Health. 14:390. doi: 10.1186/1471-2458-14-390.

Parker, R., & Aggleton, P. (2002). HIV/AIDS-related Stigma and Discrimination: Conceptual Framework and Agenda for Action: Population Council.

Piwoz, E., & Bentley, E. (2005). Women's voices, Women's choices: The Challenge of Nutrition and HIV/AIDS. The Journal of Nutrition. 135;4:933.

Rimer, B., & Glanz, K. (2005). Theory at a Glance; A Guide For Health Promotion Practice (2nd Edition): National Institute of Health.

Shongwe, C. (2014). The experiences of HIV-positive mothers breastfeeding exclusively in Swaziland. African Journal of Food, Agriculture, Nutrition and Development. 14:5.

Tuthill, E. L., Chan, J., & Butler, L. M. (2015). Challenges faced by health-care providers offering infant-feeding counseling to HIV-positive women in sub-Saharan Africa: a review of current research. AIDS Care. 27;1:17-24. doi: 10.1080/09540121.2014.951310.

Walcott, M., Hatcher, A., Kwena, Z., & Turan, J. (2013). Facilitating HIV status disclosure for pregnant women and partners in rural Kenya: a qualitative study. BMC Public Health. 13:1115. doi: doi:10.1186/1471-2458-13-1115.

WHO, UNAIDS, UNFPA, & UNICEF. (2010). HIV and Infant-feedingGuidelines, Principles and recommendations for infant-feeding in the context of HIV and a summary of evidence. Geneva: World Health Organization.

WHO, UNICEF, UNAIDS, & UNFPA. (2012). The 2010 WHO Guidelines on HIV and Infant Feeding: An updated framework for priority action. Geneva: World Health Organization

Chapter 10

Discussion, implications, conclusions and recommendations

Introduction

This thesis is a report of an ethnographic study on HIV and infant feeding, an analysis of choices and decision-outcomes in the context of prevention of mother-to-child transmission among HIV-positive mothers in Lusaka. The overall aim was to analyse choices and decision-outcomes on infant feeding in the context of prevention of mother-to-child transmission of HIV and enhance safer feeding practices during the first six months of the infants' life.

The ethnography

The qualitative approach in this study was an ethnography. Available definitions for ethnography include elements such as the study of social interactions, behaviours, and perceptions that occur within groups, teams, organisations, and communities (Creswell, 2007; Reeves, Kuper, & Hodges, 2008). My task was to document the 'culture', the perspectives and experiences of the HIV-positive mothers during the first six months of infant feeding. The aim was to immerse myself in the lives of my participants and how they viewed their infant feeding practice.

The unique contribution of ethnography in this research helped me to understand the context in which infant feeding takes place through the close observations I made of social practices, behaviours and interactions of HIV-positive mothers coupled with understanding their views regarding their behaviours and experiences. The participant observations and individual interview methods enabled me to interpret through rich descriptions the participants' construction of choices and decision-outcomes of infant feeding in the context of prevention of mother-to-child transmission of HIV and to build a theory/model/conceptual framework for follow-up informed by scientific evidence that was generated. In applying the ethnographic approach, it was fundamental to adhere to the following principles:

1. **Contextual**: This research was conducted within the environment where women lived, worked and accessed health care and particularly PMTCT interventions. When

I visited some participants with permission, it was especially important to see the opportunities and limitations that HIV-positive mothers have in their daily lives and as health care workers strive to make them adhere to safer infant feeding practices based on recommended guidelines. The conclusions that I made in this thesis are a reflection of my experiences interacting with HIV-positive mothers in their own environment.

2. **Unobtrusive**: There was no manipulation of the participants' choices for infant feeding methods, for counselling process, treatment and follow-up care. However, where appropriate, together with my research assistants we referred mothers and their babies for follow-up care when they were found with complications or challenges.
3. **Longitudinal:** I had a prolonged engagement during data collection running over a period of six months. This opportunity enabled me to gather as much information as possible that grounded the conclusions. It was also important to note that mothers were eager to learn more about infant feeding so that they could protect their their infants from HIV infection.
4. **Collaborative:** I engaged stakeholders at national, district, health facility and community level during the research project. For each of these stakeholders, the message I gathered was their sense of satisfaction with the success recorded in the fight against HIV and especially in prevention of mother-to-child transmission of HIV. I equally endeavoured to share with them the actual picture of the implementation of the interventions by mothers in their environments where they lived and worked. It is therefore my wish that they will take time to read the publications/manuscripts that make up this thesis in order strengthen the operationalisation of infant feeding counselling to the benefit of HIV-positive mothers and their exposed infants.
5. **Interpretive analysis:** My interpretation of the results was strengthened by empirical evidence and I recognised that PMTCT interventions are evolving at a rapid rate. For instance, this study was conceived at the time the Ministry of Health was implementing the 2010 national infant feeding guidelines. As the project was winding up the focus had shifted regarding treatment and infant feeding guidelines for the country and this has been reflected in the chapters.

The strength of the ethnographic approach was derived from the following procedures:

Theoretical triangulation

The theoretical framework that guided this study was based on social constructivism, Social Cognitive Theory, Feminist approach. Together these theories were used to interpret HIV and infant feeding in the context of prevention of mother-to-child transmission of HIV. Literally, the results of the study brought to life these theories because they were contextualised based on realities on the ground.

Methodological triangulation:

- **Participant observations:** This hallmark of ethnography was maintained through extended first-hand participant observation and interactions with participants in the study setting. These observations were extended to activities that mothers engaged in such as group health education and during growth monitoring and immunizations.
- **Individual interviews:** Individual interviews were conducted with mothers to address complex and sensitive topics and allowed them to talk about what it was like to be HIV-positive, getting pregnant, giving birth and having to feed their babies and protect them from HIV infection. They spoke freely, using their primary language and sometimes the interviews were full of emotions that, from human nature, transferred to me as the researcher.
- **Focus group discussions:** These were conducted with community-based volunteers and men accessing antiretroviral therapy to complement individual interviews with mothers and health care workers and to explore the diversity within a population on culture and breastfeeding.
- **Investigator triangulation:** This research resulted in 3 published papers and 2 manuscripts. The published papers were co-authored by experts in the fields of nursing and midwifery, gynaecology and obstetrics, and social science. In the initial phase of compiling the thesis, the manuscripts were subjected to reviews from the journals in which these publications/manuscripts were accepted or rejected. Every aspect of the papers were subjected to substantial review for their intellectual content and critique of methods and procedures. This input gave me an opportunity to apply a wider perspective on HIV and infant feeding.
- **Reflexivity:** This was a process of self-examination and self-disclosure about aspects of my own background, identity, subjectivity and assumptions that influenced data

collection and interpretation of the results. This was based on my background working as a nurse/midwife as well as teaching courses related to maternal and child health services for the institutions I have worked for.

- **Respondent validation:** Mothers were interviewed at 6 days, 6 weeks, 12 weeks and 18 weeks. At each stage, issues of focus in the previous interviews were reflected on and verified, depending on what the participant had experienced. The constructions on infant feeding were thus validated for each mother throughout the engagement. Health care workers were interviewed at the inception of the study to plan the focus of interview with mothers, community based volunteers and HIV-positive men.
- An **inductive analysis** enabled me to examine and identify categories and themes on key issues that emerged from the data and to generate tentative theoretical explanations from the findings. The patterns, categories and themes evolved as data collection proceeded and were not imposed a priori.

Key findings

The thematic areas that formed the basis for the thesis were:

1. HIV and infant feeding: Serostatus disclosure and associated risk factors among HIV-positive mothers in Lusaka, Zambia
2. Social-cultural determinants of breastfeeding; lessons learnt from experiences of HIV-positive mothers in Lusaka
3. HIV-positive mothers' perception of infant feeding counselling in the context of prevention of mother-to-child transmission of HIV in Lusaka, Zambia
4. Promotion of exclusive breastfeeding among HIV-positive mothers: an exploratory qualitative study
5. Exclusive breastfeeding: an exploratory qualitative analysis of experiences of HIV-positive mothers in Lusaka, Zambia
6. Community perception of HIV and infant feeding
7. Understanding the decision-outcome on infant feeding in the context of mother-to-child transmission of HIV: a conceptual framework

Local context of serostatus disclosure in the promotion of exclusive breastfeeding

Generally, HIV-positive mothers disclosed their serostatus to someone in the family or a friend. This was comparable with national indicators that showed that 97 per cent of women who were tested during antenatal clinic (ANC) and knew their test results disclosed at least to someone (CSO, MoH, & ICF, 2014) – resembling a trend in various settings of sub-Saharan Africa (Hardon et al., 2012; Madiba & Letsoalo, 2013; Visser, Neufeld, de Villiers, Makin, & Forsyth, 2008). However, Chapter 3 describes that in other settings, high rates of anticipated male-partner stigma and fear of negative male-partner reactions, including intimate partner violence during pregnancy and postpartum, is associated with lack of disclosure of serostatus (Mucheto et al., 2011; Onono, Cohen, Jerop, Bukusi, & Turan, 2014). The community volunteers and HIV-positive men (Chapter 9) added their perspective by highlighting the difficulties that mothers encounter when they test HIV-positive during ANC in the absence of their social support networks. Therefore, serostatus disclosure among mothers accessing PMTCT needs to be encouraged because it is associated with whether or not breastfeeding is exclusive.

Cultural determinants of breastfeeding; the empirical evidence versus the cultural norms of breastfeeding

We need to recognise that childbirth, and the time around birth, is a social and cultural event that is often governed by norms in populations driven by culture. But because the health care system is seen as regulating the way health issues are perceived and dealt with, a distance is created between the culture of health care services and that of the service users, which has been recognised as a major issue in service delivery (Coast, Jones, Portela, & Lattof, 2014). My finding that breastfeeding is a customary way of feeding newborn babies has been reported before in Zambia (Ng'andu & Watt, 1990). However, the recommended exclusive breastfeeding was alien to the culture-driven population studied in this research. Mixed feeding was widely practiced as a cultural norm and to compensate for the delay in initiation of breastfeeding for HIV-exposed infants. Use of herbs was reported for reasons that included medication to treat abdominal pains and protection of the baby from childhood illnesses. Chapter 4 describes how the practice of mixed feeding is not unique to the population studied as reported in South Africa (Thairu, Pelto, Rollins, Bland, & Ntshangase, 2005), Tanzania (Leshabari, Blystad, & Moland, 2007), Swaziland (Shongwe, 2014), Namibia (Shirunga,

2010), Malawi (Chinkonde, et al., 2012), and Nigeria (Lawani, et al., 2014). These results and evidence from similar settings reported highlight the fact that these practices will continue to plague PMTCT interventions and that this is a fight that is far from being won to ensure HIV-free survival for exposed infants (WHO, UNICEF, UNAIDS, & UNFPA, 2012). As recommended by other scholars there is need therefore to integrate culture in maternal and child health services in order to respond to the needs of the recipients of the services offered.

Promotion of exclusive breastfeeding; *a Public Health approach*

As I have mentioned in Chapter 6, this research was conceptualized within the context of promotion of EBF for HIV-exposed infants. During the time of data collection, the health facilties were implementing the option B^+. The emphasis on infant feeding guidelines in the current 2014 consolidated guidelines encourages all HIV-positive mothers to exclusively breastfeed for the first six months of infant feeding, with initiation of combination antiretroviral therapy [cART] in all pregnant and breastfeeding women regardless of CD4 count (option B^+). However, replacement feeding would only be considered if it fulfilled the AFASS criteria: acceptable, feasible, affordable, sustainable and safe (MoH, 2014). Although EBF is important for PMTCT, there appeared to be other factors that influenced decision to practice safer infant feeding for the HIV-exposed infants. Factors such as the perception that a breastfed baby is health, the cost of formula and protecting the baby from HIV infection influenced whether a mother was to practice EBF. Therefore, this research brought to the fore that this transitional period was not without challenges because mothers were subjected to different perspectives while the health care workers were clearly confused in the way they were counselling mothers on the best feeding method for their infants. This confusion had a trickle-down effect on the mothers practising EBF and the community at large (Chapter 9). The risk to practice mixed feeding was equally high because of late initiation of breastfeeding when breastfeeding rituals were expected to be practiced by a mothers who had just given birth (chapters 4 and 5). This led to pressure from family and friends to mix the feed, perception of breastmilk insufficiency and lack of knowledge on how to prevent and manage breast complications (Chapter 6). I also recognised that in situations where there was quality and effective counselling, client and health care worker shared decision-making interactions on infant feeding prevailed, a trend that has been reported in similar settings (Gourlay et al., 2014; Leshabari, Blystad, de Paoli, & Moland, 2007). Although clearly defined, methods of infant feeding counselling in PMTCT programmes have shown practical and theoretical

variations by sites (Desclaux & Alfieri, 2009). The consequences for this approach are discussed in detail in Chapter 5.

This situation therefore impacted on the principle of informed decision on infant feeding, as counselling was done without providing a choice, a fact that was communicated by both health care workers and HIV-positive mothers. I concluded that the health care workers were poorly prepared to undertake this process during the transition, resulting in subjective counselling as observed in similar settings such as Ethiopia (Adegbehingbe, Paul-Ebhohimhen, & Marais, 2012). What this research has brought out is that the top-down approach to promotion of exclusive breastfeeding applied by health care workers impacted negatively on exclusive breastfeeding practice. Mothers referred it to the "*the usual talk that goes on at the clinic"*. The consequences are discussed in the next section.

Infant feeding and HIV: Behaviour change in the context of PMTCT

Being infected with HIV and having to adapt to a prescribed infant feeding method requires behaviour change which cannot be accomplished in one counselling session as it is a learning process that requires ongoing support, guidance and evaluation, and this is what is indicated in the Ministry of Health infant feeding guidelines for Zambia (MoH, 2010). This research was guided by a theoretical framework (details are discussed in Chapter 1) and theories adapted were social constructivism, social cognitive theory (SCT) and the feminist approach. In my reflection on how HIV-positive mothers dealt with infant feeding, attention will be paid to the contributions these theories have had on the conclusions I have made.

The basic tenet of social constructivism is that knowledge is formed by people in their daily interaction with one another. Participants in this study each created their own realities or truths (knowledge) based on their experience with infant feeding. For instance, I wanted to know how mothers constructed exclusive breastfeeding in the context of PMTCT. While recognising challenges faced in the operationalisation of infant feeding guidelines in resource-poor settings (Ciaranello et al., 2014; Leshabari, Koniz-Booher, Astrom, de Paoli, & Moland, 2006; Moland et al., 2010; Nuwagaba-Biribonwoha, Mayon-White, Okong, & Carpenter, 2007; Sagoe-Moses, Mwinga, Habimana, Toure, & Ketsela, 2012), mothers in the context of this study felt that they were not given a choice on how best to feed their infants. In my observation, this was because the balance of power leaned strongly towards the health care workers, who adopted a traditional approach of teaching and instructing mothers whom

they perceived as learners rather than as participants in the process, and this phenomenon is common in similar settings of sub-Saharan Africa (Desclaux & Alfieri, 2009; Fadnes et al., 2010; Tuthill, Chan, & Butler, 2015). This had a subsequent bearing on the way mothers carried out the instructions (so to speak) that they received on infant feeding. What was missing in this context is what Albert Bandura refers to as cognitive learning. The tenets of social cognitive theory describe a dynamic, ongoing process in which personal factors, environmental factors, and human behaviour exert influence upon each other to achieve an outcome. There are three main factors that affect the likelihood that a person will change a health behaviour: (1) self-efficacy, (2) goals, and (3) outcome expectancies (details in Chapter 1). The assumption is that if an individual has a sense of personal urgency or self-efficacy, they can change behaviours even when faced with obstacles. For this research, HIV-positive mothers faced challenges to implement exclusive breastfeeding. If they did not feel that they could exercise control over their health behaviour, they were not motivated to act, or to persist through those challenges. This was seen in the way they expressed doubt about the safety of breastmilk, perceived breast milk insufficiency, perceived breast complications and and potential for abrupt weaning. Although support from partners, family and friends (HIV buddies) is associated with uptake of interventions across the cascade of PMTCT services (Andreson et al., 2013; Matji et al., 2009; Nyondo, Chimwaza, & Muula, 2014), mothers in this study expressed it in passing. Therefore, behaviour change is not just a product of the environment and the person, and the environment is not just a product of the person and behaviour (Rimer & Glanz, 2005) because the two facets complement each other.

My findings from this research had a pattern that subsequently led to an emerging model for follow-up of HIV-positive mothers in the first six moths of infant feeding to improve child health-outcomes in Zambia.

A conceptual framework; a proposed model for follow-up of HIV-positive mothers in the first six months infant feeding

The WHO recommended infant feeding guidelines are designed to be applied to the local context. As stated earlier in my writing, infant feeding takes place in communities where women live, work and feed their babies. Therefore, the context within which infant feeding is implemented is not "*one size fits all"* because of the variations brought about by individual circumstances within the dynamic environments and the health care system factors. This

research culminated in development of a theoretical model for follow-up that was informed by HIV-positive mothers' construction of infant feeding from disclosure of serostatus, cultural determinants of breastfeeding, infant feeding counselling to experiences with exclusive breastfeeding. I have described the conceptual framework in detail in Chapter 9. Thi theoretical model can be applied to a local context because it is adaptable, simple and significantly general because it allows for partial control.

The results that informed the design of the model were based on data collected within the Maternal, Neonatal and Child Health (MNCH) programme. The contacts that mothers have after delivery are 6 days, 6 weeks, 12 weeks and 18 weeks, were used as contact periods in order to avoid working outside the prescribed schedules in MNCH services. These contacts also were discussed on the basis that they are within the first six months of infant feeding. Hence the model does not require health care workers to re-align their schedules in order to attend to the needs of the HIV-positive-mother pair. The health care workers closest to the HIV-positive mothers are the nurses, the midwives, the nutritionists, the clinical officers and, to a larger extent, the medical doctors. The current training for each cadre incorporates HIV and PMTCT strategies. Hence there is no additional training required to use the model other than familiarization with the process and ensuring accountability for safer infant feeding practices at all levels where PMTCT interventions are provided and can be linked to the community. Although infant feeding guidelines evolve around emerging evidence, the model can still be applied within the changing context informed by the global texts and or guidelines.

Implication for health care practice, policy and research

Implications for health care practice

1. **Serostatus disclosure-**this aspect in PMTCT programme implementation should be encouraged and facilitated because it is associated with achieving EBF among HIV-positive mothers. The nurses, midwives, counsellors and all who are involved with HIV counselling and testing should have the skills to inform mothers and enable them understand and believe that sharing their serostatus results with significant others would make it easy for them to achieve EBF. To that effect, couple counselling should be encouraged at antenatal booking with mutual disclosure of serostatus. For mothers who may find it difficulty to disclose, they should be supported with

alternative options to do so. The emphasis is that serostatus disclosure should however be aimed at protecting EBF rather than as a social aspect to the mothers' lives.

2. **Sociocultural determinants of breastfeeding-** the different sociocultural norms practiced in different cultures are deep rooted and are passed on from one generation to the other. Documenting these practices from all the regions in Zambia will assist in understanding how they may impact EBF. Therefore, informing mothers that these practices are known and that they could be assited to appreciate how cultural norms impact breastfeeding in the context of MTCT is a step that would win mothers' confidence in sharing their fears and challenges faced as regards respecting the particular norms and practices.
3. **Promotion of exclusive breastfeeding-** this aspect in PMTCT programme should shift from being prescriptive, top-down approach even if it is policy for Zambia to that of empowering women to make independent informed-decisions in order to enhance EBF and reduce the risk of MTCT of HIV. Promotion of EBF therefore should be an intergral part of every level of health care delivery in Zambia.
4. **Infant feeding counselling:** Strengthening skills for more effective communication among all those involved in counselling to facilitate quality counselling that translates into informed-decision on safer infant feeding regardless of the method of feeding promoted is fundamental in enhancing safer feeding practices for HIV-exposed infants in Zambia. All health care workers should be encouraged to develop the culture of reading updates on infant feeding guidelines to strengthen their ability to handle all possible questions that would arise during their interaction with HIV-positive mothers in selected populations and where literacy levels are low.
5. **Socia support structures and services for HIV-positive mothers during the infant feeding experience:** there is need for more structured linkages for HIV-positive mothers with women empowerment programmes (such as programmes to counter gender based violence) with the health care system as a way to facilitate behaviour change among women and assist them to defend what they see and learn as positive drives towards positive health outcomes for themselves and their exposed infants. In addition, provision of a conducive environment such as improved infrasture for health care workers in the health facilities to support PMTCT programme implementation is fundamental to enhance safer infant feeding practice.

Implications for research

Some research questions have emerged from this study which would benefit significantly from further investigation in similar settings:

1. Follow-up research to explore further the relationship between nondisclosure of serostatus and the difficulties in deciding on safer infant feeding practices.
2. Develop a screening mechanism to identify women at risk of lack of disclosure with possible alternative options to support them to do so.
3. A national survey on prevalence of exclusive breastfeeding among HIV-positive mothers is required to determine the applicability of the strategy to promotion of exclusive breastfeeding for Zambia.
4. Integration of community-based approaches in the implementation of infant feeding guidelines. The success of this approach also lies in the strategies that would facilitate integration of spouses, family (in-laws, mothers, grandmothers) in care to ensure accountability of behavioural practices of breastfeeding.
5. Test, validate and implement the model for follow-up of HIV-positive mothers in the first six months of infant feeding among the populations studied in preparation for roll-out to the rest of the sites. This will provide a continuum of infant feeding experience in populations affected by HIV and where childbearing is not only a biological function but also a social responsibility.

Implications for policy

1. When a pregnant woman is found with HIV infection it should be understood by health care workers that for mothers this requires behaviour change in order to take on additional roles and responsibilities. Knowledge of health risks and benefits are the preconditions for such change to take place and, according to Bandura, knowledge in itself is not sufficient to overcome the impediments to adapting and maintaining new behaviour/practices (Bandura, 1977). It requires mothers to believe that they have the power to change the outcome of their infant feeding practices and be motivated to defend what they see as the best choices for their HIV-exposed infants, no matter the challenges that may come their way during the infant feeding experience. This aspect to the operationalisation of infant feeding guidelines was missing for HIV-positive mothers in the PMTCT programme sites studied.

2. During operationalisation of infant feeding guidelines, there is need to ensure that all programmatic arrangements are attended to, such as training and health education materials, to ensure quality counselling that translates into behaviour change for HIV-positive mothers. Individual considerations should also be taken into account.
3. The health care workers need to adopt strategies that support participatory approaches to planning, implementation and evaluation of PMTCT programmes that embrace communities at all levels and these should be supported at national level.
4. Zambia is a multicultural nation with minimal variations across the major regions, therefore future research across the country on cultural determinants of breastfeeding would identify the common norms and practices that could be documented and addressed adequately during infant feeding counselling. Culturally appropriate counselling tools that address the known cultural practices of the populations affected would supplement the much needed behaviour change strategies linked to the process of learning new ways of feeding in relation to PMTCT.

Study limitations

Methodological limitations

- This study was based on a sample that was recruited from two sites and hence the results can not be generalized to a larger cohort.
- Bias could have been introduced through participant observation because I was particularly interested in identifying the missing elements in health promotion messages to enhance feeding practices for HIV-exposed infants as opposed to how the counsellors were trained and the environment within which the activities were taking place. The gaps identified could therefore have been due to other factors such as poor communication skills, lack of training and infrastructure.
- Recruitment procedures were adjusted because of challenges in screening mothers. After screening and diagnosis by clinical offcers, mothers did not pass through the nurses' desk. In such instances, there was a lost opportunity to talk to potential participants for recruitment.

Researcher bias

This research was conceived in relation to my training in maternal and child health care service provision and research. My reflections on the results are therefore biased towards this background. In some instances my maternal instinct to protect children leaned towards sympathising with HIV-positive mothers because I felt that they were vulnerable. My presence in the health facility may have caused a Hawthorne effect. The Hawthorne effect is a psychological phenomenon that produces an improvement in human behavior or performance as a result of increased attention from superiors, clients or colleagues (Flick, von Kardorff, & Steinke, 2004; Krueger, 1994). The health care workers may have tried to do things better at the time I was observing them during health education talks and their interactions with HIV-positive women.

Language barrier

Almost all the interviews were conducted in the primary language used by respondents and they were able to express their emotions freely. Therefore, translating their views, emotions and expressions in English had potential to lose the emotional impact of their experiences with HIV and infant feeding, although efforts were made to maintain the original meaning of through verbatim transcriptions.

Loss to follow-up for participants

This exposes the difficulties that would potentiality impede applicability of the theoretical model in hard-to-reach areas. In some situations, I was, however, able to keep track of some participants via mobile phone communication.

Follow-up theoretical model

To what extent the theoretical model can yield better outcomes to enhance infant feeding practices is not covered in this thesis. I did not test the model to provide evidence for its applicability, but this does reduce its potential for enhancing safer infant feeding practices in the prevention of mother-to-child transmission of HIV for the affected populations because it is grounded in the data.

Conclusions

Enrolling in a PMTCT programme for HIV-positive mothers should be the first step in protecting their children from possible transmission of HIV through breastfeeding. Given that HIV-positive mothers were able to understance the risks of MTCT, entails that educing the rate of MTCT of HIV can be achieved in this and similar settings.

Reference list

Adegbehingbe, S., Paul-Ebhohimhen, V., & Marais, D. (2012). Development of an AFASS assessment and screening tool towards the prevention of mother-to-child HIV transmission (PMTCT) in sub-Saharan Africa - A Delphi survey. BMC Public Health. 12:402.

Andreson, J., Dana, N., Hepfer, B., King'ori, E., Oketch, J., Wojnar, D., . . . Israel-Ballard, K. (2013). Infant-feeding buddies: a strategy to support safe infant-feeding for HIV-positive mothers. Journal of Human Lactation. 29:1;90-93. doi: 10.1177/0890334412469056

Bandura, A. (1977). Self-efficacy: Toward a Unifying Theory of Behavioral Change. Psychological Review. 84:2;191-215.

Baxter, P., & Jack, S. (2008). Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers. The qualitative Report. 13:4;544-559.

Bitsch, V. (2005). Qualitative Research: A Grounded Theory Example and Evaluation Criteria. Journal of Agribusiness. 23:1;75-91.

Busza, J., Walker, D., Hairston, A., Gable, A., Pitter, C., Lee, S., . . . Mpofu, D. (2012). Community-based approaches for prevention of mother to child transmission in resource-poor settings: a social ecological review. Journal of International AIDS Society. 15:Supplement 2;17373. doi: 10.7448/IAS.15.4.17373.

Charmaz, K. (2008). Constructionism and the Grounded Theory Method. In: J. Holstein & J. Gubrium (Editors.), Handbook of Constructionist Research (pp. 397-412). New York The Guiford Press.

Chinkonde, J., Hem, M., & Sundby, J. (2012). HIV and infant-feeding in Malawi: public health simplicity in complex social and cultural contexts. BMC Public Health. 12:700. doi: 10.1186/1471-2458-12-700.

Ciaranello, A. L., Leroy, V., Rusibamayila, A., Freedberg, K. A., Shapiro, R., Engelsmann, B., . . . Walensky, R. P. (2014). Individualizing the WHO HIV and infant-feeding

guidelines: optimal breastfeeding duration to maximize infant HIV-free survival. Aids. 28:Supplement 3;S287-299. doi: 10.1097/QAD.0000000000000337.

Coast, E., Jones, E., Portela, A., & Lattof, S. R. (2014). Maternity care services and culture: a systematic global mapping of interventions. PLoS ONE. 9:9;e108130. doi: 10.1371/journal.pone.0108130.

Creswell, J.W. (2007). Qualitatice inquiry and research design; choosing among five approaches (2nd Edition). London: Sage Publications

CSO, MoH, & ICF. (2014). Zambia Demographic and Health Survey 2013-14. Rockville, Maryland, USA: Central Statistical Office.

Desclaux, A., & Alfieri, C. (2009). Counseling and choosing between infant-feeding options: overall limits and local interpretations by health care providers and women living with HIV in resource-poor countries (Burkina Faso, Cambodia, Cameroon). Social Science and Medicine. 69:6;821-829. doi: 10.1016/j.socscimed.2009.06.007.

Fadnes, L., Engebretsen, I., Moland, K., Nankunda, J., Tumwine, J., & Tylleskar, T. (2010). Infant-feeding counselling in Uganda in a changing environment with focus on the general population and HIV-positive mothers - a mixed method approach. BMC Health Services Research. 10:260. doi: 10.1186/1472-6963-10-260.

Flick, U., von Kardorff, E., & Steinke, I. (Eds.). (2004). A Companion to qualitative research. London, Thousand Oaks, New Delhi: Sage Publications

Frizelle, K., & Solomon, V. (2009). Strengthening PMTCT through communication: A review of literature. UNICEF: South Africa.

Gourlay, A., Wringe, A., Birdthistle, S., Mshana, G., Michael, D., & Urassa, M. (2014). ‘‘It Is Like That, We Didn’t Understand Each Other’’: Exploring the Influence of Patient-Provider Interactions on Prevention of Mother-To-Child Transmission of HIV Service Use in Rural Tanzania. PLoS ONE. 9:9. doi: 10.1371/journal.pone.0106325.g001

Hardon, A., Vernooij, E., Bongololo-Mbera, G., Cherutich, P., Desclaux, A., Kyaddondo, D., . . . Obermeyer, C. (2012). Women's views on consent, counseling and confidentiality in PMTCT: a mixed-methods study in four African countries. BMC Public Health. 12:26. doi: 10.1186/1471-2458-12-26.

Katepa-Bwalya, M., Kankasa, C., Babaniyi, O., & Siziya, S. (2011). Effect of using HIV and infant-feeding counselling cards on the quality of counselling provided to HIV positive mothers: a cluster randomized controlled trial. International Breastfeeding Journal. 6:13. doi: 10.1186/1746-4358-6-13.

Krueger, R. A. (1994). Focus groups. A practical guide for applied research. 2nd edition. London: Sage Publications.

Lawani, L. O., Onyebuchi, A. K., Iyoke, C. A., Conoh, R., & Nkwo, P. O. (2014). The challenges of adherence to infant-feeding choices in prevention of mother-to-child transmission of HIV infections in South East Nigeria. Patient Preference & Adherence. 8:377-381. doi: 10.2147/PPA.S61796.

Leshabari, S.C., Blystad, A., de Paoli, M., & Moland, M.K. (2007). HIV and infant-feeding counselling: challenges faced by nurse-counsellors in northern Tanzania. Human Resource for Health. 5:1-11. doi: 10.1186/1478-4491-5-18.

Leshabari, S., Blystad, A., & Moland, K. (2007). Difficult choices: Infant-feeding experiences of HIV positive mothers in northern Tanzania. Journal of Social Aspects of HIV/AIDS. 4:1.

Leshabari, S., Koniz-Booher, P., Astrom, A., de Paoli, M., & Moland, K. (2006). Translating global recommendations on HIV and infant-feeding to the local context: the development of culturally sensitive counselling tools in the Kilimanjaro Region, Tanzania. Implementation Science. 1:22. doi: 10.1186/1748-5908-1-22.

Leshabari, S., Koniz-Booher, P., Burkhalter, B., Hoffman, M., & Jennings, L. (2007). Testing a PMTCT Infant-feeding Counseling Program in Tanzania. Agency for International Development (USAID) by QAP.

Madiba, S., & Letsoalo, R. (2013). HIV disclosure to partners and family among women enrolled in prevention of mother to child transmission of HIV program: Implications for infant-feeding in poor resourced communities in South Africa. Global Journal of Health Science. 5;4:1-13. doi: 10.5539/gjhs.v5n4p1.

Matji, J., Wittenberg, D., Makin, J., Jeffery, B., Maclntyre, U., & Forsyth, B. (2009). Factors affecting HIV-infected mothers' ability to adhere to antenatally intended infant-feeding choice in Tshwane. South Africa Journal of Child Health. 3:1-20.

MoH. (2010). National Protocol Guidelines for Infant feeding; Integrated Prevention of Mother to Child Transmission of HIV/AIDS. Lusaka: Ministry of Health.

MoH. (2014). Zambia Consolidated Guidelines for Treatment and Prevention of HIV infection. Lusaka: Ministry of Health.

Moland, K.M.I., de Paoli, M., Sellen, D., van Esterik, P., Leshabari, S.C., & Blystad, A. (2010). Breastfeeding and HIV: experiences from a decade of prevention of postnatal

HIV transmission in sub-Saharan Africa. International Breastfeeding Journal. 5:10-16. doi: 10.1186/1746-4358-5-10.

Mucheto, P., Chadambuka, A., Shambira, G., Tshimanga, M., Notion, G., & Nyamayaro, W. (2011). Determinants of nondisclosure of HIV status among women attending the prevention of mother to child transmission programme, Makonde district, Zimbabwe. PanAfrican Medical Journal. 8:51.

Ng'andu, N., & Watt, T. (1990). Child growth and duration of breast feeding in urban Zambia. Journal of Epidemiology and Community Health. 44:281-285.

Nuwagaba-Biribonwoha, H., Mayon-White, R. T., Okong, P., & Carpenter, L. M. (2007). Challenges faced by health workers in implementing the prevention of mother-to-child HIV transmission (PMTCT) programme in Uganda. Journal of Public Health. 29;3:269-274. doi: 10.1093/pubmed/fdm025.

Nyondo, A., Chimwaza, A., & Muula, A. (2014). Exploring the-relevance of male involvement in the prevention of mother to child transmission of HIV services in Blantyre Malawi. BMC International Health and Human Rights. 14:30.

Onono, M., Cohen, C., Jerop, M., Bukusi, E., & Turan, J. (2014). HIV serostatus and disclosure: implications for infant-feeding practice in rural south Nyanza, Kenya. BMC Public Health. 14:390. doi: 10.1186/1471-2458-14-390.

Reeves, S., Kuper, A., & Hodges, B. D. (2008). Qualitative research methodologies: ethnography. BMJ. 337:a1020. doi: 10.1136/bmj.a1020.

Rimer, B., & Glanz, K. (2005). Theory at a Glance; A Guide For Health Promotion Practice (Second Edition): National Institute of Health (NIH).

Sagoe-Moses, C., Mwinga, K., Habimana, P., Toure, I., & Ketsela, T. (2012). Implementation of the new who recommendations on HIV and infant feeding: challenges and the way forward African Journal of Food, Agriculture, Nutrition and Development. 12:4.

Shamu, S., Zarowsky, C., Shefer, T., Temmerman, M., & Abrahams, N. (2014). Intimate Partner Violence after Disclosure of HIV Test Results among Pregnant Women in Harare, Zimbabwe. PLoS ONE. 9:10. e109447. doi: 10.1371/journal.pone.0109447.

Shirunga, M. (2010). Cultural and Social Factors Impacting on the Programme to Prevent-Mother-To-Child-Transmission (PMTCT) of HIV in Namibia: A Case Study of the Kavango Region. Master of Medical Anthropology Research University of Western Cape.

Shiyoyen, N. M. (2013). Non-disclosure of HIV serostatus to partners among HIV-positive pregnant women enrolled on the prevention of mother to child transmission (PMTCT) program at Katutura Antenatal Clinic, Windhoek, Namibia. PhD Stellenbosch University, South Africa.

Shongwe, C. (2014). The experiences of HIV positive mothers breastfeeding exclusively in Swaziland. African Journal of Food, Agriculture, Nutrition and Development. 14:5.

Thairu, L., Pelto, G., Rollins, N., Bland, R., & Ntshangase, N. (2005). Socio cultural influences on infant-feeding decisions among HIV infected women in rural KwaZulu Natal, South Africa. Maternal and Child Nutrition. 1:2-10.

Tuthill, E. L., Chan, J., & Butler, L. M. (2015). Challenges faced by health-care providers offering infant-feeding counseling to HIV-positive women in sub-Saharan Africa: a review of current research. AIDS Care. 27;1:17-24. doi: 10.1080/09540121.2014.951310.

Visser, M. J., Neufeld, S., de Villiers, A., Makin, J. D., & Forsyth, B. W. (2008). To tell or not to tell: South African women's disclosure of HIV status during pregnancy. AIDS Care. 20;9:1138-1145. doi: 10.1080/09540120701842779.

WHO, UNICEF, UNAIDS, & UNFPA. (2012). 2010 WHO Guidelines on HIV and Infant-feeding: An updated framework for priority action (pp. 12). Geneva: World Health Organization .

Appendix 1

Interview guide for HIV-Positive mothers

Selection Criteria: HIV-positive, accessed results, on treatment regime, chosen method of infant feeding and giving written/signed consent

Interviewer : _____

Date : _____

Location : _____

Safe motherhood No : _____

GUIDE TO MODERATOR

- Copies of informed *consent* forms should be provided to the respondent and read aloud for the benefit of those who cannot read.
- The respondent should be provided an opportunity to ask any questions.
- Verbal agreement should be audio recorded.
- Try to ask all the questions below in the order given, but it is more important to maintain the flow of discussion.
- Suggested probes have been included.

Before we start I would like to remind you that there is no right or wrong answers in this discussion. I am interested in knowing what you think, please feel free to share your views, regardless of whether you agree or disagree with what you know.

Interviewer should introduce herself/himself and explain the purpose for the interview.

INTRODUCTION

1. What was your age last birthday?
2. What is your marital status? (*Probe: Single, Married, Divorced, Widowed)*
3. Which religion do you belong to? *(Probe: Christian, Moslem and any other)*
4. What do you do for your living?
5. What does your spouse/partner do for his living?
6. How far did you go with education? *(Probe primary, Secondary, Tertiary)*

HISTRORY OF CURRENT PREGNANCY

7. How many pregnancies have you had before? If more than one.
    - *Probe*: *Number of children alive*

- *Probe: If any died, probe for reasons for the death*
- *Probe: For the ones that died, how did you feed them*
- *Probe: How did the reason for the death affect the decision for this baby*

8. For this pregnancy, when did you book for ANC? *(Probe: during 1st trimester, 2nd trimester or 3rd trimester or specify the month)*
9. When did you take the first test for HIV? (*Probe before pregnancy or during ANC visits).*
10. Why did you take the HIV test? *(Probe if coerced, routine program, a need to know for her own good and that of the unborn baby)*
11. What do you think about HIV testing when you are pregnant?
    - *Probe: It should be done before pregnancy;*
    - *Probe: It is fine at ANC;*
    - *Probe: when else it should be done).*
12. What do you think about making a decision on infant-feeding after testing HIV positive when you are pregnant?
13. Tell me who you shared the HIV test results with.

    Probe: Spouse/partner and other relatives.

    Probe: Reasons for the decision to share the results.

SECTION A: SOCIAL-CULTURAL DETERMINANTS OF INFANT FEEDING *(BREAST FEEDING)*

14. Tell me what you know about HIV transmission from the mother to the child.
    - *Probe: during pregnancy;*
    - *Probe :at delivery*
    - *Probe: during breastfeeding;*
15. Please tell me any social-cultural beliefs and practices that you know about breast feeding.
16. How does HIV transmission through breastfeeding affect your social-cultural beliefs and practices?
17. In your culture, why is breastfeeding important? *Probe:*
18. What do people in the community and your relatives say about HIV transmission through breastfeeding?

19. Tell me your views about what the people in the community and your relatives expect you to do in respecting the cultural beliefs and practices on breastfeeding and other methods of infant feeding.
20. During the infant-feeding period, who is always present and what role do they play in the feeding process.
    - *Probe: observance of the cultural beliefs and practices,*
    - *Probe: administering traditional herbs etc*.

SECTION B: EXISTING INFORMATION ON INFANT-FEEDING COUNSELLING

21. During your pregnancy, tell me what information you were given on infant feeding.
    - *Probe: Type of information on infant feeding*
    - *Probe: Source of information*
    - *Probe: Type of information related to options on infant feeding (Exclusive breast feeding, exclusive formula feeding etc.*
    - *Probe: Did the information assist you in making a decision on infant feeding.*
22. Did the health care worker show you any educational materials about feeding your baby? (*Probe: If yes, please describe the materials that they showed you)*
23. Did the health care worker give you any educational materials to take home? *Probe.*
    - *If yes, can you show me what she gave you;*
    - *If yes, can you describe those educational materials to me?*
    - *If no, can you remember seeing any other educational materials at the clinic about feeding or taking care of babies?*
24. Please tell me how you used the educational materials to choose the method of feeding your baby.
    - *Probe: If the material guided her to choose a method of feeding.*
    - *Probe: Other factors that helped to make a decision on method of feeding*

SECTION C: DECISION-MAKING FOR METHOD OF INFANT FEEDING

25. How have you decided to feed your baby?
    - *Probe: The chosen method of infant feeding, exclusive breast feeding or exclusive formula feeding).*

26. How did you come to this decision?
    - *Probe: who was consulted eg spouse/partner, mother and significant others.*

27. What do you think this choice will mean:
    - *For you?*
    - *Your baby?*
    - *Your family?*

28. Tell me any other factors that influenced your choice of the method of infant feeding.
    - *Probe: Availability of money;*
    - *Probe: Protecting the child from HIV infection;*
    - *Probe: Pressures from relatives and the community;*
    - *Probe: Pressure from the health workers;*
    - *Probe: To avoid stigma.*

29. Please explain how you will be able to sustain the chosen infant-feeding method.
    - *Probe for barriers and opportunities(Motivation)*

SECTION C: PLAN FOR FOLLOW UP

30. What services have you been told to use during the first six months of infant feeding?
    - *Probe: Hospital/health facility;*
    - *Probe: PMTCT services-specify;*
    - *Probe: Community services etc.*
    - *Probe: What do you think about the community PMTCT services*

31. Explain where you will find the services for follow up. (*Probe distance/access, available support systems and structures at community level).*

CONCLUSION

Tell me any other information you would like to share about infant-feeding and prevention of infection from the mother to the child.

*****************Thank you for taking the time to talk to us!!*****************

Appendix 2

Interview guide for HIV-Positive mothers (follow-up)

Selection Criteria: HIV-positive mothers practicing their chosen infant feeding method within the first six months of infant feeding. This guide will be used for at 6 weeks and 12 weeks follow up interviews.

Interviewer : _____

Date : _____

Location : _____

Safe motherhood No : _____

GUIDE TO MODERATOR

- Copies of informed *consent* forms should be provided to the respondent and read aloud for the benefit of those who cannot read.
- The respondent should be provided an opportunity to ask any questions.
- Verbal agreement should be audio recorded.
- Try to ask all the questions below in the order given, but it is more important to maintain the flow of discussion.
- Suggested probes have been included.

Before we start I would like to remind you that there is no right or wrong answers in this discussion. I am interested in knowing what you think, please feel free to share your views, regardless of whether you agree or disagree with what you know.

Interviewer should introduce herself/himself and explain the purpose for the interview.

INTRODUCTION

1. How old is your baby?
2. How are you doing?
3. How is the baby doing?

SECTION A: SOCIAL-CULTURAL DETERMINANTS OF BREASTFEEDING

4. Please explain to me the social-cultural beliefs and practices that you are observing during infant-feeding (*Breastfeeding*).
    - *Probe:* The breast milk is not enough for the baby
    - *Probe:* Bathing the baby in herbal medicine for protection

- *Probe:* Herbal medicine for the baby to wear to prevent diarrhoea or "*Chibele"*
- *Probe:* Herbal medicine to wash the breast if the last baby died
- *Probe: "Kupeleka mwana ku mpasa"*
- *Probe: Any one not mentioned above but that you are following*

5. I would like to know how the culture of *Kupeleka mwana kumpasa* is practiced when the couple knows that they are HIV-positive.
6. What do people in the community and your relatives expect you to do in respecting the cultural beliefs and practices on infant-feeding *(Breast feeding)*.
7. During your infant feeding *(Breast feeding)* period, who has been present?
    - *Probe: What role they have played in the feeding process;*
    - *Probe: To make sure you observe the cultural norms and practices;*
    - *Probe: For Social support*.
    - *Probe*: *If there has been no one, ask the mother why so*

SECTION B: EXPERIENCES DURING INFANT FEEDING

8. How are you now feeding the baby?
    - *Probe: Breast feeding;*
    - *Probe: Formula feeding;*
9. Why are you feeding your baby in this manner?
    - *Probe: Anxiety and fear of failure;*
    - *Probe: To protect the baby from HIV infection;*
    - *Probe: Barriers to the method of choice eg*
        - ✓ *Cost;*
        - ✓ *lack of support;*
        - ✓ *Adherence to social-cultural norms;*
        - ✓ *Fear or pressure from the health care worker;*
        - ✓ *Being suspicious of the program.*
10. What do you think about your decision on feeding the baby in this manner?
    - *Probe: Beliefs;*
    - *Probe: Values;*
    - *Probe: Advice from the health care workers.*
11. What opportunities have you derived from the way you are feeding the baby?

- *Probe: Intention to adhere to feeding practice;*
- *Probe: Motivation to prevent transmission of HIV to the baby;*
- *Pressure: Internal/external pressures to succeed;*
- *Probe: Good social circumstances;*
- *Probe: Good support systems (family, community, health services delivery).*

12. Please tell me if you are staying away from the baby for extended hours.
    - *Probe*: Return to work for mothers in formal employment
    - *Probe*: Engaged in activities away from home for longer time of the day
13. Please tell me if you have changed the method of feeding the baby from the last time we talked.
14. If feeding practice has changed, probe for reasons.
    - *Probe: Establish if the mother under-estimated challenges associated with the first method of choice eg*
        - ✓ *Conformity to Social-cultural demands;*
        - ✓ *Dictation by the Health Care Workers;*
        - ✓ *Pressure from the partners supporting the PMTCT program;*
        - ✓ *Lack of support from the family (social support system).*
15. If the feeding practice has not changed, probe for reasons.
    - *Probe: If the mother anticipated the outcome of her decision this far; eg*
        - ✓ *Conformity to social-cultural demands;*
        - ✓ *Conformity to the advice from the health care workers*
        - ✓ *Support from the family (Social support).*

SECTION C: FOLLOW UP CARE DURING THE FIRST SIX MONTHS OF INFANT FEEDING PERIOD

16. What services have you been using during your infant feeding period?
    - *Probe: Community based support systems eg lay counsellors;*
    - *Probe: Health centre/Hospital care of the baby for treatment and investigations).*
17. How do you get to these services from where you live?
    - *Probe: Using public transport;*

- *Probe: Using outreach programs;*
- *Probe: Using available community support systems and structures.*

18. How are you feeding yourself?
    - *Probe:* Number of meals in a day
    - *Probe:* The type of foods for breakfast, lunch and supper
    - *Probe:* Any foods taken in between meals
19. Please explain to me what you think about your experience on infant feeding (Breast feeding) and having to deal with your HIV status.
    - *Probe: If too demanding to care about herself;*
    - *Probe: Too demanding to care about the welfare of the baby;*
    - *Probe: What is your priority given your situation;*
    - *Probe: What would like to achieve first.*

CONCLUSION

Tell me any other information you would like to share about infant-feedingand prevention of HIV infection from the mother to the child.

***********Thank you for taking the time to talk to us!!**********

Appendix 3

Interview guide for HIV-Positive mothers (exit from research)

Selection Criteria: HIV-positive mothers practicing their chosen infant feeding method and ready for discharge from the PMTCT program. This guide will be used at the exit from the study at 18 weeks.

Interviewer : _____

Date : _____

Location : _____

Safe motherhood No : _____

GUIDE TO MODERATOR

- Copies of informed *consent* forms should be provided to the respondent and read aloud for the benefit of those who cannot read.
- The respondent should be provided an opportunity to ask any questions.
- Verbal agreement should be audio recorded.
- Try to ask all the questions below in the order given, but it is more important to maintain the flow of discussion.
- Suggested probes have been included.

Before we start I would like to remind you that there is no right or wrong answers in this discussion. I am interested in knowing what you think, please feel free to share your views, regardless of whether you agree or disagree with what you know.

Interviewer should introduce herself/himself and explain the purpose for the interview.

INTRODUCTION

1. How old is the baby?
2. How is the baby doing?
3. Has the baby been introduced to other foods in addition to your choice of feeding?
    - *Probe why and what type of other foods, how often?*
    - *Source of information on type of other foods).*
4. *What activities are you participating in for now? (Probe)*
    - *If mother has reported back for work or is engaged in some income generating activities that will keep her away from the baby)*

5. In your absence, who helps to care for the baby? *(Probe)*
    - *Grandmother;*
    - *Baby minder;*
    - *Day care centre or;*
    - *Takes baby along etc).*
6. In your absence how do you ensure that the baby is fed according to the way you decided to feed your baby? *(Probe: If she prepares the feed or expressed breast milk and what she actually does).*

SECTION A: DECISION OUTCOME ON THE CHOICE OF INFANT FEEDING

7. What was your choice of infant feeding method at ANC and or delivery?
8. If infant feeding method has not changed, what benefits have you derived from the way you were feeding the baby? *(Probe)*
    - *If there is a feeling of achievement;*
    - *If there is a feeling of failure;*
    - *If she faced challenges;*
    - *If the outcome was predictable;*
    - *If the outcome was unpredictable;*
    - *If she is disappointment;*
    - *If she is feeling cheated by health care system; and*
    - *If she is feeling cheated by the social support system, blame shifting to family, relatives, community etc).*
9. If infant feeding method has changed, what opportunities have you derived from the way you were feeding the baby? *(Probe)*
    - *If there is a feeling of achievement;*
    - *If there is a feeling of failure;*
    - *If she faced challenges;*
    - *If the outcome was predictable;*
    - *If the outcome was unpredictable;*
    - *If she is disappointment;*
    - *If she is feeling cheated by health care system; and*
    - *If she is feeling cheated by the social support system, blame shifting to family, relatives, community etc).*

10. How did you manage to feed the baby according to your method of choice? *(Probe)*
    - *Norms and feeding practices;*
    - *Being suspicious of authority and health professionals;*
    - *Leaving things to chance;*
    - *Overwhelming barriers eg more 'cost' than 'benefit';*
    - *Lack of support.*

CONCLUSION

11. I would like to ask you if you have heard about the way the health care workers are looking after women that are HIV positive. *(Probe)*
    - During their whole life;
    - Option B+

***********Thank you for taking part in this project!!**********

Appendix 4

Focus Group guide for Community Volunteers

Selection Criteria: Communality volunteers (Lay counsellors)

Moderator : _____

Note taker : _____

Date : _____

Location : _____

GUIDE TO MODERATOR

- Copies of informed *consent* forms should be provided to the respondent and read aloud for the benefit of those who cannot read.
- The respondent should be provided an opportunity to ask any questions.
- Verbal agreement should be audio recorded.
- Try to ask all the questions below in the order given, but it is more important to maintain the flow of discussion.
- Suggested probes have been included.

Before we start I would like to remind you that there is no right or wrong answer in this discussion. I am interested in knowing what you think, please feel free to share your views, regardless of whether you agree or disagree with what you know. Please treat others in the group as you want to be treated by not telling anyone about what you hear in this discussion today.

Interviewer should introduce herself/himself and explain the purpose for the interview.

INTRODUCTION

1. Please tell me your age and marital status?
2. What do you do as a community volunteers? *(Probe eg Lay counsellor)*
3. Explain to me your involvement in the PMTCT program *(Probe recruiting mothers, follow up care, supplying drugs, giving health education, escorting mothers to other services etc)*
4. How long have you been working in the PMTCT program?

SECTION A: SOCIAL CULTURAL DETERMINANTS OF INFANT FEEDING

5. Based on your experience with mothers, please tell me any social-cultural beliefs and practices that you know regarding infant feeding. *(Probe those that were learned through interaction with mothers or those they teach mothers in the community).*
6. What social-cultural significance of breastfeeding and other infant-feedingmethods? *(Probe those that relate to those discussed during infant feeding counselling).*
7. Explain what you know about HIV transmission through breastfeeding *(Probe those discussed during infant feeding counselling).*
8. How do social-cultural norms affect infant feeding practices?
9. What does the community say about the cultural norms and practices on infant feeding. *(Probe: Family, partners/spouses, friends).*

SECTION B: CHOICE OF METHOD OF INFANT FEEDING

10. Explain to me how you assist mothers make a choice on the method of infant feeding *(Probe on counselling on infant feeding).*
11. Tell me any circumstances that influence the choice of the method of infant feeding for mothers that you have encountered during your practice.
12. Tell me any barriers/obstacles that may influence the choice of method of infant feeding for mothers that you have encountered during your practice in the community.
13. Tell me any motivational/positive factors that may influence the choice of method of infant feeding for mothers that you have encountered during your practice in the community.
14. How does the program involve spouses/partners and others in the decision on method of infant feeding?

SECTION C: PLAN FOR FOLLOW UP

15. What services are available for mothers during the first six months of infant feeding? (*Probe: Health facility based, community based, nutritional health services)*

16. Explain where the services for follow up are found *(Probe at the health facilities, the community, the hospital etc)*.
17. How accessible are these services by mothers? *(Probe distance, available support systems and structures)*.
18. Explain how you work with the health care workers on follow up of mothers during the first six months of infant-feeding *(Probe the role of Community volunteers)*.
19. Explain to me the guidelines/instructions you use at community level to follow up mothers during the first six months of infant-feeding *(Probe for any written instructions and feedback system on follow up)*.

CONCLUSION

What would you like to see done differently regarding follow up of mothers in the first six months of infant feeding?

*********************Thank you for taking the time to talk to us!!*******************

Appendix 5

Focus Group guide for Men Attending ART Clinic

Selection Criteria: Married, Wife delivered in the last one year, Knows the HIV status for the wife, wife enrolled in PMTCT.

Moderator : _____

Note taker : _____

Date : _____

Location : _____

GUIDE TO MODERATOR

- Copies of informed *consent* forms should be provided to the respondent and read aloud for the benefit of those who cannot read.
- The respondent should be provided an opportunity to ask any questions.
- Verbal agreement should be audio recorded.
- Try to ask all the questions below in the order given, but it is more important to maintain the flow of discussion.
- Suggested probes have been included.

Before we start I would like to remind you that there is no right or wrong answer in this discussion. I am interested in knowing what you think, please feel free to share your views, regardless of whether you agree or disagree with what you know. Please treat others in the group as you want to be treated by not telling anyone about what you hear in this discussion today.

Interviewer should introduce herself/himself and explain the purpose for the interview.

INTRODUCTION

1. Please tell me your age the last birthday?
2. What is your level of education?
3. What do you do for your living?

SECTION A: SOCIAL CULTURAL DETERMINANTS BREAST FEEDING

4. Based on your experience with mothers/spouses, please tell me any social-cultural beliefs and practices that you know regarding breast feeding.
    - *Probe:* The breast milk is not enough for the baby

- *Probe:* Bathing the baby in herbal medicine for protection
- *Probe:* Herbal medicine for the baby to wear to prevent diarrhoea "*Chibele"*
- *Probe:* Herbal medicine to wash the breast if the last baby died
- *Probe: "Kupeleka mwana ku mpasa"*
- *Probe: Any one not mentioned above*

5. In your culture, why is breastfeeding important?
    - *Probe:* The only way to feed the baby
    - *Probe:* To bond with the baby
6. How do social-cultural norms affect breast feeding when the mother is HIV positive?
7. What does the community say about the cultural norms and practices on infant feeding. *(Probe: Family, partners/spouses, friends).*

SECTION B: CHOICE OF METHOD OF INFANT FEEDING

8. What infant feeding methods do you know which HIV positive mothers can use to feed their babies?
    - *Probe:* Exclusive breast feeding
    - *Probe:* Formula feeding
9. When a pregnant woman is found HIV positive, what help do you think she needs to make a choice on feeding the baby?
    - *Probe:* Financial support
    - *Probe:* Emotional support
10. Tell me any other circumstances that may influence the choice of the method of infant feeding for mothers that you have encountered in your communities.
    - *Probe: Protecting the child from HIV infection;*
    - *Probe: Pressures from relatives and the community;*
    - *Probe: Pressure from the health care workers;*
    - *Probe: To avoid stigma.*
11. Tell me any barriers/obstacles that may influence the choice of method of infant feeding for mothers that you have encountered in the community.
12. Tell me any motivational/positive factors that may influence the choice of method of infant feeding for mothers in the family or in the community.

13. How does the program involve spouses/partners and others in the decision on method of infant feeding?

SECTION C: PLAN FOR FOLLOW UP

14. What services are available for mothers during the first six months of infant feeding?
    - *Probe:* Health facility base
    - *Probe:* Community based and nutritional health services
15. How accessible are these services by mothers?
    - *Probe: Walking*
    - *Probe: Using Public Transport*
16. Please explain to me how the Health Care Workers can best involve you in PMTCT program and making a decision on infant feeding.
    - *Probe:* To provide educational materials on PMTCT for men to read
    - *Probe:* By encouraging women to tell their spouses/partners about the results in order to offer assistance to the mother based on circumstances
    - *Probe:* To encourage the couple decide the method of feeding
    - *Probe:* To involve men in the decision-making process

CONCLUSION

What would you like to see done differently regarding follow up of mothers in the first six months of infant feeding?

********************Thank you for taking the time to talk to us!!*********************

Appendix 6

Interview guide for Health Care Workers

Selection Criteria: Health Care Workers working in the PMTCT programmes

Interviewer : _____

Date : _____

Location : _____

GUIDE TO MODERATOR

- Copies of informed *consent* forms should be provided to the respondent and read aloud for the benefit of those who cannot read.
- The respondent should be provided an opportunity to ask any questions.
- Verbal agreement should be audio recorded.
- Try to ask all the questions below in the order given, but it is more important to maintain the flow of discussion.
- Suggested probes have been included.

Before we start I would like to remind you that there is no right or wrong answer in this discussion. I am interested in knowing what you think, please feel free to share your views, regardless of whether you agree or disagree with what you know.

Interviewer should introduce herself/himself and explain the purpose for the interview.

INTRODUCTION

1. What was your age last birthday? What is your marital status?
2. What are your qualifications?
3. How long have you been working as a nurse/midwife?
4. How long have you been working in the PMTCT program?
5. What does your work involve in the PMTCT program?

SECTION A: SOCIAL-CULTURAL DETERMINANTS OF BREASTFEEDING

6. Based on your experience with mothers, please explain to me any social-cultural norms and practices that you know regarding infant feeding. *(Probe)*
    - *Those that were learned through interaction with mothers.*

- *If they are part of the information discussed during counselling on infant feeding).*

7. What is the social-cultural significance of breastfeeding and other infant feeding methods? *(Probe those discussed during infant-feeding counselling).*
8. Explain what you know about HIV transmission through breastfeeding and its impact on social-cultural norms and practices. *(Probe those discussed during infant-feeding counselling).*
9. Tell me your views regarding the expectations by the community and significant others on adherence to prescribed cultural norms and practices on infant feeding. *(Probe if partners/spouses or significant others are involved in the discussions).*
10. Tell me how social-cultural norms and practices observed by mothers affect your work on counselling and follow up for infant feeding.

SECTION B: CHOICE OF METHOD OF INFANT FEEDING

11. Explain to me how you assist mothers make a choice on the method of infant feeding.
    - *Probe: During group counselling on infant feeding*
    - *Probe: During individual counselling*
12. What additional information is available on infant feeding that you avail to mothers?
    - *Probe: Infant and Young Child feeding Counselling tools*
    - *Probe: What is their relevant to infant feeding and HIV*
13. Based on your experience, how are partners/spouses and significant others involved in the decision on infant feeding. *(Probe)*
    - *Willingness by mothers to involve the significant others in the choice of infant feeding method;*
    - *Advising to involve their partners/spouses*
14. Tell me any barriers/obstacles that may influence the choice of method of infant feeding for mothers that you have encountered during your practice.
15. Tell me any motivational/positive factors that may influence the choice of method of infant feeding for mothers that you have encountered during your practice.

SECTION C: PLAN FOR FOLLOW UP

16. What services are available for mothers during the first six months of infant feeding? (*Probe: Health facility based, community based, nutritional health services)*
17. Explain where the services for follow up are found *(Probe at the health facilities, the community, the hospital etc).*
18. How accessible are these services by mothers? *(Probe distance, available support systems and structures).*
19. Explain how you work with the community based volunteers to follow up on mothers during the first six months of infant feeding *(Probe the role of Community volunteers).*
20. Explain to me the guidelines/instructions you use to follow up mothers during the first six months of infant feeding *(Probe for any written instructions and feedback system on follow up)*.

CONCLUSION

What would you like to see done differently regarding follow up of mothers in the first six months of infant feeding?

***********Thank you for taking the time to talk to us!!**********

Appendix 7 Gulu amene asebenza muminzi

Kasankidwe kabotenga mbali ku nkani : magulu

Alamulili: _____

Olemba :_____

Siku :_____

Malo :_____

TANDIZO KULI BO LAMULILA

- Mapepa yovomekeza ku tenga mbali ya pasiwe kulionse asankidwa, belengani mapepa kuti onse anvele, makamaka amene sakwanisa kubelenga.
- Otenga mbali apasiwe mpata yofunsa mafunso.
- Zivomekezo zonse zapa kamwa zifunika ku fakiwa pa tape recorder
- Muyese ku funsa mafunso yonse mupepala iyi mwamene yalembelewa, kuyambilila pamwamba kuyenda pansi koma chikulu chikulu nikukonka mayendedwe ya nkani zamene mukambapo.
- Ma funsisiso yo konkapo yaikidwa mu ma funso.
- Yambililani ku uza botenga mbali mayendedwe za nkani lelo munjila iyi;

Tikalibe ku yamba, nifuna nikukumbuseni kuti kulibe yanko yazona olo yaboza munkani yatileta pano lelo. Tili kufuna kuziba zamene muganiza, munkale bomasuka na ozi peleka pakupasa ganizo lanu.

Gulu ya apunzisi – uzani bantu zina lanu na kwamene mwachoka

MAU OMASULILA

1. Tiwuzeni zaka zanu zobadwa
2. Kodi mupita kuchalichi kuti
3. Nanga munafika pati mumaphunzilo anu?
4. Ninchito yotani yamene musebenza mu gulu lanu.
5. Niuzeni nchito yamene mumasebenza mu PMTCT.
    - *Funsisani: kupeza azimai bali na matenda ya HIV*

- *Funsisani: kusamalila azimai bali namatenda ya HIV*
- *Funsisani: kupunzisa azimai bali na matenda ya HIV*

6. Mwankhala zaka zingati mukali kusebenza mu PMTCT.

MALAMULO NA MWAMBO YAMENE MUKONKA PANTHAWI YONYONSHA MWANA BELE

7. Ndi masulilenkoni zimene mudziwa pankhani yonena zopatsirana matenda a HIV pakati pa mwana ndi make?
   - *Funsisani:mmimba*
   - *Funsisani: pobala*
   - *Funsisani: poyamwitsa mwana kubele*
8. Conde ndiuzenkoni mwambo uliwonse umene azimai amakonkha panthawi yoyamwitsa mwana kubele
   - *Funsisani:* Mwana afunanika kumwa mandzi ndi zakumwa zina cifukwa mukaka ndi wocepela ku mabele
   - *Funsisani:* mukaka woyamba ndi wadothi ndipo ufunika kutaya
   - *Funsisani:* mwana akabadwa nikumusambika mankwala yocingiliza matenda osiana siana
   - *Funsisani:* ngati mai anataya mimba, kapena mwana anapitilila, muzimai uyo akabala mwana wina, ayenela kutsuka mabele ake ndi mankhwala akalibe kuyamwitsa mwana wina
9. Nanga nindani amene afunitsitsa kuti mwambo utsatiridwe nthawi yo yamwitsa mwana?
   - *Funsisana: a bambo apanyumba, achikulile amumunzi, athandizi a pobala amumunzi.*
10. Mwambo wopeleka mwana ku mphasa-usebenza bwanji ngati mai ndi tate wamwanayu ali ndimatenda ya HIV.
11. Kodi ndi cifukwa ciani mwambo wanu ufunitsitsa mai kut ayamwitse mwana kubele?)
    - *Funsisani:* ndiyo njira yokha yodyesela mwana
    - *Funsisani:* kuonetsa cikondi ca mai ndi mwana wake

12. Ndiuzenkoni zimene anthu akudela kwanu ndiponso zimene abale anu afunitsitsa inu kucita kuti muonetse kutsata mwambo wacikuda pa khani yo yamwitsa mwana kubele.
13. Panthawi yoyamwitsa mwana, kodi ndani wacibale amene amapezekako?

CIGAWO COYAMBA: NJIRA YOYAMWITSA MWANA IMENE MUKONDA

14. Niuzeni, kodi mumathandiza bwanji azimai bali na matenda ya HIV ngati bapezeka namimba napathawi yonyonsha mwna.
    - *Funsisani:* kuthandiza kusanka modyesela mwana
15. Pamene mkazi wamimba wapezeka ndi matenda ya HIV, kodi muganiza ndi thandizo lotani limene afunika kuti asankhe njira yodyetselamo mwana.
    - *Funsisani: ndalama*
    - *Funsisani: cikondi cocokela ku banja*
16. Kodi ndi zinthu zina zotani zimene zingapangitse kusankha njira yodyetselamo mwana mudela lanu?
    - *Funsisani: ndalama*
    - *Funsisani: kucingiliza mwana kumatenda ya HIV*
    - *Funsisani: cikakamizo kucokera kwa acibale ndi anthu okhala nawo mmadela*
    - *Funsisani: cikakamizo kucokela ku manasi ku cipatala*
    - *Funsisani: kusafuna kudziwika kuti muli ndi matenda ya HIV*
17. Nenani zovuta zimene zingapangitse kusankha njira yodyeselamo mwana pakati pa azimai zimene munakumana nazo pancito yanu mumadela
    - *Funsisani*: *cocingiliza*
    - *Funsisani: mabvuto*
18. Ndizinthu zotani, zimene zingacititse mai ali ndi matenda ya HIV kunkhala ndi mpamvu yosankha njira yodyetselamo mwana.
    - *Funsisani: ndizinthu zabwino zotani*
    - *Funsisani: zinthu zabwino*
19. Kodi maphunziro imaikamo bwanji anthu okwatirana/ abwenzi ndi anthu ena kuti asankhe njira modyetselamo mwana?

CIGAWO CACIWIRI: THANDIZO YAKUSOGOLO

20. Kodi ndithandizo bwanji ilipo yoti azimai angagwiritse nchito kudyetsera mwana miyezi isanu ndi umodzi yoyambirira?
    - *Funsisani: cipatala*
    - *Funsisani: kumalo kumene pita azimai ali ndi matenda ya HIV*
    - *Funsisani: nanga ndi thandizo bwanji mumidzi mumene mukhala*
21. Kodi azimai amayenda bwanji kuti apeze thandizo iyi?
    - *Funsisani: kugwiritsa nchito mamini-basi*
    - *Funsisani: kugwitsa nchito zipatala za matent*
    - *Funsisani: othandiza amumidzi*
22. Niuzeni mwamene musebenzela na ma nasi yaku cipatala munkhani yoona azimai ali na matenda ya HIV pamene mwana akalibe kunkhala na myezi isano naumozi?
23. Kodi mulinavosonyeza/malamulo popasa thandizo kuli azimai ali na matenda ya HIV mwana akailibe kufika myezi isano na umozi?
    - *Funsisani: lamulo lolemba*
24. Kodi ndi ubwino wotani umene inu mufuna kuona kulinga ndi matenda ya HIVmu dziko la Zambia?

KUMALIZA

Tiyeni tipitemo pangono pa ngono nkani zikulu zikulu zimene ta kambapo lelo. Kuli nkani zina zimene mufuna kuonjezelapo? Kodi muli na mafunso yali yonse?

*****************Zikomo kwambiri*****************

Appendix 8 Gulu la amuna ali ndi matenda ya HIV

Okwatira, mkazi wao anabala caka catha, mkazi wao adziwika kukhala ndi matenda ya HIV, mkazi analembedwa mu PMTCT

Alamulili: _____

Olemba:_____

Siku:_____

Malo :_____

THANDIZO LA OLAMULILA

- Mapepala yovomekeza kutengako mbali ya patsidwe kwa onse asankhidwa ndipo welengani mapepalayo kuti onse amvetsetse, makamaka amene sakwanisa kubelenga.
- Otenga mbali apasidwe mpata yofunsa mafunso.
- mayankho onse apakamwa afunika kuikidiwa pa tapu rekoda
- Muyese kufunsa mafunso onse mupepala iyi kulingana ndi m'mene yalembeledwa, kuyambila pamwamba kupita pansi koma cofunikila kwambiri nicakuti mufunika kulondola kamasulidwe ka nkani zimene mukambapo.
- Mafunso otsatira yaikidwe m'mafunso yapaciyambi.
- Yambililani kuuza otengako mbali m'mene ndondomeko iriri.

Tikalibe kuyamba, kukambitsana nifuna nikukumbutseni kuti kulibe yanko yazona kapena yaboza pa nkhani yatibweretsa pano lero. Tifuna kuziwa zimene muganiza, mukhale omasuka ndi wodzipeleka pakupatsa ganizo lanu.

Gulu la aphunzitsi – wuzani bantu dzina lanu ndi kumene mwachokera.

MAU OMASULILA

1. Tiwuzeni zaka zanu zobadwa
2. Kodi mupita kuchalichi kuti
3. Kodi nchito imene musebenza ikuthandiza kupeza ndalama zothandiza mu umoyo wanu?
4. Nanga munafika pati mumaphunzilo anu?

CIGAWO COYAMBA: MIYAMBO YIMENE MUKONKHA PANTHAWI YOYAMWITSA MWANA KUBELE

5. Ndi masulilenkoni zimene mudziwa pankhani yonena zopatsirana matenda a HIV pakati pa mwana ndi make?
    - *Funsisani:mmimba*
    - *Funsisani: pobala*
    - *Funsisani: poyamwitsa mwana kubele*
6. Conde ndiuzenkoni mwambo uliwonse umene azimai amakonkha panthawi yoyamwitsa mwana kubele.
    - *Funsisani:* Mwana afunanika kumwa mandzi ndi zakumwa zina cifukwa mukaka ndi wocepela ku mabele
    - *Funsisani:* mukaka woyamba ndi wadothi ndipo ufunika kutaya
    - *Funsisani:* mwana akabadwa nikumusambika mankwala yocingiliza matenda osiana siana
    - *Funsisani:* ngati mai anataya mimba, kapena mwana anapitilila, muzimai uyo akabala mwana wina, ayenela kutsuka mabele ake ndi mankhwala akalibe kuyamwitsa mwana wina
7. Nanga nindani amene afunitsitsa kuti mwambo utsatiridwe nthawi yo yamwitsa mwana?
    - *Funsisana: a bambo apanyumba, achikulile amumunzi, athandizi a pobala amumunzi.*
8. Mwambo wopeleka mwana ku mphasa-usebenza bwanji ngati mai ndi tate wamwanayu ali ndimatenda ya HIV
9. Kodi ndi cifukwa ciani mwambo wanu ufunitsitsa mai kut ayamwitse mwana kubele?
    - *Funsisani:* ndiyo njira yokha yodyesela mwana
    - *Funsisani:* kuonetsa cikondi ca mai ndi mwana wake
10. Ndiuzenkoni zimene anthu akudela kwanu ndiponso zimene abale anu afunitsitsa inu kucita kuti muonetse kutsata mwambo wacikuda pa khani yo yamwitsa mwana kubele.
11. Panthawi yoyamwitsa mwana, kodi ndani wacibale amene amapezekako?

CIGAWO CACIWIRI: NJIRA YOYAMWITSA MWANA IMENE MUKONDA

12. Ninjila zotani zimene inu mudziwa zoti azimai ali ndi matenda ya HIV anga dyetsele mwana?
    - *Funsisani:* kuyamwitsa mwana cabe bele kosapatsa cakudya cina kapena madzi pamyezi yokwana isano ndi umodzi
    - *Funsisani:* mukaka wogula womwetsera mu botolo
13. Pamene mkazi wamimba wapezeka ndi matenda ya HIV, kodi muganiza ndi thandizo lotani limene afunika kuti asankhe njira yodyetselamo mwana.
    - *Funsisani: ndalama*
    - *Funsisani: cikondi cocokela ku banja*
14. Kodi ndi zinthu zina zotani zimene zingapangitse kusankha njira yodyetselamo mwana mudela lanu?
    - *Funsisani: ndalama*
    - *Funsisani: kucingiliza mwana kumatenda ya HIV*
    - *Funsisani: cikakamizo kucokera kwa acibale ndi anthu okhala nawo mmadela*
    - *Funsisani: cikakamizo kucokela ku manasi ku cipatala*
    - *Funsisani: kusafuna kudziwika kuti muli ndi matenda ya HIV*
15. Nenani zovuta zimene zingapangitse kusankha njira yodyeselamo mwana pakati pa azimai zimene munakumana nazo pancito yanu mumadela
    - *Funsisani*: *cocingiliza*
    - *Funsisani: mabvuto*
16. Ndizinthu zotani, zimene zingacititse mai ali ndi matenda ya HIV kunkhala ndi mpamvu yosankha njira yodyetselamo mwana.
    - *Funsisani: ndizinthu zabwino zotani*
    - *Funsisani: zinthu zabwino*
17. Kodi maphunziro imaikamo bwanji anthu okwatirana/ abwenzi ndi anthu ena kuti asankhe njira modyetselamo mwana?

CIGAWO CACITATU: THANDIZO YAKUSOGOLO

18. Kodi ndithandizo bwanji ilipo yoti azimai angagwiritse nchito kudyetsera mwana miyezi isanu ndi umodzi yoyambirira?
    - *Funsisani: cipatala*

- *Funsisani: kumalo kumene pita azimai ali ndi matenda ya HIV*
- *Funsisani: nanga ndi thandizo bwanji mumidzi mumene mukhala*

19. Kodi azimai amayenda bwanji kuti apeze thandizo iyi?
    - *Funsisani: kugwiritsa nchito mamini-basi*
    - *Funsisani: kugwilitsa nchito zipatala za matenti*
    - *Funsisani: othandiza amumidzi*
20. Masulani mumene muganizira kuti anasi angazikuikamoni munkhani ya PMTCT ndi kusankha njira yodyetseramo mwana akazi anu.
    - *Funsisani:* maphunzilo ya amuna pa nkhani ya HIV kuti azibambo aziwerenga
    - *Funsisani:* kuthandiza azimai kuti akaziuza amuna ao ngati apezeka ndi matenda ya HIV kuti apatsidwe thandizo.
    - *Funsisani:* kuthandiza azimai ndi azimuna ao kusankha pamodzi njira yodyesera mwana
    - *Funsisani:* kuti azimuna agwepo pomanga nfundo

KUMALIZA

Tiyeni tipitemo pangono pa ngono nkani zikulu zikulu zimene ta kambapo lelo.

Kuli nkani zina zimene mufuna kuonjezelapo? Kodi muli na mafunso yali yonse?

********************Zikomo kwambiri******************

Appendix 9 Zofunsitsa kudziwa pakati pa azimai ali ndi matenda ya HIV

Kasankhidwe kawotengako mbali ku nkhani: *Azimai ali ndi zaka 15 kufika 49 bamene bali na matenda ya HIV* **(POYAMBA)**

Ofunsa:_____

Olemba:_____

Tsiku:_____

Malo:_____

THANDIZO KWA OFUNSA

- Mapepala ovomekeza kutengako mbali apasidwe kwa onse asankhidwa ndipo welengani mapepalayo kuti onse anvetsetse, makamaka amene sakwanisa kubelenga.
- Otenga mbali apasidwe mpata wofunsa mafunso.
- Mayankho onse apakamwa afunika kuikidwa pa tepu rekoda
- Muyese kufunsa mafunso onse ali mupepala iyi kulingana ndi m'mene yalembeledwa, kuyambila pamwamba kupita pansi koma cofunikila kwambili nicakuti mufunikilia londola kamasulidwe kankani zimene mukambapo.
- Mafunso otsatira yaikidwa m'mafunso yapaciyambi.
- Yambililani kuuza otengako mbali m'mene ndondomeko iliri.

Tikalibe kuyamba, kukambitsana nifuna nikukumbustane kuti kulibe yanko yaboza kapena yazoona munkhani yatibweletsa pano lero.

MAU OMASULILA

1. Tiwuzeni zaka zanu zobadwa?
2. Kodi muli ndi ana angati?
3. Kodi ndimwe okwatiwa?
4. Kodi mumapita kuchalichi?
5. Kodi musebenza?
6. Ngati ndinu okwatiwa, kodi amuna anu asebenza?
7. Nanga munafika pati mumaphunzilo anu?

MBILI YA MIMBA YAMWANA WAKHANDA MULINAYE

8. Kodi mwakhala ndi mamimba angati kucokela pamene munayamba kubala?
    - *Funsisani*: *kodi ndi ana angati amoyo*
    - *Funsisani: Nanga ndi ana angati anapitilila*
    - *Funsisani: kodi ana amene anatisiya anafa ndimatenda otani*
    - *Funsisani: How did the reason for the death affect the decision for this baby? Kodi matenda amene anapha anawo anathandiza kusankha njira yina yodyesela mwana uyu?*
9. Kodi pa mimba yamwana uyu, munayamba kupita ku cipimo pa myezi ingati?
10. Munapimitsa liti matenda ya HIV?
    - *Funsisani:* Akalibe kunkhala ndi mimba?
    - *Funsisani:* Panthawi yolembesa cipimo?
11. Kodi ndi ciani cinapangitsa kuti mupimitse matenda ya HIV?
    - *Funsisani: anamupatikizani*
    - *Funsisani: munauzidwa kuti cinali cofunira kupitsa kucipatala)*
    - *Funsisani: ninali kufuna kudziwa kuti ndi teteze umoyo wanga ndi wamwana wanga)*
12. *Kodi muganizapo bwanji pankhani yopimitsa matenda ya HIV pamene muli ndi pakati?*
    - *Funsisani: akalibe kunkhala ndi pakati*
    - *Funsisani: pathawi ya cipimo*
    - *Funsisani: kodi muganiza ndi nthawi yotani yoyenera*
13. Kodi muganiza bwanji pakhani yosankha modyesela mwana ngati mwapezeka ndi matenda ya HIV pamene muli ndi pakati?
    - *Funsisani*: ninkhani yovuta kwa ine muzimai ndi mwana wanga
14. Ndiuzeni, kodi munauzako munthu aliyense kuti munapezeka ndi matenda ya HIV.
    - *Funsisani: adzimuna ndibanja*
    - *Funsisani: kodi ndi ciani cimene munabauzila*
    - *Funsisani: ngati kulibe amene munauza, kodi ncifukwa cani?*

CIGAWO COYAMBA: MIYAMBO YIMENE MUKONKHA PANTHAWI YOYAMWITSA MWANA KUBELE

15. Kodi munganiuzeko ciani pankhani yonena zopatsirana matenda a HIV mwana ndi make?
    - *Funsisani: mmimba*
    - *Funsisani: pobala*
    - *Funsisani: poyamwitsa mwana kubele*
16. Conde ndiuzenkoni mwambo uliwonse umene azimai amakonkha panthawi yoyamwitsa mwana kubele
    - *Funsisani:* Mwana afunanika kumwa mandzi ndi zakumwa zina cifukwa mukaka ndi wocepela ku mabele
    - *Funsisani:* mukaka woyambilira ndiwadothi ndipo ufunika kutaya
    - *Funsisani:* mwana akabadwa afunika kumusambika mankhwala yocingiliza matenda osiyana siyana
    - *Funsisani:* ngati mai anataya mimba kapena mwana anapitilila, muzimai uyo akabala mwana wina, ayenela kutsuka mabele ake ndimankhwala akalibe kuyamwisa mwana wina
17. Nanga nindani amene afunitsitsa kuti mwambo utsatiridwe nthawi yo yamwitsa mwana?
    - *Funsisisana: a bambo apanyumba, achikulile amumundzi, athandizi apobala amumundzi.*
18. Mwambo wopeleka mwana ku mphasa-usebenza bwanji ngati mai ndi tate wamwanayu ali ndimatenda ya HIV
19. Kodi ndi cifukwa ciani mwambo wanu ufunitsitsa mai kut ayamwitse mwana kubele?
    - *Funsisisani:* ndiyo njira yokha yodyetsela mwana
    - *Funsisisani:* kuonetsa cikondi ca mai ndi mwana wake
20. Ndiuzenkoni zimene anthu akudela kwanu ndiponso zimene abale anu afunitsitsa inu kucita kuti muonetse kutsata mwambo wacikuda pa khani yo yamwitsa mwana kubele.
21. Pa nthawi yoyamwitsa mwana, kodi ndani wacibale amene amapezekako?

CIGAWO CACIWILI: MAPHUNZILO ONENA PAKADYESEDWE KA MWANA

22. Panthawi yimene munapezeka ndi matenda ya HIV, kodi munaphunzila modyesela mwana kucipimo?
    - *Funsisani: Kodi munganiuzeko maphunzilo yomweyo*
    - *Funsisani: Kodi maphunziloyo yanakunthandizani kusankha njira yodyesela mwana ngati mai wake ali ndi mtenda ya HIV*
23. Kodi kuli maphunzilo yena yomwe munapasidwa ndi anasi kucipatala yolembedwa kuti muziwelenga kunyumba?
    - *Funsisani: mulinayo kuti tiyaone*
24. Ngati mulinayo maphunzilo yolembedwa, kodi yanakuthandizani modyesela mwana?

CIGAWO CACITATU: KUSANKHA NJIRA YODYESELA MWANA

25. Kodi ndi njila iti yimene munasankha kudyetsela mwana wanu?
    - *Funsisani: Kuyamwitsa cabe bele kapena kupatsa mukaka wogula wamu botolo*
26. Kodi munakwanitsa bwanji kufika pa maganizo otere
    - *Funsisani: Amuna anu/ bwenzi lanu kapena banja*
27. Niuzeni zinthu zina zimene zinanakupangitsani kuti musankhe njira yodyesela mwana.
    - *Funsisani: ndalama*
    - *Funsisani: kucingiliza mwana kumatenda ya HIV*
    - *Funsisani: cikakakamizo cocokera kubanja ndi*
    - *Funsisani: cikakamizo kucokera ku manasi*
    - *Funsisani: kusafuna kudziwika kuti muli ndi matenda ya HIV*
28. Conde, nimasulilenkoni mmene muzakwanitsila kudyesa mwana munjila yimene munasankha.
29. Kodi mumasiya mwana wanu kwakanthawi?
    - *Funsisani*: kubwelela kuncito kwa azimai osebenza
30. Kodi munasintha njila yamene munasankha paciyambi yodyesela mwana?
31. If feeding practice has changed, ask for reasons.
    - *Funsisani*: *mabvuto*
    - *Funsisani*: *cikakamizo kucokera ku banja ndi azanga*

- *Funsisani*: *cikakamizo kucokera ku manasi*

32. Funsisani: Ngati simunasinthe njila yamene munasankha paciyambi yodyesela mwana, munakwanisa bwanji
    - *Funsisani*: *kukonkha mwambo*
    - *Kukonkha lamulo ku cokera kumanasi*

CIGAWO CACINAI: THANDIZO YAKUSOGOLO

33. Kodi ndi thandizo bwanji yimene munauzidwa kugwiritsa nchito kudyetsa mwana pa miyezi isanu ndi umodzi oyambilira?
    - *Funsisani: cipatala, kumalo yazimai ali ndi matenda ya HIV*
    - *Funsisani: nanga mumidzi mumene mukhala*
34. Kodi mumayenda bwanji kuti mupeze thandizoyi?
    - *Funsisani: kugwitsa nchito ma minibasi*
    - *Funsisani: cipatala ca matenti*
    - *Funsisani: othandiza ocokera mumidzi*
35. Kodi mukwanitsa bwanji kupeza cakudya canu?
    - *Funsisani:* mukudya kangati patsiku
    - *Funsisani:* niuzeni mitundu yacakudya ca mmawa, mmasana ndi mmadzulo
    - *Funsisani:* niuzeni ngati mumadya cakudya cina nthawi yina yace
36. Conde ndi masulileni maganaizo anu pa zimene mwapitamo podyetsa mwana kulingana ndi umoyo wanu wokhala ndi matenda ya HIV?
    - *Funsisani: mabvuto niyambili*
    - *Funsisani: mabvuto niyambili pa mwana*
    - *Funsisani: niciani cimene mufuna kukwanisa kucita pali ino nthawi?*
37. Kodi ndi ubwino wotani umene inu mufuna kuona kulinga ndi matenda ya HIVmu dziko la Zambia?

KUMALIZA

Tiyeni tipitemo pang'ono pa ng'ono nkani zikulu zikulu zimene takambapo lelo. Kodi kuli nkhani zina zimene mufuna kuonjezelapo? Kodi muli ndi mafunso ena ali onse?

*****************Zikomo kwambiri*****************

Appendix 10 Zofunsitsa kudziwa pakati pa azimai ali ndi matenda ya HIV

Kasankhidwe kawotengako mbali ku nkhani: *Azimai ali ndi zaka 15 kufika 49 bamene bali na matenda ya HIV.* **(ZOKONKHAPO)**

Ofunsa:_____

Olemba :_____

Tsiku:_____

Malo :_____

THANDIZO KWA OFUNSA

- Mapepala ovomekeza kutengako mbali apasidwe kwa onse asankhidwa ndipo welengani mapepalayo kuti onse anvetsetse, makamaka amene sakwanisa kubelenga.
- Otenga mbali apasidwe mpata wofunsa mafunso.
- Mayankho onse apakamwa afunika kuikidwa pa tepu rekoda
- Muyese kufunsa mafunso onse ali mupepala iyi kulingana ndi m'mene yalembeledwa, kuyambila pamwamba kupita pansi koma cofunikila kwambili nicakuti mufunikilia londola kamasulidwe kankani zimene mukambapo.
- Mafunso otsatira yaikidwa m'mafunso yapaciyambi.
- Yambililani kuuza otengako mbali m'mene ndondomeko iliri.

Tikalibe kuyamba, kukambitsana nifuna nikukumbustane kuti kulibe yanko yaboza kapena yazoona munkhani yatibweletsa pano lero.

MAU YO MASULILA

1. Mwana ali na myezi ingani yobadwa?
2. Munvela bwanji umoyo wanu?
3. Mwana ali bwanji?
4. Kodi munayamba kupasa mwana cakudya cina kupambana nacamene munasankha paciyambi.
    - *Funsisani: niuzeni mutundu wacakudya*

- *Funsisani : munacosa kuti maphunzilo yopasa mwana cakudya camene mumupasa manje*
- *Funsisani : kodi munayamba nchito mwina kuyenda kusakila vakudya*

5. *Ndani asunga mwana ngati imwe kulibe.*
    - *Funsisani: bambuya bake*
    - *Funsisani: wancito*
    - *Funsisani: mumaenda naye*
6. *Ngati mwacokapo na mwana mwamusiya, mumasimikiza bwanji kuti mwana apasiwa cakudya monga mwamene munaphunzisidwa.*
    - *Funsisani: amapikilatu mukaka mwina mwace kufina bele.*

CIGAWO COYAMBA: NJIRA YOYAMWITSA MWANA IMENE MUKONDA

7. Niuzeni njila yamene munasankha yodyesela mwana pamene munapezeka na matenda ya HIV.
8. Ngati simunasinthe njila.
    - *Funsisani: munakwanisa mukufuna kwanu*
    - *Funsisani: munakangiwa kafunilo kanu*
    - *Funsisani: niuzeni mabvuto yamene munapeza*
9. Ngati munasintha modyesela mwana
    - *Funsisani: munakwanisa mukufuna kwanu*
    - *Funsisani: munakangiwa kufuna kwanu*
    - *Funsisani: niuzeni mabvuto yamene munapeza*
10. Munakwanisa bwanji kudyesa mwana munjila yamene munasankha.
    - *Funsisani: kukonkha myambo*
    - *Funsisani: kusakhulupilila ma stafu yaku cipatala*
    - *Funsisani: kusiya mwamene cabe*
    - *Funsisani: kusoba thandizo*

KUMALIZA

Tiyeni ti pitulukemo pangono pa ngono nkani zikulu zikulu zamene ta kambapo lelo.

Kuli nkani zina zamene mu funa kuonjezelapo? Kodi muli na mafunso yali yonse?

*****************Zikomo kwambiri*****************

Appendix 11 Zofunsitsa kudziwa pakati pa azimai ali ndimatenda ya HIV

Kasankhidwe kawotengako mbali ku nkhani: *Azimai ali ndi zaka 15 kufika 49.* **(POSILIZA)**

Ofunsa:_____

Olemba: _____

Tsiku: _____

Malo :_____

THANDIZO KWA OFUNSA

- Mapepala ovomekeza kutengako mbali apasidwe kwa onse asankhidwa ndipo welengani mapepalayo kuti onse anvetsetse, makamaka amene sakwanisa kubelenga.
- Otenga mbali apasidwe mpata wofunsa mafunso.
- Mayankho onse apakamwa afunika kuikidwa pa tepu rekoda
- Muyese kufunsa mafunso onse ali mupepala iyi kulingana ndi m'mene yalembeledwa, kuyambila pamwamba kupita pansi koma cofunikila kwambili nicakuti mufunikilia londola kamasulidwe kankani zimene mukambapo.
- Mafunso otsatira yaikidwa m'mafunso yapaciyambi.
- Yambililani kuuza otengako mbali m'mene ndondomeko iliri.

Tikalibe kuyamba, kukambitsana nifuna nikukumbustane kuti kulibe yanko yaboza kapena yazoona munkhani yatibweletsa pano lero.

MAU YO MASULILA

1. Nanga mwana ali na myezi ingati?
2. Munvelako bwanji umoyo wanu?
3. Nanga mwana alibwanji?

CIGAWO COYAMBA: MYAMBO YAMENE MUKONKA PANTHAWI YODYESA MWANA

4. Conde niuzeni myambo yamene mukonkha manje?

- *Funsisani:* Mwana afunanika kumwa mandzi ndi zakumwa zina cifukwa mukaka ndi wocepela ku mabele
- *Funsisani:* mukaka woyambilira ndiwadothi ndipo ufunika kutaya
- *Funsisani:* mwana akabadwa afunika kumusambika mankhwala yocingiliza matenda osiyana siyana
- *Funsisani:* Ngati mai anataya mimba kapena mwana anapitilila, muzimai uyo akabala mwana wina, ayenela kutsuka mabele ake ndimankhwala akalibe kuyamwisa mwana wina.

2. Ndiuzenkoni zimene anthu akudela kwanu ndiponso zimene abale anu afunitsitsa inu kucita kuti muonetse kutsata mwambo wacikuda pa khani yo yamwitsa mwana kubele.
3. Pa nthawi yoyamwitsa mwana, kodi ndani wacibale amene amapezekako?
    - *Funsisani:* bamamuthandizani cani
    - *Funsisani:* kuona kuti mukonkha myambo
    - *Funsisani:* kuthandiza na kunkhala pamodzi

CIGAWO CACIBILI: ZOPITAMO PANTHAWI YODYESELA MWANA

5. Kodi pali pano mudyesa bwanji mwana?
    - *Funsisani: anyonka bele*
    - *Funsisani: akumwa mukaka waku botolo*
6. Niuzeni cifukwa camene mudyesela mwana munjila yamene mwakamba?
    - *Funsisani: kuyopa kukangiwa*
    - *Funsisani: kucingiliza mwana ku matenda ya HIV*
    - *Funsisani: kulephela kukwanisa njila yamene munasankha paciyambi*
    - *Funsisani: muganiza bwanji panjila yomweyo*
7. Niubwino wabwanji wamene mwapeza munjila yamene mudyesela mwana?
8. Kodi mumasiya mwana wanu kwakanthawi?
    - *Funsisani*: kubwelela kuncito kwa azimai osebenza
9. Kodi munasintha njila yodyesela mwana kusiya yamene munasankha pa ciyambi.
10. Ngati yoyamba njila munasintha.
    - *Funsisani: Niuzeni cifukwa camene munasinthila.*
11. Ngati simunasinthe yoyamba njila.

- *Funsisani: Niuzeni cifukwa camene simunasinthe.*

CIGAWO CACITATU: THANDIZO YAKUSOGOLO

12. Kodi ndi thandizo bwanji yimene munauzidwa kugwiritsa nchito kudyetsa mwana pa miyezi isanu ndi umodzi oyambilira?
    - *Funsisani: cipatala*
    - *Funsisani: kumalo yazimai ali ndi matenda ya HIV*
    - *Funsisani: nanga mumidzi mumene mukhala*
13. Kodi mumayenda bwanji kuti mupeze thandizoyi?
    - *Funsisani: kugwitsa nchito ma minibasi*
    - *Funsisani: cipatala ca matent*
    - *Funsisani: othandiza ocokera mumidzi*
14. Kodi mukwanitsa bwanji kupeza cakudya canu?
    - *Funsisani:* mukudya kangati patsiku
    - *Funsisani:* niuzeni mitundu yacakudya ca mmawa, mmasana ndi mmadzulo
    - *Funsisani:* niuzeni ngati mumadya cakudya cina nthawi yina yace
15. Conde ndi masulileni maganaizo anu pa zimene mwapitamo podyetsa mwana kulingana ndi umoyo wanu wokhala ndi matenda ya HIV?
    - *Funsisani: mabvuto niyambili*
    - *Funsisani: mabvuto niyambili pa mwana*
    - *Funsisani: niciani cimene mufuna kukwanisa kucita pali ino nthawi?*
16. Kodi ndi ubwino wotani umene inu mufuna kuona kulinga ndi matenda ya HIVmu dziko la Zambia?

KUMALIZA

Tiyeni ti pitulukemo pangono pa ngono nkani zikulu zikulu zamene ta kambapo lelo.

Kuli nkani zina zamene mu funa kuonjezelapo? Kodi muli na mafunso yali yonse?

********************Zikomo kwambiri******************

Appendix 12 Letter from Translator

THE UNIVERSITY OF ZAMBIA
SCHOOL OF HUMANITIES AND SOCIAL SCIENCES
LITERATURE AND LANGUAGES

Telephone: 252514/292884
Telegrams: UNZA Lusaka
Telex: UNZALU ZA 44370
FAX: +260 - 253952
EMAIL: head-litandlan@unza.zm

P. O. Box 32379
Lusaka, Zambia

Our Ref

29th September 2015

The Principal Investigator
University of KwaZulu Natal
Durban, South Africa

Dear Madam

Attention: Alice Ngoma Hazemba

RE: TRANSLATION OF THE RESEARCH INSTRUMENTS

Reference is made to the above subject.

This consultancy was done in January 2014 and was provided in relation to the research: **HIV and Infant Feeding; Choices and Decision Outcomes in the Context of Prevention of Mother-to-Child Transmission among HIV-Positive Mothers in Zambia.** As requested, the following interview guides were translated from English to Cinyanja, a primary language spoken by participants in Lusaka, Zambia. The procedures that were used in translation include:

1. **Free Translation**: This kind of translation was used to preserve the meaning of the source language while using natural forms of the target language, including normal word order and syntax, so that the translation can be naturally understood.
2. **Transference**: This involved borrowing of words from the source (English) to the target language (Cinyanja) in order to maintain the original meaning of the words.
3. **Communicative Translation**: This was used to help reproduce the exact message of the source text where content and context are concerned and yet putting emphasis on naturalness and acceptability/ comprehensiveness to the target text readership.

The following tools were translated:

- In-depth interview guide for HIV-positive mothers recruited in the PMTCT program
- In-depth interview guide for HIV-positive mothers recruited in the PMTCT program (Follow-up 1&2)
- In-depth interview for HIV positive mothers recruited in the PMTCT program (Exit from the research)
- Focus group guide for community volunteers
- Focus group guide for men attending the antiretroviral therapy at the health facilities

Please find attached the translated interview guides. Thanking you for the opportunity to assist with this assignment.

Yours faithfully

Naomi Njobvu
(MA Linguistics-, Lecturer/Translator/Researcher)

Appendix 13

Informed Consent for Community Volunteers

INTRODUCTION:

My name is…….the research assistant for this research.

TITLE: HIV and infant feeding: choices and decision-outcomes in the context of prevention of mother-to-child transmission among HIV-positive mothers in Zambia

NAME OF RESEARCHER: Alice Ngoma Hazemba, MPH, BSc

INDEPENDENT CONTACT PERSON:

- The Chairperson, Dr James Munthali, Research Ethics Committee of the University of Zambia, Phone 260-211-256067.

IDENTIFICATION OF THE SUBJECT: Community volunteers working with the health facilities staff in PMTCT programs and are in contact with mothers.

PURPOSE OF STUDY: The purpose of this study is to learn from you the experiences on infant feeding and outcome of the decision on method of choice in the prevention of mother to child transmission of HIV.

PROCEDURES: Your participation in the study will require answering questions about yourself and your experiences as a volunteer in the PMTCT program and any other issues you may want to share. The interview will take about 30 minutes to one hour. Your answers will be recorded in order to refer back to the interview for answers to the questions. Only I and the people on our research team will have access to the recording. At the end of the study, we will share with you what we have found if you so wish.

RISKS / DISCOMFORTS: There are no risks to your body in this study. However, you may feel uncomfortable answering some of the questions. You may refuse to answer any questions that you do not want to answer. You may stop the interview session at any time. Your responses or participation in this study will not affect how you work in this health facility or any health facility belonging to the Ministry of Health (MoH) anywhere in this town or country.

BENEFITS: There is no direct benefit to you personally for participating in this study. Being in this study may not change the way you work at MoH facilities but the results from this

study may help you in the way you care for the HIV positive mothers and the way the mothers receive care during pregnancy and the infant-feeding period.

CONFIDENTIALITY: Your name will not be used on any survey forms. You will be assigned a study number so that it will not be possible to identify you individually. Only people who are in this study will be able to get this information. When we finished with the study, audio tapes and other information collected will be destroyed after 5 years.

VOLUNTARY PARTICIPATION: Your taking part in this study is completely voluntary. You are free to withdraw at any time, for any reason. In the event that you decide to withdraw from the study, the information you have already provided will be kept in a confidential manner and will not be shared with anyone else to personally harm or affect you. This will not in any way affect you or you're taking part in future or any other privileges.

RE-IMBURSEMENT: There is no financial re-imbursement for participating in this study. However, transport refund and refreshments will be provided depending on where you choose to have the interview.

If you agree to join the study, you will be given a signed copy of this consent form and a written summary of the study at every stage of the study. Do you agree to join the interview/discussion?

Yes ☑___/ No☒___

By signing below, I agree to take part in the study.

Print ID number: _____

Signature/Thumbprint Date

_____ _____

Signature of person obtaining consent Date

_____ _____

IF THE RESPONDENT DECIDES **NOT** TO PARTICIPATE, SHE WILL THANKED

Appendix 14

Informed Consent for Health Care Workers (HCWs)

INTRODUCTION: My name is ……the research assistant for this research.

TITLE: HIV and infant feeding: choices and decision-outcomes in the context of prevention of mother-to-child transmission among HIV-positive mothers in Zambia

NAME OF RESEARCHER: Alice Ngoma Hazemba, MPH, BSc

INDEPENDENT CONTACT PERSON:

- The Chairperson, Dr James Munthali, Research Ethics Committee of the University of Zambia, Phone 260-211-256067.

IDENTIFICATION OF THE SUBJECT: Nurses, midwives and community volunteers working in health facilities that provide PMTCT services and are in contact with mothers.

PURPOSE OF STUDY: The purpose of this study is to learn from you the experiences on infant-feeding and outcome of the decision on method of choice in the prevention of mother to child transmission of HIV.

PROCEDURES: Your participation in the study will require answering questions about yourself and your experiences as a care provider for HIV positive mothers and any other issues you may want to share. The interview will take about 30 minutes to one hour. Your answers will be recorded in order to refer back to the interview for answers to the questions. Only I and the people on our research team will have access to the tape. At the end of the study, we will return and share with you what we have found if you so wish.

RISKS / DISCOMFORTS: There are no risks to your body in this study. However, you may feel uncomfortable answering some of the questions. You may refuse to answer any questions that you do not want to answer. You may stop the interview session at any time. Your responses or participation in this study will not affect how you work in this health facility or any health facility belonging to the Ministry of Health (MoH) anywhere in this town or country.

BENEFITS: There is no direct benefit to you personally for participating in this study. Being in this study may not change the way you work at MoH facilities but the results from this study may help you in the way you care for the HIV positive mothers and the way the mothers receive care during pregnancy and the infant-feeding period.

CONFIDENTIALITY: Your name will not be used on any survey forms. You will be assigned a study number so that it will not be possible to identify you individually. Only people who are in this study will be able to get this information. When we finished with the study, audio tapes and other information collected will be destroyed after 5 years.

VOLUNTARINESS: Your taking part in this study is completely voluntary. You are free to withdraw at any time, for any reason. In the event that you decide to withdraw from the study, the information you have already provided will be kept in a confidential manner and will not be shared with anyone else to personally harm or affect you. This will not in any way affect you or you're taking part in future or any other privileges.

RE-IMBURSEMENT: There is no financial re-imbursement for participating in this study. However, transport refund and refreshments will be provided depending on where you choose to have the interview.

If you agree to join the study, you will be given a signed copy of this consent form and a written summary of the study at every stage of the study. Do you agree to join the interview/discussion?

Yes ☑___/ No☒___

By signing below, I agree to take part in the study.

Print ID number: _____

Signature/Thumbprint Date

_____ _____

Signature of person obtaining consent Date

_____ _____

IF THE RESPONDENT DECIDES **NOT** TO PARTICIPATE, SHE WILL THANKED

Appendix 15

Informed Consent for HIV-Positive Mothers

INTRODUCTION: My name is ……. the research assistant for this research.

TITLE: HIV and infant feeding: choices and decision-outcomes in the context of prevention of mother-to-child transmission among HIV-positive mothers in Zambia

NAME OF RESEARCHER: Alice Ngoma Hazemba-MPH, BSc

INDEPENDENT CONTACT PERSON:

- The Chairperson, Dr James Munthali, Research Ethics Committee of the University of Zambia, Phone 260-211-256067.

IDENTIFICATION OF THE SUBJECT: The mothers attending ANC booking, counselled, tested and received the HIV test results will be recruited to the study. The criteria for selection will be willingness to participate and to be interviewed at home after delivery.

PURPOSE OF STUDY: The purpose of this study is to learn from your experiences on infant feeding and outcome of the decision you will make on method of choice of feeding your infant in the prevention of mother-to-child transmission of HIV.

PROCEDURES: Participation in the study will require answering questions about yourself, your recent experiences with this current pregnancy and any other issues you may want to share. The interview will take about 30 minutes to one hour. Your answers will be recorded in order to refer back to the interview for answers to the questions. At the end of the study, we will return here and share with you what we have found if you so wish.

RISKS / DISCOMFORTS: There are no risks to your body or the baby in this study. However, you may feel uncomfortable answering some of the questions. You may refuse to answer any questions that you do not want to answer. You may stop the interview session at any time. Your responses or participation in this study will not affect you in any way or even to receive care at any health facility belonging to the Ministry of Health (MoH) anywhere in this town or country.

BENEFITS: There is no direct benefit to you personally for participating in this study. Being in this study may not change the way you receive care at MoH facilities but the results from this study may help you or other HIV positive mothers in the future in the way health care workers will look after them in pregnancy and infant feeding period.

CONFIDENTIALITY: Your name will not be used on any survey forms. You will be assigned a study number so that it will not be possible to identify you individually. Only people who are in this study will be able to get this information. When we finished with the study, audio tapes and other information collected will be destroyed after 5 years.

VOLUNTARISM: Your taking part in this study is completely voluntary. You are free to withdraw at any time, for any reason. In the event that you decide to withdraw from the study, the information you have already provided will be kept in a confidential manner and will not be shared with anyone else to personally harm or affect you. This will not in any way affect you or you're taking part in future or any other privileges.

RE-IMBURSEMENT: There is no financial re-imbursement for participating in this study. However, transport refund and refreshments will be provided depending on where you choose to have the interview. If you agree to join the study, you will be given a signed copy of this consent form. Do you agree to join the interview/discussion?

Yes ☑___/ No☒___

By signing below, I agree to take part in the study.

Print ID number: _____

Signature/Thumbprint Date

_____ _____

Signature of person obtaining consent Date

_____ _____

IF THE WOMAN DECIDES **NOT** TO PARTICIPATE, SHE WILL THANKED

Appendix 16

Informed Consent for spouses/partners of HIV-positive mothers

INTRODUCTION:

My name is…….the research assistant for this research.

TITLE: HIV and infant feeding: choices and decision-outcomes in the context of prevention of mother-to-child transmission among HIV-positive mothers in Zambia

NAME OF RESEARCHER: Alice Ngoma Hazemba, MPH, BSc

INDEPENDENT CONTACT PERSON:

- The Chairperson, Dr James Munthali, Research Ethics Committee of the University of Zambia, Phone 260-211-256067.

IDENTIFICATION OF THE SUBJECT: Community volunteers working with the health facilities staff in PMTCT programs and are in contact with mothers.

PURPOSE OF STUDY: The purpose of this study is to learn from you the experiences on infant-feeding and outcome of the decision on method of choice in the prevention of mother to child transmission of HIV.

PROCEDURES: participation in the study will require answering questions about yourself, your recent experiences with your spouse/partner's pregnancy and delivery and any other issues you may want to share. The interview will take about 30 minutes to one hour. Your answers will be recorded in order to refer back to the interview for answers to the questions. Only I and the people on our research team will have access to the information on tape. At the end of the study, we will return here and share with you what we have found if you so wish.

RISKS / DISCOMFORTS: There are no risks to your body in this study. However, you may feel uncomfortable answering some of the questions. You may refuse to answer any questions that you do not want to answer. You may stop the interview session at any time. Your responses or participation in this study will not affect you in any way or even to receive care at any health facility belonging to the Ministry of Health (MoH) anywhere in this town or country.

BENEFITS: There is no direct benefit to you personally for participating in this study. Being in this study may not change the way you receive care at MoH facilities but the results from

this study may help you or other spouses/partners of HIV positive mothers in the future in the way health care workers will look after them.

CONFIDENTIALITY: Your name will not be used on any survey forms. You will be assigned a study number so that it will not be possible to identify you individually. Only people who are in this study will be able to get this information. When we finished with the study, audio tapes and other information collected will be destroyed after 5 years.

VOLUNTARISM: Your taking part in this study is completely voluntary. You are free to withdraw at any time, for any reason. In the event that you decide to withdraw from the study, the information you have already provided will be kept in a confidential manner and will not be shared with anyone else to personally harm or affect you. This will not in any way affect you or you're taking part in future or any other privileges.

RE-IMBURSEMENT: There is no financial re-imbursement for participating in this study. However, transport refund will be provided depending on where you choose to have the interview. If you agree to join the study, you will be given a signed copy of this consent form.

Do you agree to join the interview/discussion?

Yes ☑___/ No☒___

By signing below, I agree to take part in the study.

Print ID number: _____

Signature/Thumbprint Date

_____ _____

Signature of person obtaining consent Date

_____ _____

IF THE RESPONDENT DECIDES **NOT** TO PARTICIPATE, SHE WILL THANKED

Appendix 17 Permission to carryout the research

Telephone: (260) 211 235341
Fax (260) 211 235342

In reply please quote:

No.:
MCDMCH/101/5/1

REPUBLIC OF ZAMBIA

MINISTRY OF COMMUNITY DEVELOPMENT, MOTHER AND CHILD HEALTH

OFFICE OF THE PERMANENT SECRETARY
COMMUNITY HOUSE
SADZU ROAD
PRIVATE BAG W 252
LUSAKA

27th June, 2013

Ms. Alice Ngoma Hazemba
University of Zambia
Department of Public Health
P.O. Box 50110
LUSAKA

RE: REQUEST FOR PERMISSION TO CONDUCT A STUDY IN LUSAKA URBAN

I am pleased to inform you that your request to conduct your study in named health centres has been granted. The Ministry of Community Development Mother and Child Health has no objection for you to conduct this research on **Infant feeding and HIV: Ethnographic assessment of choices and decision outcomes on prevention of mother to child transmission experiences of HIV positive mothers.**

Kindly inform the District Medical Officer for Lusaka urban being the direct supervisor of the facilities.

We look forward to sharing the outcome of your study.

Prof. Elwyn Chomba
Permanent Secretary
MINISTRY OF COMMUNITY DEVELOPMENT MOTHER AND CHILD HEALTH

Appendix 18 Permission to carryout the research

Telephone: (260) 211 235341
Fax (260) 211 235342

In reply please quote:

No.:.....
MCDMCH/101/5/1

REPUBLIC OF ZAMBIA

MINISTRY OF COMMUNITY DEVELOPMENT, MOTHER AND CHILD HEALTH

OFFICE OF THE PERMANENT SECRETARY
COMMUNITY HOUSE
SADZU ROAD
PRIVATE BAG W 252
LUSAKA

27th June, 2013

Ms. Alice Ngoma Hazemba
University of Zambia
Department of Public Health
P.O. Box 50110
LUSAKA

RE: REQUEST FOR PERMISSION TO CONDUCT A STUDY IN LUSAKA URBAN

I am pleased to inform you that your request to conduct your study in named health centres has been granted. The Ministry of Community Development Mother and Child Health has no objection for you to conduct this research on **Infant feeding and HIV: Ethnographic assessment of choices and decision outcomes on prevention of mother to child transmission experiences of HIV positive mothers.**

Kindly inform the District Medical Officer for Lusaka urban being the direct supervisor of the facilities.

We look forward to sharing the outcome of your study.

Prof. Elwyn Chomba
Permanent Secretary
MINISTRY OF COMMUNITY DEVELOPMENT MOTHER AND CHILD HEALTH

Appendix 19

Ethical approval, UKZN

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

3 September 2013

Mrs Alice Ngoma Hazemba 211519338
School of Nursing and Public Health
Howard College Campus

Protocol reference number: HSS/0104/013D
Project title: Infant feeding and HIV: choices and decision outcomes on prevention of mother to child transmission: a qualitative inquiry of experiences of HIV positive mothers.

Dear Mrs Hazemba

Full Approval Notification – Committee Reviewed Protocol
This letter serves to notify you that your application in connection with the above has now been granted full approval.

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. Please quote the above reference number for all queries relating to this study. Please note: Research data should be securely stored in the discipline/department for a period of 5 years.

Best wishes for the successful completion of your research protocol

Yours faithfully

.....
Dr Shenuka Singh (Acting Chair)

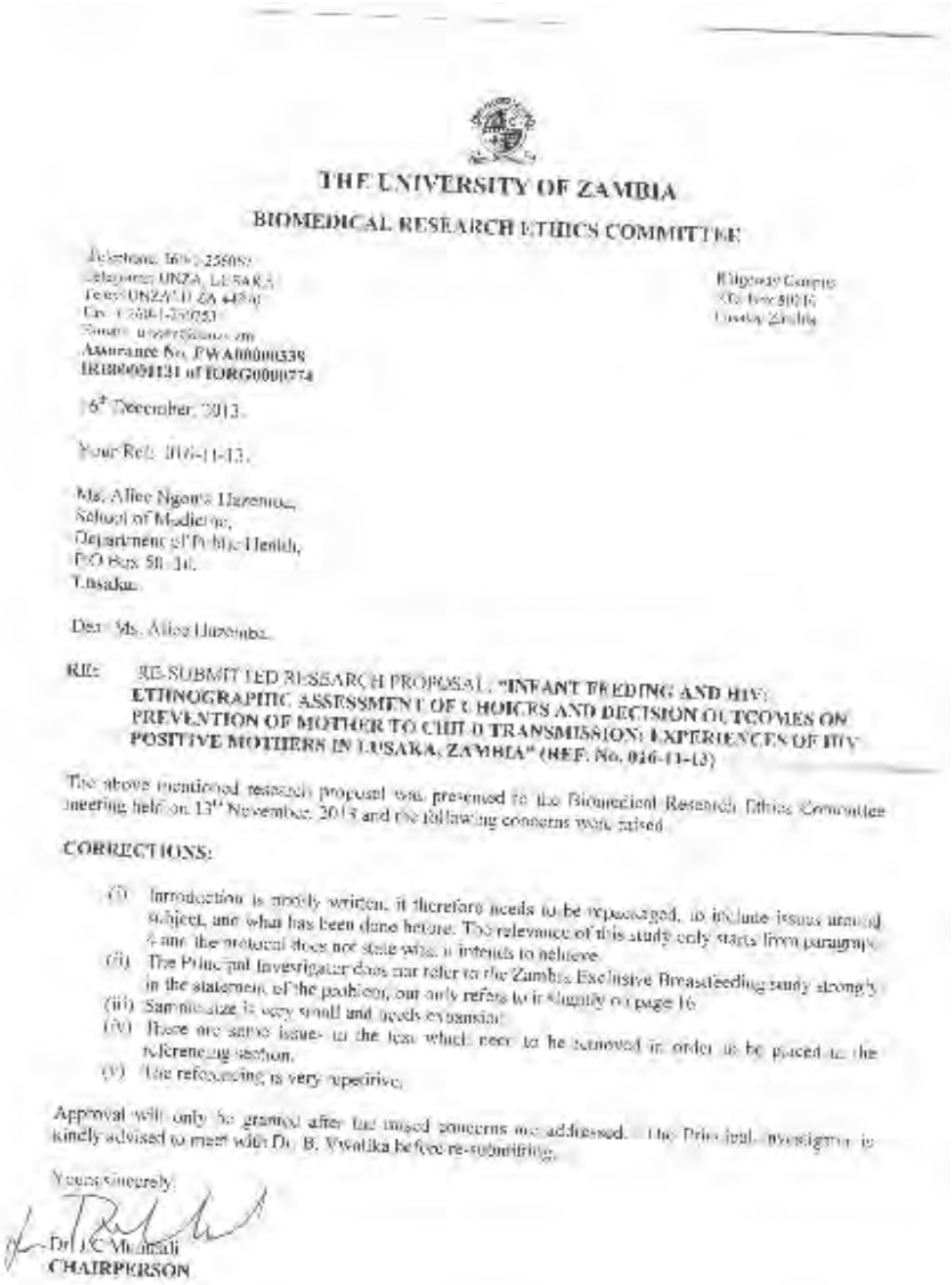
/px

cc Supervisor: Professor BP Ncama
cc Academic Leader Research: Professor M Mars
cc School Administrator Mrs C Dhanraj

Humanities & Social Sciences Research Ethics Committee
Dr Shenuka Singh (Acting Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban, 4000, South Africa
Telephone: +27 (0)31 260 3587/8350/4557 **Facsimile:** +27 (0)31 260 4609 **Email:** xmbap@ukzn.ac.za / snymarm@ukzn.ac.za / mohunc@ukzn.ac.za
Website: www.ukzn.ac.za
Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville

Appendix 20

Ethical approval, University of Zambia



THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

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Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

16th December, 2013.

Your Ref: 016-11-13.

Ms. Alice Ngoma Hazemba,
School of Medicine,
Department of Public Health,
P.O. Box 50110,
Lusaka.

Dear Ms. Alice Hazemba,

RE: RE-SUBMITTED RESEARCH PROPOSAL: **"INFANT FEEDING AND HIV: ETHNOGRAPHIC ASSESSMENT OF CHOICES AND DECISION OUTCOMES ON PREVENTION OF MOTHER TO CHILD TRANSMISSION: EXPERIENCES OF HIV POSITIVE MOTHERS IN LUSAKA, ZAMBIA" (REF. No. 016-11-13)**

The above mentioned research proposal was presented to the Biomedical Research Ethics Committee meeting held on 13th November, 2013 and the following concerns were raised.

CORRECTIONS:

(i) Introduction is poorly written, it therefore needs to be repackaged, to include issues around subject, and what has been done before. The relevance of this study only starts from paragraph 5 and the protocol does not state what it intends to achieve.
(ii) The Principal Investigator does not refer to the Zambia Exclusive Breastfeeding study strongly in the statement of the problem, our only refers to it slightly on page 16.
(iii) Sample size is very small and needs expansion.
(iv) There are server issues in the text which need to be removed in order to be placed in the referencing section.
(v) The referencing is very repetitive.

Approval will only be granted after the raised concerns are addressed. The Principal Investigator is kindly advised to meet with Dr. B. Vwalika before re-submitting.

Yours sincerely,

Dr J.C Mudenda
CHAIRPERSON

Appendix 21 Editing assistance letter

grammarline
editing services

30 September 2015

To whom it may concern

This is to certify that I provided editing assistance to Alice Ngoma-Hazemba in the preparation of her doctoral thesis, "HIV and infant feeding: choices and decision outcomes in the context of prevention of mother-to-child transmission among HIV-positive mothers in Zambia".

The editing covered English grammar, idiom, orthography, punctuation and sentence structure.

I will be happy to furnish additional information if requested.

David Newmarch BA (Hons)(Natal), M Phil (York)

Associate
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