

The mother, her confidants and the prevention of mother-to-child transmission of HIV (PMTCT) services in the Kilimanjaro region, Tanzania

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Scientific environment

This study emerged from the Centre for International Health, Faculty of Medicine and Dentistry, University of Bergen, Norway. The existing collaboration with the Department of Community Health, Tumaini University, Kilimanjaro Christian Medical College, facilitated the research project.

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II

Eli Fjeld Falnes, Karen Marie Moland, Thorkild Tylleskär, Marina Manuela de Paoli, Sia E Msuya, Ingunn MS Engebretsen: "It is her responsibility": partner involvement in prevention of mother to child transmission of HIV programmes, northern Tanzania

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III

Eli Fjeld Falnes, Karen Marie Moland, Thorkild Tylleskär, Marina Manuela de Paoli, Sebalda C Leshabari, Ingunn MS Engebretsen : The potential role of mother-in-law in prevention of mother-to-child transmission of HIV: a mixed methods study from the Kilimanjaro region, northern Tanzania

Submitted

List of abbreviations

AFASS	Affordable, feasible, acceptable, sustainable and safe
AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
AZT	Zidovudine
CVCT	Couple voluntary counselling and testing
DHS	Demographic and Health Survey
DPT-HB	Diphtheria, pertussis, tetanus and hepatitis B
EBF	Exclusive breastfeeding
EPI	Expanded Programmes for Immunisation
FGD	Focus group discussion
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
IATT	Interagency Task Team on Prevention of HIV Transmission in Pregnant Women, Mothers and their Children
KCMC	Kilimanjaro Christian Medical Centre
MCH	Mother and child health
MTCT	Mother-to-child transmission of HIV
NGO	Non-governmental organisation
NVP	Nevirapine
PCA	Principal component analysis
PITC	Provider initiated testing and counselling
PMTCT	Prevention of mother-to-child transmission of HIV
RCH	Reproductive and child health
UNAIDS	Joint United Nations Program on AIDS
UNFPA	United Nations Population Found
UNICEF	United Nations International Children's Emergency Fund
ZDV	Zidovudine
VAS	Visual Analogue Scale
VCT	Voluntary counselling and testing
WHO	World Health Organisation
3TC	Lamivudine

Summary

Introduction

In Tanzania, the prevention of mother-to-child transmission of HIV (PMTCT) programme was introduced in 2000 and has thereafter been scaled up. The overall aim of this thesis from the Kilimanjaro region, was to assess mothers' knowledge and utilization of the PMTCT services eight years after the programme was introduced, focusing on the role of significant others, and to yield knowledge that can be used to improve the PMTCT programme implementation and its utilization.

Methods

This study was conducted in 2007 and 2008 in rural and urban areas of Moshi in the Kilimanjaro region of Tanzania. Mixed methods were used. We interviewed 446 mothers when they brought their four-week-old infants to one of five reproductive and child health clinics for immunization. We also conducted 13 focus group discussions with mothers, fathers and mothers-in-law. Further, 34 in-depth interviews were carried out with health personnel, mothers, fathers, mothers-in-law and HIV-infected mothers. We also conducted observations of mothers receiving counselling.

Results

Routine testing for HIV of women at the antenatal clinic was highly accepted among all participants. Compared with previous studies in the area, this study found that PMTCT knowledge among the mothers had increased. However, the nurse counsellors - although knowledgeable and motivated - did not have sufficient time to counsel the mothers adequately. The mothers seemed particularly confused about the infant feeding options for an HIV-infected mother.

Very few men joined their wives at the antenatal clinic for testing. The main barriers reported were that women did not have the authority to request their husbands to test for HIV, and that the arena for testing, the antenatal clinic, was defined as a female domain where men were out-of-place. The recommendation of using condoms during pregnancy and breastfeeding was met with resistance, and the male partners did not accept a non-customary infant feeding method without having been given the rationale for it.

The mother-in-law saw herself as responsible for family health issues in general and child care in particular. However, she received limited trust, and couples, particularly those living in urban areas, tended to exclude her from decisions concerning family health issues and infant feeding. Mothers-in-law expected their daughters-in-law to breastfeed in a customary manner and were generally negative towards the infant feeding methods recommended for an HIV-infected mother i.e. exclusive replacement feeding and exclusive breastfeeding.

Conclusion

The implementation of routine counselling and testing facilitated testing of the mother, partly by reducing stigma associated with testing. However, the mothers' participation in the programme was hampered by lack of male partner involvement, inadequate counselling, and insufficient knowledge about safe infant feeding.

The study clearly demonstrated that efforts promoting male partner involvement, such as asking the women to bring their partners, have so far been insufficient. To improve male involvement, we argue that strategies adapting local realities and which are cultural sensitive need to be explored.

The study also demonstrated that the infant feeding counselling was unclear, both due to insufficient time to deliver the counselling and guidelines that conflicted with local knowledge and reality construction. Thus there is need to augment counselling capacity, so that the counselling is clear and sufficient to enable the mothers to take preventive actions. The infant feeding choice was strongly influenced by the male partner, and in many cases also by the mother-in-law. Therefore, information about safe infant feeding needs to be delivered also to those surrounding the mother.

Summary in Swahili

Muhutajari

Utangulizi

Zaidi ya asilimia 90 ya watoto wanaoishi na virusi vya ukimwi wapeta maambukizo kutoka kwa mama zao. Nchini Tanzania, mpango wa kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa motto ulianzishwa mwaka 2000 na umekuwa ukipanuliwa siku hadi siku. Madhumuni makuu ya kazi hii iliyofanyika mkoani Kilimanjaro yalikuwa kupima uelewa wa kina mama juu ya mpango wa kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa mtoto na kupima utumiaji wa huduma hiyo baada ya miaka minane tangu mpango ulipoanzishwa. Lengo ni kutaka kuboresha huduma zinazotolewa katika mpango wa kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa motto.

Kazi ilivyofanyika

Utafiti huu ulifanyika kati ya mwaka 2007 na 2008 katika mkoa wa Kilimanjaro ukihusisha sehemu za mijini na vijijini. Njia tofauti za utafiti zilitumika kukamilisha tafiti hii. Tuliwasaili kina mama 446 wenye watoto wa umri wa wiki nne ambao waliletwa kwenye kliniki tano kwa ajili ya chanjo. Tuliendesha pia mijadala 13 ya makundi tofauti. Mijadala mitano ilihusisha kina baba, minne ilihusisha kina mama na minne mingine ilihusisha kina mama mkwe. Zaidi ya hapo tulifanya usaili yakinifu na watu 34. Kati ya hao, 11 walikuwa watoa huduma za afya, 8 kina mama, 5 kina baba, 5 kina mama mkwe na mitano na kina mama walioathirika na virusi vya ukimwi. Kwa nyongeza tuliangalia vipindi vine vya ushauri nasaa vinavyotolewa kabla na baada ya kupima ukimwi.

Matokeo

Watu walioshiriki kwenye utafiti wameonyesha kuwa na uelewa mkubwa wa mpango wa kuzuia maambukizi toka kwa mama kwenda kwa mtoto. Washiriki wa utafiti wanaukabili utaratibu wa upimaji wa virusi vya ukimwi kwa kina mama wanao udhuria kliniki ya wajawazito. Karibu akina mama wote (98%) walipewa nafasi ya kupima ukimwi, na wote waliopeva nafasi hiyo walikubali kupima ukimwi. Ukilinganisha na tafiti zilizopita katika eneo hili, utafiti wetu unaonyesha uelewa wa kina mama kuhusu mpango wa kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa motto umeongezeka. Japokuwa watoa ushauri nasaa wana uelewa na mori, lakini hawana muda wa kutosha wa kutoa ushauri kwa kina mama kama inavyopaswa. Akina mama walioathirika na virusi vya ukimwi walionekana kuchanganyikiwa juu ya uchaguzi wa jinsi ya kumlisha mtoto Karibu akina mama wote waliofanyiwa utafiti (95.5%) walisema wanatiwa moyo na washauri nasaa kuwaleta wanaume wao kwenye kliniki ya wajawazito kwa ajili ya upimaji wa virusi vya ukimwi. Hata hivyo ni wanaume wachache sana walikubali kuja kupima na wanawake zao. Kati ya vikwazo vilivyotajwa ni pamoja na wanawake kutokuwa na mamlaka ya kumwomba mwanaume akapime virusi vya ukimwi na kliniki ni eneo la wanawake na hivyo wanaume wanaona siyo mahali pao. Mapendekezo ya kutumia kondomu wakati wa ujauzito na unyonyeshaji usio wa kawaida yalipokelewa kwa vipingamizi na wanaume na walitaka wajue sababu za msingi za kuto mnyonyesha mtoto kwa njia ya kawaida

Mama mkwe anajiona anawajibika kwa maswala ya afya ya familia na ya mtoto. Lakini hata hivyo wakwe hawaminiki sana yanapokuja maswala ya afya ya familia na ulishaji wa mtoto, hili lipo hasa kwa watu wanao ishi mijini. Na hivyo basi huwa hawausishwi katika maswala yanayohusu afya ya familia na unyonyeshaji wa mtoto. Mkwe anategemea mke wa mwanae anyonyeshe mtoto anapozaliwa, hivyo huwa hawakubaliani na swala la kutomnyonyesha mtoto ziwa la mama.

Hitimisho

Utaratibu wa ushauri nasaa katika kliniki ya wajawazito umesaidia upimaji wa virusi vya ukimwi kwa kina mama kwa sababu kwa kiasi fulani unapunguza unyanyapaa unao ambatana na upimaji wa virusi vya ukimwi. Ushiriki wa kina mama katika mpango wa kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa mtoto uliingiliwa na dosari ya kukosekana kwa maudhurio ya kina baba, ushauri nasaa usiojitosheleza na kutokuwa na uelewa wa kutosha wa jinsi ya njia salama za kumnyonyesha mtoto

Utafiti umeonyesha kwamba juhudi za kumshirikisha mwanaume kwa kumwambia mama mjamzito amlete mwanaume wake kliniki hazitoshi. Ili kuboresha ushirikishwaji wa wanaume, utafiti huu unashauri kwamba mbinu nyingine zitakazotumia manzingira halisi za faa kuchunguzwa.

Utafiti pia umeonyesha kwamba ushauri nasaa wa jinsi ya kumnyonyesha mtoto hauweleweki, kwa sababu muda wa kutoa ushauri nasaa hautoshi na mwongozo uliopo unakinzana na maarifa asilia. Hivyo inabidi kuimarisha utoaji ushauri nasaa ili ushauri unaotelewa uweleweke, ujitosheleze na umwezeshe mama kuchukua hatua sahihi za kuzuia maambukizi ya virusi vya ukimwi kutoka kwa mama kwenda kwa mtoto. Baba ndiye muamuzi wa njia gani itumike kumnyonyesha mtoto na mara nyingine mama mkwe huwa na maamuzi hayo. Hivyo basi, taarifa kuhusu unyonyeshaji salama zinapaswa kutolewa kwa jamii inayo mzunguka mama

Summary in Norwegian

Introduksjon

Hovedmålsetningen med denne avhandlingen fra Kilimanjaro regionen var å studere mødres kunnskap om og bruk av helseprogrammet for forhindring av mor-til-barn smitte av HIV (PMTCT), åtte år etter at programmet ble etablert i regionen, med fokus på rollen til hennes partner og svigermor. I tillegg søkte vi å få kunnskap som kan bli brukt til å forbedre helseprogrammet videre.

Metoder

Studien ble utført i 2007 og 2008 på landsbygden og i byen Moshi i Kilimanjaro regionen i Tanzania. Vi kombinerte kvalitative og kvantitative metoder: 446 mødre ble intervjuet når de kom til klinikkene for å vaksinere barna sine som var fire uker gamle. Vi utførte også 13 fokus gruppe diskusjoner med fedre, mødre og svigermødre. Videre ble 34 dybdeintervjuer utført med helsepersonell, mødre, fedre, svigermødre og HIV smittede mødre. Fire systematiske observasjoner ble gjennomført på klinikkene der mor fikk råd av helsepersonell før og etter HIV testing.

Resultater

Rutinemessig HIV testing av mødre som en del av svangerskapsomsorgen var akseptert av samtlige deltakere. Sammenliknet med tidligere studier i området, fant vi at kunnskapen blant mødre om forhindring av mor-til-barn smitte av HIV hadde økt. Til tross for at sykepleierne var kunnskapsrike og motiverte, hadde de ikke tilstrekkelig tid til å gi mødrene tilfredsstillende råd. Mødrene syntes å være spesielt forvirret i forhold til hvordan en HIV smittet mor skulle mate barnet sitt.

Svært få menn ble med konen sin til svangerskapsklinikken for å teste seg. Ifølge vår studie hadde ikke kvinnene autoritet til å be mannen om å teste seg for HIV. Videre var stedet for testingen, svangerskapsklinikken, definert som et sted for kvinner hvor menn ikke hadde noe å gjøre. Anbefalingen om å bruke kondom gjennom svangerskapet og ammeperioden ble møtt med motstand av de mannlige partnerne. Dersom de mannlige partnerne ikke ble gitt en forklaring først, aksepterte de ikke at kvinnen matet barnet på annen måte enn den tradisjonelle.

Svigermoren så seg selv som ansvarlig for helsespørsmål i familien, spesielt vedrørende barnestell. Imidlertid ble hun vist lite tillit, og spesielt par som bodde i de urbane områdene pleide å holde henne utenfor i avgjørelser som hadde med familiehelse og mating av barn å gjøre. Svigermødrene forventet at svigerdatteren skulle mate barnet på tradisjonelt vis og var generelt negative til de måtene å mate barnet på som var anbefalt for en HIV smittet mor; utelukkende erstatningsføde eller utelukkende amming.

Konklusjon

Implementeringen av rutine testing og rådgivning ved svangerskapsklinikkene gjorde det lettere for mødre å teste seg for HIV, delvis ved å redusere stigmaet assosiert med testing. Mødrenes deltakelse i programmet var imidlertid hindret av mangel på involvering av partner, utilstrekkelig rådgivning og manglende kunnskap om trygg mating av barn.

Studien viste tydelig at tiltak for å fremme deltakelse av mannlige partnere, slik som å spørre kvinnen om hun kan ta med seg mannen, har så langt vært utilstrekkelige. For å øke deltakelsen av menn argumenterer denne studien med at strategier som tar hensyn til lokale forhold må utforskes.

Videre viste studien at rådgivningen vedrørende mating av barn var uklar grunnet utilstrekkelig tid til å gi råd og fordi retningslinjene kom i konflikt med lokal kunnskap og forståelse. Det er derfor et behov for å øke rådgivningskapasiteten slik at rådene som gis er klare, tilstrekkelige og gjør moren i stand til å ta preventive forhåndsregler. Valget av hvordan barnet skulle mates var tydelig påvirket av den mannlige partneren, og i mange tilfeller også svigermoren. Det er derfor viktig at informasjonen om trygg mating av barn også blir gitt til de som står moren nær.

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Introduction

Even though there are effective interventions to reduce the risk, mother-to-child transmission (MTCT) of HIV remains a huge global health problem [1, 2]. The prevention of mother-to-child transmission of HIV (PMTCT) programme is being scaled up and making progress in most parts of the world. Nevertheless, there are still many unresolved challenges to the utilization of the programme by mothers. In this thesis, the focus will be on some of these challenges in the Kilimanjaro region, north-east Tanzania, namely: knowledge gaps, utilization and acceptability of the programme in general, involving the acceptability of testing, the quality of the counselling provided, and the influence and involvement of significant people in the mother's life, represented by the male partner and the mother-in-law.

PMTCT

Mother-to-child transmission of HIV

Although the rates of transmission are decreasing, 370 000 children were newly infected with HIV in 2009 [1]. This raised the estimated number of children living with HIV to 2.5 million (1.7-3.4 million) in 2009 [1]. Sub-Saharan Africa remains the region most heavily affected by HIV. In 2008, the region accounted for 67% of HIV infections worldwide, 68% of new HIV infections among adults and 91% of new HIV infections among children [3]. Over 90% of the children living with HIV are infected through MTCT [4]. In the absence of any intervention, the estimated risk of transmission is 5-10% during pregnancy, 10-20% during labour and delivery, and 5-20% through breastfeeding [5]. Thus, the rate of MTCT is approximately 15-30% in non-breastfeeding HIV-infected populations where there is no intervention. With prolonged breastfeeding into the second year of life, the cumulative likelihood of infection can be as high as 45% [5]. However, in high income countries, MTCT rates of < 2% are reported, due to routine testing, access to antiretroviral (ARV) therapy, caesarean section before onset of labour or rupture of membranes, and the use of safe, affordable and accessible breast milk substitutes [6, 7]. In Norway, there has been zero transmissions since year 2000 [8].

The prevention of mother-to-child transmission programme

Following initial reports of the efficacy of various antiretroviral regimens for prevention of peripartum MTCT of HIV [9-11], governments in many high HIV prevalence countries started implementing PMTCT programmes from 1998. However, the issue of PMTCT was complex. There were many controversies, particularly surrounding confidentiality, stigma and whether breastfeeding should be recommended when a mother was infected with HIV [12]. A new task force, the UN Interagency Task Team (IATT) on MTCT was established in 1998 to develop and publish guidelines and recommendations. It involves UNICEF (United Nations International Children's Emergency Fund), UNFPA (United Nations Population Fund), WHO (World Health Organisation), the World Bank and UNAIDS (Joint United Nations Program on AIDS) Secretariat and works with the governments of various low and middle-income countries to set up PMTCT programmes [12]. In 2003, the

United Nations adopted a comprehensive strategic approach to the prevention of HIV infection in infants and young children that includes the following four components [13]:

1. Primary prevention of HIV infection among women of childbearing age;
2. Preventing unintended pregnancies among women living with HIV;
3. Preventing HIV transmission from a woman living with HIV to her infant; and
4. Providing appropriate treatment, care and support for mothers living with HIV and their children and families.

This thesis will focus mainly on the first and third components. The first component, primary prevention of HIV infection among women of childbearing age, is one of the most cost-effective ways of preventing HIV infections among children [14], but has so far been less prioritized in the PMTCT programmes [15]. Interventions include health information, education on HIV and sexually transmitted infections, HIV testing and counselling and promotion of condom use [2]. A large proportion of new HIV infections occur among HIV discordant couples [16], which highlights the importance of male involvement and condom use. However, the promotion of condom use faces problems due to the negative association with lack of trust, so compliance remains low [2].

The third component, prevention of HIV transmission from a woman living with HIV to her infant, requires a set of sequential interventions [2]:

1. HIV testing and counselling for pregnant women and their partners;
2. Clinical and immunological (CD4) assessment to determine the eligibility of the mothers for treatment;
3. Antiretroviral therapy for eligible mothers for their own health, or antiretroviral prophylaxis for mothers and antiretroviral prophylaxis for their infants to prevent vertical transmission;
4. Safer delivery practices;
5. Counselling on and support for feeding infants and young children in the context of HIV

The first and fifth of these interventions will receive most attention in this thesis.

Routine counselling and testing as part of the antenatal services

HIV testing and counselling for pregnant women is the main gateway to providing HIV prevention, treatment, care and support services to women and children in resource-limited settings [2]. Of equal importance is knowledge of HIV status among HIV-negative pregnant women, to provide them with the necessary information to remain uninfected, in particular during pregnancy and breastfeeding [2]. Although voluntary counselling and testing (VCT) has existed for over 20 years, the global coverage of HIV testing and counselling programmes has remained low [2]. There has been growing evidence suggesting that provider-initiated HIV testing and counselling (PITC), also known as routine counselling and testing or 'opt-out' approach, facilitates diagnosis and access to treatment [17]. As access to antiretroviral (ARV) treatment was scaled up in low and middle income countries, it was seen as critical to simultaneously expand access to HIV prevention strategies [18]. In 2004, WHO and UNAIDS recommended routine counselling and testing for pregnant mothers in generalized epidemic settings, defined as a HIV prevalence of > 1% among pregnant women [18], and in 2007 they issued guidance on provider-initiated HIV testing and counselling in health facilities [17]. The guidelines recommend that HIV testing and counselling is offered to all women attending antenatal, delivery and postnatal services in

generalized epidemics [17]. Implementation of routine counselling and testing are thought to contribute to normalizing HIV as an integral part of the package of maternal, newborn and child health services [15]. Several studies from sub-Saharan Africa has shown that the introduction of routine counselling and testing as part of the antenatal care services has increased HIV testing among pregnant women [2, 17, 19-22]. According to WHO, routine HIV testing is justified on clinical and public health grounds in the described settings. However, concerns have been expressed about the potential negative impact this approach has on women. Women are more often likely to be offered testing than men because of regular contact with the healthcare system, and thus will be more likely the first of a couple who is tested. At the same time, women are more likely to face stigma, violence and abuse when disclosing a HIV-positive result to their partner [23, 24]. The routine counselling and testing model has also received criticism for putting a low focus on counselling, with the risk of undermining autonomy and reducing the focus on the preventive aspects of HIV testing [24-26]. The scale-up of the testing has not been met by a simultaneous scale-up of human resources in the health sector, thus adding further tasks to an already heavily burdened health system [21, 22, 27-29]. Furthermore, it has been questioned whether it is truly possible to opt-out [23-25]. Health personnel enjoy high social status and patients commonly obey their authority [23, 25]. Fear of receiving inferior care as a result of opposing routine testing may make it difficult to opt-out [23]. Although significant advances have been made in providing access to antiretroviral therapy (ART) in many countries in sub-Saharan Africa, there is still a lack of follow up with access to treatment for all those testing positive. Rennie and Behets ask: “to what extent does access to treatment have to be ‘assured’ before routine HIV-testing policy is justified on human rights ground?”[23]. Correspondingly, Maman argues that efforts to expand access to testing must be run in parallel with efforts to expand treatment access [24].

Antiretroviral therapy

As a result of the global scale up of the PMTCT programme, 45% of pregnant women living with HIV in low- and middle-income countries received ARV drugs in 2008, up from 35% in 2007, and 10% in 2004 [2]. Since the first issued PMTCT ARV guidelines from WHO and UNAIDS in 2000, further evidence on the safety and effectiveness of various antiretroviral regimens has accumulated and the guidelines have been revised accordingly in 2004, 2006 and 2010 (Appendix 1). The 2006 guidelines represented an advance from previous recommendations by emphasising the importance of providing lifelong ART to eligible pregnant women to protect their own health and that of their children. They also moved from provision of a single dose of the drug nevirapine (NVP) to the mother and newborn to a more effective combination of drugs for prophylaxis [30]. However, significant evidence has accumulated since the 2006 guidelines, especially with regard to: 1) the benefits of starting ARV prophylaxis earlier during pregnancy; and 2) ARV prophylaxis for mothers or infants significantly reduce the risk of transmission through breastfeeding. Thus, the 2010 guidelines recommend earlier ART for a larger group of HIV-infected pregnant women and longer provision of ARV prophylaxis for HIV-infected pregnant women who do not need ART for their own health [31]. For the first time there is now enough evidence to recommend provision of ARV's to the mother or the child to reduce the risk of HIV transmission during the breastfeeding period. Several studies has demonstrated that the provision of highly active antiretroviral therapy (HAART) to the mother in pregnancy and the breastfeeding period reduce the risk of MTCT [32-35]. A similar low risk

of MTCT has been found when the infant is given ARV prophylaxis [34, 36]. There are advantages and disadvantages for both methods, in terms of feasibility, cost and safety for mothers and infants. The guidelines recommend that the choice for a preferred option should be made and supported at country level [31]. There is still need for more information on potential side effects and the risk of developing resistance for both the mother and the infant.

Infant feeding guidelines for HIV-infected mothers

Infant feeding in the context of HIV is complex because of the major influence that feeding practices exert on child survival. The dilemma is to balance the risk of infants acquiring HIV through breast milk with the higher risk of death from causes other than HIV, in particular undernutrition and serious illnesses, such as diarrhoea, among non-breastfed infants. WHO, UNICEF and UNAIDS have issued a series of revised guidelines on infant feeding for HIV-infected mothers in resource-poor settings over the time period 1992-2010 (Appendix 2) [37]. During these years there has been a change from the 1992 guidelines recommending that HIV-infected mothers should breastfeed in countries with high infant mortality [38], to an increased focus between 1998-2007 on replacement feeding as the safest infant feeding method for HIV-infected mothers, and to re-establishing breastfeeding as the recommended method for HIV-infected women in settings with high infant mortality based on the same epidemiological argument as in 1992, namely the risk of death from replacement feeding could be greater than the risk of acquiring HIV through breastfeeding in resource poor settings.

The 2001 guidelines were issued following new evidence of the risk of HIV-infection when breastfeeding and the elimination of post-natal HIV transmission when exclusive replacement feeding was practised [5, 39, 40]. However, the AFASS criteria introduced, “*When replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), avoidance of all breastfeeding by HIV-infected mothers is recommended*”, were seen as difficult to adopt in resource poor settings. New guidelines were developed in 2006 [41] due to increasing evidence on the reduced risk of transmission when exclusively breastfeeding (EBF) compared to mixed feeding [42, 43] and the increased morbidity and mortality if not breastfeeding [44-46]. In these guidelines, child survival was regarded as a greater goal than the avoidance of HIV infection, and EBF was recommended if the AFASS conditions for replacement feeding could not be met. Neither early nor abrupt cessation was recommended any longer; neither was cow’s milk as replacement feeding [47].

In the 1997 infant feeding guidelines, the so-called ‘informed choice’ was introduced; the decision about whether or not to breastfeed should be made by every mother based on full information of the available options [48]. There has been a lot of discussion on how ethical it is to present HIV-infected mothers in poor resource settings with a choice of infant feeding method, when women often experience that there is no choice [49, 50]. In the most recent 2010 guidelines from WHO [51], it is emphasised that the national health authorities should decide whether health services will principally counsel and support mothers known to be HIV-infected to either: 1) breastfeed and receive ARV interventions, or 2) avoid all breastfeeding. That is, the mothers are given a single option as the standard of care, but will also receive information about other options. Mothers who breastfeed should exclusively breastfeed their infants for the first six months of life, introducing complementary foods

thereafter, and continue breastfeeding for the first 12 months of life. When the mother decides to stop, it should be done gradual over one month [52]. Formula feeding has received an even less prominent position than in the 2006 guidelines, and it is emphasised that it should only be given if the mother can meet all the AFASS criteria. To replace breastfeeding when these conditions are not met can be hazardous to the child, whether the mother is HIV-infected or not [44, 53, 54].

Counselling

General

High quality counselling is key to the success of the PMTCT programme. Lack of understanding of the messages given at the clinic may hinder utilization of the PMTCT services provided [55-58]. Nevertheless, there are many barriers to adequate counselling. The counsellors are supposed to deliver complex biomedical information about transmission of HIV and preventive measures to a population with varying levels of education. Quality counselling takes time; within the context of the busy antenatal clinics, it is not surprising it has often been found poor [55, 58-60]. The implementation of PMTCT at the antenatal clinics has increased the staff workload [27, 28]. The constantly increasing workload and chronic shortage of staff reduces the quality of care. Additionally, the frequent shift in guidelines and lack of time to keep staff updated compromise the counsellors' knowledge about PMTCT, and thus the quality of the counselling provided. Inadequate counselling has been shown to be an important reason for the mothers' lack of knowledge about PMTCT [27, 28, 55, 56, 58, 60].

Infant feeding counselling

Infant feeding counselling is an important component of PMTCT programmes. Improved infant feeding practises could result in significant reduction in child mortality through decreased postnatal transmission of HIV, and reduced morbidity and death from infectious diseases. The counselling skills of health workers are key factors in improving the feeding practices [61]. However, this counselling has been suffering from problems associated with the frequent shifts in the policy and lack of time to follow up the new guidelines [37]. Lack of confidence among the counsellors has been a major barrier to the infant feeding counselling. The nurse counsellors have been confused about the feeding messages they should be disseminating [28, 58, 59], and have had limited time to update themselves [28, 62]. Consequently, mothers have been receiving mixed messages that have led to confusion of which infant feeding method to choose; thus many have ended up mixed feeding [61]. The counsellors also have to deal with the challenges the mothers face related to the feasibility and acceptability of their infant feeding recommendations. Infant feeding is an issue which is subjected to social pressure and control, and the mother is often left to choose between the advice from the health personnel or from influential people surrounding her. Recommended infant feeding methods often conflict with local knowledge, practices and reality constructions. The customary mixed feeding pattern - breastfeeding with early supplements of fluids and solids - strongly increases the risk of transmission [42, 63]. Mothers who do not breastfeed are often suspected of being HIV-infected, and not to breastfeed is associated with poor mothering [64, 65]. Thus the stigma associated with replacement feeding prevails [64] and disclosure of HIV status, which is seen as a precondition for optimal infant feeding, continues to be a major challenge. Additionally, lack of resources often makes replacement feeding an impossible option. If the mother

chooses to EBF, she might face difficulties when she needs to leave the child for work. Furthermore, deep-seated ideas about insufficient milk and the need for water prevail and are prominent barriers to EBF [66].

PMTCT and significant people surrounding the mother

Participation in the PMTCT programme forces pregnant women to think about and make decisions on complex and sensitive issues such as HIV testing, drug treatment and alternative infant feeding practices. Included in this process are partners, family, and community members, who may influence the decisions that pregnant women make about each of these issues.

Male involvement in PMTCT

The male partner is a key contributor to the mother's utilization of the PMTCT programme; the importance of involving him in the programme has been increasingly recognised [2, 15]. He plays a role both in terms of the mother's risk of acquiring HIV [67] and her utilization of the PMTCT programme: for the mother to test for HIV [57, 68-72], for her to return for result [57, 72], for the couple to use condoms [70, 73, 74], for the mother to receive medication [57, 73, 75], and for her to follow infant feeding advice [62, 73, 75-79]. In several studies, mainly from sub-Saharan Africa, fear of a partner's negative reaction towards the mother testing for HIV and fear of disclosure of the test results [69, 71, 80-82] are barriers to HIV testing by pregnant women in the PMTCT programme. The women's fears appear related to abandonment, stigma and violence [80, 81]. At the same time, many studies have shown that the negative attitudes ascribed men are often exaggerated, both by their female partner and health personnel [73, 83-85]. Indeed, men are quite supportive of their partners participating in the PMTCT programme [80-82, 84]. A minority of the women who disclosed a HIV-positive test result experienced negative outcome. The majority of the partners was understanding and provided moral support [76, 80-82, 86], and the majority of the relationships continued after the disclosure of a HIV-positive test [74, 87]. Nevertheless, negative outcomes such as blame, abandonment, anger, violence, stigma and depression exist and need to be acknowledged [81].

Although the importance of partner involvement has been recognised, very few partners participate in antenatal HIV counselling and testing [2, 73, 75, 85]. In 2008, 57 countries documented the proportion of pregnant women attending antenatal care whose partner were tested for HIV, the average being 5% [2]. The antenatal clinic, the entry point for PMTCT, is virtually male-free. Men have not traditionally been involved in health seeking activities; hence the services offered at the clinic have not been accessed by men. Several studies have suggested that couple counselling and testing should be promoted within the antenatal setting [73, 75, 85, 87]. Other suggestions have been to make the antenatal clinic more male friendly, e.g. to have a special day in the week for men, a special waiting area, or to give them an invitation letter from the health personnel [84].

Role of mother-in-law

Little attention has been paid to the role of the mother-in-law in the PMTCT programme. In many sub-Saharan settings, especially where kinship is counted in the male line (patrilineal),

it is common for the married couple to reside with or near the husband's parents. This virilocal residence pattern tends to place the young woman in a position of dependence on her affinal kind, in particular her mother-in-law. Ethnographic research in sub-Saharan Africa shows that the mother-in-law plays an important role when it comes to infant feeding and infant care after delivery [88-92]. A study from Malawi showed that she commonly decided when to introduce foods other than breast milk to the infant [89]. The role of the mother-in-law as a complication in achieving safe infant feeding through EBF and early cessation was reported in a study from Cote d'Ivoire [88]. Another study from the Kilimanjaro region in Tanzania demonstrated that HIV-infected women who perceived replacement feeding as the best feeding option and spent their confinement period in their mothers-in-law's house all felt they had to breastfeed and ended up doing so [90]. They also experienced great problems preventing the mother-in-law from giving water and other supplements to the infant, often within the first days or weeks after birth [90]. The powerful influence of the mother-in-law has been shown to make the daughter-in-laws obey her in child feeding issues, rather than following hospital advice [89]. Nevertheless, the mother-in-law has so far been more or less ignored in the PMTCT programmes [93].

Rationale for this study in the Kilimanjaro region, Tanzania

PMTCT in Tanzania – experiences from implementation of the programme

Among the countries with the highest estimated numbers of pregnant women living with HIV, Tanzania is ranked fifth [2]. In 2007, the estimated HIV prevalence of pregnant women attending antenatal care was 8.2% [94]. The national PMTCT programme was launched in five hospitals in 2000 as a pilot project [95]. The experience gained in the pilot phase ending in 2003, was of a high acceptance rate of testing among pregnant women, but the voluntary opt-in strategy to counselling and testing impeded coverage [95]. Even though the counsellors were generally well motivated, they appeared to lack skills due to inadequate training. Counsellors were confused about the infant feeding issues as the messages were inconsistent and unclear. Further, the vast majority of the mothers did not disclose their HIV serostatus to their partner due to fear of abandonment and violence. The lack of disclosure and male involvement were prominent barriers to the mothers' utilization of the PMTCT services. Among the main recommendations in the evaluation report was to implement an opt-out approach of testing and counselling, improve the quality of the counselling, and increase community awareness of PMTCT [95]. In the national PMTCT guidelines from 2004 adhered to during our investigations, the importance of the involvement of the male partner in the programme was further emphasised. It was stated that all mother and child health (MCH) facilities should adopt strategies that encourage pregnant women to attend PMTCT providing facilities with their partners [96]. However, by the end of 2009 only 8% of male partners of pregnant women were aware of their HIV status [97]. Furthermore, the 2004 guidelines recommended implementation of routine counselling and testing [96]. The infant feeding guidelines included were in accordance with the 2001 guidelines from WHO [40], i.e. exclusive breastfeeding with early weaning or exclusive replacement feeding.

In 2007, updated national guidelines were introduced [98], in which routine counselling and testing were launched as the recommended strategy for HIV testing in the Tanzanian

reproductive and child health services (RCH). The antiretroviral treatment guidelines included were in accordance with the 2006 WHO ARV guidelines [30]. The infant feeding guidelines were in accordance with the 2006 WHO guidelines [41], with the exception that home-modified animal milk (which had been removed in the WHO 2006 version) continued to be an option in the national PMTCT guidelines.

Since the pilot in 2000, the PMTCT programme in Tanzania has been scaled up. By the end of 2008 the national coverage of health facilities offering PMTCT was 65% [97]. From 2005 to 2008, the proportion of HIV-infected women reached by PMTCT services increased from 11 to 80% [97]. Furthermore, the proportion of HIV-infected women who received ARV prophylaxis rose from 9 to 55% over the same time period [97].

Previous studies in the Kilimanjaro region

Before and during the pilot testing phase of PMTCT in Tanzania, four studies were conducted in the Moshi district of the Kilimanjaro region by de Paoli *et al.* [62, 77, 99, 100]. They were conducted at antenatal clinics and explored the mothers' knowledge about PMTCT, their infant feeding intentions, their willingness to test for HIV, and the counsellors' perspectives on the PMTCT programme. They found, among others, that the counselling given was insufficient, leaving the mothers confused about the messages they received. The findings called for further investigation on the broader, cultural context and the psychosocial stress the mothers face as participants in the PMTCT programme. Exploration of the importance of partner involvement in particular was emphasised [62, 77, 100].

In 2003-2004, a series of studies on the infant feeding counselling and decisions relating to the PMTCT programme were conducted in the Moshi district by Leshabari *et al.* [28, 64, 90]. These studies highlighted the importance of the social expectations of infant feeding and significant persons surrounding the mother, e.g. her partner and mother-in-law. They found that counsellors expressed a lack of confidence in their own counselling and that the mothers received insufficient infant feeding counselling.

A third series of studies in Moshi on the PMTCT programme and male partner involvement was conducted in 2002-2004 by Msuya *et al.* [67, 72, 75]. Male partner factors were important in determining whether women returned for test results. When actively encouraging the male partners to test for HIV, 12.5% of them came to the antenatal clinic and were tested. Women who managed to bring their partner for testing were significantly more likely to use nevirapine prophylaxis and to adhere to the infant feeding method selected than women who did not. The studies concluded that the traditional clinic-based approached reached few men, different approaches to encourage male partner attendance in the PMTCT programme should be explored.

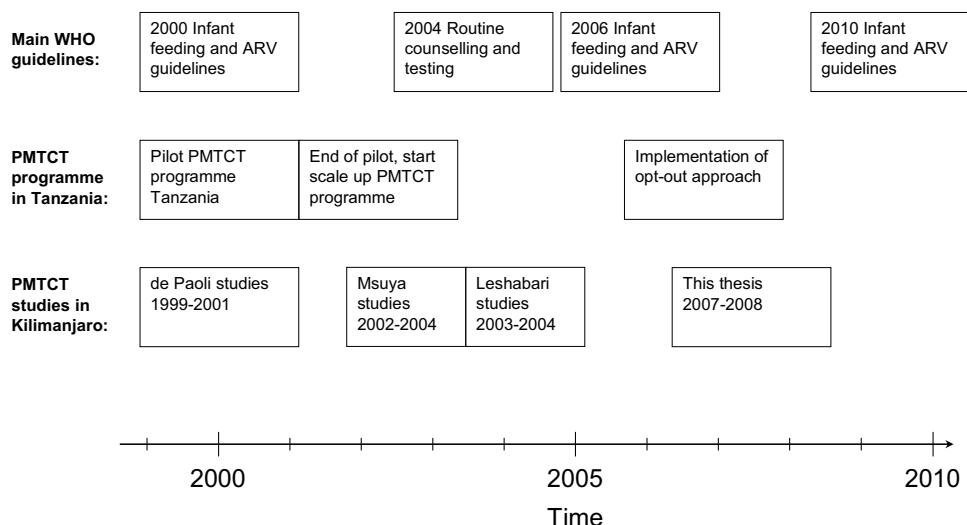


Figure 1: Timetable with an overview of the main WHO guidelines, the main PMTCT programme events in Tanzania and studies conducted in the region

Justification

A report from the pilot phase of the programme as well as findings from the three previous series of studies in the area, illustrated that there are several barriers to successful PMTCT programme implementation. At the time of the study, eight years had elapsed since the programme had been introduced, during which the programme had been scaled up and expanded country-wide. At this stage, we felt that there was a need to explore how the programme had developed in terms of knowledge about PMTCT among the mothers, the quality of the counselling given, and the mothers' acceptance and utilization of the programme. We also wanted to identify the strengths and the weaknesses of the different programme components, including testing and counselling, safe sex and infant feeding. Treatment and safe delivery were not included in the study because of time and resource constraints; participation in these components was also considered less controversial with regard to the role of the male partner and mother-in-law in this particular context.

Both the report from the pilot phase and the three previous series of studies pointed to the importance of involvement of significant others for the mothers' utilization of the programme. Significant others were in this area commonly defined as the male partner and the mother-in-law. In particular, there was a need to understand the factors that hinder male participation in the PMTCT programme, and how the partner influences the pregnant mother's utilization of and adherence to the programme. So far, there have been few qualitative studies focusing on the involvement of the partner. To understand factors hindering male participation, it was important to ask the men themselves and involve them as study participants. Furthermore, in Kilimanjaro, particularly its rural areas, the paternal grandmother remains influential in child care, but the mother-in-law/daughter-in-law

relationship has received little attention in studies related to PMTCT. Hence, there is a need to understand the influence of the mother-in-law has on a woman's utilization and adherence to the programme components, and to what extent the mother-in-law should be targeted for interventions in the PMTCT programme.

Study aims

The overall aim of this study was to assess mothers' knowledge and utilization of the PMTCT services eight years after the programme was established, focusing on the role of significant others, and to understand how to best improve the implementation and utilization of the PMTCT programme.

The aims of Paper I were:

- 1) to assess the utilization of the PMTCT services, in particular HIV counselling and testing, in five reproductive and child health clinics in Moshi after the implementation of routine counselling and testing;
- 2) to explore the level of knowledge the postnatal mothers had about PMTCT; and
- 3) to assess the quality of the counselling given.

The aims of Paper II were to explore the acceptability of the PMTCT programme components and identify structural and cultural challenges to male involvement. More specifically, the study explored the men's attitudes to the testing procedure and partner disclosure, condom use, and infant feeding recommendations.

The aim of Paper III was to explore the influence of mothers-in-law on PMTCT service utilization. More specifically the study sought to explore:

- 1) expectations and experiences related to the influence of mothers-in-law on disclosure of HIV positive status and choice, and adherence to infant feeding method; and
- 2) the potential for the participation of mothers-in-law in the promotion and support of safe infant feeding practices.

Subjects and methods

Study setting

This mixed methods study was conducted from October 2007 to February 2008 in urban and rural areas of the Moshi district in the Kilimanjaro region of northeast of Tanzania (Figure 2).



Figure 2: Map of the Kilimanjaro region and surroundings

The Kilimanjaro region

Kilimanjaro is one of 26 regions in Tanzania, located in the north-eastern part of the country. The region is administratively divided into six districts: Rombo, Hai, Moshi rural, Moshi urban, Mwanza and Same. Moshi is the regional capital and is a rapidly expanding business centre. In the 2002 population census, it had 145, 000 inhabitants [101].

Kilimanjaro region can be divided into two distinct economic and cultural zones, namely the mountainous area (Mt. Kilimanjaro and Mt. Pare) and the plains [102]. The regional altitude varies substantially between these zones, which are reflected in the diverse vegetation and climatic conditions. People who live in the mountains are mainly involved in agriculture, primarily cultivating coffee and bananas. The drier, lower plain area is traditionally the home of pastoralists, the Masai in particular, with their moving livestock herds. The large population growth of the 20th century has resulted in increasing land pressure. Thus, this

division has gradually changed and agricultural people from the mountainous areas have moved to the plains and started cultivate the savannah, competing with the Masai for land [102]. In addition, the increasing scarcity of land and limited employment opportunities have forced young people to leave the villages and move to urban centres in search of jobs [102].

Population, health and development indicators

Kilimanjaro has ~1.4 million of the 34.4 million inhabitants of Tanzania [103], and is the most densely populated rural area. The majority of the population is subsistence farmers [102]. At the same time, they depend upon the market for a number of goods and services, and for sale of agriculture produce [102]. The population of Kilimanjaro is multi-ethnic, the most prominent tribes being the Chagga, the Pare and the Masai. The Chagga is the most dominant ethnic group not only in numerical terms, but also in terms of political and cultural influence. They are known to be the most well-educated and economically successful people in Tanzania. They also utilize public health services to a high extent [102, 104]. The second largest ethnic group is the Pare, closely related to the Chagga in terms of economic adaptation and their traditional political organisation [105]. The majority of the Chagga is Christian, while the Pare is mostly Muslim. Compared to national figures, the population of the Kilimanjaro region has a higher education rate (64.9 vs. 50.2% of the women had completed primary school) [106]. There is a near universal antenatal service coverage in the region (99 vs. 94% nationally). Most of the women in the region give birth in a health facility (70 vs. 47% nationally). Diphtheria, pertussis, tetanus and hepatitis B (DPT-HB) and polio immunisation at four weeks of age has a coverage of 100% in the Kilimanjaro region (cf. 93.3% nationally) [107]. (In most Expanded Programmes for Immunisation (EPI) in Africa, however, this immunisation is usually given at six weeks of age [108]). There is a strong tradition of breastfeeding in the region, with 98.4% of children having been breastfed [107]. The median duration of breastfeeding is 21 months [107]. However, although exclusive breastfeeding for six months is advocated nationally, only 41% of the infants below six months of age are exclusively breastfed in Tanzania [107]. The customary mixed feeding pattern involves early introduction of water, other fluids and porridge in addition to breast milk [99]. The under-five mortality rate was 112 per 1000 live births according to the 2004-2005 demographic health survey (DHS). Although this figure is still markedly high, a decline in mortality over the past years has occurred [107].

Family structure

In the Kilimanjaro region, kinship is still counted in the paternal line (patrilineal) [91, 102, 105], and when a woman marries she joins the lineage of her husband. Customarily, the man is the head of household. Although state law upholds equal rights for men and women, women cannot inherit land or livestock, but have access to property primarily through men as fathers, husbands and sons. Women's status is closely knit to reproduction and their role as mothers is basic in social life. Marriage has traditionally been viewed as a contract between two lineages and the transfer of the bridal wealth gives the husbands lineage claim to the offspring [91, 105]. In this system, the conjugal union has been relatively weak. Decisions related to reproduction and family health in this context have not been made solely by the couple, but have involved the extended family, particularly the husband's parents [105]. The traditional patrilocal residence pattern in the region implies that women move to their husband's home after marriage. High pressure on land in the highlands has

reduced the importance of this custom among the Chagga, but it is still upheld in rural areas, particular among the youngest sons who are expected to take over the '*kihamba*' (the homestead) and look after their parents in old age [91]. When practised, patrilocal residence places the young women in a position of dependence on her affinal kin, in particular her mother-in-law [92]. Traditionally, the mothers-in-law have exerted significant influence over their sons', daughters-in-law and grandchildren. During the postnatal period, they have customarily had an important role as a caregiver to their daughters-in-law and the newborn baby. With their seniority and attained position in the patriclan, mothers-in-law can exercise considerable power in issues relating to household and reproduction [91].

With urbanization and social change, family structures are changing. In 1997, Hollos *et al.* found among the Pare population that the patrilinear power in the Kilimanjaro region was weakening and conjugal tie was strengthening. When the young men became wage earners, they no longer needed to rely on their patrikin, making the power of senior male relatives weaker. Authority is closely connected to seniority and defined gender roles where men are the providers and the heads of household. However, the seniority system is undermined because most sons today are better educated and earn more than their fathers. Bride wealth is rarely paid and the choice of marital partners is increasingly in the hands of the young men and women. In this context, the nuclear family has been strengthened. Some couples appear to have developed a new type of relationship where they view their interests and responsibilities as convergent and shared. This results in an increased level of communication about joint goals and problems [105].

HIV/AIDS

The Kilimanjaro region was previously considered one of the regions in Tanzania most severely affected by the HIV/AIDS epidemic, but its prevalence has recently decreased below the national level. From figures in the Tanzania HIV/AIDS indicator survey from 2007-2008, the HIV prevalence in the region was 2.5% among women and 1.2% among men, compared to the national figures of 7% and 5% respectively [109]. In the same survey, 54.2% of the women and 34.6% of the men in the Kilimanjaro region had been tested at least once for HIV [109].

The PMTCT programme

The PMTCT programme in the region at the time of the study offered routine counselling and testing to all mothers at the time of their first antenatal visit [96]. Both pre-and post-test counselling were offered. The pre-test counselling was given in groups, on an individual basis, or a combination. Thereafter the mother was asked if she would be willing to test for HIV, in which case testing was subsequently conducted individually. Finally, each mother received individual post-test counselling which included information about the window period, and where she was offered to be tested again after three months. All mothers were asked to bring their partner for testing and the importance of using condoms until the partner also had been tested was explained. If the mother succeeded in bringing her partner, couple counselling and testing was offered. Information about infant feeding was supposed to be given to all mothers, but was usually prioritized only to the HIV-infected mothers. The information given about infant feeding for HIV-infected mothers was in accordance with the 2001 guidelines from WHO [40]. Mothers were offered three options: (a) exclusive breastfeeding for six months or early cessation any time convenient to the individual

woman's situation, (b) replacement feeding with commercial infant formula, and (c) replacement feeding with home modified cow's milk. HIV-infected mothers were referred to care and treatment clinics for CD4 count and possible treatment, where deemed necessary. According to the 2004 national PMTCT guidelines, treatment was either single dose nevirapine to the mother at the onset of labour or ZDV/AZT daily starting at 36 weeks of pregnancy [96]. With either regimen, the infant was given nevirapine syrup within 72 hours of delivery. HIV-infected mothers were also informed about the importance of a safe delivery at a clinic or a hospital.

Mixed methods

In this thesis, mixed methods with a concurrent triangulation design was used [110]. A survey was conducted concurrently with qualitative in-depth interviews, focus group discussions and observations at the clinics. In the following, I will first give a general introduction to mixed methods, and thereafter I will describe the methods used in this thesis.

Definition

The following definition of mixed methods is applied in this thesis: 'A mixed method study involves the collection or analysis of both quantitative and qualitative data in a single study in which the data are collected concurrently or sequentially, are given priority, and involve the integration of the data at one or more stages in the process of research' [110].

The paradigm debate

Quantitative and qualitative research relies on different assumptions about reality (Appendix 3) [111]. The aim of qualitative research is to discover multiple, subjective realities, whereas quantitative research aims to find an objective reality. Furthermore, the methods differ in how the knowledge is produced. In qualitative research, the researcher and the informants are considered to be interactive and inseparable: the researcher is the survey instrument. The research is viewed as value bound, and it is important to be open about the researcher's pre-understanding, his or hers expectations and potential biases. While in quantitative research, the researcher should not interact with the participants to avoid influencing them. Furthermore, the two methods have different ways of reasoning. In qualitative research, the line of reasoning is inductive: data collected with an open mind can discover new concepts/hypothesis/theories. In contrast, quantitative research is deductive, and a predefined hypothesis is tested against reality and verified or rejected.

Substantial discussion has taken place in the mixed methods literature about whether quantitative and qualitative methods can be mixed, referred to as the paradigm debate [110]. Following this debate, an incompatibility thesis was launched [112]; compatibility between quantitative and qualitative data is not possible due to the incompatibility of the paradigms that underlie the methods. This view is held by the 'purists' [111]. 'Pragmatists', however, claim that the two methods can be mixed [111], arguing that the overarching aim in any research is to use methods that effectively answer the research questions [111, 113]. Generally, mixed methods have been increasingly accepted over the years and has now been viewed by many as a third paradigm [114].

Why use mixed methods?

Numerous reasons for using mixed methods have been brought up. Tashakkori and Teddlie highlight three areas in which mixed methods are superior to a single approach design [114, 115]: 1) *mixed methods can answer research questions that other methodologies cannot*. It enables the researcher to answer simultaneously confirmatory and exploratory questions, and therefore verify and generate theory in the same study; 2) *mixed methods provide better (stronger) inference*. By using mixed methods the researcher can draw from the strengths and minimize the weakness of the quantitative and the qualitative method. This is referred to by Johnson and Turner as the fundamental principle of mixed methods research [113, 116]. If findings are corroborated across different approaches, then greater confidence can be held. If the findings conflict, then greater knowledge is achieved, and the interpretations and conclusions can be modified [113]; 3) *mixed methods provide the opportunity for presenting a greater diversity of divergent views*. One of the main reasons for using mixed methods is to elucidate the divergent aspects of a phenomenon [116]. It has also been argued that social phenomena are complex, and different kind of methods are needed to get a better understanding of these complexities [110]. In conclusion, mixed methods analysis allow the researcher to use the strengths of quantitative and qualitative analysis techniques to understand a phenomenon better, get more out of the data, and to enhance the quality of the data interpretation [117].

Different types of mixed methods

When planning a mixed method study, the researcher needs to make several decisions [110, 118]: 1) Priority: should priority be given to the qualitative or the quantitative method, or should it be equal. 2) Implementation of data collection: should the data collection be sequential or concurrent. 3) Stage of integration: at what stage/stages will the data be integrated, at the level of: a) research questions, b) data collection, c) data analysis, d) data interpretation, e) combinations. 4) Use of a theoretical lens or not. The lens provides a framework for topics of interest, methods for collecting data, and outcomes or changes anticipated by the study.

There are numerous classifications of mixed methods designs [110]. This thesis adheres to the classification by Creswell which presents three general strategies [110, 119]: 1) Sequential: the researcher seeks to elaborate or expand on the findings from one method with another method; 2) Concurrent: the researcher converges or merges quantitative and qualitative data to provide a comprehensive analysis of the research problem; and 3) Transformative: when the researcher uses a theoretical lens. On the basis of these three strategies, he presents six major designs [110, 119]: 1. Sequential explanatory, 2. Sequential exploratory, 3. Sequential transformative, 4. Concurrent triangulation, 5. Concurrent nested, and 6. Concurrent transformative. In this thesis the concurrent triangulation design is applied, which is further described in the 'Methods applied' section.

Difficult integration

Although mixed methods have a wide number of recognized advantages, integrating quantitative and qualitative research is seen as difficult. Mixed methods are time and resource consuming, requiring careful planning of both the quantitative and qualitative method, and of how and when to combine the methods. The researcher needs to have knowledge and skills of both methodologies and to be able to combine the methods in a way

that has complementary strengths and non-overlapping weaknesses [113, 116]. When writing up mixed methods, the researcher needs to pay attention to how to integrate the results, in order to avoid reporting just one of the methods, giving one of the methods far more attention, and end up with the findings being presented in parallel, without adequate integration [120].

Rationale behind the use of mixed methods in this study

The overall aim of this study was to assess mothers' knowledge and utilization of the PMTCT services eight years after the first implementation, with a focus on male partner involvement and the role of the mother-in-law. Thus, we aimed to study a complex social phenomena in which mixed methods is known to be helpful [110]. The research questions were both quantitative (i.e. numbers of mothers tested for HIV) and qualitative (i.e. attitude to HIV testing). Mixed methods enabled us to attain a quantitative assessment of the PMTCT services and a qualitative exploration of the social context of the mother. Broad numeric trends from quantitative research and details of qualitative research were combined to cross-validate the findings and reach a greater understanding of the research aims. The qualitative data served to obtain information from different sources, provide a broader perspective, and facilitate the interpretation of the quantitative data. According to Creswell, the concurrent triangulation design is convenient when the researcher aims to use the two different methods to confirm, cross-validate or corroborate the findings within a single study, as was the purpose of this thesis [110, 118, 121]. Additionally, the concurrent design is convenient with respect to limited time and resources which is relevant within the PhD-framework, and serves the need for more rapid programme feed-back which is also relevant with respect to the study aims of this thesis.

Methods applied

This mixed methods study consisted of one formative qualitative study, followed by the main study including focus group discussions and in-depth interviews with mothers, fathers and mothers-in-law and a survey of 426 mothers bringing their four-week-old infants for immunisation at five reproductive and child health clinics. An overview is given in Figure 3. Each component will be explained within the mixed methods framework below.

In February 2007, a formative qualitative study was carried out. We performed qualitative in-depth interviews with health staff at three of the participating clinics in the main survey, with VCT counsellors and health personnel working at a local HIV non-government organisation (NGO). Information obtained in these interviews was used to assist in the designing of the quantitative questionnaire and qualitative interview guides [121].

The main study was carried out from October 2007 until February 2008. A concurrent triangulation design was used with equal priority given to the qualitative and quantitative method [110]. Qualitative and quantitative data was mainly integrated at two levels: 1) The research questions were both confirmatory (quantitative) and exploratory (qualitative). 2) The results from the separately analysed qualitative and quantitative data were integrated during the interpretation of the results (Figure 3).

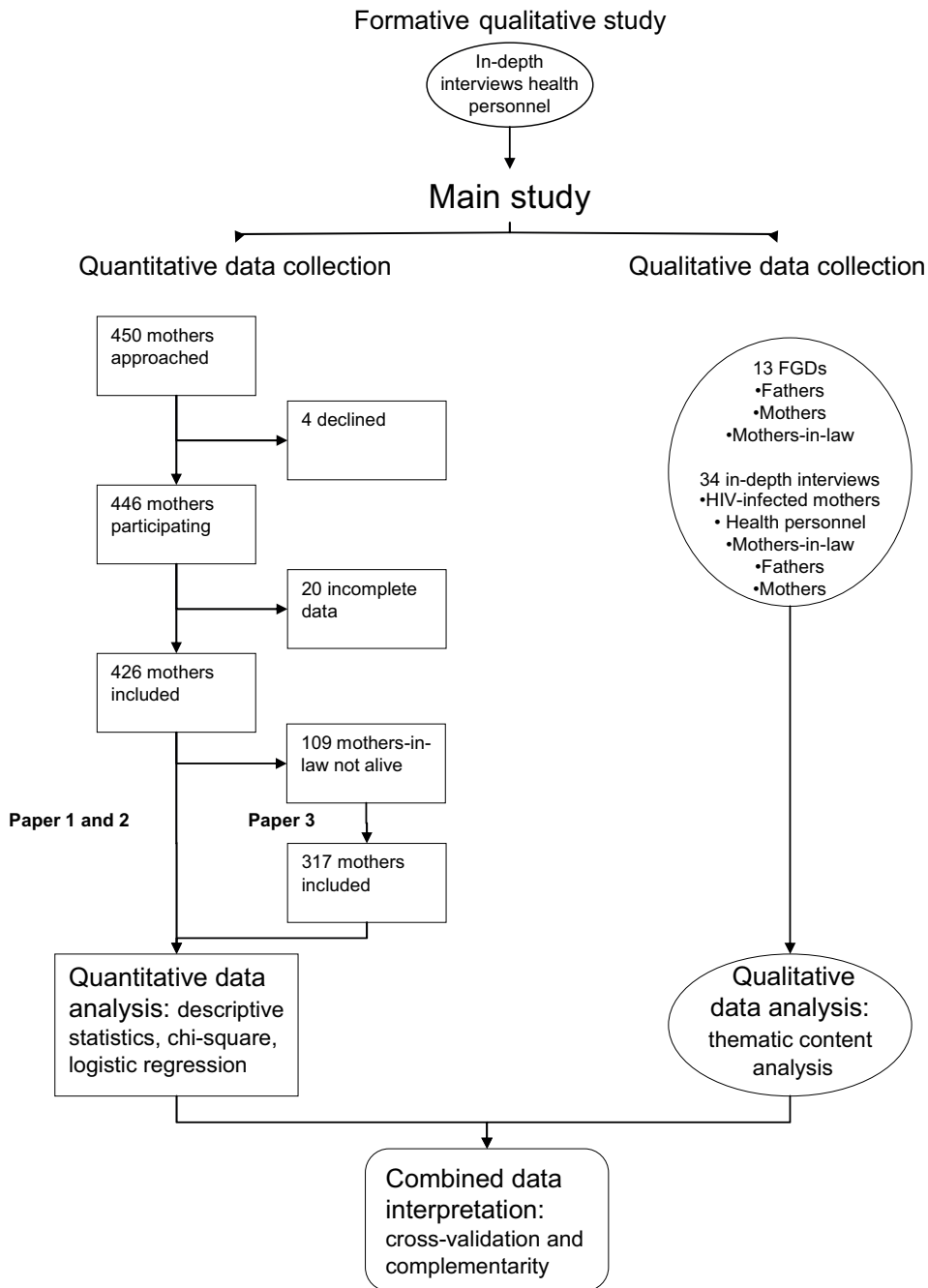


Figure 3: Overview of the study profile highlighting the concurrent triangulation

Quantitative data

Participating antenatal clinics

This study took place at five governmental reproductive and child health clinics in urban and rural districts of Moshi in the Kilimanjaro region. The three urban clinics included were Kilimanjaro Christian Medical Centre (KCMC), Mawenzi Hospital and Majengo Clinic. The two rural clinics included were Marangu Hospital and Kibosho Hospital. The five clinics were purposively selected to represent both urban and rural areas of Moshi. Furthermore, they were selected to enable follow-up of previous research conducted at the same sites [28, 62, 64, 77, 90, 99, 100].

Research assistants

Four research assistants conducted the quantitative interviews; three were students, of which one had experience of conducting quantitative interviews. The fourth, who served as the main research assistant, was a retired nurse. She had extensive experience in mother-and-child health issues and was well known at the participating clinics as she had been the Zonal MCH coordinator for several years. She also served as the main research assistant in one of the previous studies in the area [62, 77, 99, 100], and had experience in conducting both quantitative and qualitative interviews.

Prior to the start of the study, the research assistants were familiarized with the questionnaire and trained in interviewing techniques by me. Every question included in the survey was discussed and they were provided with a manual with thorough description on how to fill out each question. The research assistants also took part in the pre-testing of the questionnaire at the five clinics included in the study.

Quantitative study population

In order to collect information about experiences from the PMTCT services, the mothers were recruited when they came for the first postnatal follow-up. Due to the high coverage of the DPT-HB and polio vaccine given to infants at four weeks of age and the relatively short period of time since antenatal attendance, we decided to use this immunisation as the inclusion criterion. Since the number of mothers coming daily for immunisation at the respective recruitment clinics usually did not exceed ten (range 0-10), every mother who came was asked if she was willing to participate in the survey. Prior to the study, the nurses working at the respective clinics had been thoroughly informed about the study purposes. They informed each mother coming for immunisation about the study and inquired about her willingness to participate. Individual informed consent in the national language, Swahili, was obtained prior to the interview (Appendix 4).

Prior to the study, we had calculated the sample size based on a point estimate of $p = 0.5$ (no *a priori* knowledge of the proportion), which gives a maximum sample size. The reason for choosing 0.5 was to avoid underestimating any proportion of a parameter that would show to be important in the study. Furthermore, we chose a 95% confidence interval (CI), which gave a constant $c = 1.96$. The precision, d , was set at 0.05. With $p = 0.5$, $q = 1-p = 0.5$, $c = 1.96$ and $d = 0.05$, the sample size, n , was equal to $c^2 \times pq/d^2 = 1.96^2 \times 0.5 \times 0.5/0.05^2 = 384$.

We added 66 to account for non-participation or withdrawal and approached a total of 450 (Figure 3). Of these, 446 (99.1%) agreed to participate. During data analysis, 20 were excluded due to incomplete information; the remaining 426 were included in the main analysis. In Paper III, 109 (25.6%) of the mothers reported that they did not have a living mother-in-law and were excluded from the final analysis of this paper; the remaining 317 (74.4%) were included in the analyses.

Quantitative questionnaire

The questionnaire was translated from English to Swahili by an experienced Swahili teacher, fluent in English, and back-translated to confirm wording and meaning. Thereafter, the questionnaire was pre-tested at the five participating clinics in the study and revised accordingly. The questionnaire consisted of the following sections (Appendix 5): (1) socio-demographic characteristics, (2) information on clinical attendance, birth, and infant feeding, (3) PMTCT practice at the clinic: counselling and testing for HIV, (4) knowledge about PMTCT, (5) relationship to male partner, and (6) relationship to mother-in-law. Information about HIV status was not collected.

The questionnaire included six questions about the mother's relationship to her partner and six similarly phrased questions on her relationship to her mother-in-law (Paper III). For these questions, the Visual Analogue Scale (VAS) was used as a tool to collect the data [122]. VAS is an instrument that measures a characteristic or attitude believed to range across a continuum of values that cannot easily be more directly measured [123]. The ends of the scale are defined as the extreme limits (worst and best) of the parameter to be measured, orientated from the left (value zero) to the right (value ten). In our study, zero represented 'I do not agree at all' and ten represented 'I totally agree'. Prior to the questions applying VAS, the mothers were given a thorough explanation and two test questions in order to illustrate the scale and assess their understanding of it. The mothers were asked to move the marker to the position they felt was correct (Figure 4).



Figure 4: A mother using the VAS scale during the interview

Quantitative analysis

Data was double-entered into Epidata 3.1 software (www.epidata.dk) and analysed using SPSS PASW. In all three papers descriptive statistics were used to assess categorical baseline characteristics. Pearson χ^2 was used to address potential differences between groups (Paper I and III). More details on analysis carried out in Paper I and Paper III will be given below.

Paper I

In Paper I, we used crude and adjusted logistic regression to explore factors associated with having little knowledge about PMTCT. The dependent variable was knowledge about PMTCT. The adjusted logistic regression analysis included the same variables as the crude analysis. We used the SPSS ‘backward conditional’ command: removal was set at 0.2; and 95% CI were given.

All but one of the 17 questions about PMTCT knowledge included in the questionnaire were drawn from an already tested questionnaire [124], with only minor modifications to some of the questions being made, as shown in Table 1 of Paper I. Eight of the questions were the basis for constructing a knowledge index. In two of the questions (‘If there are 10 HIV infected pregnant women, how many do you think would have babies born with HIV virus?’, ‘Would you know the number of babies that could get infected through breastfeeding out of 10 HIV infected mothers?’) the answers 1, 2, and 3 were classified as correct, while 0 and 4-10 were classified as wrong [5]. All remaining questions had the response options ‘yes’, ‘no’ and ‘do not know’ and ‘yes’ was scored correct. Each question was weighted equally; one point per correct answer. We used the mean number of points in the study population as the cut-off; those who had 0-5 correct answers were classified as

having little knowledge about PMTCT, whereas those who had 6-8 correct answers were classified as having considerable knowledge about PMTCT.

Socio-economic status was assessed by constructing an index using principal component analysis (PCA), commonly used when creating socio-economic indices in low-income settings [125]. PCA is a 'data reduction' technique that transforms a number of possibly correlated variables (here socio-economic variables) into a smaller number of uncorrelated variables called principal components. The following background variables were included in our model: 1) the number of rooms and beds in the household, and the number of people living in the household per room and per bed; 2) type of toilet, source of fuel for lighting and cooking; 3) assets: TV, refrigerator, sofa, cupboard, mobile phone; 4) building material: floor and walls; 5) number of chickens, goats, pigs and cows owned; and 6) use of land for farming, and whether the household had purchased seeds or fertiliser the previous year. The first principal component, expected to explain wealth, explained 44.8% of the variance in our model. Socio-economic quintiles were constructed based on an index derived from the first component.

Among the 426 mothers included in our analysis, 115 (27.0%) had attended antenatal care at a clinic other than one of the recruitment clinics where they came for immunisation (Figure 1, Paper I). Since we were interested in antenatal practices and were unable to collect comprehensive information of all the other antenatal clinics, we did a sub-group analysis including only the 311 participants who had attended antenatal care at one of the five recruitment clinics. In this analysis, we explored whether there were any differences in PMTCT practices and PMTCT knowledge between mothers who had antenatal attendance at the urban as opposed to the rural recruitment clinics.

Paper III

For each of the questions on the mother's relationship to her mother-in-law and her partner, we calculated the mean scores with 95% CI. The mean scores on the questions about her mother-in-law were compared with the mean scores on the questions about her partner, using a paired t-test (Table 3, Paper III).

Qualitative data

Pre-knowledge

I am a medical doctor from Norway. During the field work I was a medical student. Prior to this study, I had field experience of a relative similar context in Zambia, where I had carried out a qualitative study on infant feeding practises [66]. My pre-knowledge regarding the PMTCT programme and the local context was gained merely by reading the relevant literature. When the study was planned, the literature suggested amongst others that: there was low acceptance of HIV testing, the male partners inhibited the mothers' participation in the PMTCT programme, and nurse counsellors had limited knowledge about PMTCT. Thus, this was part of my pre-knowledge, which influenced the planning of the study, the design of the questionnaire and the interview guides.

Design

In accordance with the principles of qualitative methodology, we used a flexible design. The FGDs and in-depth interviews were planned; we had defined which groups of informants we sought and the inclusion criteria to be applied. The estimated numbers of FGDs needed was beforehand set to 3-4 groups with mothers, fathers and mothers-in-law respectively. For the in-depth interviews, we estimated up to 7-8 informants were needed from each category. Time, costs and the capacity to analyse and handle the data after the collection also influenced the estimation of the numbers of participants required. During the data collection, I read through the transcribed and translated interviews before another further interview were undertaken. In this way, I could include new questions in the interview guides and the estimated numbers of FGDs and in-depth interviews was adjusted slightly to reach a level of saturation fulfilling the study aims. During the data collection period, observations of PMTCT counselling sessions emerged as a valuable approach and were consequently conducted.

Participants

The mothers, fathers and the mothers-in-law in the qualitative interviews were recruited from various villages in urban and rural Moshi. The villages were within the catchment areas of the recruitment clinics in the quantitative study. Mothers and fathers with children under one year of age were purposively selected, assuming they were offered or had been exposed to the PMTCT programme in the last pregnancy. Similarly, the recruitment criterion for the mothers-in-law was having a paternal grandchild under one year of age. The participants were recruited by the main research assistant, and her acquaintances in the respective villages and village leaders. The same recruitment criterion was applied when recruiting the HIV-infected mothers. Two of them were recruited by a nurse working in a local HIV organisation, while the other three were recruited through acquaintances of the main research assistant. The nurse counsellors were approached at the respective recruitment clinics by me and asked if they were willing to participate. The VCT counsellors were approached at different VCT centres by me and asked if they were willing to participate. Individual informed consent was obtained from all of the participants before starting the interviews.

Focus group discussions

By employing FGDs, we aimed to make use of the group interactions that might help people to explore and clarify their views in a way that would be less accessible than in one-to-one interviews [126, 127]. Further, FGD is known to facilitate discussion about sensitive topics, like HIV, and was therefore convenient in our research. We conducted 13 FGDs: five with fathers, four with mothers and four with mothers-in-law (Figure 3). A topic guide prepared specifically for each group of informants, with a written list of questions and probes, was used throughout all the FGDs (Appendix 6). Topics covered were the execution and utilization of the PMTCT services at the clinic, knowledge of PMTCT, attitudes towards PMTCT, perceived barriers to PMTCT, male involvement in PMTCT and the role of mother-in-law in PMTCT.

The FGDs had between five and twelve participants in each group. They were conducted outdoors, in a private home, in a church, or in a school building. The discussions were moderated by a nurse working at a local HIV organisation. She was used to talking to groups of people about sensitive issues like HIV, and had training and experience in

conducting FGDs. Notes were taken by one of the research assistants. All of the discussions were conducted in Swahili. They ranged in length from 45-90 minutes.

The group interaction overall seemed good. Although the moderator was female, the flow in the discussion with the fathers did not seem to differ from the discussions with the mothers.



Figure 5: FGD with fathers

In-depth interviews

In-depth interviews are used to explore the meanings of social phenomena experienced by individuals in their natural context [128, 129]. By employing in-depth interviews, we aimed to get the individual experiences from the mothers, fathers and mothers-in-law as well as to elaborate on issues revealed in the FGDs. It also provided an opportunity to interview other informant groups than the ones we interviewed in the FGDs. In total, we conducted 34 in-depth interviews: 1) three with mothers coming to one of the recruitment clinics for immunisation; 2) five with mothers; 3) five with HIV-infected mothers; 4) five with fathers; 5) five with mothers-in-law; and 6) eleven with health personnel, including five PMTCT counsellors working at the recruitment clinics, four counsellors working at VCT centres and two employees at a local HIV organisation. Rural and urban areas were represented among all informant groups.

A semi-structured interview design was used. An interview guide was prepared for each key informant category (Appendix 7). The guides for the mothers, fathers and mothers-in-law covered the same topics as the FGDs, but the questions were designed to explore the individual perceptions and experiences of the participants. The counsellors were asked about the counselling, the acceptance and utilization of the PMTCT programme, about their own knowledge of issues related to PMTCT, their attitudes and opinions about the programme, about the involvement of male partners and the role of the mothers-in-law. The

HIV-infected mothers were mainly asked about their experiences of the PMTCT programme, disclosure and reactions to disclosure, role of male partner and mother-in-law, and infant feeding experiences.

The mothers who came for first-time vaccination and the nurses were interviewed at the clinic, whereas the mothers, fathers and mothers-in-law were interviewed in their respective homes. The HIV-infected mothers were interviewed in settings chosen by them. All of the in-depth interviews were carried out by me. The interviews with the health personnel were performed in English, while all the other interviews involved the main research assistant as an interpreter. She was fluent in English and Swahili, as well as the main local languages. The interviews ranged in length from 45-90 minutes.

Observations at facilities

During the study, I spent time at the recruitment clinics. The PMTCT antenatal clinic register books for 2007 at four of the recruitment clinics were viewed. These books included records concerning the number of women and men tested for HIV at that antenatal clinic during that year. Furthermore, I observed at total of four PMTCT pre-and post-test counselling sessions at three of the recruitment clinics. In one of the urban clinics, I was not permitted to observe the counselling sessions, while in one of the rural clinics it was not possible for logistic reasons. The observations were made after having received consent from the nurse counsellor and the mother being counselled.

Qualitative data analysis

The in-depth interviews, the FGDs and the observations at the clinics were tape-recorded and subsequently transcribed verbatim. Interviews conducted in English were transcribed by the principal investigator. Interviews conducted in Swahili were transcribed and then translated into English by the experienced English teacher who also translated the questionnaire. Qualitative data analysis was conducted by me, in collaboration with my co-authors. We used a thematic content approach, which was guided by the Graneheim and Lundman framework [130]. The material was read systematically, line by line, in order to identify the meaning units. Meaning units were defined as string of the text that expressed a single coherent thought, up to the point at which the coherent thought changed. Thereafter, the meaning units were marked by a code, a describing cue of what the text bit was about, e.g. testing for HIV. Next, the codes were written up and organised so that those that referred to the same subject were grouped into categories. The interview guide was used as a starting point for grouping the information, but during the analysis new categories were developed, e.g. from the category 'attitudes to testing' to the category 'female responsibility'. The underlying meaning of the categories was formulated into a theme, e.g. the theme 'gender roles'. The information obtained in the in-depth interviews and FGDs was analysed and merged according to the codes and themes. Illustrative quotations were selected. All the original data were re-assessed by me and one of the co-authors after analysis in order to detect any concepts or information that had been missed and arrive at a consensus of opinion between the analysts.

Mixed methods analysis

The results from the formative qualitative study were used to assist designing the quantitative questionnaire and qualitative interview guides for the main study. In this, quantitative and qualitative data were analysed separately by employing a concurrent triangulation design. During the interpretation of the results, the findings from the two methods were integrated. Issues from the qualitative and quantitative data were largely overlapping and the mixed methods analysis aimed to compare and cross validate the findings. Furthermore, we sought complementarity and to reach a greater understanding when combining the results from the two methods than if only one method was chosen.

The qualitative and the quantitative approach were given equal priority during the data collection, and the methods were given unequal priority in the different papers for the data analysis (Table 1): In Paper I, the findings from the quantitative data provided the basis for data interpretation, and the qualitative data served to obtain information from different sources, provide a broader perspective and facilitate interpretation of the quantitative data. In Papers II and III, themes from the qualitative analysis served as the basis for the data interpretation, and the quantitative data mainly served to complement the qualitative data.

Table 1: Data method, topic and main analysis

Paper	Concurrent triangulation Predominant method:	Topic	Main analysis
I	Quantitative	Assessment of the PMTCT services	<ul style="list-style-type: none">• descriptive statistics• logistic regression• content analysis
II	Qualitative	Involvement of male partners in PMTCT	<ul style="list-style-type: none">• content analysis• descriptive statistic
III	Qualitative	Role of mother-in-law in PMTCT	<ul style="list-style-type: none">• content analysis• descriptive statistic

Ethics

The study was given research clearance by National Institute for Medical Research, the Tanzanian Commission for Science and Technology, the Kilimanjaro Christian Medical Centre Ethical Research Committee and the Regional Committees for Medical and Health Research Ethics for Region West, Norway (Appendix 8).

In the survey, all participants had a consent form in Swahili (Appendix 4) read to them before starting the interview. They were informed about the study purpose and their rights as study participants. They could withdraw at anytime and their participation would not affect other health services. The consent form was thereafter either signed or given a thumbprint.

Similarly, the respondents in the qualitative interviews were given the information about the study purposes and their rights as participants. They were reassured of confidentiality and asked if it was acceptable to tape-record the interview/discussion. The consent form was thereafter either signed or given a thumbprint.

Results

The summary of the results of the three papers will be presented together: 1) First a brief introduction about the sample characteristics and the roles and responsibilities in the family. Thereafter, I will move to the PMTCT programme: 2) HIV counselling and testing and 3) HIV prevention. The results will be presented within the mixed methods framework. The quantitative and the qualitative findings will be presented for each component, when applicable. Table 2 summarises the results.

Quantitative sample characteristics (Papers I, II and III)

The median age of the 426 mothers was 25 years. Nearly half of them reported that they lived in a rural area (Table 3, Paper I). Almost half (43.7%) of the respondents were Catholic. The most common ethnic group was Chagga (62.4%). Near half the mothers (44.8%) and 60.6% of the fathers had completed secondary or higher education (Table 2, Paper II). Most of the mothers (74.4%) reported to have a living mother-in-law.

In Papers I and II, a total of 426 mothers were included in the data analysis, while in Paper III only the 317 mothers with a living mother-in-law were included. The sub-group analysis (Paper I) included 311 (72.9%) mothers, of which 233 mothers (74.9%) had attended antenatal care at one of the three urban clinics included in the study, and 78 (25.1%) had attended one of the two rural clinics (Table 3, Paper I). We found significant differences ($p < 0.001$) between the mothers in the following areas: mothers who went to an urban clinic were more often Muslim, less often Chagga and usually wealthier than those who went to a rural clinic.

Table 2: Summary of the responses from the different groups of participants

PMTCT components	Mothers	Fathers	Mothers-in-law
Knowledge about the PMTCT programme	- well informed about its content including HIV testing	- aware of its existence - knew that mothers were requested to test for HIV	- aware of its existence - variable knowledge of its content
Attitude to HIV testing for pregnant women	- purely beneficial - no objections - 100% accepted to test	- purely beneficial - no objections - 100% of those asked accepted their wife to test	- purely beneficial - would encourage their daughter-in-law to test
View on male partner testing	- advantageous - difficult to ask partner to test - desirable if he could be requested through others	- positive attitude - few had tested - main barrier: asked by their wife to attend a female arena	- not commented
View on disclosure for HIV-infected wife/daughter-in-law	- fear of responses - responsibility to disclose to partner - mother-in-law received limited trust	- a responsibility to support - a few: would treat her badly due to lack of trust	- some: would blame her and chase her away - others: responsibility to support
View on condom use	- important for prevention - main barrier: partner's reluctance	- associated with distrust - unacceptable within the marriage - needed to be his decision	- not commented
Infant feeding option for HIV-infected mother	- overestimating transmission risk - few would have opted for EBF - some knowledgeable about the protective advantages of EBF	- all: not breastfeed	- all: not breastfeed

PMTCT components	Mothers	Fathers	Mothers-in-law
View on non-breastfeeding	- only possible if disclosing HIV status to partner - need for disclosure if living with mother-in-law	- only acceptable if HIV-infected	- only acceptable if HIV-infected or pregnant
Attitudes toward EBF	-generally beneficial - more scepticism if HIV-infected - need to explain to partner and mother-in-law	- acceptable since it was a clinical advice	- sceptical - incongruent with own experience and knowledge - potentially giving water
View on decision making in the family	- not empowered to disobey partner or tell him what to do - the majority stated that it was the partner, not the mother-in-law, who had the final word	- women not empowered to disobey their partner or tell him what to do - had the final word - potentially supporting the wife against his mother	- expecting authority - receiving little authority

Family structure and decision making power (Papers II and III)

The majority (90.1%) of the mothers was married or cohabiting. In most of the households (87.1%), the father of the child was reported to be the head of the household. The qualitative findings suggested that women's position in relation to their partners was generally weak. The mothers expressed the view that they could not act in a way their partner could disapprove of. Both the mothers and fathers emphasised that a woman could not tell her male partner what to do.

In the findings from both the qualitative and the quantitative data, we observed a tendency towards urban couples seeking more independence in living by themselves, whereas rural couples often followed the custom and moved near the husband's home after marriage. The mother-in-law was less likely to exert power if she did not live nearby the couple. Some of the rural mothers expressed an inferior position regarding their mother-in-law. However, there was a general discrepancy between the expectations of the mother-in-law of her influence and the sceptical attitude expressed by the sons and daughters-in-law. She was commonly not assigned any decision-making power in neither the quantitative (Table 2, Paper III) nor the qualitative data. If there were any disagreements in the family, it seemed to be the partner who had the final word and could disregard his mother's opinions: "*My mother has no right to make decisions in my house, its mine and my wife's.*" Both the quantitative (Table 3, Paper III) and the qualitative data illustrated a large discrepancy

between the trust and influence the mothers assigned to their partner compared to their mother-in-law.

The PMTCT programme

Knowledge about the PMTCT programme (Papers I, II and III)

There seemed to be widespread knowledge of the PMTCT programme as a part of the antenatal clinic services among all the respondents. The services included in the programme appeared to be viewed entirely beneficially. Mothers had a much more detailed knowledge about the contents of the programme than their partners and mothers-in-law. The majority of the mothers had received the messages: HIV testing being part of antenatal care, the prospect of receiving medication that could protect the child from HIV infection, and the risk of transmission of HIV through breastfeeding.

HIV counselling (Paper I)

The mother's knowledge about PMTCT

The mothers in both the qualitative and quantitative findings were generally informed about the different routes for MTCT, but tended to overestimate the risk of infection (Table 2, Paper I). However, one third of the mothers did not believe that the child could be infected during pregnancy. The prevalent misconception in the qualitative data was that *"The baby has security in the uterus."*

The mothers were aware that it was possible to prevent infection of the child. Among the different preventive means, the use of medication for mother and child and alternative infant feeding was known by the majority. However, a smaller percentage knew of the protective effect of condoms during pregnancy (54.4%) and the breastfeeding period (37.3%), and of the protective effect of EBF (50.5%).

In the quantitative data, a major difference in knowledge about PMTCT was observed comparing mothers attending the urban and the rural antenatal clinics (Table 2 and Figure 2, Paper I). Those attending an urban antenatal clinic tended to be more knowledgeable about PMTCT than the rural counterparts. In the adjusted logistic regression analysis, rural antenatal attendance remained significantly associated with a poor knowledge of PMTCT (Table 5, Paper I). In the sub-group analysis, no significant difference ($p < 0.05$) between the urban and rural antenatal attendees with regards to receiving counselling and testing was found (Table 4, Paper I). The qualitative data, however, did not confirm the rural/urban divide regarding knowledge about PMTCT.

Counselling

Nearly all the 426 mothers had received information about HIV (94.6%) as part of the antenatal service, and two-thirds reported having received infant feeding counselling (Table 4, Paper I). The nurse counsellors were generally knowledgeable in PMTCT. The counselling, however, was often given hastily, with little time for clarifications. The mothers in the qualitative interviews expressed a wish to have learned more and to be given more thorough explanations. The nurse counsellors regretted the time constraints and the increasing burden of care: *"We have a lot of clients and few nurses, so the counselling will*

sometimes not be quite good". Infant feeding counselling seemed to be prioritized to the HIV-infected mothers. The infant feeding guidelines adopted were in accordance with the WHO 2001 guidelines.

HIV testing

High acceptance of routine counselling and testing (Papers I, II and III)

The survey documented a near complete coverage of HIV testing: 97.7% of the mothers had been offered an HIV test, all of whom had accepted to be tested, and only one had not received her results (Table 3, Paper I). Similarly, the qualitative interviews with mothers, fathers, mothers-in-law and health personnel demonstrated a universally positive attitude to testing for HIV as part of routine antenatal care. There was widespread knowledge in the population that if the mother tested positive, transmission to the child could potentially be prevented. It seemed to be common for the couples to discuss HIV testing before the mother arrived at the antenatal clinic. Even though the majority of the fathers said that it was unnecessary to ask their permission to test as part of the routine antenatal care, most of the mothers in the quantitative (78.6%) interviews stated that they had asked their partner for consent to test. This finding was confirmed in the qualitative data. According to the mothers in the quantitative interviews, all the partners asked had accepted. In the qualitative findings, the fathers argued that it was important for the mother to follow clinical advices during the pregnancy for the sake of the baby. Discussions with the fathers also revealed that it was far less acceptable for a woman to go for voluntary counselling and testing than to receive routine antenatal clinical care. It was interpreted as her suspecting him of being unfaithful or that she had been unfaithful herself: *"It is acceptable for pregnant women to test according to the clinical advice without permission. But if she is not pregnant and she plans to go for testing, she needs to go with me, the husband."*

Partner's reluctance to testing (Paper II)

Nearly all the mothers in the survey (95.5%) stated that they had been encouraged by the nurse counsellors to bring their partner to the antenatal clinic for testing. However, according to the PMTCT antenatal clinic registers at four of the recruitment clinics, only 3% of the partners were tested in 2007. Correspondingly, the nurse counsellors working at the recruitment clinics stated that very few partners attended the antenatal clinic and even fewer were tested for HIV. The two main barriers revealed in the qualitative interviews with the mothers and fathers were: 1) the antenatal clinic was perceived as a female arena, and 2) a woman could not tell her man what to do. Even though the fathers commonly saw it as important for them to test, the social norms inhibited them from attending: *"Generally our women should not tell us men what to do, even though the advice comes from the doctor. Our tradition does not allow the women to lead their men. I may personally agree to test for HIV, but the majority would worry why they [health personnel] told the woman to bring me."* Both the mothers and the fathers perceived that it was more appropriate for men to test in other arenas, like other VCT units, than the antenatal clinic. Furthermore, the mothers expressed a wish that their partners were informed about HIV testing by others than herself. Even though the majority of the fathers expressed a positive attitude to couple counselling and testing, both the fathers and the counsellors stated that they rarely came.

HIV prevention

Disclosure (Papers II and III)

Nearly all the mothers (95.9%) in our survey reported to have shared the test result with their partner (Table 3, Paper II). The majority of the mothers in both the survey (61.7%) and the qualitative interviews stated that they would have had their partner as their primary confidant if they hypothetically were HIV-infected. Nevertheless, some mothers in the qualitative interviews expressed a fear of violence and rejection in disclosing a positive test result to their partner. Yet, the importance and obligation of telling him seemed to weigh stronger: *“My husband would be the first to know so that we can go together for the testing to find out about him also.”* A few fathers confirmed the rationale behind the mother’s fears, but the majority expressed a commitment to support an HIV-infected wife.

The mother-in-law received limited trust; only four of the 317 mothers (1.3%) in the survey would have chosen her as their primary confidant (Table 2, Paper III). In the qualitative interviews with the mothers, the mother-in-law was often referred to as the last person they would have told that they were HIV-infected. Mothers commonly feared her reactions and did not trust her to be supportive: *“I would not tell her because she would not understand me. She would think I brought it [HIV infection] to her son and would send me away.”* Some mothers-in-law stated that they were obliged to be supportive of a HIV-positive daughter-in-law. Others confirmed the widespread belief that that the daughter-in-law would be blamed for bringing HIV into the family and be chased away.

Condom use (Papers I and II)

In the PMTCT programme, it was the woman who was taught about the importance of condom use during pregnancy and breastfeeding period, and the one who was encouraged to ask her partner to use condoms. Although some mothers in both the quantitative and qualitative interviews seemed confused about the protective effect of condoms, several were aware of the importance of using condoms during pregnancy and the breastfeeding period. However, due to the partner’s reluctance towards using condoms, they were generally unable to protect themselves. The fathers expressed two main objections towards using condoms within the marriage when asked by their wife: 1) according to customary gender roles, a woman could not tell a man what to do; and 2) the fathers seemed to lack the knowledge the mothers received at the clinic about the rationale for using condoms during pregnancy and breastfeeding period; thus they defined condom use as an issue of trust between partners and not a measure to prevent the baby from getting HIV: *“Why should I use a condom while I am her husband?”*

Infant feeding for HIV-infected mothers (Papers I, II and III)

Although several of the nurse counsellors saw replacement feeding as a safer option for an HIV-infected mother, they generally regarded EBF as the most feasible option for them. The mothers seemed confused about the infant feeding options for an HIV-infected mother. Nearly 80% of the mothers in the survey would have opted for replacement feeding if they were hypothetical HIV-infected, while one fifth would have practised EBF. In the qualitative interviews, some mothers showed notable knowledge about the protective effect of EBF, while others questioned the safety of it. *“I heard that if you are HIV infected and you breastfeed your baby, your baby will be infected as well, so how can you breastfeed?”*

Neither the father nor the mother-in-law was usually involved in infant feeding decisions as long as the mother fed the child according to the customary mixed feeding. However, breastfeeding is highly valued in this society and closely linked to the survival of the infant. Consequently, if the mother was HIV-infected and opted for alternative infant feeding, neither her partner nor a mother-in-law living nearby would agree if she did not disclose her HIV status. *“I will not agree that my grandchild is denied breastfeeding without a good reason.”*

EBF seemed to be accepted by most of the fathers as clinical advice. However, it was difficult for the mothers-in-law to understand because it conflicted with the infant feeding education they had received. Some of the mothers-in-law admitted that they could potentially give the infant water in its mother’s absence. However, the mothers-in-law had strong faith in health personnel and were likely to accept EBF, and even non-breastfeeding, if they were told that it was clinically advisable.

In summary, antenatal clinical activities seemed acceptable to all the respondents. Neither the partner nor the mother-in-law seemed to be a barrier for the PMTCT components regarding HIV testing, receiving medication or safe delivery. However, it would be very difficult for a mother not to breastfeed without disclosing to her male partner. If the mother lived close to her mother-in-law, the mother-in-law could oppose to both non-breastfeeding and EBF if the mother did not communicate with her and disclose her HIV status.

Discussion

I will first discuss the main findings and thereafter focus on methodological issues, including strengths and limitations of the study.

Major findings

A more detailed discussion of the findings related to the specific study objectives can be found in the individual Papers I to III. In the following I will discuss strengths and weaknesses of the PMTCT programme in the Kilimanjaro region after almost a decade of implementation. More specifically I will discuss the mothers' knowledge and utilization of the PMTCT programme in view of the 1) evolving acceptability of the programme components and, 2) remaining challenges related to a) programme implementation and b) the local context of power linked to gender and seniority.

The main findings can be summarised as follows:

- 1) routine counselling and testing of pregnant women was highly acceptable in this population;
- 2) the main barrier to male partner involvement was the definition and organisation of the programme as fundamentally female oriented;
- 3) the major obstacles to safe infant feeding was insufficient and confusing infant feeding counselling in the PMTCT programme, and the influence of the male partner and the mother-in-law who lacked relevant knowledge on the subject.

The status of the PMTCT services in the Kilimanjaro region

Compared to the experience gained in the pilot phase of the PMTCT programme in the region [62, 77, 95, 99, 100], the following seemed to have improved: 1) knowledge about the programme in the community; 2) the mothers' knowledge about PMTCT; 3) acceptability of the services provided in the programme; 4) the nurse counsellors' knowledge about PMTCT and confidence in counselling; and 5) disclosure to the male partner. However, some challenges remain. There is room for further strengthening of: 1) the provision of counselling; 2) involvement of male partners; and 3) involvement of mothers-in-law as grandmothers in breastfeeding promotional campaigns.

High acceptance of routine counselling and testing

We found 100% acceptance of routine counselling and testing among the mothers who were offered a test and the partners who were asked for permission for her to test. Thus, in concordance with numerous studies, it looked as though expansion of HIV counselling and testing as part of the routine antenatal care services increased the proportion of pregnant women testing for HIV [19-22, 131]. In agreement with the quantitative findings, the qualitative interviews with the mothers, fathers and mothers-in-law indicated that routine counselling and testing was viewed beneficially in this population. We suggest several factors that may have contributed to the high acceptance of routine counselling and testing found: 1) the stigma associated with testing was reduced due to the general perception of

testing being part of the standard care offered to all antenatal attendees [21, 22, 132]; 2) widespread knowledge in the population about the benefits of participating in the PMTCT programme [21], and; 3) prior awareness of testing being part of the routine antenatal care provided the opportunity to prepare for the test and discuss testing with the partner. Accordingly, the fear of disapproval by the partner about HIV testing - documented in other studies [69-71, 100] - was not an obstacle in this study.

Although there seemed to be a universally positive attitude to routine counselling and testing in our study, we do not know if mothers experienced that their right to opt-out was respected. The health personnel seemed to be highly esteemed and their knowledge respected. Considering the big knowledge gap and the asymmetric power relationship between the educated nurse counsellors and the average woman attending the antenatal clinic, it may have been difficult for mothers to reject testing. Thus, we question whether opting out was a real possibility as experienced by the mothers. Considering that the principle of informed choice is also supposed to underlie routine testing, this is a major concern and has been one of the criticisms of the routine counselling and testing approach [23, 25]. Furthermore, since routine counselling and testing was part of the antenatal care, the woman was often the first in the couple to test for HIV. Although the majority of the partners said that they would have been supportive of a HIV-infected wife, a few partners admitted that they might have blamed and even divorced a HIV-infected wife. Furthermore, we do not know if women who feared testing did not attend antenatal care. In the DHS for Tanzania 2009-2010, which is not yet published, it will be interesting to see if the regional antenatal attendance has declined from the nearly universal coverage of 99% found in the 2004-2005 DHS [107]. In a recent study from Uganda, some women saw HIV testing as compulsory after routine counselling and testing. For these women, this was seen as a constraint to use the health facility [133]. This is in contrast to a Botswana study in which the introduction of routine counselling and testing in the antenatal clinics did not appear to reduce the use of prenatal care [134].

Our study did not assess if the increased coverage of testing led to increased use of PMTCT services. Lack of follow-up with access to treatment for all who tested positive in the routine counselling and testing model has been criticised [23]. There have been reports of increased uptake of ARV's following the implementation of routine counselling and testing [19, 21, 132]. However, a recent study from Ethiopia showed that although routine counselling and testing led to a remarkable increase in the numbers of mothers tested, the numbers of mothers receiving ARV's did not increase [131]. One of the main arguments for implementing routine counselling and testing was increased coverage of treatment, thus efforts are needed to expand treatment access in parallel with increased testing access [24].

The problem of scale: Quantity at the expense of quality?

Although we argue that the scale up of the PMTCT programme has been successful in terms of increased acceptance of HIV testing and general knowledge about PMTCT, the quality of the counselling provided may suffer when the number of mothers increases. The rapid scale-up of PMTCT services superimposed on routine antenatal care, without an increase in the number of formally trained health workers, has led to additional and growing workload on staff [21, 22, 27-29]. Although the nurse counsellors seemed to have increased knowledge and confidence in their own counselling compared to previous studies in the area [28, 62],

the counselling given was often insufficient due to time constraints [28, 60] (Paper I). Inadequate counselling is an important reason for the mothers' lack of knowledge and understanding about PMTCT [27, 28, 55, 56, 58, 60].

These findings add substance to some of the criticism that routine counselling and testing model has received for weakening the counselling and the prevention aspects of HIV testing [24-26]. Concerns have been raised whether routine counselling and testing is merely a successful screening programme and not a preventive programme [131]. In view of the health worker shortage, it has been argued that 'task shifting', the process of delegation where tasks are moved to less specialized health workers when appropriate, or incorporating lay or volunteer workers into HIV control efforts, are essential in scaling up HIV services. The use of community or peer counsellors to augment counselling capacity has been successful in other sub-Saharan Africa settings and exploring this possibility in the context of the Tanzanian policy is an issue that can be pursued [135-137].

Programme components

Challenges related to partner involvement

Although male involvement has increasingly been recognized as a priority to be strengthened in PMTCT programmes, very few partners participate in antenatal HIV counselling and testing [2, 15, 21, 73, 75, 85]. Implementation of routine counselling and testing has increased the numbers of mothers testing at the antenatal clinic, but the numbers of male partners testing has remained relatively unchanged [132]. This study suggested an even lower male testing rate at the antenatal clinic (3%) than other studies from Eastern and Southern Africa, ranging from 7 to 15% [21, 75, 85] (Paper II). However, these figures are not readily comparable since different data collection tools were used: the quantitative number of male partner tested in this study was gained by reading the antenatal clinic registers and counting the number of male partners tested. The qualitative data further illustrated a discrepancy between the favourable attitude expressed by partners to test for HIV during their spouse' pregnancy and actual practice [84, 85]. The study indicated that it is not primarily the partner's attitudes that need to be addressed, but rather the definition and organisation of the programme. Using the antenatal clinic as the entry point became a barrier to testing of the partner. Due to a general view of the antenatal clinic being a female arena, men feared being socially stigmatized if they accompanied their wives to the clinic [138-141]. Cultural norms and gender roles seemed to make it difficult for men to attend the programme [142]. Furthermore, this study indicated that the existing gender hierarchy, - i.e. that women in this society generally have a lower status than men - was a major obstacle to male participation in the PMTCT programme. In the PMTCT programme, access to the partner is gained through the mother: the mother is expected to share the knowledge received at the clinic with her partner and ask him to be tested for HIV. However, in the social and cultural context of the Kilimanjaro region setting up such a programme, designed to reach men through women, in which a woman is supposed to tell her partner what to do or for a man to do what his spouse asked him to do, remains a challenge. Likewise, other studies have shown that when women invited their partners to join them at the antenatal clinic, this strategy was ineffective [21, 75, 143].

Couple voluntary counselling and testing (CVCT) at the antenatal clinic has obvious benefits [73, 75, 85, 87], but this study has shown that partners demonstrated reluctance to attend the 'female' antenatal clinic when asked by their spouses. Low acceptance of couple counselling and testing within the antenatal clinic is consistent with findings from other settings in sub-Saharan Africa [73, 87, 144]. Thus, there is a need to investigate how to invite men to test for HIV when their wife is pregnant, and where to offer male partner testing, alternatively CVCT. Several of the participants in our study suggested that male partners could be offered testing in separate clinics or testing facilities distinct from the antenatal clinic [100, 144, 145]. One way to overcome the gender hierarchy is to invite the men to test directly. Some studies have suggested that men could be given a personal letter of invitation from health personnel [146, 147]. A more direct communication between health personnel and a male partner could potentially make it more acceptable for him to test for HIV. In this way, the invitation to test for HIV might be more likely to be perceived as a request from the health personnel rather than the mother herself. However, this is also a question of capacity, and the feasibility of it would have to be further assessed.

Community sensitisation or community mobilisation is necessary to increase male partner involvement [147]. A study from Zambia showed that the numbers accessing CVCT increased in tandem with promotional activities [148]. In Tanzania, a national HIV-testing campaign was launched by the President in July 2007, and 3.2 million people had been tested by the end of December 2007 [94]. Similar campaigns could be used to promote male partner testing. Furthermore, the programme, either by using health personnel or peer counsellors, could reach out to men where they socialize. Our study illustrated that men are likely to be more comfortable in getting this information from their fellow men than from the staff at the antenatal clinic. Influential men in the community could be recruited to serve as peer discussion leaders to deliver educational sessions in their communities about the importance of men's support and engagement in PMTCT programme activities, including testing for HIV [142, 149]. Furthermore, men who have tested for HIV during their spouse's pregnancy could be recruited to inform and mobilize other men to attend and act as peer counsellors. However, more research is needed on the feasibility of these suggestions. There are still many unsolved questions on how to involve the male partners in the 'female oriented' PMTCT programme.

Challenges related to disclosure

In the report of the pilot of the PMTCT programme in Tanzania, lack of disclosure to male partners was a prominent barrier to the mothers' utilization of the PMTCT services [95]. Correspondingly, previous studies from sub-Saharan Africa have found that fear of disclosure of test results has been a barrier for the mother testing for HIV in the PMTCT programme [69, 80, 81, 86]. In our study, however, nearly all the mothers stated in both the quantitative and the qualitative interviews to have told their partner their test result (Paper II). The partner's prior awareness and acceptance of testing as part of the antenatal care are likely to have facilitated disclosure [82]. Although many mothers in the qualitative interviews expressed fear of their partners potential negative reactions, the obligation to tell him seemed to weigh stronger [100]. Moreover, it would be difficult for an HIV-infected mother to adhere to the infant feeding guidelines without disclosing her HIV status to her partner. Hence, disclosure to the male partner did not seem to be merely an issue of trust, in which the mothers could choose to disclose or not. It was also experienced as a necessity.

However, we cannot give disclosure rates by HIV status as we did not collect information about the HIV status of the participating mothers. Previous studies indicate that only half of the HIV-infected mothers disclose their results compared to non-infected mothers [74, 76]. Furthermore, although the mothers in general stated that they would have told their partner a hypothetical positive HIV test result, we know little about the real experiences of disclosure of a positive HIV test result. Although the majority of the partners expressed a supportive attitude to an HIV-infected spouse, a few of the partners admitted that they would have accused their spouse of infidelity and therefore might have treated her badly. Thus, negative outcomes of HIV status disclosure are likely to exist and need to be acknowledged [81]. A recent study from Malawi found that the PMTCT programme in certain areas was called the 'the divorce programme' due to the high rates of disruptions of families after HIV status disclosure [150].

The discrepancy between the quality of the mother's relationship with her partner and mother-in-law became particularly evident in the discussions about disclosure. The mother-in-law generally received limited trust, 1.3% of the mothers would have chosen her as their primary confidant. Although some of the mothers-in-law expressed that they would have treated their daughter-in-law badly if she had been HIV-infected, many stated that they would have supported her if only they had been given the opportunity. Thus, the lack of open communication between the daughter- and mother-in-law may have inhibited valuable support for an HIV-infected mother.

Obstacles to safer infant feeding

Safer infant feeding for HIV-infected mothers is a complex issue with numerous obstacles. In the following section, I will discuss the two main obstacles found in this study; namely insufficient and confusing infant feeding counselling, and the potential influence by male partners and mothers-in-law.

The difficult infant feeding counselling

Although the nurse counsellors' knowledge concerning infant feeding for HIV-infected mothers seemed to have improved compared to previous studies in the region [28, 62, 90], the infant feeding counselling given was commonly insufficient. Mothers seemed to be confused about the infant feeding options for an HIV-infected mother, which may reflect unclear counselling messages [65] (Paper I). Inadequate knowledge may be an obstacle to safe infant feeding as it might increase the risk of mixed feeding [55, 61].

One main barrier to adequate infant feeding counselling was the constant lack of time the nurse counsellors faced during counselling sessions. The frequent shifts in the infant feeding guidelines may have added to the counsellors' and the mothers' confusion (Appendix 2) [37]. Health personnel had limited time to update themselves, as previously reported [28, 62]. Although there had been a revision of the infant feeding guidelines in 2006 [41], the 2001 WHO guidelines were adhered to during this study. It is obviously confusing for the mothers to receive different messages in previous from their current pregnancies, due to changes in the guidelines. Implementation of the 2010 infant feeding guidelines [51], giving a single option as the standard of care and with increased focus on EBF, could potentially reduce confusion about the issue.

The influence of significant others

The infant feeding guidelines in the PMTCT programme is based on an assumption that the mother can make an autonomous decision on how to feed her infant. However, as this study demonstrated, this assumption ignores the social environment of the individual mother. The actual choice of infant feeding method is strongly influenced by the mother's wider social environment. In previous studies in this region, the partner and the mother-in-law were seen as particularly influential [62, 64, 77, 90, 100]. This was also the case in the present study, where infant feeding seemed to be the main area where the male partner and the mother-in-law could actively interfere, creating a barrier to PMTCT. The mother was generally expected to feed the infant according to the customary mixed feeding introducing water and other nutrients, like cows milk, from a very early stage. In contrast to the mothers-in-law, the majority of the male partners seemed to have accepted EBF. However, if the mother chose to wean the child early, the partner was likely to interfere. If the mother did not breastfeed she was likely to be suspected of being HIV-infected or accused of being a 'bad mother'. In this society, breastfeeding is closely connected to motherhood and is seen as a condition of child survival. The mother has a duty to breastfeed which is not only her duty to the child, but also to the clan to which the child belongs. Not breastfeeding an infant is commonly interpreted as an act of disrespect to the lineage and the mother-in-law [64, 92].

In accordance with previous studies in the region, it seemed to be very difficult for an HIV-infected mother not to breastfeed without disclosing her HIV status to her partner [62, 77, 100]. Similarly, if the mother lived near her mother-in-law, it was probably difficult to follow the infant feeding guidelines for HIV-infected mothers, as demonstrated in previous studies in the Kilimanjaro region [64, 90]. The lack of trust and open communication that seemed to characterize daughter- and mother-in-law relationship represented a potential barrier to safe infant feeding. However, the mother might be able to attain a higher level of control over infant feeding in more urban and modern contexts.

If the partner was involved in the infant feeding decision, he was likely to have the final word in discussions with the mother-in-law, further underscoring the importance of male involvement in PMTCT [2, 15]. The importance of support from the partner to withstand social pressure has been demonstrated [79]. In a previous study from Moshi, Tanzania, adherence to the infant feeding method selected was strongly associated with partner participation in PMTCT [75].

The changing influence of the partner and the mother-in-law

In the Kilimanjaro region decision making power is closely connected to gender and seniority. In the local gender hierarchy, men have been the heads of households and the overall decision makers. Women have gained power primarily through their role as natal mothers, mothers-in-law and grandmothers. Thus, our hypothesis when planning this study was that the mothers' possibility to utilize the PMTCT programme depended on their relation to their male partner and their mother-in-law. According to the findings in this study, neither the partners nor the mothers-in-law seemed to be a barrier to testing for HIV. However, due to lack of active participation in the programme at the antenatal clinic, neither

had sufficient knowledge about preventive measures. Even if the mother was knowledgeable about preventive measures, e.g. condom use and safe infant feeding, commonly a male partner with limited knowledge about PMTCT and preventive measures had the final word. The main influence exerted by the mother-in-law seemed to be on infant feeding. Her influence appeared to be related to how close she lived to the young couple, and whether the young mother stayed in the house of the mother-in-law after delivery. It was generally reported that the mother-in-law was more influential in the rural areas.

The customary local knowledge of seniors, the mothers-in-law, tended to conflict with the bio-medically defined knowledge, particularly in the area of infant feeding. Mother-in-law used to have the authority of knowledge on infant feeding, making sure her daughter-in-law fed her grandchild according to customary practice. Hence, intergenerational disagreements on the best way to feed an infant were expected and young mothers commonly sought distance to the mother-in-law to prevent conflicts and unsafe infant feeding. As we have seen in this study, and which has been previously documented [105], gender relations and the intergenerational relations are changing. The power of knowledge attached to seniority seemed to be weakened, and the modern knowledge seemed to be increasingly trusted. Nevertheless, when young mothers lived in the proximity of their mothers-in-law, she was likely to interfere with infant feeding. Although mother-in-law represents a challenge in a PMTCT context, she also represents an underutilized resource that can be mobilised for the benefit of safer infant feeding. In view of the strong local emphasis on breastfeeding and prolonged breastfeeding, the potential of involving grandmothers in breastfeeding campaigns should be explored.

The male partner seemed to have taken on the role previously assigned the mother-in-law. The study indicated that the young couple increasingly decided on issues regarding family health and infant feeding without consulting elders, possibly indicating a shift of power between generations. The customary gender hierarchy however, seemed to persist with the decision making power on family issues remaining primarily with the male partner. The mother commonly could not act in a way her male partner did not accept. Thus, this study re-emphasised the importance of involving the male partners in the PMTCT programme. However, as we have seen in this study, this needs to be done in a way that is gender sensitive as well as sensitive to the local cultural context.

Summary

To summarize, the study clearly showed that the PMTCT programme was gaining in social acceptance and in programme maturity. At the time of the field work it was firmly established as a routine at the antenatal clinic and was well known in the population. Challenges related to counselling, male involvement and infant feeding need to be addressed in a context of changing family relations where the conjugal family seems to become a stronger decision making unit.

Methodological considerations

Methodology issues specific to the studies have been discussed in the separate papers. I will discuss here some methodological concerns relevant for all papers and focus on mixed method methodology.

Design

Knowledge gained in the **formative qualitative study** was employed when planning the second and main phase of the study, the concurrent triangulation (Figure 3), and it allowed improving the quality of the instruments used.

One main limitation of the **concurrent mixed methods design** is that it does not allow for information gained by one method to inform the next method, as in a sequential design. If this design had been employed, it might have been easier to resolve discrepancies that arise when comparing the results from the two methods. Unexpected findings in one method could then have been addressed by the other method. It could be the case, for example, for the knowledge gap between the urban and rural mothers found in the quantitative data but not seen in the qualitative data (Paper I).

Mixed methods requires careful planning of both the qualitative and the quantitative methods, and how and when to combine them. A weakness in the mixed method design of this study was that there was not optimal overlap between the topics in the quantitative and qualitative instruments, so that mixing did not take place at all levels. However, the qualitative instruments allowed us to address issues the quantitative instruments failed to capture. An even more careful planning of the quantitative and the qualitative method and, not least, how to combine the methods, could have made the integration of the results easier [113, 116].

The main limitation of a **cross-sectional survey** is that we cannot assess causal relationships, only associations. In quantitative studies, caution need to be taken concerning selection and measurement bias [151]. A weakness of the survey tool was that information about the fathers and mothers-in-laws was collected from the mothers. It would have been preferable to use data collected from the fathers and mothers-in-law themselves when studying their involvement. Female reports, however, have been shown to be an acceptable alternative to male reports when studying male involvement in PMTCT [85].

Another limitation of our study design was that we did not collect information about HIV status for ethical reasons. This prevented comparison of the experiences of the PMTCT services among women who were HIV-infected with women who were not infected. Only data from the general population including both HIV-infected and un-infected mothers can be presented. We do not know if the experiences of HIV-infected mothers differed from those who were not HIV-infected.

Sampling

Quantitative

The sampling for the quantitative data collection was done in a systematic and predetermined way - every mother who came to the antenatal clinic for the first doses of

DPT-HB and polio immunisation was asked if she was willing to participate. In this way, each eligible mother attending the clinic had an equal probability of being selected. However, sampling through the health system might have introduced a **selection bias**, e.g. mothers attending the clinic may have differed from mothers who did not attend the clinic. Due to the active involvement of nurses in the recruitment process, it might have been difficult for the mothers declining participation and this could have contributed to the high participation rate. The involvement of nurses might also have resulted in socially desirable answers which will be discussed below.

Qualitative

The majority of the participants of the in-depth interviews and FGDs were purposively selected by the main research assistant, using her contacts in the respective villages and village leaders. Convenience sampling, selecting those most readily available, has the lowest credibility of the different qualitative sampling strategies [111]. In addition, familiarity with the main research assistant or the village leader may have affected the informants' willingness to participate. Several of the participants were familiar with each other in some of the FGDs, which may have inhibited openness in discussing sensitive issues. However, familiarity could also have facilitated disclosure of socially acceptable attitudes and values.

Truth value

Truth value refers to the ability of the study to capture what the research primarily aimed at achieving. It is described as internal validity in quantitative design and as credibility in qualitative design (Appendix 3) [111].

Internal validity

I discussed the possibility of **selection bias**, which is a potential threat to the internal validity, in the 'sampling' section. Cross-sectional studies are also prone to **measurement bias**. I will discuss the following measurement bias relevant to our data: recall bias, interviewer bias, social desirability bias and the research tool employed. By design, we aimed to minimize **recall bias**. As we interviewed the mothers when the infant was four weeks old, the interview only expected a recall of the last pregnancy. Nevertheless, some time had elapsed since they attended antenatal services and recall bias might still be present.

There may have been **interviewer bias** e.g. systematic differences in how the different research assistants collected information from study participants. To reduce variability between the interviewers, all the research assistants were provided with the same training before data collection started. However, the research assistant's had had different data collection experiences, which may have affected their performance. The main research assistant was a retired nurse, which may have influenced the responses given to her compared to the other research assistants. Without speaking the local language, I could not assess whether the various interviewers performed differently. However, I collected the completed questionnaires several times per week, which enabled me to give the interviewers rapid correctives if there were any irregularities.

The recruitment procedure and the fact that the mothers were interviewed at the clinic may have introduced a **social desirability bias**. The mothers may have answered the questions as

to what they thought might be ‘correct’ instead of what they actually believed. Some of the findings may suggest that this bias was present, such as the high percentages of mothers who reported that they had tested for HIV, received the test result, or disclosed their HIV status to their partner. However, these quantitative findings were supported by the qualitative findings. Although social desirability bias might also have been present in the qualitative data, greater confidence to the findings can be held when they corroborate across the different approaches [113].

The **research tool**, the questionnaire, may have introduced information bias, although efforts were made to reduce it. During its development, it was discussed with various people working with PMTCT and different researchers with knowledge about the setting. The questionnaire was then translated and back-translated to confirm the wording and meaning. Thereafter, the questionnaire was pre-tested at the five clinics in the study and revised accordingly.

The nature of the questions may have introduced bias. The questions regarding the mother’s knowledge about PMTCT were all close-ended, which imply passive knowledge. Thus, the knowledge level about PMTCT may have been falsely high. However, in the qualitative interviews, open-ended questions were applied, implying that active knowledge was sought. These findings largely confirmed the quantitative findings. We asked mothers about such sensitive issues as HIV testing and condom use, and we are not sure how these might have affected the responses. The use of the VAS scale could have introduced a bias if the mothers did not understand the scale. We tried to deal with this problem by giving them the test questions in advance. The scale from 0-10 could introduce a bias by the numbers in the very end of the scale, 0 and 10, or the number in the middle of the scale, 5, being preferred. This did not seem to be the case in our data analysis. Lastly, some of the questions asked were hypothetical, which only reflects attitudes. We acknowledge that the answers might have differed from true experiences.

Credibility

Credibility refers to our ability to capture properly the multiple realities of those we study. How well have we understood and reconstructed the subjective reality of our study participants? The fact that I was not conversant in the **local language** was a major limitation of the qualitative data. The use of an interpreter may have distanced somewhat the interviewer and the interviewee, thereby reducing the quality of the interviews. Despite this limitation, it was considered important that I took the lead since I knew my research objectives best. I was also unable to take active part in and moderate the FGDs. Efforts were made to decrease this limitation; the moderator was given a topic guide with probes and was thoroughly informed about the topics of interest. Each FGD was transcribed and translated before the next was performed, so that I could give the moderator feedback and adjustment to her performance could be made if necessary.

There is always a compromise in qualitative studies between too many and too few participants, both of which can compromise quality. We ended up with a large amount of material: 13 FGDs and 34 in-depth interviews. Since we wanted to interview many different groups of participants as well as to combine FGDs and in-depth interviews, the material became larger than that usually advised in qualitative research [128].

When the material is this extensive, the researcher might tend to treat it more superficially [128]. We were well aware of this potential pitfall when conducting the study. I found it very useful to read through each interview as soon as it had been conducted and transcribed, both to do further adjustments to the research tool, and also to keep a constant overview of the data that had been collected in trying to get a sense of saturation. In this way, the material was systematized as it was collected and preliminary analyses were done. The information was grouped into categories that made it easier to keep a constant overview. During the analysis process, some of the material was deemed less relevant and left out of further analysis. This might have left out pieces of potentially important information. However, I was assisted by one of the co-authors who also read through the transcribed material and analysed it. Thus, the material was thoroughly discussed and reassessed to meet consensus of opinion between the analysts, and to detect any concepts or information that had been missed.

Although all participants agreed to the use of a tape-recorder, it may have constrained their answers. I analysed qualitative data from transcripts that had been translated to English. Translation is always associated with some loss or modification of meaning; therefore, some of the original meanings might have been lost.

The FGDs with the fathers were all moderated by a woman. We are unable to assess whether this affected their answers. The flow in the discussions did not seem to differ from the FGDs with the mothers or mothers-in-law. Some of the questions we asked during the qualitative interviews were hypothetical, e.g. how would the father react if the wife was HIV-infected. We acknowledge that the answers might differ from what would have been the answers about their true experiences.

We do not know if my presence in the PMTCT observation sessions could have affected the mother being counselled or the nurse doing the counselling. It might have made it more difficult for the mother to decline testing and it might have restrained the communication in the counselling.

There are several strategies to increase credibility [111, 119, 126], which include: 1) prolonged engagement; 2) triangulation; 3) peer-debriefing; 4) member checks; 5) clear exposition of methods, data collection and analysis; and 6) reflexivity.

Five months of field work was allocated for this study. Ideally, I would have liked to spent longer time in the field to study the social and cultural context of PMTCT service provision in the Kilimanjaro region and thereby increase the likelihood of a deeper understanding of those studied [111]. A longer period of field work could have enabled me to investigate further questions that arose from the data analysis. It could also have enabled me to gain a deeper understanding of gender roles and the seniority system which emerged as central to the PMTCT service utilisation. However, the design chosen was a time and resource efficient way to yield current knowledge of the topic.

Triangulation of the qualitative data was performed by employing different data sources and collection methods. By interviewing mothers, fathers, mothers-in-law and health

personnel about similar topics, looking for patterns of convergence and divergence, credibility of the interpretations increased [126]. On several occasions we found that the different participant groups differed in their opinions about the topics, such as the discrepancy between the mother-in-law's view of her central role in the family and the resistance to her involvement expressed by the mother and father. By using both FGDs and in-depth interviews, we argue that we have increased the credibility of the data collected because two methods had different strengths and limitations. The in-depth interviews provided personal experiences and the opportunity to go deeper into the various topics. The FGDs tended to reflect social norms rather than personal experiences. The group processes in the FGDs may have assisted exploring and clarifying the participants' views about sensitive topic compared with one-to-one interviews [126]. Further, the participants in the FGDs seemed freer in their responses, thus giving richer answers. We noted that the mothers in the in-depth interviews had a more optimistic view of their partners and mothers-in-law than the mothers in the FGDs. However, we were unable to tell whether differences in the answers were due to social desirable answers in the in-depth interviews or social norms reflected in the FGDs.

Peer debriefing was performed by presenting the preliminary findings to colleagues and individuals with local knowledge. However, the results obtained were not brought back to those being studied for clarifications of the information provided and confirmation of the researcher's interpretations (member check). Efforts have been made to give an extensive description of the methods, data collection and data analysis [126]. To increase the credibility of the data analysis, the principal investigator and one of the co-authors revised the interviews after completion of the analysis, checking for missed information, misinterpretation and similar matters.

Reflexivity

In qualitative research, the researcher is the research instrument. It is important to be explicit about the background, pre-knowledge of the field and position of the researcher [111, 126, 129]. Ideally, we would have liked to provide a fuller description of the author's background and pre-knowledge in the papers, but were constrained by space.

My approach in the field was one of relative naïvity, which influenced the design of the study instruments, the way I conducted the field work and the interpretation of the results. More knowledge of the local context would have been preferable when designing the study. The study design was largely influenced by the knowledge gained by reading relevant literature. During the study I had to change many of my pre-conceptions that did not fit the reality in the study setting, for example there was a much higher acceptability of routine counselling and testing than expected, the male partners was not a barrier to the mother testing for HIV, and the mothers-in-law often lived far away from their daughters-in-law where they were less influential than expected.

I was assisted by four researchers experienced in different areas relevant to this research. Some of them had extensive experience in quantitative methods, others in qualitative, and some had used mixed methods. Further, two of them (KKM, MMdP) had previously conducted field work in the Kilimanjaro region, and one of them was the author of one of the series of studies mentioned in the 'Introduction', that our research built further on

(MMdP). The other two researchers (IMSE, TT) were familiar with the PMTCT programme in other African contexts. The knowledge of these four researchers was especially valuable when planning the study, but also when conducting the study and interpreting the results.

I was a medical student during the field work. Being a relatively young, female student may have diminished my authority in this setting, in particular when approaching men. However, I usually felt that I was met with helpfulness and assistance, in particular among the nurse counsellors. When approaching the study population, it seemed that being a foreigner increased my authority and I was met with respect. Exhibiting local naïveté had both advantages and disadvantages. It has been suggested that people are more willing to share their experiences with someone who has limited knowledge and open minded [111]. On the other hand, it is also important when conducting qualitative research to use the “native language”, in terms of being able to speak the local language, but also to understand the local meaning of terms and know the jargon in speech [111]. Thus, originating from a different context may have made it difficult for me to ask the appropriate questions in the correct way and understand the true meaning of the participants’ answers. It may also have made it more difficult to determine when the participants were expressing views consistent with social standards rather than their own opinions.

Applicability

Applicability is described by external validity in quantitative design and as transferability in qualitative design [111] (Appendix 3).

Extern validity

How representative are the sample for the target population? Consecutive sampling over a limited time period was chosen in a selection of clinics. Neither the clinics included nor the mothers recruited were randomized, which may have inhibited generalisation. However, due to the high participation at the DPT-HB and polio immunisation (100%), and the high participatory rate (99%) in the study, the mothers who participated are likely to represent those with a four-week-old infant in Moshi urban and rural. In the study, 50% of the study population lived in rural areas, while in the Kilimanjaro region, about 80% of the population lives in rural areas, thus our selection of participants is not completely reflecting the demographic patterns for the Kilimanjaro region. The fact that Moshi and the Kilimanjaro region is known for its relatively high educational level and clinical attendance may suggest that the findings are not entirely representative for women with four-week-old infants in the country as a whole. Furthermore, it is important to acknowledge the differences between the urban and the rural populations, which may suggests that results in an urban population in this area are not easily transferable to a rural population and visa versa. However, the huge differences in PMTCT knowledge observed between the urban and the rural antenatal attendees may also be due to difference in the start-up time of the PMTCT programme, suggesting that the findings are mostly relevant to settings with similar duration of PMTCT programme implementation.

Transferability

How applicable are the findings from a qualitative research project to other contexts? Qualitative findings are context-dependent. Whether the findings are transferable or not has in qualitative literature been suggested as up to the reader to decide, not the researcher

[111]. However, the researcher should assist the reader. Consequently, efforts has been made to give a description of the research context, enabling the reader to make an informed choice about transferability to other contexts [111, 129]. However, we believe that many of the same arguments that where used concerning applicability of the quantitative data are also relevant for the qualitative data. The differences found in the qualitative data between the urban and rural population, in particular those concerning family constellations and the relationship to the mother-in-law, imply that findings in an urban population in this area may not be easily transferable to a rural population and visa versa.

Strengths of using mixed methods in this study

Mixed methods were a valuable approach in this study. It enabled us both to answer the confirmatory and exploratory study questions [114, 115]. Using mixed methods gave us a more complete understanding of the research topics. For example, the survey provided the number of mothers tested for HIV, and the qualitative interviews presented the mothers' attitudes to and experiences of testing. The use of mixed methods provided stronger and better inferences [114, 115]. For instance, the quantitative data showed a knowledge gap between mothers attending a rural as opposed to an urban clinic. However, this gap was not found in the qualitative data, which may indicate that the qualitative instrument allowed a deeper understanding of the mother's actual knowledge than the quantitative more rapid assessments. When the findings corroborated each other, there was greater confidence in them [113], for example, the high percentages of mothers that had informed their partner about their test results in the survey and the corresponding attitude expressed by the mothers in the qualitative interviews stating that it was important to inform the partner about the test result. The qualitative data provided information from different sources than the quantitative data, increasing the validity of the mothers' reports about their partner and mother-in-law in the latter. The use of different sources enriched our understanding of the research topics.

Call for future research

Three main research questions needing further investigation emerged from our work:

- 1) How to continue scaling-up of the PMTCT programme and simultaneously ensure the quality of care offered? Although the scale up of the programme in the region has been successful in terms of acceptability of testing and the mothers' knowledge about PMTCT, the quality of the counselling seemed to be insufficient.
- 2) How to involve the male partners in the PMTCT programme? The study demonstrated that although this has been an area of priority for many years, little progress had been made. Efforts to include the male partners have not been context-sensitive and have been unsuccessful.
- 3) How to deliver the infant feeding counselling in a way that is clear and culturally appropriate? The infant feeding counselling was insufficient and confusing, and the guidelines conflicted with customary practice. Influentially people surrounding the mother were not included, which could be a barrier to safe infant feeding.

Although inadequate counselling, confusing infant feeding counselling and lack of male partner involvement are well known barriers to utilization of the PMTCT programme by mothers, little progress has been achieved. Thus, future research needs to investigate how to put this knowledge into practice. For interventions to be effective, they need to be applicable within the available health system framework and implemented appropriately so that the end-user can benefit from them. From this study, it was evident that interventions need to be context-sensitive in order to succeed. Concerning the three research questions raised from this study, some suggestions to future implementation research are:

- 1) The feasibility of task-shifting to see whether this is a way to augment counselling capacity in this setting.
- 2) Research addressing the cultural issues brought up in this study, namely the gender hierarchy and the definition of the antenatal clinic as fundamentally female oriented, so to explore some alternative organisation of the PMTCT programme that facilitates male participation, are needed. The feasibility of using men as peer counsellors to recruit other men for testing is another area for further investigation.
- 3) When implementing the 2010 infant feeding guidelines, research is needed on how to best inform the mothers on the national infant feeding strategy and how to best support them. More research is needed on how to deliver this information also to those surrounding the mother. Taking into account their seemingly high confidence in health personal, strategies to include male partners and mothers-in-law in the infant feeding education should be further explored. Future research could also explore if community interventions are a realistic approach to mobilise the mothers-in-law in breastfeeding promotion programmes.

Conclusions

In this study, the mothers' knowledge and utilization of the PMTCT programme was assessed, focusing on male partner involvement and the role of the mother-in-law. Eight years after the first introduction in the Kilimanjaro region, the programme has been firmly established. There was widespread knowledge in the population about the benefits of participating in the programme and testing for HIV at antenatal clinics was highly acceptable. The study indicated that implementation of routine counselling and testing facilitated testing of the mother, partly by reducing stigma associated with testing. However, the mothers' participation in the programme was hampered by inadequate counselling, lack of male partner involvement, and insufficient knowledge about safe infant feeding.

Although knowledgeable about PMTCT and motivated to counsel the mothers, the nurse counsellors did not have sufficient time to counsel the mothers adequately. This was perceived as a challenge among nurse counsellors and mothers. In order to be a preventive programme and not merely a screening programme, there is a pivotal need to increase counselling capacity, to make it clearer, adequate and enabling for mothers to take preventive actions.

The study re-emphasised the importance of male partner involvement in utilization of the programme by the mother's. However, the organisation of the programme remains a barrier to male attendance. Women did not have the authority to request their husbands to test for HIV and the arena for testing, the antenatal clinic, was defined as typically a female domain. Existing gender roles and hierarchy were major obstacles to male participation in the PMTCT programme. The study clearly demonstrated that efforts in promoting male partner involvement, such as asking the women to bring their partners, have so far been inadequate. In order to improve male involvement, we argue that further strategies adapting to local realities need to be explored.

The study also showed that the infant feeding counselling remained unclear, both due to insufficient time to deliver the counselling and guidelines that conflicted with local knowledge and reality construction. The most recent guidelines, which argue for giving the mother only one choice how to feed her infant, could reduce confusion. As breastfeeding is intimately associated with motherhood in this setting, EBF with ARV prophylaxis could be a better option as the standard of care than replacement feeding in this region. Although promising, the new guidelines do not discuss how to target significant others in the infant feeding information. Our study demonstrated that the infant feeding choice was strongly influenced by the male partner, and also in many cases by the mother-in-law. In order to succeed with her infant feeding option, the mother needs social support. The newest guidelines, promoting breastfeeding as the first choice of infant feeding method, is closer to local practice and infant feeding advice given to mothers in general, thus providing a better opportunity of involving the mothers-in-law in its promotion. Thus, when implementing the new 2010 guidelines, we argue that information about safe infant feeding, and particular EBF, needs to be delivered also to those surrounding the mother.

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