Promotion of Exclusive Infant Feeding in South Africa

Community-Based Peer Counselling in high HIV Prevalent Area

BARNI NOR
Dissertation presented at Uppsala University to be publicly examined in Universitetshuset, Sal IX, Biskopsgatan 3, Uppsala, Wednesday, December 15, 2010 at 13:15 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in English.

Abstract

Despite global efforts, exclusive breastfeeding is rarely practiced in South Africa where infants are at risk of diarrheal infections, malnutrition and HIV transmission. The present study was conceptualized within the context of a multi-country, cluster randomized community-based behavioural intervention known as PROMISE-EBF in South Africa, Burkina Faso, Zambia and Uganda (www.clinicaltrials.gov, no: NCT00397150). The aim of this thesis was to identify and describe contextual factors that are important for the effectiveness of community-based peer counselling with a special focus on the promotion of exclusive breast and formula feeding. This thesis identifies the paradoxes and discrepancies embedded in the notion of community-based “peer” counselling approach, especially in the South African context of poverty, HIV and social distrust. Peer counselling, while perceived useful, was associated with social distrust which might have resulted in reduced effectiveness of the intervention. The thesis further illustrates that, while there is strong support for breastfeeding, there was a general openness for early introduction of commercial foods and liquids. Mothers’ perceptions on infant feeding and peer counselling varied substantially according to HIV-status and geographical area. Nevertheless, the infant feeding peer counselling approach neither modified the mothers’ perceptions on feeding nor its associated barriers. Thus, several important barriers to exclusive breastfeeding including the risk for HIV stigmatization still remain. The results of this thesis highlight the need to rethink current approaches to the promotion of exclusive breastfeeding. It further draws attention to the gap between theoretical assumptions inherent in health interventions and the actual dynamic processes and realities of women in low-income high HIV settings.

Keywords: Promotion, Exclusive Breastfeeding, Formula Feeding, Peer Counselling, HIV, South Africa

Barni Nor, Department of Women’s and Children’s Health, Akademiska sjukhuset, Uppsala University, SE-75185 Uppsala, Sweden.

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To my mother and father
Research Collaboration

This doctoral thesis was developed in collaboration with members of the School of Public Health, University of Western Cape (UWC), Health systems Research Unit. South African Medical Research Council (MRC) and Department of Women’s and Children’s Health (IMCH), Uppsala University. The two South African institutions together with IMCH collaborate in a number of research projects funded jointly by Sida/SAREC and the National Research Foundation (NRF), South Africa. The PROMISE-EBF trial was mainly funded by EU 6th Framework INCO DEV, contract no INCO-CT 2004-003660.
“Breastfeeding is a life and death issue”
List of Publications

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


II. Nor B, Ahlberg BM, Doherty T, Jackson D, Zembe Y, Ekström E-C. Mother’s perceptions and experiences of infant feeding within a community-based peer counselling intervention in South Africa (Submitted for publication)

III. Nor B, Doherty T, Ahlberg BM, Jackson D, Ekström E-C. Exclusive infant feeding promotion in high HIV prevalence area: a community-based cross-sectional study. (Manuscript).


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<th>Description</th>
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<tr>
<td>AFASS</td>
<td>Acceptable, Feasible, Affordable, Sustainable, Safe (WHO’s criteria for formula feeding/replacement feeding)</td>
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<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>BFHI</td>
<td>Baby Friendly Hospital Initiative</td>
</tr>
<tr>
<td>CG</td>
<td>Control Group</td>
</tr>
<tr>
<td>EBF</td>
<td>Exclusive breastfeeding</td>
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<td>EFF</td>
<td>Exclusive formula feeding</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>IG</td>
<td>Intervention Group</td>
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<tr>
<td>IMR</td>
<td>Infant Mortality Rate</td>
</tr>
<tr>
<td>MDG</td>
<td>Millennium Development Goals (8 goals of WHO to end poverty by 2015)</td>
</tr>
<tr>
<td>MF</td>
<td>Mixed-feeding</td>
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<tr>
<td>MTCT</td>
<td>Mother-to-Child Transmission of HIV</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother-to-Child Transmission of HIV</td>
</tr>
<tr>
<td>PROMISE-EBF</td>
<td>Promoting Infant Health and Nutrition in Sub-Saharan Africa: Safety and Efficacy of Exclusive Breastfeeding Promotion in the Era of HIV</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<td>UNAIDS</td>
<td>Joint United Nations Program on HIV/AIDS</td>
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<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<tr>
<td>USS</td>
<td>US Dollar</td>
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<td>ZAR</td>
<td>South African Rand</td>
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 Preface

“On the road to discovery”

In the words of Robert Chambers [1] “A Nutritionist may see malnutrition, but not the seasonal indebtedness, the high cost of medical treatment, the distress sales of land and the local power structures which generates it”. This quotation captures perfectly the journey of my four year doctoral training within a university medical department. As a nurse and nutritionist, I came into the PROMISE-EBF intervention trial at the end of 2005, concerned about the health implications of HIV-infected mothers’ unsafe and inappropriate (mixed-feeding) infant feeding practices for the newborn infant. I was also very much concerned about the poor quality of health care services, particularly the inadequate infant feeding counselling offered to these mothers. So naturally, the point of departure for my research studies was to explore and learn how PROMISE-EBF intervention could potentially help South African mothers achieve safe (exclusive breastfeeding practice). A special interest was to explore the mechanisms through which PROMISE-EBF could “work” in order to modify or even change some of the cultural norms that are known to negatively affect mothers’ infant feeding choices and behaviour. By 2006, however, during my first field work and data collection, I was confronted with the complex, multifaceted and dynamic realities of mothers in this setting. During the interviews, the mothers did not talk much about infant feeding as their primary concern (despite our repeated direct enquiries during the interviews) nor did they emphasize peer counselling in their remarks. However, puzzling as this was, I did not at that time fully understand the significance of these emerging findings. I was guided to read several articles and books, none of which dealt with child feeding. I read two of these books with great interest, and both had a profound impact on my curiosity and interest about the processes of translating health research into policy and then practice, as well as about the important place and role of community members in improving their own health.

The books are entitled, Rural Development by Robert Chambers [1] and a doctoral thesis entitled Whose Knowledge Counts? by Thubelihle Mathole [2]. Riding on this enthusiasm, I was further advised to advance my skills in qualitative research methods by participating in several courses. In my opinion, the most influential were “Participant action research for strategic
change” and “Out of the lab and into the world: a paradigm repair workshop” because they opened up an opportunity for me to start seeing connections in my work. Notwithstanding, I take this present opportunity to admit that it was not until recently that I had an “Aha! Moment”, where I finally understood the place for all these literature readings and course works: the Law of Ecology applies also to infant feeding! Everything is connected to everything else! Infant feeding is not an isolated health issue! As Dr Mathole eloquently puts forward, we “need to broaden the conceptualization and practice of evidence-based care to incorporate different types of evidence and include realities, knowledge and practices of not only beneficiaries but also those implementing change”. The question is then, how? How can we or should we – as health professionals and researchers – incorporate local knowledge into the design, implementation, and analysis of health interventions and programmes? How can we involve the mothers themselves in the conceptualization, planning and implementation of health interventions and programmes? Inspired and influenced by the work on community participation and/or mobilization in Asia, I contend there might be a place for this model in the promotion of exclusive breastfeeding, especially in the South African context of poverty, high HIV prevalence and social distrust.
Introduction

Benefits of breastfeeding for infant survival

The significant benefits of breastfeeding on infants’ nutritional, immunological and developmental status and health are well recognized in the medical literature [3,4,5,6]. Breast milk is rich in protein nitrogen components (i.e. immunoglobulins), essential fats (i.e. fatty acids), carbohydrates (i.e. lactoferrin and oligosaccharides), enzymes, hormones, growth factors, minerals, electrolytes, vitamins and water and has an optimal pH [7]. It contains everything that an infant needs in the first months of life. These components are necessary for protecting infants against malnutrition (which is an underlying cause of an estimated 54 percent of the 12 million child deaths every year) [8], diarrhoea [5,9] and acute respiratory infections [5]. It further promotes optimal infant growth [10,11] and cognitive development [12] during the first six months of infant’s life. Because of the superiority of breast milk over all other alternative infant foods (i.e. formula milk), breast milk has been referred to being a natural “white blood cell” [7].

The composition of breast milk fulfils the infant’s total nutrient requirements for the first six months of life and remains a valuable source of nutrition up to two years of age or beyond [13]. Breastfeeding, especially exclusive breastfeeding (EBF) (breast milk alone with no additional foods or liquids, except for prescribed medicines) is particularly important source of nutrition for infants in low-income countries such as South Africa where rates of diarrheal and other childhood infectious are high and where conditions critical for safe usage of formula milk can be guaranteed for only a minority of infants [14]. Accordingly, a collaborative study in 42 low-income countries [15] indicates that intervention programmes promoting exclusive breastfeeding could directly prevent, as many as 1.3 million child deaths each year (about 13% of the approximately 12 million under-5 deaths) compared to other interventions such as micro-nutrient supplementations and some child vaccinations. The authors of this study conclude that exclusive breastfeeding is the most cost-effective and feasible child survival intervention that could be implemented in low-income countries such as South Africa.

The beneficial effects of exclusive breastfeeding on infant health have also been reported in other settings including high-income countries such as
USA. In a large cluster randomized trial in Belarus with more than 17,000 mother-infant pairs from 31 maternity hospitals and clinics, showed that infants who were exclusively breastfed at three months (IG 43.3% vs. CG 6.4%; \( P=.001 \)) and at six months (IG 7.9% vs. CG 0.6%; \( P=.01 \)) had a significant reduction in the risk of both gastrointestinal tract infections and of atopic eczema [16]. A recent cost-analysis study conducted in the USA evaluating the cost benefit of exclusive breastfeeding for infant diseases and deaths show that if 90% of US women complied with recommendations of exclusive breastfeeding in the first six months, the government of United States would save 13 billion US dollars each year [17]. It further shows an 80% compliance of exclusive breastfeeding would prevent approximately 911 infant deaths each year [17]. It is however important to note that the effects of breast milk on infant health is largely dependent on the duration and exclusivity of breastfeeding [18].

Formula feeding and risk of infant disease and death

The risk of death from acute lower respiratory infections and diarrhoea has been reported to be five to seven times higher in formula fed infants compared to infants exclusively breastfed during the first six months of life [19]. In one large longitudinal cohort study of almost 10,000 urban infants in the Philippines [20] the risk of death from diarrhoeal infections alone was documented to be 10 times higher for formula fed infants compared to breastfed infants. In Brazil, the risk of hospitalization for acute lower respiratory infections in infants less than five months of age was 17 times higher (OR 16.7, 95% CI 7.7 – 36.0) for formula fed infants compared to breastfed infants [21]. An observational study [22] in India confirm the results in Brazil and suggests that formula fed infants are more likely to be hospitalized in the first six months of life compared to breastfed infants. The findings of these studies are consistent with previous data from pooled analysis of studies from low-income countries [5] reporting a significantly lower mortality rates for breastfed infants compare to a group of formula fed infants. This prominent pooled analysis shows striking results of pooled odds ratio of 6.1 (95% CI 4.1 – 9.0) towards protection against diarrhoea and pneumonia (two leading cause of deaths in children in low-income countries) for breastfed infants less than six months of age. This protective effect gradually diminished however, as the infant grew older indicating that infants in their first year of life are more vulnerable to these circumstances and that inappropriate feeding practices such as mixed-feeding further increases their risks for infections.
Exclusive breastfeeding and risk of HIV transmission

Although HIV has been cultured in breast milk as early as 1980, the exact mechanisms and timing for HIV transmission during breastfeeding is still unknown. There are three stages at which the HIV virus can be vertically transmitted from an infected mother to her infant – during pregnancy (in utero), at the time of delivery (intrapartum) and or after birth through breastfeeding (postpartum) [23,24]. This process is in the medical literature referred to as Mother-to-Child Transmission (MTCT) of HIV. In general, the risk of MTCT of HIV is estimated to be greater during delivery with as much infection occurring within hours as occurs postnatally within months of breastfeeding [25]. In the absence of any interventions such as antiretroviral prophylaxis and/or safe delivery practices (i.e. elective caesarean section), approximately 5-10% of infants are HIV-infected during pregnancy, 10-20% during labour and 10-20% during breastfeeding [26]. The risk of HIV transmission through breastfeeding has been reported from studies from all parts of the world and transmission rates vary widely from 2% to almost 30% [23,27,28,29,30]. In general, HIV transmission rates from studies from the low-income countries report higher HIV rates than those from high-income countries. For example, in a multi-centre pooled analysis of data from eight cohorts from high and low-income countries, the risk of postpartum HIV transmission (after four months of age) is estimated to be 3.2% for every year of breastfeeding [31]. In Malawi, however, the risk of transmission is documented to be higher 3.5% in the early months of life and remained substantial as long as breastfeeding continued [32]. The disproportionately high HIV transmission rate observed in low-income countries is particularly observed among recent seroconverters and chronically infected women and is suggested to be most likely caused by a range of risk factors known to increase the risk of HIV transmission in the breastfed infant [33]. It has also been suggested that the variation in HIV infection rate in low compared to high-income countries may be due to differences in methodology between studies [34].

Over the last decade, several maternal and infant factors have been shown to increase the risk of HIV transmission in breastfed infants. The maternal factors include high RNA viral levels in plasma and breast milk, recent maternal HIV infection, low CD4 cell count, breast pathologies such as cracked bleeding nipples and clinically evident mastitis, and prolonged duration of breastfeeding (more than six months) [23,24,31,33]. The infant factors include damage to the mucous membranes (i.e. by oral thrush), damage to the intestinal mucosa by cow’s milk or allergic reactions to complementary foods, and mixed-feeding which may affect intestinal permeability [35]. Mixed-feeding (breast milk in addition to solid foods and other liquids) is correlated with three to four fold increased risk of HIV transmission com-
pared to exclusive breastfeeding in several large epidemiological cohort studies conducted in South Africa [29,36], Zimbabwe [37], Zambia [38] and Côte d’Ivoire [39]. Mixed-feeding is further estimated to result in two to three times higher risks of death from diarrhoea and pneumonia when compared to exclusive breastfeeding [19]. Exclusively breastfed infants are thought to have a less permeable gut lining compared to mixed-fed infants. Other potential mechanisms which may explain the observed lower risks of HIV-infection in exclusively breastfed infants compared to mixed-fed infants could be that exclusive breastfeeding i) may reduce dietary antigens and pathogens which are thought to provoke an inflammatory response or damage the infants gut integrity, ii) promotes beneficial intestinal microflora, which are assumed to increase the resistance to infections, iii) possible modulation of anti-inflammatory and immuno-modulating properties of breast milk, and iv) the role of exclusive breastfeeding in maintaining breast health in the mother [35,37]. Prospective cohort studies suggests that the risk of HIV transmission through breastfeeding might be substantial among women who become infected during lactation [28] while women who become infected during pregnancy probably have a lower risk of transmitting HIV to their child during breastfeeding [40], suggesting primary prevention of the infection to be very crucial. Antiretroviral prophylaxis or treatment offered to either the HIV-infected mother or HIV-exposed infant can significantly reduce the risk of postnatal transmission of HIV through breastfeeding. Zidovudine prophylaxis at 36 weeks gestation until delivery or single dose Nevirapine during labour has been shown to reduce the risk of postnatal transmission by 40% [41,42]. This regimen is the recommended minimum prophylaxis that should be provided to HIV-infected mothers and their newborn infants [43].

Infant feeding practice and decision-making

Although breastfeeding remains the norm and a core component of child care in most countries [44,45,46,47,48,49,50] exclusive breastfeeding rates are low, even if data vary widely across the world. In settings where almost all women initiate breastfeeding, mothers were breastfeeding their infants up to the age of two years (range: 18-24 months) [44]. Exclusive breastfeeding rates (less than four months of age) are found to be generally lower in Africa compared to Asia and Latin-America [51]. In Western Europe and USA, exclusive breastfeeding rates are generally higher among educated white women as compared to ethnic minority immigrant groups [52,53]. England is an exception to this, as exclusive breastfeeding rates are higher among women of Asian and African origin as compared to white majority population group [52,54]. The latest Demographic Health Survey in South Africa [55], report a rate of exclusive breastfeeding of only 12% in infants less than
There are multiple factors for why mothers introduce semi-solid foods and liquids in early infancy. Maternal education [57,58,59], parity [57,60], marital status [61], maternal employment and/or housework [48,62], perceived breast milk insufficiency and/or cultural practice of traditional medicines [49,63,64] (see Figure 1), influence and pressure from partner and family [65], HIV [66,67,68], hospital practices [58,69,70], formula milk advertisement [47] and quality of infant feeding counselling within the health system [50,68,71,72] have all been shown to be important predictors for duration and exclusivity of breastfeeding. In high HIV prevalent areas such as sub-Saharan Africa, additional dynamics and barriers potentially complicating the goal to exclusive breastfeeding are observed. For example, a Zambian research group [45] report that HIV-infected mothers are even less successful in sustaining exclusive breastfeeding practice compared to their HIV-uninfected peers. An ethnographic study in Kwa-Zulu Natal, South-Africa [67] suggests two main reasons for the observed poor rates of exclusive breastfeeding in sub-Saharan Africa. Firstly, the mode of mixed-feeding is reported to be considered by HIV-infected mothers as a “safer” option than exclusive breastfeeding, because of the perception of small quantities or volume of the infected breast milk exposed to infants. However, the perception of mixed-feeding as a “safer” option has not been confirmed by other studies. Secondly, breast milk alone is perceived by majority of mothers including HIV-infected mothers to be an inadequate nutrition for infant weight gain and growth. As a result, semi-solid foods and other liquids were given to infants prematurely in order to complement breastfeeding.

In a longitudinal cohort study in rural South Africa where HIV is highly prevalent, out of 130 infants 46% were reported to have received non-breast milk fluids or feeds within 48 hours after birth [49]. At six weeks, only 10% of the infants were exclusively breastfed. A cross-sectional survey of 500 pregnant women in the Kilimanjaro region of Tanzania, also report 46% prevalence of introduction of liquids in early infancy [61]. An ethnographic study conducted in 11 sites (areas) across three southern African countries namely Namibia, Swaziland and South Africa, similarly document early introduction of foods primarily due to perception of milk insufficiency [73]. In this study, breast milk was considered by women a “drink” rather than “real food” and was thus a strong reason for why breast milk was complemented with other foods. In rural Yoruba communities of south-western Nigeria, exclusive breastfeeding was considered a harmful practice due to the perception that water is necessary component of “life” as to reduce thirst and for normal development of the infant [74]. A large observational study [44] from Tanzania and Uganda supports previous results of wide acceptance of
the pattern of early introduction of foods and liquids. The significant finding of this study is however, that the time of introduction of semi-solid foods and other liquids was not associated with women’s occupation, education, or any of the other measured demographic characteristics among study population, suggesting wide acceptance of this practice among all women in these settings.

Figure 1. An example of some of the traditional and over-counter medicines commonly used by mothers in South Africa.

Translating global infant feeding policy into practice

Prior to the discovery of HIV virus in the breast milk, in late 1980s, breastfeeding was promoted by the World Health Organisation as the ideal method of feeding infants in the first six months of life [75]. The period 1985 – 1998 saw however a drastic change in research advances and policy responses on HIV and infant feeding. The main question during this period was whether HIV-infected mothers should breastfeed or not. This question was, and still is, only relevant and applicable to low-income countries, particularly in South Africa which has been recently reported to be one of the 12 countries where child mortality has increased, rather than declined since 1990 when the Millennium Development Goals were first developed [76].
In 1987 and again in 1992, the WHO/UNICEF/UNAIDS released a set of divergent policy guidelines on HIV and infant feeding in low compared to high-income countries. The recommendation given in these policy guidelines was that “where the primary cause of infant deaths are infectious diseases and malnutrition all women should breastfeed including those known to be HIV-infected”. It further recommended that “where infectious diseases are not the primary cause of infant death, HIV-infected women should avoid all breastfeeding” [77]. Following these recommendations, governments in high-income countries mainly in the US and Western Europe quickly established formula milk as a standard policy recommendation for all HIV-infected mothers. In contrast, policy makers in low-income countries, especially in sub-Saharan Africa struggled to recommend one single feeding method for HIV-infected mothers.

This because the promotion of formula milk within the contexts of contaminated drinking water, limited access to adequate health care services, unreliable formula supply, and inadequate community support could result in excess in infant morbidity and mortality [78,79]. As a result, both exclusive breastfeeding and formula feeding was recommended to HIV-infected mothers in living in these settings. Between 1994 and 1997, data from four cohort studies in Africa – Congo Kinshasa (previously known as Zaire), Kenya, Cote d’Ivore and Rwanda, documented an excess HIV transmission risk of 4-22% in breastfed infants compared to formula fed infants [77]. The results of these four epidemiological studies influenced the development of a new policy guideline in mid-1998 on HIV and infant feeding by WHO/UNICEF/UNAIDS – one specifically tailored for decision makers and another for health care providers. The specific recommendations given in these policy guidelines for populations where both HIV and diarrheal infections are highly prevalent was that complete avoidance of breastfeeding should only take place if, Acceptable, Feasible, Affordable, Sustainable, and Safe (AFASS) in the local context (Table 1) [80,81].
Table 1. The World Health Organisation’s criteria for assessing the appropriateness of formula feeding in low-income settings [82].

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<tr>
<td><strong>Acceptable</strong></td>
<td>The mother perceives no problem in formula feeding. Potential problems may be cultural, social, or due to fear of stigma and discrimination.</td>
</tr>
<tr>
<td><strong>Feasible</strong></td>
<td>The mother (or family) has adequate time, knowledge, skills, resources and support to correctly feed the infant up to 12 times in 24 hours.</td>
</tr>
<tr>
<td><strong>Affordable</strong></td>
<td>The mother and family, with community or health system support if necessary, can pay the cost of formula feeding without harming the health or nutrition status of the family.</td>
</tr>
<tr>
<td><strong>Sustainable</strong></td>
<td>Availability of a continuous and uninterrupted supply and distribution of all ingredients needed for safe formula feeding for up to one year of age or longer.</td>
</tr>
<tr>
<td><strong>Safe</strong></td>
<td>Formula milk is correctly and hygienically prepared and stored, and fed preferably by cup.</td>
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These guidelines particularly stressed the idea that HIV-infected women should be fully informed and supported in order to make “free” choice of exclusive infant feeding mode (breast or formula). Currently, in South Africa, infant feeding counselling takes place in primary health care clinics by various types of health workers and only HIV-infected mothers are targeted for specific infant feeding counselling. The South African National policy guidelines on PMTCT of HIV programmes support the idea of women’s individual and “informed decision” making of either exclusive breast or formula feeding. As part of this policy guideline, HIV-infected women who choose not to breastfeed their infants were provided with free formula milk for a period of six months. Translating the 1998 policy guidelines into action proved difficult however, as WHO/UNICEF review of programmatic experience found a number of shortcomings in the coverage and quality of infant feeding counselling and support across Prevention of Mother-to-Child Transmission (PMTCT) of HIV programmes [83]. For example, the AFASS criterion that are meant to guide health professionals in counselling mothers on exclusive breast or formula and which is further critical for women’s “in-
formed decision” making was reported to be complex and confusing for health professionals [83].

A South African study which evaluated the health systems constraints to optimal uptake and coverage of PMTCT programmes in operational settings, show that almost 10% of all HIV-infected women benefiting from these services had not decided on their feeding mode at time of delivery [84]. A sociological study in Kwa-Zulu Natal, South-Africa suggests, that “informed decision” can only take place when the counselling provided to HIV-infected women is “individualized”, “unbiased” and “accurate” [67]. The authors’ further stress that the given advice should be compatible with women’s belief structure, suggesting that if these conditions along with other circumstances such as appropriate environment including culturally sensitive support to women are achieved decision making process by women would be facilitated and hence the WHO recommendations fulfilled.

In 2000, Nduati and colleagues in Nairobi Kenya published in the Lancet the first data from a randomized clinical trial [27] which showed a higher mortality rate among breastfeeding mothers compared to formula feeding mothers (18 vs 6 deaths, \( p=0.009 \)). This study further demonstrated an association between maternal death and subsequent infant death (relative risk 7.9, 95% CI 3.3–18.6, \( p<0.001 \)). In the same year, the WHO/UNICEF/UNAIDS revised its policy guidelines on HIV and infant feeding according to the findings from this randomized clinical trial [77]. This despite the fact that the results from this trial where highly criticized for the lack of adherence to the WHO definitions of exclusive breastfeeding and for the poor adherence to formula feeding among mothers (30% drop out after formula feeding was initiated), despite intensive follow-up of the mothers. The results of this study further created ethical debate about randomizing formula milk to women in low-income settings. The revised policy guidelines in 2000 did not however, differ substantially from the 1998 recommendations. The 2000 guideline only added the sentence “…otherwise exclusive breastfeeding is recommended during the first months of life”, to the previous recommendation in which HIV-infected mothers were recommended to avoid breastfeeding only when formula milk is AFASS.

Most recently in November 2009, there was a turning point in global HIV and infant feeding recommendations, where eight principles and seven recommendations which moved towards the direction of establishing one feeding recommendation for HIV-infected mothers in low-income countries [85]. The first recommendation outlined in this policy guideline was antiretroviral prophylaxis or treatment for the pregnant mother and infant. The second recommendation was as follows:
HIV-uninfected women or HIV status unknown
- EBF for 6 months and continued breastfeeding for 2 years or beyond
- Adequate and safe complementary feeding at 6 months

HIV-infected women
- EBF for 6 months and continued breastfeeding for 12 months
- Adequate and safe complementary feeding at 6 months

Figure 2. Prince Mshiyeni Hospital in Umlazi which is accredited as a Baby-Friendly Hospital.

Key in translating all these policy guidelines is infant feeding counselling within the health system. According to the WHO/UNICEF/UNAIDS infant feeding counselling of HIV-infected women should ideally begin during pregnancy, with continuation support to allow sufficient time in which “informed decision” making can take place [86]. Four studies, [71,87,88,89] including a relatively recent UNICEF report from 11 low-income countries (Botswana, Burundi, Cote d’Ivoire, Honduras, India, Kenya, Rwanda, Tanzania, Uganda, Zambia, and Zimbabwe) evaluated the implementation of PMTCT pilot programmes [90] and specially investigated the quality of in-
Infant feeding counselling as provided to HIV-infected women. The collective finding of these studies suggests that infant feeding counselling of HIV-infected women remain inadequate. Several reasons are suggested for the difficulty of infant feeding counselling including, inadequate training and supervision of health professionals, increased workload of health professionals, and the complexity of balancing the risks of HIV transmission against the risks of infant deaths associated with formula feeding in low-income settings.

De Paoli and colleagues [89] explored the inadequate training of health workers as an explanatory factor for poor infant feeding counselling in Northern Tanzania. They showed that even when health professionals were sufficiently trained they lacked the confidence in counselling HIV-infected mothers. The results of this qualitative study are consistent with previous studies from South-Africa [71,87,91], making the recommended “informed decision” by the WHO/UNICEF/UNAIDS to be extremely problematic. Moreover, there is an increased indication that infant feeding strategies promoted by PMTCT programmes fail to take into account local traditions and norms of infant feeding [92]. Despite the fact that infant feeding counselling is one of the priority areas in the PMTCT of HIV in South Africa, it remains the weakest component of all the services provided with the framework of PMTCT programmes [14]. A number of global initiatives have been undertaken in order to increase the support for increased breastfeeding initiation, duration and exclusivity. Some of these initiatives include the International Code for Marketing of Breast Milk Substitutes and the Baby Friendly Hospital Initiative (BHFI). However, these initiatives only focus improved breastfeeding practices within the health facilities and not in the community (see Figure 2).

Peer counselling for exclusive breastfeeding – moving from health system to community

The impact of community-based peer counselling as an approach to improve breastfeeding initiation, duration and exclusivity has been evaluated in different settings. Majority of the peer counselling studies are either randomised controlled trials or quasi-experimental and have been conducted among low-income, poorly educated, ethnic women in either the USA [93,94,95,96,97,98] or England [99]. Four more randomized trials with similar socio-demographic population profiles have been conducted in Asia (India, Bangladesh & Philippines) [100,101,102], and Latin America (Brazil) [103]. In only one trial, in urban Toronto, Canada [104], were the study population predominantly white educated women. Five more randomized
trials [99,103,104,105,106] have evaluated the effect of peer counselling on rates of exclusive breastfeeding although not initially designed for this purpose. The intensity of the peer counselling interventions across published studies varies largely, from 15 antenatal and postnatal home visits [100], to four antenatal and postnatal visits [107] or to telephone-based contact [104]. A study conducted in a periurban area in Mexico [95], where two intervention groups with different peer counselling frequencies (6 vs. 3 home-visits) were compared with a control group that had no intervention show a significant increase in breastfeeding exclusivity and duration at three months postpartum. In this study, exclusive breastfeeding rates were highest in the group receiving 6 home-visits (67%), followed by those receiving 3 home-visits (50%) and were lowest in the control group (12%).

The evidence of the effect of peer counselling on exclusive breastfeeding in these studies remain however inconclusive. In general, while randomized trials in Asia, Latin America and North America report a significant increase in exclusive breastfeeding rates, trials in England have failed to show much impact [99,107,108]. One argument for the lack of effect of peer counselling trials in England given by the authors is that this model might be more effective in low-income settings where breastfeeding initiation is generally high or where there is limited professional nurse or midwife support [99]. However, another possible explanation for the low adherence to exclusive breastfeeding in studies in England could be related to the fact that in these three trials women were provided limited face-to-face contact. The interventions were primarily either telephone-based interventions or provided limited (one or two) antenatal home visits. Further, in the study by MacArthur and colleagues [108] the coverage of peer counselled women was only 41%.

The integration of peer counsellor programmes with other child and maternal services in the health system has not been well evaluated. In only Bhandari and colleagues study in rural India [101] was the use of multiple channels evaluated. In this trial, several cadres of health workers including traditional birth attendants, health and nutrition workers and nurse midwives were used in exclusive breastfeeding promotion. Intervention effect on exclusive breastfeeding at 3, 4, 5 and 6 months postpartum was significantly higher compared to the control group. Some of the documented barriers to successful peer counselling initiatives include poorly defined job descriptions, inadequate training and supervision, lack of peer counsellors input in defining programme goals and objectives and limited funding [109]. Few studies [110,111] have assessed the role of adequate training, supervision and remuneration for effective implementation of peer counselling programmes. However, none of the studies have documented the role of the socio-cultural context on peer counselling acceptance and uptake.
Infant feeding peer counselling as an approach seeks to serve three main purposes:

- It strives to give women adequate information of different facts in order for them to make a sound judgment – informative counselling
- It aims to help women safeguard their choices by recognizing and addressing cultural norms and practices that could act as barriers – supportive counselling
- It aims to help women develop awareness for and confidence in sustaining exclusive infant feeding – preventive counselling

Using similar framework as the studies from Bangladesh, India and Mexico, a large multi country community randomised trial known as the PROMISE-EBF trial was initiated in four countries in sub-Saharan Africa, namely Uganda, Burkina Faso, Zambia and South Africa. Detailed description about this trial is given in the Methods section of this thesis.

Why community-based peer counselling programmes?

The concept of community-based lay health workers for the provision of basic health services can be dated back to 1978 Alma-Ata primary health care declaration of “Health for All by 2000” [112]. Then, the core philosophy was participation, mobilisation and empowerment. In 2003, the WHO re-enforced the advantages of lay health workers particularly in low-income countries by stating that: “Communities can make a major difference in improving infant and young child feeding. This is particularly relevant if and when community members participate in the design of interventions, and with expert support, contribute to shaping the content and mode of delivery” [113]. The idea of community participation (see Figure 3) is one of the main pillars of the Alma-Ata primary health care system and is thus nothing new [114]. The primary expectation of the process of participation and/or mobilization is that it will lead to a long-term behaviour change of individuals and communities at large. However, none of the community-based randomized trials which have evaluated the effect of peer counsellors on rates of exclusive breastfeeding have used community participation and/or mobilization as an approach. A recent publication by Rosato and colleagues in the Lancet series of Alma Ata 30 – years on, ask the question “If the failure to incorporate community participation into large-scale primary health care programmes is a major reason for why we are failing to achieve Millennium Development Goals (MDGs) 4 and 5?” [115]. Although this question is not directed specifically to infant feeding peer counselling, it raises the question as to how to optimize and ensure participation of community members in
designing, planning and implementing community-based infant feeding peer counselling interventions.

There is currently no precise and agreed definition of lay or community health workers. Rather lay or community health is an umbrella term used to describe different types of non-professional health workers, each with different responsibility, supervision structures and remuneration packages. In a Cochrane review based on 43 randomized trials where the effects of lay health worker interventions were assessed, lay or community health workers were defined as “Any health worker carrying out functions related to health care delivery, trained in some way in the context of intervention, and having no formal professional or paraprofessional certified or degree tertiary education” [116].

The National and provincial government of South Africa have deployed a cadre of lay health workers called “home based carers” for AIDS patients in order to reduce the disease burden on the health care system. In terms of recruitment and accountability of these workers, a statement from a WHO Study Group re-emphasizes a previous Alma-Ata stand point that “Community health workers should be members of the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a part of its organization and have shorter training than professional health workers” [117]. The degree of involvement of community members in the selection and training of peer counsellors within the PROMISE-EBF intervention varied across two of the four countries – Uganda [118] and South Africa [119]. These two countries were, at time of writing this thesis, the only countries that had documented the experience of the PROMISE-EBF trial. In Uganda, local community leaders were involved in the selection and training of peer counsellors. In South Africa, however, there was no involvement of local leaders in the selection of peer counsellors. Rather, peer counsellors were employed through a process of advertising, selection criteria, and formal interviews because the areas were either too large, segregated or had some influence of urban employment processes.

The South African site of the PROMISE-EBF intervention paid peer counsellors a salary of 1000 ZAR about 144 US$ every month. The amount given was influenced by the size of the clusters (areas) and whether they were shared by two peer counsellors or not. In rural Rietvlei, due to long distances, some of the peer counsellors shared clusters and thus were paid 500 ZAR about 72 US$. The main idea for paying the peer counsellors was to make the intervention in line with national government salaries for community health workers [120]. The perspective of payment of lay health workers remains however controversial. Some researchers have argued that payment
“could weaken the social respect given to female community health workers, thereby threatening their motivation” [121]. Others argue however that payment is “necessary for the long-term sustainability of community health programmes” [122,123]. There is also the opinion that non-remuneration of lay health workers is “no longer possible” and might even be “exploitive” [124].

Figure 3. An example of community participation model, adapted from Thripathy et al 2010 [125].
Rationale for this research

The dilemma of breastfeeding versus formula feeding for HIV-infected mothers in South Africa is complex and difficult. There is, however, scope and possibility to substantially improve infant feeding practices of mothers through mechanisms such as community-based peer counselling. Although, this approach has been documented to be cost-effective and scalable health programme, there is as of yet, limited knowledge about the contextual factors that facilitate or hinder effective peer counselling especially in areas where HIV and other childhood infections are highly prevalent. There is also currently a limited knowledge about the perception of peer counsellors, as perceived by mothers and the extent to which peer counselling can modify mothers’ perceptions on optimal infant feeding.
Aim and Objectives

The overall aim of this thesis was to identify and describe contextual factors important for the effectiveness of community-based peer counsellors with a special focus on the promotion of exclusive breast and formula feeding in areas where HIV is highly prevalent.

The specific objectives of the study are:

- To identify the socio-cultural barriers for effective community-based peer counselling (Study I)
- To explore mothers perspectives and experiences of the promotional messages of exclusive breast or formula feeding (Study II)
- To quantify mothers’ perceptions of peer counsellors, and the potential influence of social support for exclusive infant feeding (Study III)
- To describe the tasks and the challenges facing peer counsellor supervisors in the community (Study IV)
Theoretical Framework

It is has been long recognized that structural (i.e. quality of infant feeding counselling within the health system), cultural or traditional (i.e. use of traditional medicines), economic (i.e. affordability of formula milk) and environmental (i.e. distance to health clinics) are factors important for the determinants of health and health inequalities [126], especially for women in low-income settings. Yet, most health interventions including infant feeding support programmes have focused at the individual level. However, as argued by ethnographers and gender researchers such as Buskens and colleagues [73] improving exclusive breast or formula feeding rates is not merely a matter of providing information to mothers. Rather it is also a matter of actively engaging both the health system and the broader community. The individual mother negotiates her feeding choices and behaviour within the socio-cultural, economic and political environment in which she lives. In an attempt to highlight the importance of these complex, dynamic and diverse factors and their effects on the individual women’s health decisions, Lounsbury and Mitchell (2009) [127] argue that there is a need for shift in current way of thinking about health research. They state that: “We have the potential to make new, substantive contributions to resolving our pressing community health problems. However, to do so, we must adopt a philosophy of science that is directed towards understanding the dynamic complexity and full contextual reality surrounding these issues”. One approach that has been emphasised important in recognizing and addressing each of these factors is the social ecological model (Figure 4).
This model offers the possibility to identify the multiple factors, both known and unknown or unexpected to be addressed strategically [126], while at the same time, it generates information on the dynamic interaction between the individual and each of these diverse factors, at a given time and space. It further allows the opportunity to identify and address health issues at the system level. So far, this model has been used predominately by community psychologists who naturally interact with individuals as part of their profession [127]. In recent years however, the use of this model has gained increased attention in health research [128,129]. The success of any intervention is dependent on whether it is well received and accepted by community members and whether the contextual factors within the community are enabling or not. The social ecological model is therefore considered useful in the analysis and interpretation of the results of the promotion of exclusive infant feeding within the PROMISE-EBF intervention trial. In addition to the holistic approach of social ecological model, we have also used the conceptual framework of the social constructivist, as articulated by among others Guba and Lincoln [130] and the social support framework described by Sarafino [131]. The social constructivist was useful in understanding how the individual’s relationship to the society is socially constructed and through which mechanisms social norms are legitimised and reproduced. The social support framework made it possible for us to interpret and place
our findings of peer counsellor supervisors’ experiences in managing and supporting community-based peer counsellors. This model consists of five key components including “emotional support” – the expression of empathy, caring and concern toward the person, “esteem support” – positive regard for the person, encouragement and agreement with the individual's ideas or feelings, “instrumental support” – direct assistance of a practical nature, “informational support” – giving advice, directions, suggestions, or feedback about how the person is doing, and finally “network support” – provides a feeling of membership in a group of people who share interests and social activities.
Research Methods

PROMISE-EBF intervention

The studies included in this doctoral thesis were nested into a multi-centre cluster randomized community-based behavioural intervention known as PROMISE-EBF – “Promoting Infant Health and Nutrition in Sub-Saharan Africa: Safety and Efficacy of Exclusive Breastfeeding Promotion in the Era of HIV” (www.clinicaltrials.gov no: NCT00397150). The trial was implemented in four African countries, namely Zambia, Burkina Faso, Uganda and South Africa, having varied geographical, economic and socio-cultural contexts. In 2005, when the PROMISE-EBF trial was conceptualized, there was no experience of the peer counselling model in Africa, and in high HIV prevalence areas. The main outcome measure of the PROMISE-EBF trial was the rate of exclusive breastfeeding at 12 weeks. Secondary outcomes include the prevalence of diarrhoea at 12 and 24 weeks and infant growth at 12 and 24 weeks. In addition to the main outcomes of the trial, each of the four countries is documenting context-specific experiences of implementing the PROMISE-EBF intervention. This doctoral study is part of the evaluation of the South African site of the PROMISE-EBF trial.

In South Africa, clusters were randomized into either intervention or control. Randomization was done at site level. In Paarl, 10 clusters were randomized to intervention or control, in Umlazi 14 clusters, and in Rietvlei 10 clusters. The intervention arm had received a specific infant feeding peer counselling support at five different time points, one before childbirth and four postnatally during weeks 1, 4, 7 and 10. The task of the peer counsellor was to support mothers’ to adhere to their chosen feeding mode. In each of the five home-visits, peer counsellors were expected to:

- encourage mothers to attend antenatal care and to be tested for HIV
- support for disclosure of HIV status
- support adherence to mothers already made feeding choice of either exclusive breast or formula feeding
- address the mothers’ or families’ infant feeding concerns and difficulties
- encourage mothers to attend postnatal clinics for immunisation
- if the need arises, refer sick mothers and infants to health care facilities
All pregnant women in the intervention arm were offered peer counselling irrespective of their HIV status or infant feeding intentions. The control arm received the same number of home-visits from peer counsellors, but was given information about available child support grants (government social welfare grants for mothers in poor households), and was further helped to gain access to these grants. The mothers in the control arm also received the standard breastfeeding promotion package at the health clinics. In South Africa, the child support grant was introduced in 1998 as a social welfare policy for eliminating inequality and racism [132]. However, in order to qualify for the social grant scheme, mothers needed a birth certificate for the child and an identity document for themselves – both of which can be difficult for poor mothers to obtain [132]. The peer counsellors were expected to serve an average of 35 women each over a one year period, which would make a total of 840 peer counselled mothers.

Mothers randomly selected for data collection received a gift voucher, cash or food parcels (oil, sugar and maize) to the value of 40 ZAR about (6 US$) at each home-visit by the data collectors. The data collectors visited mothers at 3, 6, 12 and 24 weeks postpartum to collect data on infant feeding practices and other secondary outcomes of the PROMISE-EBF trial. No monetary incentive was included as part of the standard peer counselling programme, as peer counselling itself was seen as a beneficial service while data collection and blood drawing were considered an additional “burden” on mothers and their infants. Data collectors were a separate group of people trained in interviewing and collecting data on anthropometry, blood drawing, and had not participated in the delivery of the intervention.

**Recruitment, training and supervision of peer counsellors**

In total, 34 peer counsellors (10 in Paarl, 10 in Rietvlei and 14 in Umlazi) were selected based on the following criteria: 12 years of education, interest in child health, prior experience of community involvement and resident within the selected trial areas (clusters). No requirement was placed on personal breastfeeding experience or age limit. All of the selected peer counsellors were women. The majority of them were unemployed young women, who at the time of the study had completed secondary school. This was especially the case in two (Umlazi and Paarl) of the three study areas. The peer counsellors were not matched with mothers on the basis of age. The concept of peer was used in a rather loose sense. However, this mismatch was observed to be problematic. The peer counsellors received a modified training package adapted from the WHO/UNICEF “HIV and Infant Feeding Counselling: A Training Course” [86] and WHO/UNICEF “Breastfeeding Counselling Course” [133]. These courses were simplified and shortened to meet
the requirements of the peer counsellors. The training was composed of 40-hours in class and one week of observation and supervision in the hospital postnatal ward. The content of the course included overview of the health and economic benefits of exclusive breastfeeding, breastfeeding management, dangers of mixed-feeding, safe preparation and storage of formula milk, management of common infant illnesses, counselling techniques and information about how to facilitate and support HIV disclosure. An important difference between earlier trials in India, Bangladesh, Mexico and the South African site of the PROMISE-EBF trial was the dual promotion of exclusive breast and formula feeding. The peer counsellors were trained on site by a skilled lactation consultant and site supervisors. Each peer counsellor had a designated geographic area. The peer counsellors were supervised through monthly group meetings, by telephone contact, face-to-face individual contact sessions at least once a week, and field observations during peer counselling home-visits at least once a month.

Recruitment, training and supervision of peer counsellor supervisors

The three supervisors, one in each respective research site, had varied skills, age and background, and all were women. Each was a member of existing research staff, who had worked on the previous Good Start cohort study within the three research sites. The supervisor from the peri-urban site of Paarl had undergraduate training in counselling and psychology. The supervisor from the rural site of Rietvlei had experience as a hospital administrator. The supervisor from urban township was trained as neonatal nurse and midwife, but has worked as a researcher for 10 years. The three peer counsellor supervisors had received similar training as that of peer counsellors with some additional information on supervision, management and PROMISE-EBF study operating procedures. A paediatrician and lactation consultant who is one of the principle investigators of the PROMISE-EBF intervention, and the same lactation consultant involved in the training of peer counsellors, were responsible for the training of the supervisors. The main responsibility of the supervisors was to coordinate the peer counselling intervention. Each of the three supervisors managed and supported between 10-14 peer counsellors. The supervisors were themselves supervised telephonically or in person by a member of the research team who visited each of the research sites on a regular basis. This was at least the case for Paarl, which received visits on a monthly basis. This person, a qualified social worker, functioned as an intermediary between the peer counsellor supervisors and the senior research project managers.
Study Area and Population

South Africa (Figure 5) is one of the countries with the greatest burden of HIV infection in Sub-Saharan Africa. As many as one in three women aged 25-34 years are HIV-infected, exposing HIV to approximately 300,000 infants each year [134]. South Africa is also one of the 42 countries, worldwide, that bear the burden of under-5 mortality, of which 60% are accountable to HIV [15,135]. Approximately half of South Africa’s population lives in rural areas with limited access to adequate health care services. Thus far, South Africa’s strategy to provide health care services has relied predominantly on the primary health care approach based on the principles of equity and community participation. As with many other parts of the world, South Africa is experiencing rapid urbanization. The PROMISE-EBF intervention was implemented in three of the 18 districts which in 2001 were selected for National PMTCT pilot programme sites. The three districts – Paarl, Rietvlei and Umlazi – were purposively selected to reflect different socio-demographic conditions, rural-urban locations, HIV prevalence rates and health system infrastructure found in South African context. Paarl is a well resourced peri-urban township in the Western Cape, which is situated in an area of commercial farming. The HIV prevalence among pregnant women attending antenatal care services was at the time of the study 10% and the IMR is estimated to be around 40/1000 live births. Rietvlei is situated in the Eastern Cape, and is one of the poorest rural districts of South Africa with an antenatal HIV prevalence of 34% at the time of the study and an Infant Mortality Rate (IMR) of 99/1000 live births. Umlazi is a large peri-urban township on the outskirts of Durban, in the province of KwaZulu Natal. The area comprises formal and informal housing. The province has the highest rate of HIV infection in South Africa, with a prevalence of 42% amongst antenatal clients. The IMR is estimated to be around 60/1000 live births [134]. In South Africa, antenatal attendance is estimated to be 94% [14]. Similarly, hospital delivery is high (84%) [14].
Data collection

The PROMISE-EBF trial was designed to collect robust quantitative data on the effect of peer counselling on rates of exclusive breast (for both HIV-infected and uninfected mothers) or formula feeding (for HIV-infected mothers only). This information alone is not sufficient, especially when researching such a dynamic, multifaceted and complex topic as exclusive breast and formula feeding. Data on socio-cultural and contextual factors for effective promotion of exclusive infant feeding is therefore necessary to inform the conditions which are potentially important for the trial to “work”. Because of the limited experiences of infant feeding peer counselling in African settings, at the time of study, we were also interested to understand the mechanisms through which the peer counsellors could potentially modify some of existing barriers on exclusive breastfeeding. This thesis has therefore combined both qualitative and quantitative methods. Each of these methods has their strengths and weaknesses. The strengths of qualitative research methods are several and include the: [136,137,138].

- possibility to unpack the meanings of key concepts for individual women’s experiences and perceptions
• possibility to study the applicability of given concepts and phenomenon within a specific contexts and community
• possibility to explain social, cultural, and other contextual factors and their impact on women’s individual choice and behaviour
• possibility to generate new ideas and insights that would not otherwise have been gained through randomized controlled trials with highly structured data.

The purpose of qualitative research is not to generalise but to highlight particular experiences and challenges of a small sample of participants in a specific context. These experiences are meant to feed back to knowledge that is generated through other means, such as randomized controlled studies. Qualitative research methods share a common ground in which the shared assumption is often that realities are multiple, subjective and socially constructed [137]. It is thus important to remember that qualitative research methods have their roots in distinct academic disciplines and traditions ranging from cultural anthropology and ethnography, to grounded theory in sociology, to phenomenology and hermeneutics in philosophy – each of these disciplines have their inherent theories and assumptions motivating their specific choice to research questions, sampling and analysis framework. Appreciating and understanding these differences is crucial for the quality of qualitative research methods. The use of these methods should however be guided by the specific research question.

Qualitative studies
Semi-structured interviews (Study I, II, IV)
Individual semi-structured interviews with 27 mothers enrolled in PROMISE-EBF intervention was conducted in studies I and II. Criteria used to select mothers for the individual interviews include infants of age 12-16 weeks postpartum, mothers of different ages, parity and HIV status. Eligible mothers were identified and informed through the PROMISE-EBF site coordinators at the three research districts. In study I, we focused on describing the social and cultural context in which infant feeding peer counselling is implemented. In particular, the understanding of the concept of “peer” was closely examined. In study II, using the same interviews, we explored mothers’ perspectives and experiences on the promotion of exclusive breast or formula feeding. In this study, the factors promoting or inhibiting “exclusive” feeding were studied. The interviews continued until no new information was found [138,139]. In study IV, key informants responsible for supporting peer counsellors were interviewed about their experience of training...
and supervising peer counsellors in the field. The three supervisors were asked about their professional background and training as well as previous experience in research coordination and management. Further, we explored the supervisors’ motives and understanding of the tasks involved and their understanding of the role of supervision.

Participant observations (Study I)
The need to triangulate individual interviews with participant methodology in study I was not initially planned, but it arose in the course of the study, as is common in grounded theory [138]. In the interviews mothers said that they had not been visited by the peer counsellors. Mothers also expressed that peer counsellors just visited, but that they had not been counselled on infant feeding. The mothers, moreover, expressed fear and suspicions around home-based peer counselling or lack of interest in peer counselling. This raised the interest to use participant observation in order to observe the interaction between mothers and the peer counsellors. In total, 10 observations across the five peer counselling sessions (antenatal, 1, 4, 7 and 10 weeks) were conducted. Further, we made the decision to conduct informal interviews with peer counsellors about their experience of the job and to review the peer counselling visit records. The strength and value of participant observations include the opportunity to capture contexts within which people interact and the possibility to study the real situation in which health interventions are planned and implemented [138]. Field notes were taken during each peer counselling session by myself (Barni Nor) and a by our South African colleague (Yanga Zembe). Because of the language barrier, I was not able to conduct the interviews myself. Instead, I focused on documenting the physical place, body language and the direction of the conversation, while my colleague, Yanga Zembe, focused on the content of the peer counselling session. Immediately after the observed session, we performed a debriefing session where we discussed the key elements of the session. Each of us wrote their independent field notes which was later merged, and was used for reflections during data analysis.

Quantitative study
Cross-sectional survey (Study III)
In study III, the results from the qualitative studies (Study I and II) were used as a basis for developing a survey questionnaire. The two qualitative studies indentified four main contextual factors that were thought to be of importance for mothers’ ability to sustain exclusive breast or formula feeding. These factors include the perceived quality of peer counselling, includ-
ing mothers attitudes towards peer counsellors, the influence of family, health professionals and peer counsellors on mothers feeding decision, HIV stigma of not breastfeeding, as well as the costs of formula milk. A quantitative description and verification of phenomenon identified in qualitative research can enhance our understanding of the importance and relevance of these factors. However, an important disadvantage of cross-sectional surveys is that it cannot describe the association or the direction of association between different outcomes [140]. The cross-sectional study recruited mother-infant pairs between 12 to 24 weeks old, who had received at least one peer support visit and who were enrolled for data collection in the PROMISE-EBF intervention. Recruitment over a period of six months yielded a total sample of 400 mother-infant pairs.

Data analysis

Analysis of qualitative data (Study I, II, IV)

In studies I and II, data analysis was undertaken concurrently with data collection, where emerging issues were included in subsequent interviews and final sample size was determined based on the emerging data [136,138]. The audiotaped interviews were transcribed verbatim into their original languages (Xhosa, Zulu and Afrikaans) before being translated to English. The field notes were translated directly to English. To ensure that content and the core meaning of the original text were preserved during the process of translation, an independent researcher cross-checked a random sample (6 interviews, 2 in each site) of the original transcripts against the English translation. No major discrepancies were identified. In study IV, there were only three supervisors, one in each research site that was responsible for the peer counselling intervention. As such, the sample was pre-determined and data analysis took place only after data were collected. The interviews were conducted in English, a language in which all three key informants were fluent, although it was not their mother-tongue. The method of qualitative content analysis was used to sort and structure data [141]. This method was selected as it offers a concrete analytical framework useful to identifying meaning units and for getting a general picture of the total data. In studies I and II, qualitative interpretative description was used to further explore data [137]. The main justification for applying this approach was its inductive analytical value, which acknowledges the existence of socially constructed multiple realities that are complex and contextual. This method further helps to clarify the how and why of a specific phenomenon, while also recognizing the underlying philosophical principles existing within a discipline. Further, interpretive description provides more than just mere description of a phenomenon in that it allows for more exploration and interpretation to uncover
meanings. Analyses were done manually and without the assistance of any computer programme.

Analysis of quantitative data (Study III)
The cross-sectional quantitative data were entered into MS ACCESS using a double data entry system at the Medical Research Council (MRC) in Durban, South Africa. After validation, the database was exported to Stata, version 10.0 (Stata Corp., College Station, Texas, USA), and then converted to SPSS (PASW statistics 17.0) for data management and analysis. Baseline socio-demographic maternal and infant characteristics were compared between the PROMISE-EBF cohort and the cross-sectional survey using Pearson chi-square tests for categorical variables and one-way analysis of variance for continuous variables. The proportion of HIV-infected and uninfected women who are breastfeeding, formula feeding or mixed-feeding in the three study sites were assessed. Maternal HIV status and infant HIV infection was assessed from dried blood spots collected during home visits at 3, 24 and 36 weeks.

Ethical Consideration
The four studies included in this PhD thesis were conducted within the framework of the PROMISE-EBF intervention for which ethical approval has been granted by the Research Ethics Committee of the University of Western Cape in South Africa and by Bergen University (co-ordinating the multi-centre trial within which PROMISE South Africa is part of). Additional review was sought from the regional ethical review board in Uppsala, Sweden. In all four studies, written informed consent was obtained from each participant upon enrolment to the study. Further, each study population was informed that participation was voluntary and that they could withdraw any time without consequence.
Results

The main findings across the four papers included in this thesis highlight the complexity of adapting a “peer” counselling model in a context of poverty, HIV and social distrust. It further highlights the complexity of promoting and supporting exclusive breast and formula feeding in a socio-cultural context where neither exclusive breast nor formula feeding is the norm.

Acceptance of home-based peer counselling (Study I, III and IV)

Inherent in the model of peer counselling is the expectation that peer counsellors will be accepted by the mothers and by the community, particularly if peer counsellors live in the area in which they support women and are selected by the community itself. However, the intertwined and complex reality of poverty and HIV in South Africa appear to affect mothers’ acceptance and uptake of home-based infant feeding peer counselling. There was a general perception of distrust and of “evil” actions across the three study areas. Accordingly, mothers were reluctant towards the idea of receiving home-visits by someone unknown to them. We found three contextual factors including fear of “evil eye”, fear of HIV stigma and fear of theft of infants’ identity card, which each appeared to influence mothers’ acceptance and uptake of home-visits by the peer counsellors. Additionally, the reality that mothers did not acknowledge the role of the peer counsellors’ motivation for doing home-visits, placed peer counsellors in a difficult position. Consequently, peer counsellors were required to indentify themselves and the project management team before home-visits could be accepted, as one mother expressed: "(...) I thought if what she (peer counsellor) is talking about is evil, then I will go to this lady (another woman) that I know, who would then go with me and show me the woman’s house”. Paradoxically, however, a vast majority of the mothers reported that peer counselling visits were helpful (94%), and they further indicated a wish to be visited in their next pregnancy (89%) (Table 4, study III).

The belief and fear of the “evil eye”, especially during pregnancy, appeared to be a strong reason for why women did not want to be visited by the peer
counsellors. This phenomenon was particularly observed in the rural area of Rietvlei, where a number of mothers believed that they would have miscarriage or malformed infants if they accepted home-visits by such strangers as peer counsellors. The mothers did not communicate their fear directly to the peer counsellors, however. They gave instead an inaccurate home address and/or pregnancy history as an indirect way of refusing peer counselling home-visits. The peer counsellors made several home-visits, only to find either a 2 or 3 week-old infant or no mother at all. This situation was frustrating for the peer counsellors as it made it difficult for them to timely and adequately follow-up mothers. The fear of home-visits was not merely a concern of mothers, but was also highlighted by one peer counsellor supervisor, who voiced the similar, vulnerable position for both peer counsellors’ and mothers: “(...) when you go into someone’s home you don’t know what to expect (...)

Previous occurrences of theft of the infant’s identity card in the study areas further complicated mothers’ acceptance of home-visits by the peer counsellors. According to the mothers, the infants’ identity card is often stolen by people who want to prove they have a child in order to qualify for the government social welfare scheme, especially the child support grant. It was therefore believed that the peer counsellors would use the infant identity information for their own benefit, as expressed by one mother: “(...) In case she is a criminal and perhaps (is) coming to weigh the baby (but instead) take my baby’s immunisation card and photocopy it to register for child support grant. There is a lot of corruption here it is very widespread. (...) The world has become very evil, so we are scared”. Yet another reason for why mothers were reluctant towards receiving home-visits by the peer counsellors was the concurrent data collection of the intervention study with the care provision of mothers with HIV. The same vehicle was used for both purposes. As a result, mothers declined home-visits in order to avoid being potentially stigmatized as HIV-positive by neighbours and other members in the community, who are not aware of the purpose of peer counselling home-visits. This is confirmed in study III, where a significant proportion of HIV-infected and uninfected mothers, 76% and 60%, respectively, reported little or no trust in peer counsellors.

Peer counselling in the context of HIV and poverty (Study I and IV)

Studies I and IV highlight contextual, as well as structural barriers, for an effective peer counselling programme. The high HIV burden in the study area and the negative attitude towards HIV-infected people proved challeng-
ing for mothers, as well as peer counsellors and their supervisors. HIV-infected mothers expressed feelings of isolation, anger and anxiety. Mothers’ attention was also primarily focused on dealing with their recent HIV-positive diagnosis. The reality that women were not able to openly discuss their HIV status created feelings of being abandoned and neglected. Peer counselling offered HIV-infected women an opportunity to discuss and cope with their changed life situation. The emotional care and support provided by the peer counsellors is reflected in HIV-infected women’s positive response and appreciation towards peer counsellors. This, in turn, appears to influence the women’s opinion regarding the interpersonal quality of peer counsellors (Study I).

The peer counsellors struggled with the idea that they should, as part of their job, facilitate antenatal HIV-testing among mothers and encourage mothers towards adherence of exclusive breast or formula feeding without knowledge about mothers’ HIV status. The supervisors, however, felt the need to set boundaries for peer counsellors while at the same time equipping them with necessary information and skills about how to appropriately deal with potential voluntary HIV disclosure by mothers. One supervisor expressed: “We realised that it’s difficult to support when you don’t know the status of the mother…. but then again your core business is not really to be hunting for HIV positive – people, looking at their symptoms… yours is to support.”

Though peer counsellors identified a “need” to know HIV status in order to effectively support mothers towards adherence on exclusive feeding, knowing the HIV status of mothers was said to be stressful in itself. Thus, in order to help peer counsellors personally deal with the HIV disclosure of mothers, the supervisors arranged self-care workshops and group counselling. Whereas this was said to be important, it also seemed to put additional burden on supervisors. HIV was therefore not a “problem” limited only to mothers, but also affected the peer counsellors, especially in the high HIV burden area of Umlazi.

The realization that peer counsellors are equally vulnerable to HIV infection proved challenging for the supervisors, as one supervisor voiced: “At the beginning... when I was told about the illness, I said to myself wait a minute, what’s going on now?...I thought we were peer supporting, now we having the peer counsellors ill. Then I quickly corrected myself that I must not be judgmental, this is a challenge and I mustn’t separate them from the community, they are part of the community, what affects this community will also affect them”. The HIV infection among peer counsellors placed an additional burden on supervisors, who expressed a need to receive counselling in order to cope with the situation, as one supervisor expressed: “I sometimes also feel that I need counselling of some sort, myself, because I sit at home sometimes and think ‘Good heavens, she is ill again, what does one do?”. In addi-
tion to worrying about the health condition of peer counsellors, the supervisors also worried about the consequences and implications of loosing peer counsellors. “Because if that happens (loose peer counsellors) we need to train more people and training more people needs money and time which we sometimes don’t have. All those things work on one”.

A structural barrier that created tension and problems for the peer counsellors was the disparity where only women enrolled for data collection within the intervention arm of the PROMISE-EBF were provided monetary compensation for each home-visit made by the data collectors (Study I). Although the 40 ZAR offered to women was symbolic and small in its size, it was appreciated by the women, as one mother expressed: “I appreciate the project because these R40.00 ... help me ... I am able to buy her porridge and tins (infant formula)”. Nevertheless, this remuneration appears to negatively influence mothers’ experiences and perceptions of peer counsellors. This concern was voiced predominantly by HIV-uninfected women, who expressed dissatisfaction with peer counselling support (Study I). One mother said: “Though I was not getting anything really, it was enjoyable when she (peer counsellor), came...I get the baby’s food (from the clinic), if she would bring me cloth for the baby...that is what I would appreciate”.

Peer counselling as a “job” (Study IV)

Peer counsellors were employed and given a monthly salary of 1000 ZAR (about 144 US$) using similar criteria as in other national lay health programmes. However, because of the competition of lay health programmes in the area, especially in HIV programmes, the supervisors pointed out the practical consequences of the high attrition of peer counsellors, as one supervisor said: “They (peer counsellors) started last September, that was the first group that came in but because people just found better jobs and then we keep training new people”. Those peer counsellors who chose to stay with the PROMISE-EBF intervention, despite their salary expectation not being met by the trial, were, according to the supervisors, not performing their jobs appropriately. This was said to be due to two reasons. The peer counsellors prioritized the tasks expected by them as women and/or as housewives, and the fact that they were unhappy about the given salaries, both of which the supervisors found difficult to confront. One supervisor expressed: “It is a bit of a challenge to work with them (peer counsellors)....sometimes they come here and report that “no, I didn’t manage to recruit because my husband was sick or my mother-in-law was like this”...what I want them to feel is that we are working here. At home (others) undermine your job. So you have to say ‘I am also working’, you have to be proud of your job”.
Acceptability of exclusive infant feeding (Study II and III)

Breastfeeding was the main feeding mode recommended by health staff (86%), peer counsellors (78%) and mothers’ immediate family (73%). The advice of breast milk corresponds, to a large extent (69%), mothers’ own perception of the most optimal feeding mode during the first months of life (See Table 3, study III), as it was associated with improved infant health compared to formula milk: “He has never been sick. I think it is the breast milk. It keeps him from getting sick. People often say that if you give the bottle (formula milk) to your baby it makes him sick”. Mothers’ perception of breast milk as a far more optimal option than formula milk and appears to be further influenced by the high costs of formula milk, as expressed by an HIV-infected mother: “I love breastfeeding my baby. I really enjoy it because I do not suffer (financially) from having to buy tins (formula milk). Even when there is no money I just breastfeed him and I have no problem”. However, despite perceived health and economic benefits of breast milk, 1/4 of the mothers found the decision towards infant feeding difficult, as shown in study III. HIV-infected mothers experienced the decision towards breast or formula feeding choice as considerably more difficult than HIV-uninfected mothers (39% versus 22%) (See Table 3, study III). Formula milk was largely perceived as optimal (52%) by HIV-infected mothers compared to HIV-uninfected mothers (5%). We found substantial differences in mothers’ perception and experiences of infant feeding in the three geographical areas (see Table 2, study III). While none of the mothers’ in the relatively well-resourced area of Paarl perceived mixed-feeding as an optimal choice, a large proportion (38%) of mothers in the high HIV area of Umlazi, considered mixed-feeding as an alternative choice. Contrary to our expectations, we found no effect of peer counselling on mothers’ perception of optimal feeding in the intervention compared to control clusters ($P = 0.82$) (see Table 2, study III).

Both staff from the health clinics and peer counsellors were reported to have given information about the appropriate time for introduction of semi-solid foods and liquids, where a strong emphasis was said to have been placed on the importance of the practice of “one” (either breast or formula milk) feeding type (study II). However, we found important geographical differences regarding the support and acceptance towards exclusive breastfeeding. The largest support for exclusive breastfeeding was observed in Paarl, where only less than four percent were recommended to formula feed. In the urban, high HIV burden area of Umlazi, a considerable proportion (~20%) of mothers reported to have received advice in favour of mixed-feeding (See Table 3, study III). However, more than 10% of the mothers reported to not receive any feeding advice from the peer counsellors. A closer examination revealed
that this occurred predominately in Umlazi and to a lesser extent in Rietvlei, and almost not at all in Paarl. Further, in Rietvlei, almost 10% of the mothers reported that they had not received any feeding advice from the clinic (See Table 3, study III).

Barriers to exclusive infant feeding practice (Study II and III)

In Study II, we have indentified five main factors potentially limiting mothers’ ability to adhere to exclusive breast and formula feeding. This includes the prohibitive costs of formula milk, the belief of “inadequacy” of breast and formula milk, the cultural practice of the use of water and traditional medicines for “cleansing” purposes in early infancy, the possible misunderstanding of the concept of “exclusive” feeding, and finally the stigma of not breastfeeding or of collecting free formula milk from the health clinics. The high costs of formula milk appear to challenge HIV-infected mothers’ adherence to exclusive formula feeding, as supplies of free formula milk from the health clinics were not always available: “I tested HIV positive when I was eight months pregnant. The doctors said I should not breastfeed him. I should get formula milk at the clinic. They said people who are HIV positive get the tins (formula milk). So I went to get the milk but I did not find it. I went again when he was 3 months old. He breastfed for two months (...) I then gave him the bottle (formula milk)”. This is reflected in study III, where almost half (46%) of the mothers reported financial constraints as the main factor affecting the way in which they fed their infants.

The perception of “inadequacy” of breast and formula milk alone appeared to promote an idea to prematurely introduce porridge and other liquids to infant feeding. This was primarily influenced by the infants’ behaviour, where a crying infant or an infant who did not sleep during the night was considered as strong incentive for mixed-feeding: “I thought I would give him formula (...) as they advised at the clinic, but I could not do it. He gets hungry, so I give him other foods. If I don’t give him (porridge) he cries. I bought him (food) and fed him then he started sleeping. The formula milk on its own does not satisfy him”. Another mother expressed: “I saw that he becomes hungry. I saw him crying even when he was breastfeeding a lot. You could see that something was lacking. So I decided that its better that I give him food and so we sleep now. When he is not fed porridge we do not get any sleep”.

Traditional medicines and water were usually given to infants during early infancy. This practice was believed to “clean” the infants’ intestines and was
further said to protect infants from common childhood infections. Because of the strong cultural belief around the use of traditional medicines and water, information and advice of health staff was disregarded. The health staff was said to have “their own rules” and thus their advice was silently disregarded, as one mother articulated, “I am not going to listen to this nonsense” (Study II). “I usually give him water, water cleans his stomach. But the clinic does not want us to give water. They say there is no such thing that the baby gets cleaned. You see, they have their own rules, we laugh at the clinic. Yes we do. They also don’t want us to use pacifiers, but we let the baby suck it and when we go to the clinic, we hide it”. Because of the strong cultural pressure to give traditional medicines, HIV-infected mothers selected formula milk over the option of breast milk. This choice appears to be influenced by the idea that if mothers chose formula milk, then traditional Zulu medicines can still be given. While the strict definition of exclusive breastfeeding was seen as a limitation: “At the clinic, I was told to breastfeed for three months. I was also told to not give him our traditional medicines as well as water. The baby is to breastfeed only. I then realised that no, because when they at home say buy the baby traditional Zulu medicines, how would I refuse? So I decided, I do not breastfeed at all, so that she could be able to drink the Zulu medicines”.

The promotional message and concept of “exclusive” breast and formula feeding was interpreted and understood by mothers as meaning “not mixing two milks”, that is, specifically breast with formula milk. The word “only” was repeatedly used by mothers when describing “exclusive” breast or formula feeding practice. However, mothers’ descriptions of “only” did not include the early introduction of porridge and other liquids as mixed-feeding. Neither was the description of “only” reflective of what mothers did during the course of infant feeding, but reflected only what mothers did on a single occasion. Fear of HIV stigma associated with exclusive formula feeding seemed to further encourage the acceptance towards a mixed-feeding practice: “She (counsellor) tells you about the formula milk that you get from the clinic. She explained that actually this milk (formula) is given to people who have a problem, so I know that it is also going to be said that I am sick, that I do not want my baby to breastfeed because I am sick. (...) There is this girl who took this milk but now she is not taking it anymore. She became ashamed that people are actually laughing at her because she is taking the milk that is for free”. However, the fear of HIV stigma was reported by only 10% of the mothers to have an affect in the way they fed their infants, as shown in study III.
Discussion

The “peer” counselling model (study I and IV)

The use of peer counsellors, especially in the early critical postpartum phase during which women are establishing infant feeding practices, is emphasized in the literature as an important strategy [75]. This model is particularly important in South Africa, where women are usually discharged from the hospital 6-8 hours after delivery and where current postnatal follow-up support of HIV-infected mothers is limited [14]. The first few days and weeks after hospital discharge is recognized to be critical time for breastfeeding success or failure [142]. Assumptions inherent within the peer-counselling model, however, are found to be problematic, especially in the South African context of poverty, HIV and social distrust.

If peer counsellors are recruited within the selected clusters, the expectation is that they will have knowledge about the contextual factors in which women live. This assumption is questioned in study I. Here, we found three contextual factors, including fear of “evil eye”, HIV stigma and theft of infant’s identity card, which appeared to influence the acceptance and uptake of postnatal home-based infant feeding peer counselling. Our finding of the concept of “evil eye” or malevolent spirits, particularly during pregnancy, is consistent with previous studies conducted in Asia [143], where the early neonatal period was reported to be perceived as a vulnerable period for mothers and their infants; and thus, contact with the outside world was not desired by mothers. Paradoxically, however, peer counsellors did not recognize the significance of these factors even when it complicated their own ability to adequately and efficiently follow-up of mothers for infant feeding support. Our findings of social distrust and fear of crime appears to be important, as well, as it affected mothers’ acceptance of home-visits by the peer counsellors. The relevance to public health of this finding – in terms of mothers’ health seeking behaviour or the effective promotion of exclusive infant feeding – is an area in need for further research.

Notwithstanding, there is a paradox in women’s perception of peer counsellors. On the one hand, a significant proportion of mothers’ (particularly HIV-infected mothers) perceived peer counselling visits as beneficial, because it helped them to cope with their HIV status in a time when they were vulner-
able. On the other, the HIV-infected mothers also reported a higher degree of distrust. More than 75% of these mothers reported to have little or no trust in peer counsellors, as compared to HIV-uninfected mothers, as shown in study III.

A reduction in the hierarchy that separates professional health workers from local women is a second assumption of the peer counselling model, as it is assumed that mothers will be more likely to take up and adhere to promotional messages of exclusive breastfeeding if local women – with such similar characteristics as age, education and social status – approach them as peer counsellors. This assumption is also problematic. In study I, we observed that peer counsellors lacked recognition of mothers’ knowledge and previous experiences in infant and young child feeding, and also appeared to be insecure and threatened by the mothers’ demonstrated knowledge. This was seen particularly in the “peer-relationship” between the young peer counsellors and the much older, experienced mother. We therefore question the definition of “peer”: when is peer a “peer” and what makes peer a “peer”, especially in the South African context?

Nankunda and colleagues in rural Uganda [118] identified an expectation among peer counsellors, who wished to be trained as professional health workers in order to be professionally recognized within the community. Similar expectations have been documented in India [111], where peer counsellors expressed a desire to be formally linked to the health care system. Such expectations are likely derived from a wish to increase confidence to do the job, but they also serve to increase credibility within the community. The findings of these studies, especially the idea of community participation, are inline with the current global discussions about the importance of community involvement, participation and ownership of health programmes and interventions [115].

Introducing a health intervention within a community, and involving community members in the conceptualization, planning and implementation, can be a long process requiring engagement of multiple stakeholders and authorities. However, once this process is done, the likelihood of acceptance and coverage of these programmes is high, as recently documented by an Ugandan research group [144], which showed that mothers were more responsive to home-visits by the peer counsellors because they were aware that community leaders had been involved in recruiting the peer counsellors. Haider and colleagues in India [111] promote the idea of more comprehensive and integrative services to mothers and infants, as a necessary quality component for effective community-based infant feeding peer counselling.
The PROMISE-EBF infant feeding peer counselling intervention was implemented within a context where qualified health professionals, especially doctors, nurses and midwives, were migrating to USA, Canada and UK for better employment opportunities [145,146]. The PROMISE-EBF trial therefore made one important modification in its delivery package in order to resemble the health system context in South Africa: the peer counsellors were recruited using the same criteria as for community health workers within national lay or community health programmes [120] and were paid stipends (1000 ZAR) similar to those in the public health sector. The main argument for not paying peer counsellors more than other lay workers was the expectation that if proved efficient, this cadre of lay workers could be taken up by the health system without additional burden to the system. Nevertheless, our findings identified a persistent dissatisfaction among peer counsellors regarding the low payment (Study IV).

Similar experience is documented in a study conducted in rural Uganda [118], where it was shown that it is not possible to maintain the use of peer counsellors without providing monetary compensation. This finding suggests that infant feeding interventions using peer counsellors need to include discussions about how best to compensate peer counsellors for their time, as voluntary work, even in rural settings. The re-emerging interest in the use of lay health workers especially in low-income countries has nevertheless been questioned [114]. It is argued by some researchers that the renewed interest in lay health worker programmes is primarily due to the fact that this cadre of health workers are viewed by policy makers as a “cheap” solution for overcoming current shortfalls in the health system [115]. This critical viewpoint has also been raised in a recent *Lancet* publication by Haines and colleagues [147], where they suggest that lay health worker programmes should not be a “panacea” measure towards the achievement of the Millennium Development Goals of child survival (MDG 4). Rather, lay health workers should, with their focused tasks, be a complement to the health system. These programmes are further criticized for their attention to a single health issue (i.e. exclusive breastfeeding promotion) and for their limited or lack of capacity to address the social determinants of health [124]. Currently, in South Africa, most lay or community health workers are deployed for programmes in either HIV prevention or home-based care of HIV/AIDS patients and are often, if not always, employed by non-governmental organisations (NGO) [154].
The concept of “exclusive” feeding (study II and III)

The expected outcome of the PROMISE-EBF intervention was that peer counsellors would increase the rate of exclusive breast (for HIV-infected and uninfected) and formula feeding (for HIV-infected only) by modifying some of the socio-cultural norms that are known to hinder the practice of exclusive infant feeding. However, in studies II and III we found that, whereas breast-feeding was not only associated with health and economic benefits but it was also perceived as optimal (by 69% of mothers) and highly recommended as the main feeding mode by health staff (86%), peer counsellors (78%) and the mothers’ immediate family (73%), several important barriers continued to persist. These barriers include i) the perception of “insufficiency” if only breast or formula feeding is applied; ii) the cultural practice of traditional medicines and water for “cleansing” purposes; iii) the limited understanding of the concept and messages of “exclusive feeding”; iv) and the stigma associated with not breastfeeding. Although our finding that breast milk alone was perceived as “insufficient” is well described in the literature [64,148], the perception that formula milk alone is also considered as inadequate for young infants is a new concept. Porridge and formula milk were frequently given to infants as early as one month of age, due to concerns about hunger as judged by infant crying or the infant not sleeping through the night. Such concerns have been previously described in the literature [68] as being an important incentive and justification for mixed-feeding in early infancy. Further, the need of women to comply with the cultural practices of traditional medicines, used for “cleansing” purposes, and also the knowledge that these practices are not compatible with exclusive breastfeeding, become interesting, as they appeared to promote the use of formula milk for HIV-positive mothers.

The promotional messages of “exclusive feeding”, as described by the WHO and as used by both health staff and peer counsellors might have been misunderstood by the mothers. Our findings from study II indicated that the message of “exclusive” feeding, while it came across to mothers, it was misinterpreted as meaning “not mixing two milks”: breast and formula milk. Mothers did not recognize as mixed-feeding the feeding of semi-solid foods and other liquids, while still on breast or formula. This finding is important because it highlights that clinics and peer counsellors were promoting exclusive feeding with messages that assisted mothers to some degree of understanding about exclusive feeding. However, it also identifies as highly problematic the finding that almost 1/3 of the HIV-infected mothers were reported as having been advised by health staff to mix-feed their newborn infants (study III). This suggests that the current messages of exclusive feeding are still incomplete, and that mothers therefore did not fully understand the exclusive-feed concept, and thereby placed their infants at risk. The pos-
sible confusion of what is meant by “exclusive” feeding needs to be adjusted and clarified in future infant feeding promotion programmes. However, we found some evidence to indicate that adherence to one feeding mode – that is, feeding by either breast or formula – is associated with being infected with HIV or ‘sick’ of AIDS (study II), especially in communities accustomed to feeding infants (as early as one month) with a combination of different semi-solid foods and liquids or in community settings where the collective use of free formula from the health clinics is the norm.

Infant feeding counselling was performed at the health clinic, with staff who were aware of mothers’ HIV status. The role of peer counsellors as “peers” was therefore to support the mothers’ previously taken decision about feeding mode. However, knowledge was missing about the mothers’ underlying motivation for choosing the specific feeding type. Here, there are two major assumptions made. First, all peer counselled mothers are assumed to have received adequate infant feeding counselling, and thus are assumed to be knowledgeable about the dangers of mixed-feeding. Second, it is further assumed that all HIV-infected mothers, who have made the decision to exclusively formula feed, know about the “cultural risks” associated with not breastfeeding, and therefore, adherence to exclusive formula should not be problematic. Notwithstanding, it is well documented that the quality of infant feeding counselling in South Africa, particularly within PMTCT programmes, are inadequate, and that the majority of mothers are making inappropriate feeding decisions [71]. Further, free formula milk from health clinics has been associated with HIV stigma [66]. It is therefore highly problematic that our expectations in the programme are not matched with the realities on the ground. Further, it is important to take into account, the reality that peer counsellors – in deference to staff at health clinics – are not considered by community members as having the qualifications of health professionals to counsel mothers on infant feeding. Peer counsellors, despite providing support (study III) for adherence towards exclusive feeding, were not recognized for their provision of infant feeding information and advice (study I and II). This problem was confirmed in the interviews with the site-supervisors, where they described a frustration among peer counsellors over the fact that mothers did not adhere to their feeding advice (study IV).
Reflections on implications of policy changes on exclusive infant feeding

The 2009 WHO/UNICEF/UNAIDS HIV and infant feeding policy guidelines [85], specifically those recommendations to promote exclusive breastfeeding combined with maternal or infant antiretroviral therapy for HIV-infected mothers, are encouraging as they move in the direction of one single message about infant feeding. However, South Africa’s draft policy recommendations are somewhat discouraging. The implementation of the WHO/UNICEF/UNAIDS policy guideline, if implemented might address some of the factors currently promoting mixed-feeding among HIV-positive mothers, in particular the social stigma and prohibitive costs associated with commercial formula milk. Additionally, the implementation of a feeding policy that focuses on exclusive breastfeeding could also benefit HIV-negative mothers since it may be more effective in promoting exclusive breastfeeding as a norm. However, implementation of such policy would most likely not address the mothers’ perceived idea about “insufficiency” of both breast and formula milk, and thus the perceived need to give porridge, water and traditional medicines in early infancy. Challenges therefore remain in how to efficiently address prevailing socio-cultural norms and practices of infant feeding in this context.

Methodological considerations

The inductive emergent design, as well as the triangulation of different methods and the peer review of data by the co-authors of the sub-studies included as part of the evaluation of the PROMISE-EBF trial, increases the credibility and trustworthiness of the present study. The inductive, emergent design in these studies was particularly important for understanding the concept of “peer” and for exploring the different forces for and against exclusive breastfeeding. This information is important for the evaluation of the main trial. Additionally, use of interpretive description as an analytical framework in studies I and II enabled us to go beyond mere description and into problematizing the given concepts of “peer” counselling and “exclusive feeding”. It also enabled us to critically reflect upon the body of knowledge on these topics in order to unpack some of the complexity of human experiences. We were then able to produce research findings and/or questions that are useful to applied operational settings and possibly also to policy makers. This, in combination with the conceptual frameworks of social ecology and social support, enabled us to form a much more comprehensive understanding of the recognized paradoxes and discrepancies between theory and practice. Social capital might have offered us an alternative theoretical framework within which to place our findings; however, because of the deterministic
nature of the social capital approach, we required a framework that embraced the complexity and dynamic interplay of mothers and peer counsellors and peer counsellors and feeding practices, as well as the unseen factors driving mothers’ own decisions about feeding strategies. For these reasons, the social ecological framework taken together with the social support approach were considered as most likely to provide the most comprehensive interpretation of our study results. There are important limitations to this study however. Though the present study offered the possibility of deeper exploration of the context-bound and geographically-specific issues through the PROMISE-EBF intervention, we did not fully benefit from this, especially in our qualitative studies. The question of why mothers (both HIV-infected and uninfected mothers) select formula milk as a complementary food for the breastfed child remains unanswered. Complicating our understanding of this question is that mothers select formula milk despite its expense and association with HIV status. Such information is highly critical, especially in the present time, when global infant feeding recommendations for HIV-infected mothers in low-income countries are strongly supportive of exclusive breastfeeding in combination with antiretroviral therapy over the use of formula milk. Moreover, a much more detailed and comprehensive description of peer counsellors’ job satisfaction and performance, other than what is narrated by supervisors, is crucial. This is particularly important in scaling-up the peer counselling model. Regarding the transferability of the findings of this thesis, it is important to underscore that our study results essentially reflect the environment of the three areas where the study took place. It is not the goal of qualitative studies to generalise, but these findings are meant highlight a particular phenomenon in a given context. The validity of our question regarding optimal feeding might be difficult to interpret. Rather than using the WHO exclusive breastfeeding definitions, we relied on a more general question that included “the optimal way to ‘mainly’ feed a baby”. The interpretation of what is meant by “mainly” is not straightforward. Does it mean, as the question entails, “main” feeding or does it mean “exclusive” feeding? It is therefore possible that those mothers who preferred breast milk as their main option also gave smaller quantities of other foods and liquids. Similar concerns exist for the interpretation of our results regarding the questions on feeding advice from family, clinical staff and peer counsellors. While, there appears to be strong support for breastfeeding, it may be more important to note that both formula and a mixture of foods were perceived as optimal. Further, although 1/3 of the HIV-infected mothers reported that fear of stigma had affected the way in which they choose to feed their infants it is possible that mothers had modified their feeding practices already in order to minimize the risks of stigma. Thus, the response to HIV stigma might reflect an underestimation of the importance of stigma for infant feeding.
Conclusion and implications for scaling up

Over the past 10 years, there has been great recognition of the importance of social, cultural, economic and environmental structures for the determinants of health and health inequalities, especially in such high HIV-prevalent areas as South Africa. To exemplify, a frequent conclusion made in research studies is that: “interventions aiming to prevent and reduce severe childhood malnutrition in high HIV prevalence settings need to encompass the various dimensions of the disease: nutritional, economic and social” [149]. However, despite attempts, the results from the four studies presented in this thesis show that there remains a gap between the conceptualization of the socio-cultural and structural factors underlying mothers’ rational decisions on infant feeding and the actual output of health interventions or programmes. Therefore, an important question seldom addressed contends with defining the specific method or approach that should be taken to elucidate current barriers towards adherence to exclusive breastfeeding.

With the revitalization of the Alma Ata Declaration in 2008 [114], the concept of community participation and/or mobilization was once again reaffirmed as an indispensible component of lay or community-based health care programmes. Rosato and colleagues, in the 2008 Lancet series (“Alma-Ata – 30 years”) state that “…antenatal and postnatal experiences of women usually take place in the communities…strategies improving maternal and child health must therefore involve the community” [115]. This ‘community’ model has been proven to be much more effective in “picking up” and addressing key perceived health issues that are of importance for the community at large [125], and may be what Tumwine meant – in the late 1980s during in his field observations in Zimbabwe – by letting the people assess the “real needs and problems” [150]. We saw some evidence of this “need”, where HIV-uninfected mothers who received monetary compensation, 40 ZAR (about 6 US$), narrated that “they found peer counselling useful”. While mothers, who had not received the same compensation, were consequently unsatisfied with the care they received by peer counsellors. Community participation is believed to not only enhance local people’s ability to voice different factors that determine their health, but it also believed to address broader health issues affecting the welfare of the entire community. Taking into account the differences within and between communities remains therefore important. Both Tumwine, and recent research studies from
Nepal [151], India [152] and Bangladesh [153], taken together emphasize the importance of the model of community participation for achieving long-term behaviour change and modification of norms within the society. This is thought to naturally evolve if all the steps of the model are put into place and if the model is carefully examined for the specific context, including the rural – urban conditions for which it is planned.

Some of the issues identified in studies I and IV are being dealt with in an ongoing community-based trial entitled, “An effectiveness study of an integrated, community-based package for maternal, newborn, child and HIV care in a disadvantaged community in South Africa” currently taking place within the urban area of Umlazi. In this trial, peer counsellors are paid three times more, 3500 ZAR (about 502 US$), compared to peer counsellors for the PROMSE-EBF trial. Additionally, the term “peer” was dropped in this trial, as it was considered to limit the credibility of peer counsellors within the community. Instead, the widely used umbrella term of community health workers was applied. Moreover, additional staff were employed in this trial to provide greater support for the supervisors. This community-based trial offers us a great opportunity to learn more about how best to support mothers towards adherence of exclusive breast or formula feeding in the specific, socio-demographic environment in which they live, as this trial is being implemented in only one area. It further offers us the opportunity to learn about the mechanisms and factors that facilitate effective community-based support.
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A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine. (Prior to January, 2005, the series was published under the title "Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine".)