

Infant Feeding in the Context of HIV: Exploring Practice and Decision-making

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Abstract

Safe infant feeding practices are an essential component of ensuring HIV-free survival in the presence of maternal HIV infection and material deprivation. The prevention of mother-to-child transmission (PMTCT) programme advises mothers to either exclusively breastfeed or exclusively formula feed their infants for six months, avoiding all solid foods. However adherence to these practices is low, even where risks are explained and understood. Understanding how and why feeding decisions for HIV-exposed infants are made and implemented is thus critical for improving rates of HIV-free survival. This ethnographic study of 10 HIV-positive mothers and their infants contributes to this understanding by examining feeding in the context of the everyday life of raising an infant and participating in a PMTCT programme. Using observation and in-depth interviewing, actual decision-making and feeding practices were examined from initial decision-making during pregnancy until infants were at least seven months old. Despite mothers understanding the key components of safe infant feeding none of the infants were fed according protocol. Thematic analysis of the data suggests that adhering to safe infant feeding goes beyond simply making the right 'choice'. Based on cultural, social and emotional ties, others, besides the mother, have legitimate claims to decision-making and actual feeding, making their beliefs about feeding practices important. Even where mothers were able to minimise the role played by others through disclosure and/or by drawing on internal coping strategies, safe feeding was undermined by their own negative experiences of the clinic services, materially and interpersonally distressed home environments, and complex interactions between beliefs about milk, other baby foods, and interpretations of infant health and infant feeding cues. The study suggests that improving adherence to exclusive feeding requires attending to this complex and dynamic interaction of social, psychological, cultural and economic factors through ongoing assessment and support.

Keywords: Infant feeding; prevention of mother-to-child transmission; adherence; HIV; motherhood; infant care

Introduction

In the context of poverty and maternal HIV-infection, infant feeding is an essential component of ensuring HIV-free survival. One-third to one-half of all transmission of HIV from mother to child in resource-limited settings occurs postnatally through breastfeeding (Fowler & Newell, 2002), with mixed feeding (that is, feeding an infant breast milk and other fluids and foods) conferring the highest risk for transmission (Coovadia et al., 2007; Coutsooudis et al., 2001; Iliff et al., 2005). At the same time, under-nutrition is implicated in infections that result in 17% of under-five mortality (Sanders & Bradshaw, 2010); a risk compounded by the introduction of solid foods before six months and unhygienic preparation of formula (Hendricks, Eley, & Bourne, 2007; Hilderbrand, Goemaere, & Coetzee, 2003; van der Merwe, Kluyts, Bowley, & Marais, 2007).

A debate about what the appropriate infant feeding choice is for HIV-positive women living in conditions of material deprivation has ensued. In particular, policy has sought to determine when it is safe and feasible to formula feed (Hilderbrand et al., 2003), and thus how health workers should weigh the risks of feeding options to women living in poverty (Seidel, 2004).

Feeding decision-making and behaviour however, is not simply about balancing the relative risks of transmitting HIV or increasing susceptibility of infants to other diseases (Hilderbrand et al., 2003). Adherence to safe infant feeding practices for HIV-exposed infants in South Africa is low, even where information about risks has been understood (Coutsooudis et al., 2001; Doherty, Chopra, Nkonki, Jackson, & Persson, 2006). Mixed feeding remains the norm, with the majority of infants receiving solid or semi-solid food before four months, in cases within the first month (Buskens, Jaffe, & Mkhathswa, 2007; Sibeko, Dhansay, Charlton, Johns, & Gray-Donald, 2005; Thairu, Pelto, Rollins, Bland, & Ntshangase, 2005; Varga & Brookes, 2008). Understanding how and why feeding decisions for HIV-exposed infants are made and implemented is thus critical for determining the risks to and supports for different feeding options, and thus improving rates of HIV-free survival.

South African PMTCT Infant Feeding Policy

Government policy in South Africa recommends that for the first six months HIV-exposed infants are either breastfeed exclusively, avoiding all other fluids (including formula,

water and medications) and foods, or that they are fed exclusively with formula milk, avoiding all other solid and semi-solid foods¹. Exclusive formula feeding is advised only when it meets the criteria of being acceptable, feasible, affordable, sustainable and safe (AFASS) (See Appendix A for the operationalisation of the AFASS criteria). Free formula is supplied to formula feeding women for six months (Department of Health, 2008, 2010)

The AFASS criteria recognise that in addition to knowledge, social or cultural barriers (including fear of stigma or discrimination, and family or other social pressures to breastfeed) and financial resources, may impact on the exclusivity and safety of formula feeding. Studies suggest that disclosure, employment in the home, electricity and piped water are good proxies for the AFASS criteria (Doherty et al., 2006). Policy does not recognise particular barriers to exclusive breastfeeding.

Updated guidelines include more extensive antiretroviral (ARV) regimens for infants. Infants will now receive Nevirapine (NVP) and Cotrimoxazole for as long as any breastfeeding continues unless the mother is on highly active antiretroviral treatment (HAART) herself (Department of Health, 2010). These new guidelines are expected to reduce the risk of transmission through breastfeeding to 1% (Kilewo et al., 2009; Taha et al., 2008).

Theories and Models of Infant Feeding

Various theories and models of infant feeding have been developed based on research with general (non-HIV) populations in the global north. Although the models are fundamentally different, taken together they suggest that feeding is influenced by a combination of social, cultural, economic and psychological factors; and that the influence of each of these may change over time (Bentley, Gavin, Black, & Teti, 1999; Brophy-Herb, Silk, Horodyski, Mercer, & Olson, 2009; McKinley & Hyde, 2004; McMillan et al., 2009; McMillan et al., 2008; Swanson & Power, 2005).

Social cognition models. The theory of planned behaviour (TPB), a social cognition model outlined by Ajzen (1991), posits that behaviour is determined by an individual's intention to engage in the behaviour and the extent to which they see the behaviour as within their control

¹ Clinics also routinely advise formula feeding women to avoid traditional medication before the infant's HIV test (A. Boule, personal communication, October 19, 2010).

(perceived behavioural control (PBC)). Intention is a function of a person's attitudes² towards the behaviour, their subjective norms³ and PBC. As applied to infant feeding, studies of the TBP have therefore focused on the mother's cognitions and perceptions.

Attitudes have consistently predicted both feeding intentions and (contrary to the TBP) feeding behaviour (Manstead, Proffitt, & Smart, 1983; McMillan et al., 2008; Swanson & Power, 2005). The influence of normative factors on intentions seems to change over time. When the TPB variables were measured at different time points, women whose feeding behaviour changed over time were found to have significantly changed their perceptions of others' normative beliefs (Swanson & Power, 2005). This suggests limits to mothers' abilities to anticipate the role of others in infant feeding, pointing to a temporal element to decision-making and behaviour.

PBC usually predicts intentions but not always feeding behaviour (McMillan et al., 2008; Swanson & Power, 2005), suggesting a role for other factors. In one study, PBC did not predict early breastfeeding, but did predict breastfeeding by six weeks, suggesting that obstacles to breastfeeding may increase over time, making individual control more important (McMillan et al., 2008). Obstacles could be related to structural and cultural factors, as McMillan et al. (2008) found that, although not significant predictors of intentions and early feeding behaviour, social deprivation and ethnicity were independent predictors of breastfeeding by six weeks.

Ecological and structural models. Ecological and structural models support a role for contextual determinants of behaviour in addition to individual attitudes and perceptions (Bentley et al., 1999; Marks, Murray, Evans, & Willig, 2000). Bentley et al. (1999) highlight the importance of combined structural and interpersonal factors. They found that both mothers' and grandmothers' culturally informed attitudes towards feeding were important in determining the introduction of solid foods to the infants of adolescent African-American mothers. Grandmothers made and implemented feeding decisions directly because they had extensive physical access to infants and because mothers were socially and emotionally dependent on them. McKinley & Hyde (2004) suggest that the structural variables that directly facilitate or limit a feeding option may depend on the women's context (such as level of income and household structure).

² Attitudes are the overall evaluation of the behaviour and are a function of one's beliefs about the likely outcome of the behaviour weighted by the importance of these different outcomes (Ajzen, 1991).

³ Subjective norms are the perceived pressure from others to adopt a behaviour, which is a function of the individual's perceptions of others' normative beliefs, weighted by their motivation to comply (Ajzen, 1991).

Bentley et al. (1999) also demonstrate the role of the infant in shaping feeding practices. Many feeding practices were responses to infant behaviour, determined not only by beliefs about these behaviours and the role of food in addressing them, but by their actual presence over time. Recognising the reciprocal nature of feeding, this study suggests that beliefs, decision-making and behaviour may change over time as the child grows.

Summary and limitations. Taken together, these models for understanding infant feeding choices and practices suggest that individual attitudes and beliefs about feeding options are important, but determining whose attitudes are important requires looking beyond the mother's views to examine structural and interpersonal arrangements within the household. In addition, the infant's behaviour and the interpretations thereof are also important. Finally, attitudes, beliefs, interpersonal and structural factors may change over time; as may their role in determining feeding practices.

These models are however limited by their reliance on quantitative self-reports of behaviour and environmental characteristics, which limits understanding of the dynamic interaction between factors and of the meaning attached to practice. It also prohibits the identification of all relevant contextual factors as measures are pre-determined. Furthermore, their application in the context of maternal HIV infection is unclear. Additional dynamics may be involved where feeding choices are more complex and the risks to infant health more serious.

The Feeding of HIV-exposed Infants in South Africa

Limited exploratory qualitative research into the feeding of HIV-exposed infants in South Africa supports a changing role for both individual and contextual factors over time, but is methodologically limited.

A range of culturally-informed behavioural beliefs have been found to be important in determining feeding behaviour, and these extend beyond beliefs about feeding *per se*. In addition to beliefs about infant feeding cues, the associated risks, uses for and quality of breast- and formula-milk, and beliefs about infant development, the degree to which women perceived HIV stigma to be a problem in their community was a key influence in all studies. General beliefs about stigma levels, beliefs that using formula milk is tantamount to disclosing as HIV-positive, and beliefs that questions challenging the chosen method of feeding are really questions about HIV status were important (Buskens et al., 2007; Doherty et al., 2006; Hilderbrand et al., 2003;

Seidel, 2004; Seidel, Sewpaul, & Dano, 2000; Sibeko et al., 2005; Thairu et al., 2005; van der Merwe et al., 2007; Varga & Brookes, 2008).

In this context, disclosure supported adherence (Doherty et al., 2006; Health Systems Trust [HST], 2007). The ability to resist pressure and cope with potential stigma was affected by age as well as mothers' creativity and acceptance of their status. Some ignored insinuations about their status (Thairu et al., 2005), and others invented alternate explanations for suspicious feeding behaviour (Hilderbrand et al., 2003; Seidel et al., 2000). Structural factors like co-residence (and thus social and financial dependence) also played a role. Those living with the people placing pressure on them were less likely to resist (Buskens et al., 2007; Doherty et al., 2006; Thairu et al., 2005; Varga & Brookes, 2008). However, structural factors such as co-residence may change over time and the role of stigma on adherence itself was found to change over time (Doherty et al., 2006).

Perceptions of other's normative beliefs were important, but, unlike in the global north, the views of babies' fathers were generally not significant. Rather nurses, older female relatives, traditional healers and household breadwinners are influential (Buskens et al., 2007; HST, 2007; Seidel, 2004; Sibeko et al., 2005). Cultural beliefs about roles in child-care appear to underpin this (Buskens et al., 2007). Evidence suggests that it is when cultural beliefs combine with authority that the advice of health workers is undermined (Varga & Brookes, 2008). And authority changes with context: health workers were particularly influential in the clinic after delivery, but family views dominated on return home affecting maintenance of practices (Seidel, 2004).

Additional changeable structural factors related to poverty were important for formula feeding. These included having access to money to purchase formula milk and maintain access to electricity and piped water (Doherty et al., 2006; HST, 2007; Thairu et al., 2005). Low self-efficacy, inadequate counselling, and lack of postpartum support from health services further undermined adherence to the chosen feeding method (Chopra, Doherty, Jackson, & Ashworth, 2005; Doherty et al., 2006; HST, 2007).

This body of work suggests a range of behavioural and normative beliefs, interpersonal and structural factors that may be important. It also supports a dynamic view of the factors over time. Determining the range of influences on the feeding of HIV-exposed infants however

requires the use of longitudinal direct observation in addition to self-report. Only one study used observation, and this research was cross-sectional (see Buskens et al., 2007).

Research Aims

This study⁴ aimed to explore the extent to which poor and HIV-exposed infants are fed in accordance with feeding policy guidelines, and what factors related to the mother and infant, their context and experience of the PMTCT programme influence this. In particular the study set out to address the dearth of longitudinal observational research in this field. Thus the study was interested in feeding intentions as well as actual practices in context and over time, as well as the meaning attached to these practices. Given that others apart from the mother have been found to be involved in the feeding of infants, the study aimed to determine who makes the decisions about feeding of HIV-exposed infants, and what influences this. In providing a contextual account, the study also aimed to examine how the feeding is affected by raising infants in conditions of poverty. Ultimately, the study hoped to contribute to the debate about how HIV-positive women should be advised and supported to feed their infants.

Design and Methodology

Theoretical Framework and Research Design

Attending to the range of individual, interpersonal and structural factors identified as pertinent to infant feeding by the literature, this study adopted a biopsychosocial theoretical position that health experience and behaviour should be considered in their “full economic, political, ecological, social and cultural context” (Marks et al., 2000, p. 3). This approach was combined with an ecological understanding of behaviour (Bronfenbrenner, 1979; Donald, Dawes, & Louw, 2000) which recognises a transactional influence between an individual’s behaviour and their environment in which the individual’s perceptions of their context and the meaning they attribute to their experiences are important.

⁴ The present study is part of a larger study by the University of Cape Town’s Children’s Institute that investigated the everyday lives and experiences of HIV-positive women and their infants enrolled in the PMTCT programme. The project team was led by myself (a white English-speaking woman) and included a junior researcher (a black isiXhosa-speaking man) and two fieldworkers (both black isiXhosa-speaking women).

The theoretical approach requires attending to both feeding behaviour and environment over time through direct observation, and to meaning and perceptions through talking to the people concerned. A qualitative methodology was therefore employed. Specifically, the data were collected using the ethnographic methods of long-term observation and in-depth interviewing. Ethnographic methods allow the researcher to answer questions about what is happening, what cultural beliefs inform and rationalise these activities, and, what the larger contexts are in which these activities are embedded (Miller, Hengst, & Wang, 2003). This study set out to answer these questions in relation to infant feeding, looking at how feeding behaviour is informed by cultural and medical belief systems as well how it is embedded in everyday life and in the PMTCT programme. In addition, ethnographic approaches enable the meaning of behaviour and of institutions to be represented from the participants' point of view (Miller et al., 2003). This is particularly important for understanding interactions with PMTCT services and the decisions made regarding implementing feeding advice.

Setting

The study was conducted in Gugulethu; an urban township situated 20km from Cape Town. Poverty⁵ was a criterion for the study site because poverty-related structural factors are important for infant feeding in the context of HIV (Doherty et al., 2006; Thairu et al., 2005). In 2001, 61.69% of households in Gugulethu lived on less than R380 per person per month (Strategic Development Information & GIS, 2010). In addition, because the study aimed to investigate feeding practices in the context of access to a PMTCT programme, a site in which problems to do with the delivery of services would not overshadow issues to do with participants' everyday lives and experiences was required. The City of Cape Town metro health district (into which Gugulethu falls) has above average rates for all measures of PMTCT coverage (Day et al., 2010).

Participants

The core of the study was conducted with 10 mother-infant dyads (see tables 1 and 2). To capture the duration of their contact with the PMTCT programme, HIV-positive women, living in Gugulethu and attending their first antenatal appointment at the midwife obstetrics unit (MOU) in Gugulethu were eligible. To ensure confidentiality, HIV counsellors at the clinic

⁵ The poverty line is set at the 40th percentile, which in 2000 was a per capita income below R350 (Hall, 2010).

introduced the study to women during individual pre-test counselling in cases where women knew they were HIV-positive, and in post-test counselling where women had tested positive for the first time. Those who expressed interest were referred to the research team for more details. All eligible HIV-positive women took up this opportunity. In order not to overwhelm women who might have just received an HIV-positive diagnosis, brief information was given and appointments made for a later date to explain further and obtain informed consent. Forms were available in English and isiXhosa (see Appendix B). Confidentiality was ensured. Four women refused to participate, in two cases owing to work commitments and in two cases because of non-disclosure at home. Although the final sample included four participants who had not disclosed to the people they lived with, it only included one employed woman and she resigned before giving birth. The study therefore cannot shed light on the influence of work-related factors.

Table 1
Study participants: Demographics

No.	Participant^a	Age	Months pregnant at recruitment	Infant gender	Infant age at conclusion of study
1	Thandeka	23	5 months	M	9 months
2	Kholeka	38	6 months	M	7 months
3	Nosisi	28	7.5 months	F	10 months
4	Babalwa	28	6 months	M	10 months
5	Nontsasa	23	5 months	M	10 months
6	Lindiwe	21	7 months	M	8 months
7	Thozama	37	8 months	M	11 months
8	Pumla	27	7 months	M	7 months
9	Neziswa	26	8 months	F	11 months
10	Faniswa	33	6 months	M	Baby died at 2 months

^a Pseudonyms have been used to protect confidentiality

Table 2
Study participants: Living arrangements and disclosure

No.	Participant	Relationship to infant's father	Living arrangements	Disclosure to infant's father	Disclosure at home
1	Thandeka	Boyfriend	Mother, Step-father, son, 3 nieces, 1 family friend	Yes	No
2	Kholeka	Boyfriend	Mother, son, daughter, nephew, tenants	No	Yes
3	Nosisi	Boyfriend	Boyfriend	Yes	Yes
4	Babalwa	Boyfriend	Boyfriend, daughter, son	Yes	Yes
5	Nontsasa	Boyfriend	Boyfriend, boyfriend's mother, boyfriend's 2 sisters, boyfriend's 2 nieces, tenants	Yes	No
6	Lindiwe	Boyfriend	Mother, 2 brothers, nephew, son	No	Yes
7	Thozama	Boyfriend	2 Aunts, uncle, 2 cousins	Yes	Yes
8	Pumla	Deceased	Mother, uncle, daughter	Yes	No
9	Neziswa	Married	Husband, son	No	No
10	Faniswa	Ex-boyfriend	Daughter, son, tenants	Yes	Yes

The study focused on the infant and the mother and reached outwards to include others who played significant roles their lives. In-depth work was conducted with three fathers, one aunt, one neighbour and two grandmothers. Given issues around HIV disclosure and stigma, informed consent forms for other adults framed the study as investigating the raising and care of infants, without reference to HIV (see Appendix C). In addition, these individuals were only recruited with the mothers' permission. As a result, it was not possible to do in-depth work with all important family members.

Methods

Data was collected between November 2008 and February 2010. Methods were applied flexibly and sensitively, recognising that participants were at a particularly vulnerable time in their lives. Referral systems were in place for households requesting support. The study was

approved by the University of Cape Town Health Science Faculty's Human Research Ethics Committee (ref: 374/2008).

Fieldwork was typical of ethnography in that it was both microscopic and holistic (Miller et al., 2003). It aimed to describe actual practices and the influences on these practices in a way that was sensitive to nuance and variation over time. To achieve this, a range of methods was employed:

1. Informal observation captured household context and dynamics and the changing nature of the dyads' circumstances.
2. Fieldworkers accompanied mothers and infants on clinic visits to observe the dyads' interactions with the health services and the PMTCT programme, the nature of the services offered, and to track their health statuses. See Appendix D for the guidelines.
3. Infant care was systematically documented by fieldworkers, every eight days from birth until the end of January 2010 (when infants were between 7 and 11 months old)⁶. This included a 30 minute observation of the mother, infant and others involved in caregiving, and a 24-hour recall exercise which recorded household activities, care and feeding practices over the previous 24 hours. See Appendix E for guidelines. Fieldwork challenges meant that observation and recall was not conducted for all infants every eight days⁷. All infants were however observed at least once a month.
4. In-depth semi-structured interviews were conducted with mothers to explore the meanings of behaviour and experiences. Interviews reflected on both experiences and beliefs to do with feeding, mothering, infant care and development, HIV, the PMTCT programme, and family. Given the dynamic and flexible nature of ethnographic work (Miller et al., 2003), the interview schedule evolved over the course of fieldwork (see Appendix F). For this reason not all women were asked all questions. One participant was resistant to being interviewed formally and so information on key areas was gathered informally. Mothers chose whether to conduct interviews in English or isiXhosa. Where necessary, fieldworkers provided translation. To be sensitive to concerns about neighbours' curiosity and potential stigma, women chose which

⁶ This method was adapted from a study by Reynolds (1991) which examined the nature and extent of work undertaken by children within and beyond the home.

⁷ When fieldworkers were off sick or on leave it was not always possible for another team member to conduct observations and recalls owing to other fieldwork commitments. In addition, infants were not always found at home, and mothers could not always be reached in these cases.

researcher interviewed them and where. Between one and eight interviews were conducted with each mother, with a total of 52 in-depth interviews⁸.

5. Key adults involved in caring for the infant were also identified for in-depth interviewing. Semi-structured interview topic guides were developed for each interviewee. Interviews established the individuals' roles in caring for and making decisions about infant care and feeding, the meaning attached to this role and the reasons and beliefs behind decisions made. Seven individuals were interviewed between one and five times, with a total of 13 interviews⁹.

Data Analysis

The data for this study consist of observational and reflective field notes and interview transcripts. Analysis was aimed at identifying patterns in actual infant feeding practices and decision-making, as well as influences on and meanings attached to those practices and decisions. Data was analysed using thematic analysis, which identifies, analyses and reports patterns within data (Braun & Clarke, 2006).

The approach recognised that the researcher approaches the data with existing questions and conceptual frameworks in mind (Braun & Clarke, 2006; Miles & Huberman, 1994). As this study formed part of a larger project, a preliminary set of codes was developed from the research questions guiding that project together with ideas that emerged from an initial reading of the data from three dyads. As codes were applied, they were refined and new ones developed inductively. The junior researcher and I used a process of negotiated coding (Garrison, Cleveland-Innes, Koole, & Kappelman, 2006) to apply the initial framework to half the data set each using *NVIVO 2* software. Second-level coding was conducted by myself. This involved using analytical memos in the initial coding phase to identify codes relevant to the present study and record thoughts concerning possible themes, patterns, and connections between these codes. In this way important elements related to infant feeding behaviour and decision-making were identified and the connections between them established (Tesch, 1990). Once the coded data were merged into one *NVIVO 2* project, a second level of coding tested themes, patterns, and relationships and refined codes and themes on the basis of these relationships. Thus, through a process of coding

⁸ Forty-two of these interviews were conducted by me and 10 by the junior researcher

⁹ Three fathers were interviewed by the junior researcher. Two grandmothers were interviewed (one by me and one by the junior researcher). One aunt and one neighbour were interviewed by me.

and recoding, categories moved from being descriptive to inferential and explanatory (Miles & Huberman, 1994).

Because the study aimed to capture the complex interplay between various aspects of individual dyads' lives, analysis preserved the meaning generated within individual cases, while also generalising across cases in order to identify commonalities and differences in factors supporting and undermining adherence. The matrix approach advocated by Miles and Huberman (1994) was used for second-level coding whereby coded text from different households was extracted and then interpreted by making comparisons within and across households. In this way explanatory themes were established through moving back and forth between various levels of the data (Braun & Clarke, 2006).

In ethnographic research, it is particularly important to be attentive to the collective construction of data and participants' perceptions of the researcher (Parker, 2005). Memos were used to reflect on how the data were shaped in this way, and to interrogate emerging themes in light thereof.

Results

Actual Feeding Practices

At first antenatal booking, 9 out of 10 participants intended to formula feed, and the participant who intended to breastfeed changed to formula during the course of that initial clinic visit. All participants except one initiated formula feeding, and managed to avoid all breastfeeding for the duration of the study. Only the infant of the woman who initiated breastfeeding was mixed fed. After switching from breast- to formula milk however, she managed to avoid all further breastfeeding.

In this sample, therefore, the biggest threat to exclusivity was early introduction of other liquids and foods. Seven infants were given liquids or medicines not advised by the clinic before being tested at six weeks, and six infants were fed semi-solid foods in the same period. All infants were eating semi-solid foods by four months, and by six months five infants were eating family foods.

The safety of formula feeds was not high in this sample. All infants were fed bottles that were not hygienically prepared, and half of the participants ran out milk at least once during the course of the study. Only Nontsasa's baby, however, had a chronically erratic milk supply following the cessation of free milk at six months.

Many people were involved in infant feeding practices and decision-making. Most commonly, older female relatives played a role in decision-making. The baby's fathers had little say in how and what babies were fed although they were the primary group responsible for paying for formula and other foods. Some fathers were involved in preparing of bottles and in this way impacted on the extent to which feeding was hygienic and safe.

An overview of actual feeding practices is presented in tables 3 – 6 below.

Table 3

Maintenance of Exclusive Feeding Practices A

Participant	Feeding intention	Feeding initiated	Mixed feeding
			Switched to formula at 11 days.
Thandeka	Formula	Breast	Subsequently avoided all breastfeeding
Kholeka	Formula	Formula	Avoided all breastfeeding
Nosisi	Breastfeeding	Formula	Avoided all breastfeeding
Babalwa	Formula	Formula	Avoided all breastfeeding
Nontsasa	Formula	Formula	Avoided all breastfeeding
Lindiwe	Formula	Formula	Avoided all breastfeeding
Thozama	Formula	Formula	Avoided all breastfeeding
Punla	Formula	Formula	Avoided all breastfeeding
Neziswa	Formula	Formula	Avoided all breastfeeding
Faniswa	Formula	Formula	Avoided all breastfeeding

Table 4
Maintenance of Exclusive Feeding Practices B

Participant	Liquids/medicines before 6 weeks	Solid foods fed before 6 weeks	Solid foods fed 6 weeks - 4 months	Solid foods 4 - 6 months
Thandeka	Water; Saccherol; Boehoedmiddel	Nestum baby cereal	Nestum baby cereal	Nestum baby cereal; Purity jars; mashed vegetables; yoghurt
Kholeka	Nothing	Nestum baby cereal	Nestum baby cereal	Nestum baby cereal; Purity jars; yoghurt
Nosisi	Umthombothi	Nothing	Nestum baby cereal	Nestum baby cereal; Purity jars; yoghurt
Babalwa	Umuthi wenyoni	Nothing	Nestum baby cereal; Purity jars	Nestum baby cereal; Purity jars; Purity instant porridge; yoghurt; sour milk and mielie-meal; wheatbix with milk; chicken and mielie-meal pap
Nontsasa	Water; sunlight soap enemas; antacid; Panado.	Purity instant porridge	Purity instant porridge; Purity jars; nestum baby cereal	Purity instant porridge; Purity jars; Nestum baby cereal; mashed banana; squash with butter and sugar; chicken legs; yoghurt
Lindiwe	Umthombothi	Nestum baby cereal	Nestum baby cereal; Purity jars; yoghurt	Nestum baby cereal; Purity jars; yoghurt; sour-milk and bread; wheatbix; instant porridge; mashed banana; mielie-meal porridge and bread; meat
Thozama	Nothing	Nestum baby cereal	Nestum baby cereal; Purity jars	Nestum baby cereal; Purity jars; yoghurt
Pumla	Water; traditional mixture for treating colic	Nestum baby cereal	Nestum baby cereal; Purity instant porridge; purity jars	Nestum baby cereal; Purity instant porridge; Purity jars; yoghurt; mashed vegetables; meat
Neziswa	Umthombothi	Nothing	Nestum baby cereal	Nothing
Faniswa	Cough mixture (prescribed by doctor at clinic)	Nothing	Baby died at 2 months of age	n/a

Table 5
Safety and Sustainability of Formula Feeding

Participant	General bottle cleaning method	Rinsed bottles	Dirty bottles	Leftover bottles	Cereal in bottle	Interrupted milk supply
Thandeka	Washing with dishwashing liquid, tap water, and a bottle brush before preparing each new bottle. Sterilising once a day with boiling water and salt.	Yes	Yes	Yes	No	No
Kholeka	Sometimes cleaning bottles with soap and tap water, sometimes with boiled water and salt, sometimes just rinsing with tap water or boiled water, or not washing.	Yes	Yes	Yes	No	yes - once at 2.5 months
Nosisi	Washing with dishwashing liquid and water and sterilising in boiling water for 5 minutes before each feed.	No	No	Yes	No	yes - once at 5.5 months
Babalwa	Washing with boiled warm water/cold water, dishwashing liquid and a toothbrush twice a day. Storing clean bottle in an ice-cream container with boiled water.	Yes	No	Yes	Yes	Yes, once at 8 months
Nontsasa	Washing with tap water/boiled water, dishwashing liquid and a bottle brush before preparing a new bottle.	Yes	Yes	Yes	No	Yes, 3 times between 6 to 10 months
Lindiwe	Washing in warm boiled water with salt/dishwashing liquid and a brush before preparing a new bottle.	Yes	Yes	Yes	Yes	No
Thozama	Washing in cold water with dishwashing liquid and a brush, then sterilising with boiled water before preparing a new bottle.	Yes	No	Yes	Yes	No
Pumla	Washing with hot boiled water and a brush, or warm tap water and dishwashing liquid twice a day. If runs out of clean bottles at night, just rinsing with warm boiled water.	Yes	No	Yes	No	Yes, once at 2 weeks
Neziswa	Washing with warm water and dishwashing liquid once a day.	Yes	Yes	Yes	Yes	No
Faniswa	Washing with warm boiled water and salt before each newly prepared bottle.	No	No	Yes	No	Yes, once at 3 weeks

Table 6
People Involved in Feeding Practices and Decision-making

Participant	People making decisions	People preparing bottles	People actually feeding	People shopping for food	People paying for food
Thandeka	Andiswa's mother, Andiswa	Andiswa, baby's father, Andiswa's niece	Andiswa; baby's father; Andiswa's nieces; baby's maternal grandmother; baby's maternal aunt; baby's paternal aunt	Andiswa	Baby's father; baby's paternal uncle
Kholeka	Annie, Annie's mother	Annie, baby's father, baby's sister	Annie, baby's sister	Annie	Baby's father
Nosisi	Nomzekelo	Nomzekelo only	Nomzekelo, baby's father; neighbour	Nomzekelo	Nomzekelo, baby's father
Babalwa	Liziwe; neighbour	Liziwe, baby's maternal aunt, neighbour	Liziwe; baby's father; baby's maternal aunt; neighbour	Liziwe	Baby's father
Nontsasa	Minzana; baby's paternal aunts; baby's paternal grandmother	Minzana; baby's father; baby's paternal grandmother	Minzana; baby's father; baby's paternal grandmother	Minazana; baby's father; paternal aunts (buy and steal milk)	Minazana; baby's father; paternal aunts (buy and steal milk); paternal grandmother
Lindiwe	Ntombizanele; Ntombizanele's mother	Ntombizanele; baby's maternal grandmother	Ntombizanele; Ntombizanele's mother; baby's father	Ntombizanele	Ntombizanele; baby's other boyfriends
Thozama	Ntombentsha's maternal aunt, Ntombentsha	Ntombentsha; Ntombentsha's maternal aunt; baby's maternal aunt	Ntombentsha's maternal aunts; Ntombentsha's cousin; baby's maternal aunt; baby's maternal cousin	Ntombentsha's maternal aunt	Ntombentsha; Ntombentsha's maternal aunt
Pumla	Lydia; baby's maternal grandmother; baby's paternal aunt	Lydia only	Lydia; baby's maternal grandmother	Lydia	Lydia; baby's paternal aunt
Neziswa	Nandipha's mother, Nandipha	Nandipha; baby's maternal grandmother; baby's maternal aunt; baby's father	Nandipha; baby's maternal grandmother; baby's maternal aunt; baby's father	Nandipha	Baby's father
Faniswa	Ndileka	Ndikela only	Ndileka; baby's father	n/a	n/a

In a small qualitative sample it is not possible to examine risk based on actual outcomes. Despite non-adherence to feeding protocols, nine infants survived to one year and tested HIV-negative. The tenth infant died at two months (of unnatural causes) with an unknown HIV status. The analysis which follows therefore focuses on understanding the factors influencing exclusivity and safety, practices that are statistically related to rates of HIV-free survival.

Factors Influencing who Makes and Implements Feeding Choices

Understanding who actually makes and implements feeding choices is essential to understanding adherence. Only one mother, Thandeka initiated a different feeding practice to what she had chosen during pregnancy. A number of other infants were however fed in ways not chosen by the mother. What is particularly interesting about Thandeka's decision to initiate breastfeeding is that she was resolute in her desire to formula feed during pregnancy. In other cases, such as Pumla allowing her baby's paternal aunt to administer traditional medication for *umoya* (colic) when he was only one month old, the mother's feelings about the practice were less strong as was her understanding of the risks involved. In addition, Thandeka had made the decision to formula feed with her boyfriend, the baby's father, and he was anticipating an active role in supporting adherence:

I have to be there so that I can be able to stop her if she forgot to do something in feeding the baby... so I have to be there because they say you cannot breastfeed a baby when you are positive, there is milk that you get from the clinic. I heard that from her. (Cebo, father)

Key factors in this development related to Thandeka's culturally informed position within the family and household hierarchy, failure to disclose to the relevant people, a lack of internal resources for strategic resistance of the pressure to change her decision; and the relative strength of beliefs.

Family and household hierarchy and relationships. Living in extended households meant that the wishes of older women sometimes needed to be followed. Thandeka is an unmarried woman living with her mother, step-father, siblings and nieces. She described her mother as the "head of the household". Although her family was not very traditional when it comes to isiXhosa customs, *ukuhlonipha* or respect for one's elders was an important influence on intra-household arrangements. Thandeka's mother's status as matriarch was reinforced by her being employed and her active role in looking after her family. Defying her instructions regarding child care would thus run counter to maintaining peace and order within the household.

The influence of maintaining socially, culturally and emotionally important relationships was enhanced by but not dependent on co-residence. Non-resident women, who play important social, cultural or emotional roles in the everyday lives of mother or infant, may also have to have their advice followed, especially when foods or medicines are actually bought for the

infant. These dynamics emerged in the case of Pumla son being given traditional medicine for *umoya* by his paternal aunt, referred to above. Pumla's boyfriend died when she was seven months pregnant, and the paternal grandmother died shortly after her baby was born. The paternal aunt, a close friend and confidante (she was one of only three people to whom Pumla had disclosed), was thus her child's primary link to his paternal family. The interaction of factors is important: relative to these cultural and emotional ties Pumla did not feel that strongly about the traditional medicine, explaining, "if I don't want, I don't want, I tell them I don't want". Prior to this pressure however, she had been adamant about following the instruction to avoid traditional medications in the first six weeks.

Perceptions about who is knowledgeable about infant feeding influenced who made decisions, and this was shaped by age, gender and the mother's experience of raising children. Fathers had no say in how babies were fed as mothers could claim superior knowledge based on traditional gender roles, and because fathers generally did not equip themselves with knowledge. Young and/or inexperienced mothers were more likely to seek the advice of older female family members and to doubt their own ideas when it differed to the advice given. Thus Thozama, a first-time mother, had reservations about introducing baby cereal at only two months because "I was thinking that he's still young" but doubted herself when her aunt suggested doing so.

The importance of paternal family in isiXhosa culture meant that where mother and infant were living with the father's family, the mother's position and right to make decisions was further compromised in addition to age and experience. Thus Nontsasa, who although unmarried, lived with her boyfriend and his family, found that she did not have much say over what food was given to her baby and he was frequently taken into the main house without her permission. She explained how the baby's paternal aunts would tell her "you don't know anything about babies you" when she objected to the feeding of solid foods, forcing her to "just back off".

The extent to which others had access to the baby also determined whether they would be involved in making decisions about how the baby is fed. Where mothers relied on others to help them look after the baby when they had errands to run or chores to do, these people were liable to introduce foods without the mother's knowledge or consent (even if they left prepared food for the baby). This happened with Babalwa, whose neighbour introduced adult cereal, chicken and mielie-meal pap before six months, without Babalwa knowing. Others also took over infant care when mothers fell ill.

Disclosure. Disclosure is seen as an important way to mitigate against the influence of others (Doherty et al., 2006; HST, 2007). Even when Thandeka spoke of her intention to formula feed, she anticipated potential problems from her mother and thought she would need to disclose to her in order to avoid these. When the time came however, she found she was not ready to disclose:

My mother saw me buying a bottle and she asked me why I was buying a bottle and I said “no, I am going to bottle feed” and she asked why, she asked many questions and I said “no, I can keep the bottle and breastfeed him”... She said I wasn’t going to be able to use the bottle, “the baby breastfeeds”... So I hadn’t told her then about my status... and I was not yet ready to tell [her]. (Thandeka, mother)

Neziswa had also mixed fed with her previous child because she had been unable to disclose to her mother. Who needs to be disclosed is not always obvious upfront to women as it was for Thandeka, as not all women anticipated the questions and pressure they received.

Disclosure was also not always a solution. Women did not necessarily invoke HIV-risk to resist pressure for risky practices even where they had disclosed to the person putting pressure on them. For example, Pumla had disclosed to her baby’s paternal aunt, but yet did not raise the issue of HIV when pressured to use traditional medication for *umoya*. It is perhaps a mistake to assume that disclosure equates with being comfortable talking about HIV. Pumla’s relationship with the disease was far more complicated and there were times when, despite having disclosed, she seemed to deny her situation. For example, after having the baby she said she was not going to re-test her CD4 cell count because they had made a mistake, “I am not sick”.

Mothers’ strategies. In the absence of disclosure or a willingness to talk about HIV, mothers’ abilities to employ creative strategies to deal with pressure to mix feed or introduce other liquids, medicines or foods greatly enhanced the chances of maintaining exclusivity. Although Thandeka was able to develop strategies for hiding and justifying other ‘evidence’ of her HIV-positive status, such as decanting her ARVs into an iron tablet container, in the face of her mother’s strong belief and “many questions” about formula feeding she was not able to draw on these tactics. These types of strategies were frequently utilised to great success where those placing pressure on the mother were further removed and/or conveyed less strong beliefs.

Nosisi used creative tactics to explain her lack of breastfeeding to curious neighbours and family. She explained that she had tried unsuccessfully to breastfeed:

I said to them “no I was breast feeding this baby but I didn’t have enough milk on my breasts that is why I stopped breastfeeding her”... “Because she’s crying while I’m

breastfeeding her because there is not enough milk for her”... I said to them “no I was told by the nurses that Pelargon¹⁰ is the same as your breast milk”. (Nosisi, mother)

When neighbours pressurised her to introduce solid foods at three weeks she bought porridge for her baby, mixed it up and left it on the counter so that neighbours would believe she was following their advice. She did the same thing with medication that she was advised to give the baby:

There is a Panado... on that day when she was crying they were saying buy Panado. I drank it myself because it also helps me. I’m not going to give her. Even Nestum, you must buy it and put it there, so when they come they see the container there. (Nosisi, mother)

Having a plausible context for one’s story was important: Nosisi was in hospital for almost a week following the birth of her baby. Also, in Nosisi’s case no one else was actually feeding the baby because she lived alone with her baby and her boyfriend. However, she described that with her previous child she was still able to use strategies to stick to exclusive feeding even though she was living with older female family members. She created an illusion that others were involved, but this required constant vigilance:

When they say prepare a bottle for the baby I would say to them “no she just finished her bottle while you were sleeping and I gave her water because she doesn’t get full”. I was just lying to them knowing that I’m not going to give my baby water. Sometimes I would pour water into her bottle but not give her... and when they are not watching I would just drink that water myself or throw it away. When they ask me again later I would tell them I gave her. They saw water in the bottle so there is no reason why they shouldn’t believe that I gave her... I never left my baby, if I go somewhere I always took her with me up until we got the results. Even after we got the results I never went far from her. (Nosisi, mother)

Many women used the excuse of wanting to look for work to explain why they were not breastfeeding. A number of women, including Nosisi, also decanted the free formula into formula tins not marked with the clinic stamp, as free milk was thought to be generally known to be given only to HIV-positive women. In addition to creative strategies, having an attitude of not caring what the neighbours think was also helpful. As Neziswa explained, “I just told them that I decided not to breast feed and they never asked me again, *ayibafuni* (it’s none of their business)”.

Decision making scenarios. Based on the particular combination of family and household dynamics and hierarchies, disclosure, household structure and use of creative strategies different decision-making structures surrounded the feeding of individual infants. In

¹⁰ Pelargon was the brand of formula dispensed by the clinic

some cases such as Nosisi, independent and individual decision-making by the mother was evident. In other cases, collective decision-making was evident. Sometimes this would involve one (or more) people exerting their influence over the mother (Thandeka) and in other cases the decision-making seemed a more genuinely collective process (Pumla; Thozama). And finally there were cases where there seemed to be multiple independent decision-makers, such as in Nontsasa's baby's case where Nontsasa was not involved in deciding or implementing some of the practices, but could also not stop them.

Factors Influencing Adherence to Recommended Feeding Practices

Various factors were involved in determining whether feeding was exclusive, including levels of PMTCT-related knowledge; a range of different beliefs (about formula milk; breast milk; baby foods; infant feeding cues; infant health; and traditional practices); the experience of the clinic as unhelpful; poverty; infant behaviour, the mother's own health; and the ability to rationalise/play health risks off against each other. Where others were involved in feeding and decision-making, their beliefs as well as those of the mother were important.

Mothers' knowledge of recommended feeding practices. Analysis of mothers' knowledge and understanding revealed great variability, gaps and inconsistencies in their understanding of safe infant feeding practices. Despite this variability, all women appeared to have a clear understanding that "for parents like this [HIV-positive] it is very dangerous to breastfeed your baby" (Faniswa, mother). All women also knew that solid foods should not be fed to infants before six months, although none understood why. Variability in other knowledge was accounted for by factors related to the nature and quality of the infant feeding counselling at the MOU and well baby clinics, as well as mothers' own levels of experience, social and psychological resources.

Clinic factors included a lack of comprehensive individual infant feeding counselling; an over-reliance on mothers' voluntary participation in NGO services attached to the clinic¹¹; the prioritising of information about HIV-risk over information about risks of morbidity due to malnutrition and other diseases; as well as a didactic style of information dissemination and a failure to adequately explain the reasons for directives.

¹¹ These NGOs, based at both antenatal and well baby clinics offered support and information to HIV-positive women in the form of dropping-in after their clinic visits and/or attending support groups. Only six of the participants used the services of the antenatal NGO and none used the postnatal services. The women explained that they were often too tired after six to seven-hour long clinic visits, and needed to attend to chores and other children.

In terms of factors related to the women themselves, firstly, whether or not a woman had been through the PMTCT programme with a previous child impacted on her knowledge. Secondly, having an interested and engaged partner (or other) with whom the woman could discuss the information received at the clinic helped with remembering. As Thandeka explained:

The reason I was able to absorb it all is that whenever I would go to the clinic and they talk about that, I would then come home and tell him [my boyfriend] all about it, he always checks up on me, on what I am doing. (Thandeka, mother)

Thirdly, women with avoidant coping styles tended to retain less information and/or participate less in the NGO services. For example, Nontsasa consistently avoided thinking about issues that were scary or difficult, from giving birth because it “makes me scared”, to resisting questions about mothering because she saw herself as a bad mother. Similarly, in response to questions about what she understood about protecting the baby from vertical transmission, she said “I don’t want to think about this”. Pumla also tended to cope by avoiding issues. When her boyfriend died, she coped with the enormous “stress” by “not thinking so much” and distracting herself with other things. She was reluctant to lean on other people as it made her think of her problems. This reluctance was generalised to the antenatal NGO whose sessions she did not attend because “I don’t like to talk”. Avoidant coping styles were sometimes characterised by drug and alcohol use¹². Kholeka drank excessively, and Nontsasa smoked marijuana and tik. These two women had the worst understanding and recall for all PMTCT-related information.

In some cases avoidance was related to difficulties with disclosure. However, not all women who had difficulty disclosing or accepting their status had poor recall for information. Also, some women with avoidant coping styles, such as Kholeka, had disclosed to family and neighbours. Thus it seems that an avoidant coping style, rather than simply not being ready to disclose is implicated here.

Beliefs about formula, breast milk, solid foods and infant feeding cues. Complex interactions between beliefs about milk, other foods and interpretations of infant behaviour led to both early introduction of solid foods and overfeeding.

Beliefs that formula is “water” and that giving only formula is starving the baby were common. As Nosisi explained, “they say you are starving this baby... because bottle it’s water”.

¹² Participants initially concealed the extent of substance use from me as a white female. These activities were revealed more readily to the black African members of our research team. However, it is likely that the full extent of substance use was not known.

This understanding was usually the source of pressure or suggestions from others to introduce baby cereals early, and seemed to underpin interpretations of the crying baby as hungry, and the insatiable baby as ready for solid foods. As Lindiwe's mother explained: "he doesn't get enough, that is why he is always crying". Feeding was almost always the first response to crying, with other possible interpretations of the crying following on from that.

Although beliefs that breast milk was nutritionally more substantial could delay introduction of foods, they were still introduced early. Babalwa explained that she introduced solid food at three- rather than two months with her first child because she was breastfed. Food was a useful way of controlling infant behaviour, and babies were not only fed solid food in response to crying, but also to prevent them from crying, or encourage them to sleep.

Beliefs that you need to teach and encourage babies to eat solid food also played a role in its early introduction. As Nosisi explained: "I'm not going to feed her every day, I just want to teach her so that she knows about all food". Furthermore, many of those feeding the babies did not believe that foods made especially for babies (such baby cereals and Purity) were really food. This was clearly articulated by Nontsasa's baby's paternal aunt who said that purity is "not a food, ok, it's a nice thing".

Demonstrating that it these beliefs about formula's inadequacy and the appropriateness of solid foods for small infants underpin non-adherence, mothers seemed to be less sensitive to feeding cues which countered these beliefs. For example, Babalwa did not interpret her baby's negative reaction to being fed yoghurt at four months, as an indication of him not being ready for it. And Pumla persevered with solid foods at three months despite her baby crying, and clearly preferring his bottle:

He doesn't like it even when you feed him with the spoon; he likes the bottle, only the bottle... He likes the bottle, yoh! The bottle is number one...He doesn't like to eat with a spoon...But I do, I do feed him. (Pumla, mother)

Beliefs that breast milk is contaminated by illness and medicines undermined exclusive breastfeeding. Thandeka switched from breastfeeding to formula feeding when she became ill 11 days after giving birth because her mother gave her traditional medicines "to cleanse myself and she said the child would not be able to breastfeed" because the medicine would make her milk "dirty". In the context of compromised maternal health these beliefs could be a serious threat to the maintenance of exclusive breastfeeding. Thandeka had to strategise in order to avoid going

back to breastfeeding after a period of formula feeding. In the absence of an excuse, she may have returned to breastfeeding, further increasing the risk of transmission.

Beliefs in traditional practices and medicines. The extent to which those involved in making feeding and other care decisions believed in the importance of traditional cures for *umoya* (colic), *ishimnca* (baby rash), and *ukuqiniswa* (protection from evil spirits) determined whether these medicines were fed to infants. Where non-medicinal treatment options existed, women were sometimes able to avoid giving their infants medication to drink.

Beliefs about infant health. Concern about HIV was the most prominent infant health influence on feeding intentions and practices, but given the bias in feeding information towards emphasising HIV over other health concerns, this is not surprising. The avoidance of breast milk was driven by this concern and women were able to draw on strategies, resist pressure from others and deal with their own sadness about not breastfeeding because of the strength of this fear. As Pumla explained: “I don’t want to take any chances, it’s better to bottle-feed him”. Mothers were frequently rendered speechless by the thought of their infant being infected with HIV; unable to complete their thoughts or sentences for the sheer horror of the idea. Where women delayed introducing liquids and foods prior to the HIV test, this was based on an understanding that it was important to ensure that the baby would be HIV-negative.

Feeding was less likely to be implicated in mothers’ understanding of other health outcomes and indicators, partly because of a belief that a healthy baby is a well-fed baby¹³. The presence of this belief, and the clinic’s failure to make explicit links between infant health and feeding (except in extreme cases) meant that signs of overfeeding, such as chest problems, reflux and vomiting after feeds, were seldom interpreted as such. In Neziswa’s baby’s case explicit links were made between a serious illness requiring hospitalisation and the feeding of solid foods. In response, Neziswa stopped feeding solid foods. Linking solid food and illness was thus central to sustaining the recommended behaviour.

Given the importance of infant health for feeding decisions and the fact that real or perceived health benefits were associated with almost all feeding practices, mothers were able to rationalise and justify almost all choices, including non-adherence with reference to the infant’s health. Thus even Thandeka discussed her switch from breast- to formula milk in terms of

¹³ Even the isiXhosa words for healthy (*usempilweni*) and well-fed (*wondlekile*) were sometimes used interchangeably in interviews.

benefits for the infant's health, referring to HIV-infection risk of cracked nipples should her health deteriorate, and that the medicine she was taking "was not good for the baby".

Negative experiences of clinic services. Women experienced the clinic as unsympathetic and rigid in their response to the difficulties women faced with crying babies who always seemed to be hungry. The advice to increase the size of the bottle and just continue feeding formula milk did not work and was therefore experienced as unhelpful and counter-intuitive. The reasons for counter-intuitive hospital and clinic practices were also never properly explained.

In the context of health service that were generally experienced as disempowering and unhelpful, these perceptions and experiences meant that women seldom sought advice from the clinic, and when they were asked about feeding practices (which was rare) they usually lied in order to avoid being treated badly. Lindiwe's strong reaction to the question of whether she would tell them at the clinic that she was feeding her two month old baby cereal, clearly shows in what a negative light the nurses are seen:

- Interviewer: Okay, and have you told them at the clinic that you're using Nestum?
 Lindiwe: No, oh!
 Interviewer: [Laughs] that sounds like you're not going to tell them, why don't you want to tell them?
 Lindiwe: Oh! [Laughs] Those nurses will insult me, they will yell at me so much, oh!

Because of the counter-intuitive nature of the feeding advice around solid foods, even more assertive women tended to assert themselves by disengaging from the clinic around feeding. A very strong belief in Western medicine was required in order to counter this.

Poverty and distressed care environments. Poverty was not a deterrent for choosing formula feeding even in the absence of clear idea of how to supply formula after the first six months. Women often claimed they would "try" to make a plan, an everyday reality in conditions of poverty. Poverty did however have an impact of safety and exclusivity.

A concern about the cost of formula after the first six months fuelled mothers' desires to teach the eating of solid foods:

- So I'm trying to teach him to eat something and drink. Because I don't want to depend on milk every time; you have to make milk, milk, milk. It's going to cost me a lot; it's only two months left now for this thing (Nontsasa, mother).

Introducing solid foods ensured that less milk would be consumed and free milk could be stockpiled. Also as babies drank more as they grew, the free formula would sometimes not be enough. At five months, Nosisi re-introduced solid foods to her daughter when the free formula

ran out before her collection date despite having stopped feeding solid foods the previous month because her infant developed breathing problems. Concerns about resources also directly influenced the keeping of leftover milk in order to save the free formula powder. As Thozama explained, “when I see that they [the tins of milk] are getting finished, then I said “no I am not going to throw it away””.

Poverty also affected access to resources which influences hygienic preparation of formula. Infants with fewer bottles often only had their bottles cleaned once or twice a day (requiring four to eight bottles for hygienic feeding). They were also fed larger bottles that would last for more than one feed, thus exposing the infant to unhygienic leftover milk. As Neziswa explained, “It’s difficult to maintain one bottle”. In addition to bottles, having money to purchase a flask improved bottle safety by ensuring a ready supply of warm boiled water.

A lack of resources also had a profound impact on the continuous availability of formula after six months. Formula for one month cost between R400 and R550, depending on the brand used. Nontsasa relied on the baby’s paternal aunts to steal milk for her son, leading to both an erratic supply and constant switching of brands, which in turn, led to diarrhoea.

Availability of money was not always predictable. For 7 of the 10 infants, those supporting them financially had periods of sudden and unexpected unemployment. This was often due to the insecurity of the work they did, but also due to illness and unlawful behaviour¹⁴. Drug and alcohol use had a further impact on the availability of money. Nontsasa and her boyfriend both used drugs which compounded their material deprivation. Available money would sometimes be taken to buy drugs, even when the baby did not have milk. In addition, drug use interfered with her boyfriend’s ability to hold onto a job.

Sensitivity to infant needs. Caregivers who were able to anticipate when a baby would wake up and need to be fed were more likely to prepare a bottle in anticipation, or prepare a clean bottle and hot water for ease of quick hygienic preparation. As Thozama explained, when she did not manage to do this and the baby woke up crying, she was liable to give him a leftover bottle.

Conflict and violence as well as substance abuse within the home reduced sensitivity to infant needs. On a number of occasions we found Nontsasa and her boyfriend in the aftermath of

¹⁴ One father, a taxi driver, had an accident and abandoned his taxi at the scene. Another father was involved in a fight in which the other man was killed and he ran away to avoid the police.

violent confrontation. On these occasions both parents seemed completely unaware of infant cues for comfort and food, and when their attention was drawn to the needs of the child, responses were hurried, emphasising convenience rather than safety. Kholeka, who also had a problem with drinking would seldom wash bottles properly and would sometimes pass out without having fed her infant leaving others, who did not always know how to prepare bottles properly, to take responsibility for care.

Discussion

A Complex Interplay of Factors

Feeding decisions and practices were produced by a complex interplay of changeable and unpredictable factors. For example, Thandeka's mixed feeding occurred despite knowledge and a supportive and engaged partner. In the face of her social, emotional and cultural positioning vis-à-vis her mother, her variable use of strategic resistance functioned according to the strength of beliefs, her fear of disclosure, her own ill health, and ability to rationalise choices. The early introduction of liquids, medicines and foods as well as the unsafe preparation of bottles and erratic milk supply for Nontsasa's baby must be understood in terms of poverty, a distressed care environment, household structure and the cultural hierarchy within it, and Nontsasa's own coping style.

A wider range of factors than those proposed by existing theories are therefore involved in determining feeding practices. Individual attitudes and beliefs are important, but whose beliefs are important are determined not only by co-residence and cultural beliefs regarding roles in child care (Buskens et al., 2007; Doherty et al., 2006; Thairu et al., 2005; Varga & Brookes, 2008), but by the desire to maintain relationships that are culturally, socially or emotionally important to the mother or her infant regardless of co-residence.

Many of the beliefs found to be important such as those about the adequacy of formula milk, health risks associated with formula- and breast milk, infant feeding cues and meaning of infant behaviour, support previous findings. However, additional beliefs were also identified. In particular, beliefs about solid foods as non-foods, and ideas that a healthy baby is a well-fed baby encouraged early introduction of foods and prevented caregivers from linking infant health problems to feeding practices.

While fear of disclosure was an obstacle to adherence in some cases as found in previous research (Doherty et al., 2006; HST, 2007), disclosure operated in complex ways, suggesting that

psychological resources rather than disclosure *per se* may be at work. Women's cognitive, creative and psychological resources could mitigate the impact of non-disclosure or unwillingness to discuss HIV. Conversely, women with avoidant coping styles were found to retain less information, and be less able to draw on creative strategies. Both creative and strategic practices (Brandt, Dawes, & Bray, 2006) and avoidance (Dageid & Duckert, 2008) have been found among South African women coping with HIV and poverty.

Care environments distressed by poverty, substance abuse and violence posed the greatest threat to safe infant feeding. Poverty requires the involvement of others in infant care and the demands placed on women make the constant vigilance required to ensure exclusive feeding for a full six months almost impossible. Substance abuse and domestic violence lead to less sensitive caregiving and more hurried responses to infant feeding cues. Although this study did not measure levels of depression, research also links decreased sensitivity to maternal depression (Cooper et al., 2009). Mothers in distressed circumstances who also had avoidant coping styles were less likely to retain information, develop creative strategies to support adherence or care for their own health adequately, all of which further compromised adherence. Substance abuse may itself be a form of avoidant coping (Petraitis, Flay, & Miller, 1995) and both substance abuse and the use of avoidant coping strategies have been linked to poor ARV treatment adherence amongst HIV-positive people (Hinkin et al., 2004; Power et al., 2003; Weaver et al., 2005). Furthermore, the unpredictability of both the external environment and women's emotional reactions in these circumstances meant anticipating pressures or the ability to cope was difficult. Indeed, non-anticipation may be psychologically adaptive (Dageid & Duckert, 2008). Rationalising non-adherence as a way of living with the reality of unsafe feeding in difficult circumstances was also evident. Similar tactics have been demonstrated in other studies (Murphy, 2000).

Implications for PMTCT Programming

The AFASS criteria focus on disclosure, employment in the household, electricity and piped water is clearly inadequate for assessing the appropriateness of feeding choices as many more factors are involved. In addition, assessing for factors undermining safe breastfeeding may be required. Supportive infant feeding counselling needs to recognise the range of factors that may come into play over time and to explore their dynamic interaction with clients rather than simply assessing women against criteria.

Given the centrality of concern about possible transmission of HIV to mothers' feeding choices and practices, improved counselling around the health risks of early introduction of solid foods and explicit linking of health outcomes to feeding practices may improve adherence to these aspects of the policy. However, these changes need to be accompanied by recognition of the challenges of managing a distressed baby, and the utility of using food to do so. Practical alternatives need to be offered.

Even in the context new, simpler feeding protocols, which recognise the difficulty of maintaining any exclusive feeding protocol and suggest breastfeeding with ARV treatment; poverty, substance abuse and violence are likely to pose significant risks to infant HIV-free survival. The two participants most affected by these factors in this study, Nontsasa and Kholeka, both failed to care adequately for their own health, failing to access or adhere to ARV treatment, even with clinic intervention. Non-adherence to ARVs would mean a high risk for HIV transmission and mortality. Furthermore, this research suggests that even a small risk may be too big for many mothers to take. Other research, similarly found the possibility of transmitting the virus to one's child meant many mothers equated breastfeeding with 'bad mothering' (Long, 2009). Even in the absence of free formula milk, women may try to avoid breastfeeding, hoping, as the women in this study did that they would find a way to buy formula. Such practices would pose a great threat to safe feeding practices and thus to infant health and survival.

Conclusion

The debate about which feeding choices should be made or advised is only part of ensuring HIV-free infant survival because adherence is not simply about making the right 'choice'. Infant feeding is not a discreet activity involving mother and infant. Rather it is a practice embedded in the everyday dynamics and functioning of households and families, making it a difficult practice to modify. Important social, cultural and emotional ties; beliefs about food and infant behaviour; infant health; maternal health; maternal psychological resources; household structure and cultural hierarchy; poverty; substance abuse; violence; and caregiving sensitivity all interact to affect adherence to exclusivity and safety in feeding practices. The role of these factors in determining adherence to new feeding guidelines needs to be investigated in future research in order to ensure that infant HIV-free survival is not compromised in new ways.

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Appendix A

Acceptable:

The mother perceives no barrier to choosing and executing the option for cultural or social reasons, or for fear of stigma and discrimination.

Feasible:

The mother (or family) has adequate time, knowledge, skills and other resources to prepare and feed the infant, and the support to cope with family, community and social pressures.

Affordable:

The mother and family, with available community and/or health system support, can pay for the purchase/production, preparation and use of the feeding option, including all ingredients, fuel and clean water and equipment, without compromising the health and nutrition spending of the family.

Sustainable:

Availability of a continuous and uninterrupted supply and dependable system of distribution for all ingredients and commodities needed to safely implement the feeding option, for as long as the infant needs it.

Safe:

Formula milk would be correctly and hygienically prepared by clean hands, using clean, safe water and clean utensils. Nutritionally adequate quantities of formula milk would regularly be available. Clean water and fuel would be regularly available. Formula milk would be fed using clean hands and utensils, and preferably with cups rather than bottles.

Figure A1. Operationalising the AFASS Criteria

From *Policy and guidelines for the implementation of the PMTCT programme* (p. 48), by. Department of Health, 2008, Pretoria, South Africa: Department of Health.

Appendix B
English Consent Form for HIV-positive Mothers

Infants and HIV/AIDS in South Africa: The Fragility of Life

Children's Institute, University of Cape Town

Consent to participate in the study

You indicated an interest in working with us on this study. The study is described in more detail below.

Purpose of the research study

The purpose of the study is to learn about the first year of a child's life so that we can understand what influences (impacts on) the health and well-being of the HIV positive mother and her child. The aim is to learn how to best support mothers and infants when ill-health is already an issue.

Procedures

If you agree to talk to us, we want to talk to you about your life and your family. We would also like to accompany you during the day, and watch what happens each day, including visits and errands. We would like to meet with you individually and as a family (with the adult members), for several hours each week. Every two months we will assess your health and your baby's health. The length of the study will be 18 months.

Confidentiality

Information you give us or that we write down about you will be kept confidential by us, the researchers, including all information about your and your baby's health status. Any records that show your name are only for us.

In our notes and future writing, we will change your and your family's names. I will use a code to do this. We will keep all our written notes in a private, locked space.

Should we however identify that a child has been physically or sexually abused or deliberately neglected we are required by law (Children's Amendment Act) to let a social worker know about it.

The study will be described to anybody else, including those in your community as one to do with the well-being of mothers and infants.

Risks/Discomforts

I do not anticipate that you will experience any further risks or problems, in particular to do with your health, during our time together. If we talk about something that makes you uncomfortable, please let us know and we won't ask you again.

Benefits

We intend that the study will give you support and help your baby through paying careful attention to his or her development and through regular observation of both of your health. The study may also benefit others by helping to understand how best to support the well-being of mothers and their infants.

Voluntary participation and right to withdraw

Your participation is voluntary: you choose if you want to participate. If you would like, please take some time to think about whether you want to participate. If you decide to participate now, you can decide at any time to change your mind. If you decide to stop participating, please let us know as soon as you can.

Compensation

You will not receive any payment or other compensation for participating in this study.

If you have questions or concerns

You or your family can ask us questions about this research study now or at any time during the study. We can be contacted at the Children's Institute on (021) 689 5404.

Check if participant gives oral consent

Signature of participant

Date

Signature of Person Obtaining Consent

Date

Xhosa Consent Form for HIV-positive Mothers

Infants and HIV/AIDS in South Africa: The Fragility of Life

Children's Institute, University of Cape Town

Imvume yokuthatha inxaxheba koluphando

Uyewabonakalisa umdla wokusebenzisana nathi koluphando. Uphando lucacisiwe ngencukacha apha ngasezantsi.

Injongo yoluphando

Injongo yoluphando kukufunda malunga nonyaka wokuqala wobomi bomntana ukuze sizokwazi ukuba yintoni unobangela (izizathu zalo) impilo nokuziphatha kuka mama kunye nosana lwakhe. Injongo kukufunda ukuba loluphi uhlobo lokunika inxaso kumama kunye nosana lwakhe.

linqubo

Oyena ngqwalase yolu phando ngumama kunye nasana lwakhe, kungenjalo sizakuthanda ukuchitha ixesha kunye namanye amalungu osapho. Ukuba uyavuma ukuthetha nathi, singathanda ukuthetha nawe malunga nobomi bakho kunye nobo sapho lwakho. emini, Singathanda ukudibana nawe uwedwa kwaye nosapho lwakho (nelungu losapho oludala). Ubude bophando buzakuba ziinyanga ezi-18.

Imfihlelo

Incukacha osinika yona okanye esiyibhala phantsi ngawe izakugcinwa iyimfihlelo kuthi, abaphandi. Naziphina iincwadi ezibonakalisa igama lakho zezethu kuphela.

Kwizibhalo nakwi mbalelwano ezizayo zethu, sizakutshintsha wena namagama osapho lwakho. Ndizakusebenzisa uphawu ukwenza oku. Sizakuzigcina zonke imbalelwano zethu bucala, kwigumbi elivalelwayo.

Ukuba sithe saphawula ukuba umntana uthe wahlukunyezwa ngokwasemzimbeni okanye kokwasencantsini okanye akaphathekanga kakuhle sigunyazisiwe ngumthetho we (Children's Amendment Act) ukuze sazise unontlantonle ngale meko.

Uphando luzakucaciselwa nakubanina, kuquka nabo basekuhlaleni abanento yokwenza ngempilo yomama kunye nentsana.

Isichenge / nokungakhululeki

Andiqondi nakanye ngamava ukuba ungasesichengeni okanye egxakini, ngexesha lethu sikunye. Ukuba sithe sathethe into ezakwenza uzive ungakhululekanga, nceda usazise kwaye asizophinda sikubuze.

Inzuzo

Sinethemba lokuba uphando luzakunika ingxaso kunye noncedo kumama kunye nosana lwakhe ngokuthi luqwalasele ngokukhathaleleyo ukhulo nasekuqwalaseni rhoqo kwempiilo zenu. Uphando lungayinzuzo nakwabanye ngokuthi luncende ulwazi lokuxhasa iimpilo zomama kunye namasana wabo.

Ukuthatha inxaxheba ngokuzithandela ne lungelo lokurhoxa

Ukuthatha kwakho inxaxheba kukuzithandela: uyazikhethela ukuba ufuna ukuthatha inxaxheba. Ukuba uyafuna, nceda thatha ixesha lokuyicinga ukuba uyafuna na ukuthatha inxaxheba. Ukuba utha wanesigqibo sokuthatha inxaxheba ngoku, ungabanesigqibo nangeliphi ixesha lokutshintsha inqondo yakho. Ukuba uye wanesigqibo sokurhoxa ekuthatheni inxaxheba, nceda usazise ngokukhawulezileyo.

Imbuyekezo

Akukho ntlawulo onokuthi uyifumana okanye mbuyekezo ngoku thatha kwakho inxaxheba kulo phando.

Ukuba unemibuzo okanye uxhalabile

Wena okanye ilungu losapho lwakho ningasibuza imibuzo malunga noluphando ngoku okanye nangaliphina ixesha lophando. Sifumaneka eChildren's Institute kule nombolo (021) 6895404

Nceda uqaphela ukuba umthathi-nxaxheba unikeze isivumelwano ngokuthetha

Signature of participant

Date

Signature of Person Obtaining Consent

Date

Appendix C

Consent Form for Adult Household Participants

Infants in South Africa: The Fragility of Life

Children's Institute, University of Cape Town

Consent to participate in the study

Your family member has indicated an interest in working with us on this study. We would like you to consider participating. The study is described in more detail below.

Purpose of the research study

The purpose of the study is to learn about the first year of a child's life so that we can understand what influences (impacts on) the health and well-being of the mother and her child. The aim is to learn how to best support mothers and infants.

Procedures

The main focus of this study is the mother and her infant, however we would also like to spend time with other family members. If you agree to talk to us, we want to talk to you about your life and your family. We would like to meet with you individually and as a family (with the adult members). The length of the study will be 18 months.

Confidentiality

Information you give us or that we write down about you will be kept confidential by us, the researchers. Any records that show your name are only for us.

In our notes and future writing, we will change your and your family's names. I will use a code to do this. We will keep all our written notes in a private, locked space.

Should we however identify that a child has been physically or sexually abused or deliberately neglected we are required by law (Children's Amendment Act) to let a social worker know about it.

Risks/Discomforts

I do not anticipate that you will experience any risks or problems during our time together. If we talk about something that makes you uncomfortable, please let us know and we won't ask you again.

Benefits

We intend that the study will give support to the mother and baby through paying careful attention to his or her development and through regular observation of both of their health. The study may also benefit others by helping to understand how best to support the well-being of mothers and their infants.

Voluntary participation and right to withdraw

Your participation is voluntary: you choose if you want to participate. If you would like, please take some time to think about whether you want to participate. If you decide to participate now, you can decide at any time to change your mind. If you decide to stop participating, please let us know as soon as you can.

Compensation

You will not receive any payment or other compensation for participating in this study.

If you have questions or concerns

You or other members of your family can ask us questions about this research study now or at any time during the study. We can be contacted at the Children's Institute on (021) 689 5404.

Check if participant gives oral consent

Signature of participant

Date

Signature of Person Obtaining Consent

Date

Appendix D

Clinic Observation Guidelines

Checklist of things to find out/take note of in relation to the woman's visit to the clinic:

1. What time did the woman arrive at the clinic?
2. What was the process on arrival?
 - E.g. did they collect their folder, from whom, how were they treated etc
3. How long did she wait to be seen?
4. What happened while she was waiting?
 - I.e. where did she wait, what did she do, did any clinic staff interact with her and if so take note of the interaction?
 - What were the other women who were waiting do?
 - Take note of general conversation
5. Who was she seen by?
6. What was the purpose of the appointment?
7. How does the woman feel when she comes out from her appointment
 - Also note here non-verbal signs e.g. facial expressions, body language
8. What did the attending medical practitioner do during this appointment?
 - E.g. examinations, tests, questions asked, information given
9. Is the women confused or unclear about anything that happened in the consultation or any information she was given?
10. Did she ask the medical practitioner any questions?
11. Did she have to collect any medication? If so, what?
 - Also take note of the experience e.g. how long they had to wait, how they were treated by the pharmacist etc
12. Was the woman seen by a PMTCT counsellor?
 - If yes, what was the content and quality of this session?
 - NB to try and attend this session if the woman is happy.
13. Did the woman go to see M2M? (If not, ask why)
14. What happened in M2M?
 - Note any information given, what the conversation was about, who was there
 - NB to try and attend this session if the woman is happy.

Checklist of general things to be alert to when at clinic visits

1. How busy is the clinic
 - Note this over the time that you are there i.e. how busy is it when you arrive, and how busy when you leave
2. How many staff are working, especially:
 - Counsellors
 - Nurses attending to ANC visits
3. Be generally aware of how the clinic staff interact with and treat the women
4. Be generally aware of what women in the waiting room are talking about, in particular conversations about pregnancy, birth, motherhood, illness, HIV – try and remember what words they use to speak about these things.

Appendix E

Systematic Observations Guidelines

Spot observations

On first arriving in a home or at a particular scene, note what everyone is doing (first, of course, the Mother and infant) and everything you think is relevant to the scene.

24 hour recall

Interview the Mother (or Caretaker of Significant other if the Mother is not available) on what she has done over the previous 24 hours i.e. since the same time on the day before up until the moment you have just recorded for the Instant Observation. Note the times she gives you and prompt a bit if she says, for example, “I bought soap at the shop” you may like to ask, “What else did you buy?” (We have gone over this in detail and done exercises around it. Please ask if there are things that are not yet clear to you.)

30 minute observation

Observe everything that happens for half an hour. Mark the time every five minutes in a column to the left of you note book page and note what you see and hear. The focus is on the mother and infant so not everything can be captured in your notes.

Here is a list of the things to be aware of as you observe. It is not a checklist but a reminder of what is important to us:

- Food – especially for the infant but also for the mother and so the family if she eats with them or works on their meals –
 - Preparation
 - Storage
 - Cooking
 - Serving
 - Cleaning
 - Who returns home with food items

Similar notes could be placed beside each of the following words:

- Money
- Mood or atmosphere
- Relationships
- Language use
- Play/ songs/ laughter
- Baby’s wakefulness – how alert he/she seems
- Physical movement
- Shopping/ errands/messages
- Activities outside the home

- Baby supplies
- Discipline/ tears

Special notice must be made of:

- sanitation – habits, patterns, regularity – for baby, self, house
- play with baby – times, sort of play e.g. rough or gentle, who is playing, what is done or sung etc.
- language to and from the baby – words, sounds, special noises, imitation – all interchanges between mother and infant and between infant and other
- health of mother and infant – all signs, comments etc. including knowledge of illness and who asks about it from whom

Appendix F

Interview Topic Guide for Mothers

Introduction

1. Remind the participant about confidentiality and that they should feel free to speak openly. Encourage them to speak in isiXhosa
2. Remind them that if they are not comfortable answering something, they must just say so.
3. Always inform the participant of what the particular interview is about.
4. Check that it is ok to use recording equipment and explain the purpose of doing so.

Your pregnancy so far

1. Can you tell me the story of your pregnancy so far?
 - Tell me about when you first discovered that you were pregnant. What happened? How did you feel? What was your reaction? Who did you tell? Their reaction.
 - Tell me about when you told the father of the baby?
2. How does this pregnancy compare to other times when you were pregnant?
3. What have you enjoyed about this pregnancy so far?
4. What challenges have you faced in this pregnancy so far?
5. Pregnancy health circle diagram
 - What illnesses have you had
 - Who treated you
 - What medicines
6. What do you believe a pregnant woman must do in order to look after herself and her baby while she is pregnant? Any rituals that must be performed?
 - Have you been able to do these things?
7. Which other people have played an important role during your pregnancy?
 - Father?
 - Family?
 - Friends?
8. During this pregnancy who have you been going to for advice? What advice have they given you?
9. How do you feel about becoming a mother? (If applicable, do you feel differently this time around?) Does your illness play a role in these feelings?

Care received from the health services

1. What do you think about the care you have received from the Gugulethu MOU?
 - Counsellors
 - Nurses
 - Doctors
2. Is there anything you would change about the care you've received if you could?
3. Can you tell me why you decided to book at the MOU when you did? I.e. why not earlier or later?
4. Can you tell me about that first visit? What happened during that first visit
 - Nature, content and quality of HIV counselling (pre- and post-test)

- Information received re pregnancy, HIV, PMTCT, infant feeding; and from whom
- 5. Have you been for more MOU visits?
 - Can you tell what happened at those visits?
 - Did you get more information re pregnancy, HIV, PMTCT, infant feeding; and from whom?
 - Did you see a counsellor again?
- 6. Can you tell me about the first visit to mothers-to-mothers?
 - What did you talk about?
 - What information did they give you about pregnancy, HIV, PMTCT, infant feeding
 - How did you feel about the visit?
- 7. Have you been back to M2M? Why?
- 8. Are you unclear or confused about any of the information you have received from the clinic/M2M?
- 9. Is there anything that you are worried about at the moment in relation to your pregnancy?

Plans and preparations for the baby

1. What preparations are being made for the arrival of the baby?
 - For the labour and delivery
 - For welcoming the baby home
 - Who is doing what?
 - Role of the father, his family, your family? Others?
2. How are you planning to get to the clinic? Will you go alone or will someone accompany you?
3. How will you get home from the clinic? Will someone fetch you or will you be alone?
4. How are you planning on feeding the baby? Why did you decide on this strategy?
5. What do you understand about what a baby needs in terms of food/nutrition over the first year. E.g. when to introduce solid food like porridge etc.
6. In your view, what makes a baby vulnerable? What must you do to protect a baby?
7. Are there any rituals that you have planned for the baby
 - Before birth?
 - After it arrives?
 - During the first year?
8. Traditionally are there any beliefs, rituals related to child birth and babies that you know of? Are you planning on following these? Explain.
9. Whose responsibility is it to name the baby?
 - Do you have a role in this process?
10. What does the naming of a child mean to you?
11. How are you feeling about your baby's arrival?
 - Do you have any fears? (for the birth or for your child more generally)
 - What are your hopes, dreams and desires for your child?

Family roles in raising a child

1. In your view, what are the features of a good mother?
2. What do you consider as a good family environment to raise a baby?
 - What role would a good mother play?

- What role would a good father play?
 - Who else would be involved in providing a good family environment?
 - What role would your family play?
 - What role would the father's family play?
3. How possible is it to provide this environment?
- What are the challenges?

HIV and understandings of PMTCT

1. Tell me about your experience of discovering your status?
 - When was it?
 - Why did you decide to test?
 - What was it like for you?
 - How did you react, feel?
2. How do feel now about your status?
3. Have you disclosed to anyone?
 - Can you tell me about each disclosure (when, why, what happened etc)
4. How do you feel about being HIV+ and pregnant?
5. Who supports you in all of this? How?
6. What do you understand about how to prevent your baby from getting HIV?
 - Do you think you will be able to do these things?
 - Who will support you?

Labour and delivery and PMTCT

1. Tell me the experience of your labour and delivery
 - At home
 - What is your understanding of when labour begins?
 - At KTC/Mowbray?
2. How do you feel about this experience and the care you received? Would you change anything if you could? (Probe specifically about nurses, counsellors, doctors).
3. Were you given any information about how to prevent the transmission of HIV to your baby? Would you change anything about how this information was given to you (e.g. timing/confidentiality/depth of explanation/who gave the information)?
4. How did you get to and from the clinic/hospital? Did anyone accompany you? Who? Why them?
5. Did you have any visitors at the clinic/hospital?
6. Now that you have been through this process, what is your understanding about how to prevent transmission of HIV to a baby if you are HIV+?
 - Where did you learn this?
 - Would you change anything about how you were given this info (e.g. timing/who gave it to you/confidentiality/depth of explanation and info given etc)
7. Did the clinic ever give you the drugs for preventing HIV transmission to the baby?
 - When did you start taking them?
 - How were you taking them (should be morning and evening e.g. 8am and 8pm)?
 - Did you ever miss a pill?
 - Did you have any difficulties in taking the medication e.g. questions from family members; trouble remembering etc?

8. Did the clinic give you NVP when you were in labour and did they give the baby NVP after birth?
9. Were you given AZT for the baby (the drops you give with a syringe to the baby to prevent HIV transmission)?
 - How did they explain you must administer this (how much, how long for)?
 - Did they explain to you what it was for?
 - How long did you give it to the baby?
 - Was it difficult/any challenges?

Bringing the baby home

1. How did you welcome the baby home?
2. What is the baby's name?
3. What does it mean?
4. Is the meaning of the name important to you? Why this name for this baby?
5. Who chose the name? Why did they choose?
6. Does the baby have any other names? Who chose these?
7. What name is on the birth certificate? Why?
8. Tell me about registering the baby's birth?
9. Tell me about registering for the CSG?
10. Have you done anything to introduce the baby to the ancestors?
11. What was done with the baby's umbilical cord?

Infant care and development

1. Tell me about these first few months of being a mother to this baby?
2. What do you believe is the correct way to raise a baby? (E.g. what kind of attention, care etc does a baby need?).
3. What is involved in caring for a baby?
4. How can you tell what a baby needs?
 - How do you know that a baby is hungry for milk or needs water, or needs to be changed, comforted etc?
5. What do you believe is the right way to respond to a baby crying?
6. What do you understand about how a baby learns to do things (e.g. sit, crawl, talk, walk etc)? Are there things that you can do to help a baby develop/learn, or does it just happen?
7. Is playing with a baby important? Why? How would you play with a baby?
8. Do you think it is important to discipline/restrict attention given to a baby? Explain why and how this would be done.
9. What do you think are the signs of a healthy baby? The signs that a baby is growing and developing well?
10. Since the birth, what have you had to buy for the baby? Who decides what he needs? Who pays for it? Who goes to buy it?
11. Who is doing what?
 - Feeding
 - Did anyone speak to you about feeding (apart from M2M after you gave birth)?

- Cleaning bottles
 - Preparing bottles
 - Actually feeding
 - Any pressure to breastfeed/questions about why not breastfeeding?
 - Have you breastfed?
- Bathing
- Playing
- 12. What are the challenges you face in raising a baby here?
- 13. Who do you think should be involved in caring for this baby?
 - If fathers are not mentioned, ask:
 - Do you think the father has a role to play in caring for your baby? What role? Why?
 - Does the father play this role? If not, why and with what impact for the baby?
 - Is there anything you do or could do to encourage this?
- 14. Who makes decisions about this baby and the care they receive?
- 15. Are you raising this baby differently to how you were raised? How? Why?
 - Probes: Are there changes in feeding practices/use of traditional and other medications/traditional work?
- 16. Baby health circle
 - Probing for any illnesses (mention common illnesses such as diarrhoea, rash, colic, fever); what treatment was sought if any (clinic/doctor/tradition/self-medication from chemist); whose idea the treatment was.
 - Probe for use of traditional healers/medications for protection etc
 - Probing for feeding practices, when formula amounts increased, new foods introduced, and use of water. In all cases probe whose idea the change was.

Current health care (for mother and baby)

1. Clinic visits
 - What is the service/care like at the baby clinic?
 - Anything you would change?
 - Has anyone spoken to you about what you need to do to prevent HIV transmission to the baby? Do they give you any advice or information when you collect the milk?
2. Baby test results
 - What was it like for you waiting for the baby's test results?
 - What does it mean to you knowing that your baby is negative?
 - What would it have meant if your baby was positive?
3. Is your HIV being managed by anyone (i.e. CD 4 count tests etc)?

Family planning and contraception

1. Do you want to have more children? Why?
2. Have you spoken to your partner about having more children?
3. Are you taking anything to prevent pregnancy? Why? Who decided?
4. Does HIV play a role at all in your decisions in this regard?
5. Are you using condoms? (Probe around challenges in this regard).