

**An exploration of emerging problems for infant
feeding options - some obstacles for the rapid
expansion of the HIV mother-to-child transmission
prevention programme - The KwaZulu-Natal
experience.**

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Declaration of originality

I hereby declare that this dissertation, unless specifically indicated to the contrary in the text, is my own work.

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List of Acronyms

AIDS.	- Acquired Immunodeficiency Syndrome.
ANC.	- AnteNatal Clinic.
AZT.	- Zidovudine.
CD4.	-HIV receptor molecule on T-lymphocytes.
COSH.	- Church of Scotland Hospital.
DALY.	- Disability-adjusted Life Years.
G.	-Grey's Hospital antenatal clinic.
HIV.	- Human Immunodeficiency Virus.
KM.	- KwaMashu antenatal clinic.
KZN.	- KwaZulu-Natal province.
MEC.	- Member of the Executive Council.
MTCT.	- Mother To Child Transmission.
PCR.	- Polymerase Chain Reaction.
STD.	- Sexually Transmitted Disease.
STI.	- Sexually Transmitted Infection.
TB.	-Tuberculosis.
VCT.	- Voluntary Counseling and Testing.

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Chapter One

Introduction

“I was never told anything about HIV and breast-feeding. I breast-fed my baby for 11 months. If I knew anything, I would not have fed my baby poison and maybe my baby would have lived for a longer time. I feel sorry for myself for the time I wasted breastfeeding. I thought I was breastfeeding, but I was breast-poisoning”.

“I had bottle-fed him since he was born – until another nurse forced me to breastfeed him...” (Seidel et al 2000:27)

These alarming experiences were quoted from Seidel et al (2000) during a qualitative investigation at the King Edward VIII hospital in KwaZulu-Natal. Mothers neither knew their HIV status before giving birth, nor were they given any information on how best to feed their babies if they suspected that they were HIV positive, illustrating the extent of the problems surrounding meaningful informed consent and the need for information to counter stigma in the community.

Furthermore, studies in the Cape Province undertaken by Jewkes et al (1998:1785) revealed how young mothers were neglected and abused by hospital and clinic staff leading to disempowerment through fear and the lack of sufficient information to enable them to make informed choices regarding their health.

Many mothers according to Seidel’s (2000:24-33) study only became aware of their HIV status and the dangers of mother-to-child transmission (MTCT) through breast milk once they had delivered and had been feeding their children for some time. In another study (Seidel 2000:510) advice regarding HIV and breast-feeding to one Zulu

speaking patient was recorded as, “we expect you to breast-feed...” “We also say of HIV positive mother that she can pass this on...” “Do you know about that? Do you know about AIDS?”

Seidel claims that the consequent stigma within the maternity ward, created by nurses and other mothers, increases their vulnerability and forces them to hide their HIV positive status from the other patients. In the ward, one woman surreptitiously bottle-fed her baby by adopting the posture of breast-feeding under the blankets (Seidel 2000:27). Further investigation revealed that many women faced domestic abuse from other family members once they returned home if they opted to bottle-feed their baby. Cosminsky et al (1993:942) found that in certain rural communities in Zimbabwe acceptance of a mother’s breast is regarded as proof of legitimacy on the part of the child.

Globally, people living with HIV at the end of the year 2000 was estimated to be 36.1 million with sub-Saharan Africa making up 25.3 million of that total, representing an alarming 70 percent of the world burden (Allen et al 2000:9). According to UNAIDS/WHO (2001:16) AIDS caused an estimated 2.3 million deaths on the African continent in the year 2001. In addition to this there was a predicted 3.4 million new infections in the past year. Grimwood et al (2000:289) projected, “By the year 2005 the total number estimated to be HIV positive in South Africa will be 6 million”.

Whiteside and Sunter (2000:46) identified three stages in the AIDS epidemic, the nascent phase, the concentrated epidemic and the generalised epidemic. The HIV/AIDS epidemic in Africa is part of the global pandemic and is characterised by being a collection of epidemics each with characteristics of its own. The spread of HIV is influenced by many factors both biological and social. The causative virus itself is characterised by being a collection of types and subtypes and these important differences will cause more rapid spread of the epidemic in eastern and southern Africa where HIV-1 is endemic than in western Africa where the less aggressive HIV-2 is endemic. Similarly within a specific area or region the incidence (newly infected)

will vary with sex and age, as women are more easily infected than men and younger people at greater risk than older (Smith. 2002 personal communication).

Adar & Stevens (2000:411) stated that in South Africa, more than half of the 4.2 million HIV infected persons are women. Women of the age group 20-29 had the highest prevalence of HIV infection in 1999. In addition there are an estimated 2.3 million women and 95 000 children (0-14) living with HIV/AIDS in South Africa. A sexually transmitted infections (STI) clinic in Durban reported an HIV prevalence of almost 58.6 percent in young women less than 25 years in 1999 (Appendix 1). UNAIDS/WHO 2002 stated that in that same year 11 million STI episodes were reported. According to the HIV/AIDS South African Human Development Report (1998:24).

“The spread of HIV and AIDS in South Africa is fuelled by the apartheid legacy of the migrant labour system, the accompanying spread of sexually transmitted diseases and the subordinate status of women.”

Barnett and Whiteside (2002:153), identifies migration as an important factor contributing to multiple sexual partners that is conducive to the spread of STI's. This, in turn, may be linked to the rapid spread of HIV. Furthermore inequality and discriminatory government policies led to the disintegration of family structures as breadwinners moved to urban areas in search of employment. Hostel dwellings, informal settlements and commercial sex, according to Barnett and Whiteside (2002), partly facilitated the rapid spread of HIV in southern Africa. Women and families, left behind by men who went in search of employment, were often forced to sell sex for food and basic needs according to Evian (2000:21).

The HIV epidemic “threatens to reverse progress in human development and the promotion of a representative and participatory democracy” (HIV/AIDS SAHDR 1998:7). Projections suggested in the report estimates that HIV and its progression to the Acquired Immune Deficiency Syndrome (AIDS) will reach almost 25 percent of

the population by 2010 and life expectancy is anticipated to fall from 68.2 to 48 years. The number of orphans is also expected to increase by the year 2010 to 750,000 (HIV/AIDS SAHDR 1998:9) this will impact directly on human and social capital.

An unborn child of an HIV positive woman stands an estimated one-third chance of becoming infected by its mother. Lallerman 1992 cited in Loewenson & Whiteside (1997:6) explains that this may occur prior to birth, across the placenta, during birth or via breast-milk. Breast-feeding accounts for approximately 15 percent of the transmission from mother to child. Child mortality rates are set to increase from 48.5 to almost 100 per 100 000 live births by 2010 according to the HIV/AIDS SAHDR (1998: 9).

Statement of the problem

Women have a greater biological vulnerability to HIV. UNAIDS (1997:3) states that a woman faces a 2-4 times higher risk than a man of becoming infected by the virus. The larger mucosal surface area exposed during intercourse, and the high concentration of virus in the semen, as compared to that in a woman's secretions allows for a higher risk of absorption and incubation through the thin vaginal and cervical lining. Socio-economic vulnerability is an additional problem. This is exacerbated by the lack of economic resources, fear of abandonment and domestic violence (UNAIDS 1997:3).

The risk of MTCT of HIV, a further problem faced by women, can be therapeutically reduced. Connor et al (1994) conducted a randomised, placebo controlled blinded trial to ascertain the safety and efficacy of a short-course treatment with Zidovudine (AZT). It was concluded in this study that there was a two-thirds reduction in maternal transmission. Much more confounding though is the problem of after-birth care and the empowerment of women to minimise further re-infection by HIV. Baggaley and van Praag (2000:1039) emphasise issues such as post-natal care, compliance and tolerance of antiviral treatment and alternative infant feeding options.

The most vulnerable time of transmission for the neonate is at delivery due to exposure to infectious maternal cervical and vaginal secretions, (Luo 2000:144) resulting in some 600,000 children being at risk of MTCT each year. Ninety percent of these children are of sub-Saharan African origin. The term used for this infection is vertical transmission, as opposed to horizontal transmission where the virus is transmitted sexually, or through the exchange of blood or blood products.

In the early 1990's medical researchers investigated 44 HIV positive pregnant women to assess the risk of HIV placental crossover from mother to child. Results, according to Ehrnst et al (1991:203), confirmed that HIV was not isolated from any of the subsequent live births. Another early researcher made reference to the mode of transmission by placental barrier crossover and the mechanism by which transfer of the virus takes place in utero as a "mystery" (Zachar and Norskov-Lauritsen 1991:1253).

Gray et al (2001:15-26) argue that strong evidence supporting MTCT is positively linked to maternal viral load, maternal CD4 count, mode of delivery, premature rupture of membranes and breast-feeding.

A European collaborative study conducted by Giaquinto et al (1992:1007-12) in 19 European centres where babies born to HIV positive mothers were monitored for risk factors for MTCT. The results concluded that transmission was higher in vaginal deliveries and this risk was increased by the use of delivery aids. Some of the other explanations given in the findings by the researchers, for the high frequency of children born before 34 weeks gestation were the presence of HIV in utero which could affect the development of the foetus and promote prematurity and where there was an advanced state of AIDS in the mother. Other significant risks were infections in the genital tract, which could be due to STI's.

Peacock (1988:1039) and colleagues early in the pandemic suggested that breast-feeding was another possible mode of HIV transmission of HIV. More recently Miotti et al (1999:749) showed in a Malawian study that "HIV transmission risk due to

breast-feeding was highest in the early months of life but remained substantial for as long as an infant continued to be breastfed". Discouraging breast-feeding was not an option in developing countries in 1990 as unsafe water posed an equally dangerous health hazard. (Pizzo 1990 :316-24).

In South Africa, to ensure that the MTCT intervention programme operates efficiently, the many problems identified elsewhere need to be addressed. These problems relate primarily to the acceptance of voluntary counseling and testing (VCT) and the choice of method for infant feeding. Both of these issues are intricately intertwined with cultural practices and beliefs.

One of the alternatives to breast-feeding is state sponsored formula milk for the first 6 months of life. Coutsoudis (2002:33) discusses the risks versus benefits with regard to breast-feeding or formula feeding, quoting UNICEF and WHO recommendations for breast-feeding in regions where safe water is not readily available. She cautions against undermining breast-feeding practices and advocates exclusive breast-feeding for at least 6 months.

Possible obstacles hindering prevention of MTCT are issues related to women and their subordinate status in many cultures, which may increase their reluctance to know their HIV sero-status. In Tanzania women refrained from VCT for fear of testing positive (Lugalla and Emmelin 1999:387). Leclerc-Mdladla (2000:28) relates how "people in KwaZulu-Natal are dying like flies" but even more tragic are the millions of women bearing the weight of compounded multiple silences of AIDS. At a Pietermaritzburg clinic, blame was placed on the mothers who had not taken advantage of VCT and were subsequently found to be HIV positive (Seidel 2000).

Additional problems envisaged besides stigmatisation include domestic violence and exclusion from the community. Lugalla et al (1999:387) emphasised findings in Tanzania where it was said "a woman is like a child, she must listen and do what we want". It was also added that minor blows, beating with a stick, pushing and kicking were not sufficient grounds for divorce. Some studies have shown that women who

are subjected to domestic-violence, often from intimate partners or husbands, are accused of inciting provocation by being a disobedient wife or “having asked for it” (Watts and Zimmerman 2002:1232).

When breast-feeding practices are discouraged to prevent further risk to the infant, extended family members, more especially in rural settings, often treat it with suspicion and disapproval. Cominsky (1993:942) found that rural women in Zimbabwe were subjected to a mother or sister in-law’s control in the absence of her husband and therefore was required to obtain their permission on feeding practices. Lack of safe drinking water for the preparation of bottle feeds in rural areas becomes an added risk to neonates. Cholera and other diarrhoeal diseases may result from the use of unsafe water and to this end UNAIDS and WHO cited in Luo (2000:148) reaffirms that women in regions of poor resources were to be offered an informed feeding option for their children. Other problems include child-rearing practices that are often communal, so that mothers seldom have continuous control of her child's feeding schedule (Cominsky 1993).

Background

The use of anti-retroviral drugs as an intervention to reduce the risk of MTCT of HIV has now become an affordable option. In a Thailand study, Baggaley (2000:1036-42) showed that a short-course of the drug Zidovudine (AZT) reduced the risk of MTCT significantly in mothers who refrained from breast-feeding. Merchant et al (2001:132-7) found that in Bombay an intervention for MTCT consisted of administering AZT for 6 weeks prior to giving birth for the mother, caesarean section birth practice, oral AZT powder for the child and avoidance of breast-feeding. This method was recommended as an alternative to Nevirapine , which in some countries is still unavailable.

In Uganda (Baggaley 2000:1036-42) it was found that a single dose of Nevirapine for mothers and infants reduced the risk of perinatal transmission of HIV in mothers who breast-fed their babies for 14 weeks postnatally. In resource poor settings such as

some parts of South Africa this treatment is now being promoted as both practical and affordable for both rural and urban settings.

Obstruction to the universal use of anti-retroviral drugs such as Nevirapine as a method for MTCT for HIV positive mothers recently experienced in South Africa was subjected to much criticism by both South African and International lobbyists, the media and the public (Rickard 2002:7). The local MEC for health in KwaZulu-Natal, insisted that it is not only the delivery or affordability of the drug that was presenting the problem, but the associated variables, which were emerging within the target society, that may complicate the delivery process. Feeding options available to HIV positive mothers and babies are bound to attract the curiosity and worsen the stigma (Mkhize 2002:3).

Programmes were being developed in South Africa to defy the National Department of Health's policy of preventing the use of drugs for MTCT intervention in provinces such as KwaZulu-Natal, Western Cape and more recently Gauteng. Rickard's (2002:7) media coverage highlighted recent legal judgments aimed at forcing the South African government to comply with strategies of drug delivery for the prevention of MTCT.

In essence, the practical issues that should support the delivery of drug interventions, are hindered by other issues including traditional practices, stigmatisation, subordinate status of women and more concrete obstacles such as lack of infrastructure, illiteracy and lack of education. Developing countries are subject to unique indigenous problems that are culturally sensitive and are deeply embedded in societal norms. More often than not, widespread poverty exists which can undermine many well-planned HIV intervention strategies (Cominsky 1993 and Whiteside 2001).

Whiteside (2001:1 and 5) links the rapid spread of the HIV/AIDS epidemic in Africa to poverty and claims that the epidemic is, in fact, driven by poverty. He stresses the point of relative poverty when even a poorly paid truck driver can be seen as a man of economic substance in the impoverished areas in which he is travelling.

Seidel (1993: 177-9) takes a more diverse view of the reasons for the rapid spread. She quotes President Museveni of Uganda who emphasised that the AIDS threat to public health is “a developmentally linked disease with deep historical roots”. She also quotes the WHO’s categorisation of ‘Pattern I and Pattern II’ epidemics, where sub-Saharan Africa was depicted as a Pattern II type in which lack of screened blood for blood transfusion purposes in addition to heterosexual and vertical transmission categorised it as “African AIDS”. She also makes reference to gender issues such as “women’s status being tied up with motherhood and large families, men’s control over women’s sexuality, rape and other violence towards women and the control of women as well as men’s access to women both in terms of sex and as a labour resource.”

Many African countries have yet to prove that they are capable of facing up to the challenges of AIDS. In Abidjan an effective VCT programme was installed during 1998-1999 and accepted as part of the strategy to support MTCT intervention protocols (Msellati et al 2001:641-7). There has also been progress in this direction (Balmer et al 2000: 15) in a similar programme in Nairobi, Kenya.

Broad aims of the study

This study explores some of the core issues that present challenges for the government, the recipients and their offspring who accept preventative drugs for reducing the risk of MTCT of HIV. Government should provide highly visible leadership through the media and other agencies as has been done in other countries such as Uganda and Thailand (Whiteside 2000:135). Mothers who accept antiretroviral drugs are faced with a number of problems due to their socio-economic dependence on partners because of unemployment.

At a basic level, there are the practical problems connected to the delivery of antiretrovirals such as Nevirapine (van Bogaert et al 2002:272-3). These include the short shelf life of the infant's Nevirapine syrup to be given after delivery, but more importantly, is the sustainability of providing alternative feeding options. The choice

is believed to increase the chances of maintaining a negative status for the neonate and this, according to UNAIDS/WHO (2001), should also include stronger commitments by governments for reducing infant HIV. Problems relating to the remoteness of some country districts such as in KwaZulu-Natal, that also survived an era of unequal development now faces the incapacity of providing adequate health support centres and it is evident that community buy-in is needed (Nyathi 2001:34).

Obstacles such as the practicality and acceptability of VCT, with specific emphasis on post-natal support for HIV positive mothers with regard to feeding options, are also critical to this discussion. An example is the follow-up of rural mothers to ensure that their babies can maintain an HIV negative status, which involves continuous health care support and monitoring which, as yet, is not being structured (SAfAIDS 2001:10).

At a more fundamental level, domestic and community issues are identified in order to free the potentially vulnerable HIV positive mother and her infant from burdens such as social exclusion and isolation (Sangiwe et al 2000:39-40). These issues are investigated against a backdrop of lack of access to post-natal health clinics. This basic support should facilitate acceptability of formula food without fear of prejudice, and most importantly, be approached with a view to links with existing supportive state structures such as AIDS education to further ensure a prolonged life for the HIV positive mother and that of her child (Strebel 1994:16).

Health care workers have discovered that post-natal prevention continues to be a daunting task and have already experienced challenges. An example of this was raised by the MEC for Health, who reacted to an attack by the Treatment Action Campaign (TAC), in a media interview (Mkhize: 2002). He discussed the stigma attached to a mother who is seen to be accepting formula food from a clinic and stated that, at some research sites, more than 46 percent of the mothers do not return for their HIV results. This he said was due to the difficulty women may have in seeking support from and understanding of their husbands who appear healthy looking.

Recent reports have fed information back to research sites where mothers have been known to misuse formula milk (Mkhize 2002). HIV positive people live in fear of exclusion and ostracism. Monitoring and evaluating the success rate of MTCT in rural areas is extremely difficult given the country's lack of infrastructure such as accessible roads, poor transport and communication systems (McCoy et al 2002:42).

In order to ensure that programmes support ready delivery of MTCT interventions it is critical to identify the current and envisaged obstacles that could hinder the National initiative of MTCT intervention. The problems illustrated in this study, will need to be seen through the eyes of those who form these communities and not by outsiders who may be unaware of local nuances or dynamics of the family units of the area. This view is supported by Nyathi (2001: 34) who, writing on “Rural Realities”, draws attention to the multiplicity of problems associated with HIV/AIDS programmes.

Primary objectives and assumptions

As stated above, there are complex social, cultural, and logistic problems associated with the provision of treatment to reduce MTCT. The main focus of this study will be directed to the following problems:

- Are the alternative ways of feeding infants posing a problem for the rapid expansion of the Nevirapine roll out?
- Do post delivery counseling support services help or hinder the informed choice process?
- Is there sufficient health care support to help the mother cope with social and cultural difficulties that may occur after accepting the formula food option?

As a primary objective the options available to HIV positive mothers regarding maintenance of a negative sero-status for the infant through feeding options, is established. Initially, revision of the guidelines of the present policy for an autonomous informed decision by the HIV positive mother is reiterated (Department

of Health 2000). Discussion of the successes of various feeding programmes and their consequences are meant to emphasise the practicalities of delivering formula infant food and their sustainability. One fundamental task is establishing realistic choices by mothers on the acceptance of MTCT prevention and how they intend to carry forward that commitment to their child (Abdool Karim et al 2002:992-3). To this end, what are the problems encountered when abstaining from breast-feeding and how, in the light of the alternative option of formula food, is this to be sustained.

Assuming that a large proportion of the population chooses the formula option, a further investigation is required to identify problems that arise from the acceptance of state subsidised formula, both from a nutritional value perspective and a societal tolerance viewpoint. A supplementary programme of Vitamin A may need to be introduced to children who are bottle-fed (Vijayaraghavan 2000:41).

It is important to link the extent of poverty and its connection to AIDS. Whiteside (2001:1) emphasises that poor people are more likely to become HIV positive if they are exposed to the virus in the absence of adequate nutrition due to a weakened immune system. Where mothers have chosen formula feeding as part of the MTCT programme there is a limit of 6 months for free formula milk. This means that after the child is six months old, the mother no longer has a means to feed it, (as her breast milk has now dried up) what alternatives are left open to her? The possibility of her being reduced to offering sexual favours in return for money for survival is discussed by Leclerc-Mdlala (2000:30).

Alternative assumptions where mothers choose to breast feed their babies, especially in environments with minimal resources, are also made. These are investigated against the realistic dangers of transferring the virus from mother to infant and attempts to minimise this risk. A novel intervention of heating the milk to inactivate the virus is discussed by Jeffrey and Mercer (2000:219-23). Such a method could once again be frustrated by lack of fuel for heating the milk in impoverished settings.

AIDS and poverty have a complex relationship, which does not necessarily mean that one causes the other but that poverty creates opportunities for HIV to spread more rapidly. Malnutrition could cause an impaired immune system and the early onset of opportunistic diseases. Information and education in this regard may be limited in poorer communities due to lack of education and illiteracy. Post-natal counseling programmes are to be intensified by the provincial departments of health to reach the poorest of the poor. One method is the use of lay counselors where challenges of conveying the message regarding MTCT interventions may need to be simple yet effective (Galloway 2001:28).

Summary

As discussed, MTCT as a mode of HIV transmission is becoming one of the highest contributors to child mortality. Yet in spite of the availability of therapeutic interventions, issues such as infant feeding practices also contribute to the transmission of the virus. Poverty together with social and cultural practices also play a large part in the problem and to this end it has been shown that many women have no control over the care and feeding choices for their children. Numerous examples have illustrated the lower social status of women in some cultures and also in some cases the high rates of extreme poverty that prevents women having the financial means for accessing formula milk. Lack of infrastructure and rural poverty prevents access to clean running water and fuel for heating milk.

Links in this study are made to these social issues in order to facilitate comprehensive culture sensitive research that can anticipate actual problems in established local rural and urban settings. It is also necessary for the sake of future research to establish recommendations for monitoring the progress of the children who are receiving the formula food and how orphans will be cared for in the future (Le Roux Booysen et al 2002:8). Evaluating the success of the programme would serve to inform policy makers planning for long-term programmes.

The next chapter covers issues surrounding the present MTCT HIV prevention policy guidelines and includes alternative methods of preventing MTCT by modifying

obstetric procedures. These methods include vaginal lavage, as discussed by Gaillard and Mwanyumba 2001:389-96, caesarean section, and minimising the use of obstetric manoeuvres, is added to by Read (editorial) (2000:231-34). A brief review is offered, by Zwi and Sonderland (2000:1331-20) in their discussion of a cost benefit analysis, where recent research indicates that anti-retroviral drugs are now cost effective in South Africa.

Coutsoudis et al (2001:379-87) expands on exclusive breast-feeding as an option with reference to recent research, which supports this choice in KwaZulu-Natal. Important research concerning the advantages of exclusive bottle-feeding as opposed to mixed feeding is also referred to in this section. When formula food is in short supply Jeffery and Mercer (2000) bring a novel method of sterilizing mother's milk to the study. The interim findings of the National Prevention of Mother To Child Transmission (PMTCT) pilot sites is to bring some first-hand feedback to this research (McCoy et al., 2002). The main emphasis of the literature review is centred on the breast-feeding benefits as opposed to those of bottle-feeding. The advantages and disadvantages of each are enlarged upon.

An in depth review on the state of poverty of areas in southern Africa and how any envisaged programmes to successfully prevent MTCT is discussed. Many local people who are unemployed, for instance, resulting in life below the poverty line, cannot be blamed, according to Nyathi (2001:34-5) "if learning about a dreaded disease shrouded with uncertainty and stigmatisation is near the bottom of the list of basic human needs".

Existing literature shows the cultural and societal factors that camouflage woman's rights remain even in a democratic society. Budlender (1997:513-29) emphasises that at a simple level, provision for pregnant woman should be a measure that promotes equality and lessens the specific burden borne by such women. Are post-natal counseling services, meant to facilitate the mother's choice, somehow influencing that choice? Mkhize (1994:9) questions whether the western model of counseling is appropriate to the South African context.

The practicalities of counseling and information dissemination are expanded upon with a specific view to attempting to establish validity of these processes and at the same time not rob the mother of her autonomy and reduce her to the role of an unimportant conduit. To complicate the counseling dilemma there is also the added obstacle of an urgent shortage of human resources as trained staff are already overloaded and cannot cope with the demands put on them by the burden of HIV and all its subsidiary consequences (Mc Coy et al 2002:13). This topic lends weight to the issues that relate to the problems of “AIDS orphans” and what is to become of them.

Chapter 3 discusses the method used in this research. Visits to some of the MTCT pilot sites where Nevirapine is being administered in KwaZulu-Natal formed the basis of this study. A primary source of information was obtained from in-depth interviews administered to available mothers at some antenatal clinics. An interview guide was used where information, knowledge, prescribed counseling options and perceived community problems were explored through the use of open-ended questions.

The intention was to target mothers and mothers-to-be, regardless of their HIV status and gain first-hand information from their experiences of the MTCT programme. A possible limitation in this section is where HIV positive people, knowing their status, may respond differently to those who are HIV negative.

In-depth interviews were also held with other individuals such as nurses and other health care workers involved in the provision of VCT. Due to the degree of stigma that is associated with HIV/AIDS, a sensitive and tactful interview guide was designed and a tape recorder was used for all of these discussions. The findings and the final discussion from these interviews will bring a significant source of local contextual information to the study and could be used productively for further research.

The research undertaken in this study, although not large enough to be representative of the entire population, promises optimistic outcomes that could assist future

planning of MTCT prevention programmes which could help in addressing the relevant obstacles faced by women and to facilitate an improved maternal health service.

Chapter Two

Literature review

HIV as the cause of AIDS is now widely accepted as the epidemic that is decimating family units, communities and has mobilised political leaders to ensure that HIV/AIDS is included in health and education policies. Sub-Saharan Africa has become the epicentre of the epidemic where approximately 3.4 million new infections occurred in 2001 and in KwaZulu-Natal the HIV prevalence among pregnant women attending antenatal clinics was 36.2 percent in 2000 (UNAIDS/WHO, 2001:2). In South Africa (MTCT) rates range from 19 to 35 percent, depending whether the child is breast-fed or not (Abdool Karim et al. 2002:992). It was estimated that 75,000 babies born in 2000 were HIV positive.

According to Bateman (2001) doctors at Pietermaritzburg's Edendale Hospital and the King Edward Hospital in Durban report that of all the patients in the medical wards, 55-65 percent are HIV positive. He further claimed that at Hlabisa district hospital a medical officer estimates that 75-80 percent of his 165 medical patients are HIV positive and that for three successive years the medical wards have had 140 percent occupancy. "The shortage of beds means that during inclement weather and overnight, each bed has one or two patients in it and sometimes one underneath on the floor" (Bateman 2001:4+6).

South Africa as a developing country, now has an estimated 4.5 million people infected with HIV and more than half are occurring in women (Shisana 2002:45). The government has in the past provided adequate immunisation programmes, but is reluctant to provide a national roll out plan against vertical transmission, commented Abdool Karim et al. (2002:992). The challenge open to the government is to translate

strong evidence, provided by medical scientists that support a substantial reduction in vertical transmission, into policy and practice.

Policy guidelines

The United Nations General Assembly set in place a global framework to attack the epidemic. One of the benchmark targets relating to prevention, care, support and treatment was that there should be a reduction of 20 percent of the proportion of infants infected with HIV by 2005. Another was to develop national strategies for health care structures to place drug provision, affordability and pricing high on their agendas. This also includes commitments by health sectors to provide HIV/AIDS treatment such as antiretroviral therapy and effective monitoring structures to prevent drug resistance (UNAIDS/WHO 2001:4).

Reconfirming the commitment, the AIDS Legal Network has used international guidelines to promote the advancement of supportive principles of non-discrimination; equality and human rights of HIV infected and affected persons. International guidelines dictate that governments should establish an effective national framework for the response of HIV/AIDS. Nations should make political and financial commitments to support community consultation through policy design programmes, implementation and evaluation. Another locally relevant issue is that governments should join forces with communities and promote a supportive and enabling environment for women, children and other vulnerable groups through the provision of health and social services (Caesar 1999:3).

Strategic Plan

The 2000-2005 Strategic Plan for HIV/AIDS in South Africa is the only attempt at a National AIDS policy at present. This plan is goal directed towards reducing the number of new HIV infections and to reducing the impact of HIV/AIDS on families and communities.

The plan identifies priority areas 1 to 4; these are prevention, treatment, care and support, research and human/legal rights.

These priority areas are goal directed and in priority area 1 have the following goals.

Goal 1. Safe and healthy sexual behaviour.

Goal 2. relates to the control of STIs in the public and private sector by syndromic management.

Goal 3. focuses on reducing the incidence of MTCT.

Goal 4 concerns blood transfusion services and HIV.

Goal 5 the provision of post-exposure prophylaxis services.

Goal 6 to improve access to VCT services.

(Dept of Health HIV/AIDS & STD'S Strategic Plan 2000).

This dissertation is concerned with priority area 1 goal 3 reduction of MTCT but other priority areas and goals impact on this goal as well.

By the end of 1999 there were an estimated 4.2 million HIV positive South Africans and close to half were women in their reproductive years. At that time there was also an estimate of 50,000 HIV positive children who sero-converted to HIV positive through vertical transmission (Dept of Health HIV/AIDS Policy Guidelines 2002:5). In the field of epidemiology the terms horizontal transmission and vertical transmission are used to distinguish between spread of an infected agent from person to person from that of the spread of mother to her offspring. MTCT occurs during pregnancy, labour, delivery or after birth and during breast-feeding.

In a review by the Health Systems Trust, (HST 2000) it was found that Tuberculosis and STIs, both associated with HIV/AIDS, show large increases in HIV positive people nationally. National antenatal HIV surveillance data identifies KwaZulu-Natal as the province with the highest prevalence at 36.2 per cent followed by Free State with 27.9 percent in 2000 (UNAIDS/WHO 2002:13) There are wide differences in HIV prevalence in the 9 provinces of South Africa. Reasons for the differences in prevalence of HIV can be attributed, in part, to historical under development, the lack of infrastructure and in some areas the geographical layout. In the province of

KwaZulu-Natal, which has the bulk of its population living in rural areas, economic development is lacking and services are difficult to deliver.

Cost effectiveness

In the Health Systems Trust Review (2000) it was found that fear and ignorance are the greatest barriers to achieving HIV prevention and to emphasise this point the report states that cost-effectiveness for MTCT intervention are higher at a mature stage of the epidemic. In the first phase of the epidemic, when opportunistic infections are not evident, HIV attracts little attention (Steinberg et al 2000:318-320).

Zwi (2000:1331-2) anticipates that MTCT therapy could become affordable given the present commitment of the health workers, lobbyists and communities. In their estimate, drawing on previous studies, and commitments for cheaper drugs by drug companies, an entire prevention of vertical transmission programme could cost less than one percent of the annual health budget including auxiliary services such as VCT. Difficulties are more complex when roll out of triple therapy antiretroviral for adults are contemplated where there would have to be strong political support and openness by citizens about being HIV positive. Programmes to prevent MTCT were, until recently, being hampered by the government's obstinate assertion that Nevirapine is unsafe and their involvement with the discredited AIDS dissidents.

Recently, Carmel Rickard reported that the legal council for the State, Marumo Moerane, stated the defendant's case to resist provision of Nevirapine more widely than the chosen test sites was because monitoring and research were not far enough advanced and that drug provision and counseling should be provided in a planned manner (Rickard: 2002).

Logistical challenges for providing treatment in South Africa will require radical and innovative thinking according to Bekker and Wood (2002:191-2). They mention essential services such as access to VCT as very critical in any prevention strategy. Effective monitoring programmes should include the capacity to manage opportunistic infections, follow-up counseling support services, reliable laboratory services, adequate drug supply, long term financial resources, human resources for

information and training would also be crucial. The success of a nationwide roll out programme for antiretrovirals would need a strong political will, community buy-in, and a parallel prevention programme for Tuberculosis control.

Rosenfield and Figdor (2001:703-4) raised an important ethical issue regarding the use of single dose Nevirapine to prevent MTCT, which in spite of being cost effective carries no benefit to the mother at all regarding her HIV infection. Concerns were that future antiretroviral treatment might be in jeopardy as this may increase drug resistance for the mother and the drug therapy is not meant to worsen the mother's chances of survival.

Ratcliffe, et al. (1998:1381-88) acknowledge that the HIV transmission rate for MTCT ranges from 15 percent to 40 percent, which is highest in developing countries where predominantly breast-feeding occurs. They reason too that the cost of reducing the MTCT rate could be more cost effective than caring for an infected child. In ideal circumstances where a mother knows her status, avoids breast-feeding and is receiving zidovudine (ZDV) antiretroviral therapy during her pregnancy and at the delivery of her child, a reduction to 5-8 percent can be achieved.

Practical interventions

Interventions that are discussed in the Health department's policy document are divided into behavioural, therapeutic and obstetric. Other risks that promote sero-conversion may be attributed to foetal trauma, which involves vigorous suctioning of the child, trauma to the mucous membranes and direct contact with maternal body fluids. Maternal trauma such as assisted delivery should be delayed as long as possible. The mode of delivery such as caesarean section to prevent MTCT should be considered if there are clinical indications for this intervention (Dept of Health HIV/AIDS policy guidelines, 2000:16).

Vaginal lavage with chlorhexidine was used in a clinical trial in Kenya where it was concluded that lavage before membrane rupture at labour was positively associated

with reduction of MTCT of HIV. This option is cheap and could also reduce neonatal and maternal mortality rates (Gaillard 2001:389-96).

Caesarean section as a mode of delivery has a role to play in MTCT intervention. Read (2000: 231-34) concludes that benefits derived from this method should not be unaccompanied by MTCT prevention extension services such as VCT and information regarding infant feeding methods, particularly the risks attached to breast-feeding. She further recommends awareness of the HIV status of the mother, an assessment of her viral load and monotherapy antiretroviral treatment before labour. These recommendations are obviously intended for developed nations and would have little place in most sub-Saharan countries.

Obstetric practices should minimise the chances of MTCT and these are to be strictly adhered to by maternity and nursing staff. Artificial rupture of membranes is to be avoided, minimising duration of ruptured membranes, minimising duration of labour and avoidance of instrument-assisted deliveries are added risk reduction methods for MTCT (McCoy2002:17).

Safe sex behaviour

Safe sex practices will go a long way in preventing increase in HIV viraemia which may not only further endanger the neonate at birth, but may also increase transmission during breast-feeding. Condom use and casual sex partners should be a constant concern for pregnant mothers. Treatment and control of STI's and opportunistic infections should also become high priorities for the expectant mother (Dept of Health HIV/AIDS Policy Guidelines, 2000).

Factors that can realistically reduce the AIDS epidemic and influence reduction of transmission of HIV should be, the continuous use of condoms, promoting AIDS education and drug therapy. Adherence to these guidelines of safe sex practices could reduce the risk of developing resistant strains of the virus, which may cause multi-drug resistance (Sanders 2000:15-6).

A novel idea for safe breast milk

Jeffery and Mercer (2000:219-23) have suggested a novel idea for the use of breast milk for bottle-feeding neonates of HIV infected mothers. They suggest that expressed breast milk be pasteurised as a means of destroying the virus's infectivity. A simple method of holding the milk at 56°C to 62.5°C for 10–15 minutes is an inexpensive method of heating expressed milk and research has shown that milk could be virus free. Jeffery and Mercer (2000) also raised concerns regarding contamination from the mother's own hands. There is also the added risk of cracked nipples which may increase the viral load significantly. Shortcomings in poorly-resourced areas may be the difficulty of ascertaining correct temperatures and heating times for a beneficial effect.

Antiretroviral treatment

Zidovudine as a MTCT antiviral intervention was shown to be successful in Thailand when administered orally during the last 4 weeks of pregnancy to lower the mother's viral load (Baggaley 2000). This placebo controlled study showed an effective 51 percent reduction in HIV transmission. The African based PETRA study yielded similar results where 2 different antiretrovirals were administered and compared. The drugs were given at 36 weeks gestation, administered orally during labour and for a week post-partum. The HIVNET 012 Ugandan trial resulted in a 47 percent reduction of transmission from a single dose of Nevirapine to the mother at the onset of labour and a single dose of Nevirapine syrup to the neonate within 72-hours of birth. The significance of this trial was that the highest reduction rates for MTCT are achieved by pre and post exposure prophylaxis (Burns and Mofenson 1999:1-6).

MTCT programmes are a health service priority in South Africa following on the court actions by AIDS activists. A simple method of preventative medication such as the HIVNET 012 trials have shown where Nevirapine has reduced transmission of HIV-1 in the first 14-16 weeks of life by nearly 50 percent. Guay et al (1999: 795-802) suggests it as ideal for developing countries where the burdens of widespread poverty, lack of resources, infrastructures and skilled labour abound.

The New York Times (Appendix 2) proposed Nevirapine as a cheaper practical therapy for developing countries. Nevirapine was quoted as costing US\$ 4 per patient compared with US\$ 268 for AZT treatment that was also being used in less developed countries. The press article quoted Dr Piot of WHO as saying that pilot programmes were needed in developing countries, as this was only one part of the complexities of preventing HIV. It was also emphasised in the article that the deaths of three women who took AZT were caused by AIDS and not the drug.

The cost effectiveness of a single-dose Nevirapine regimen was addressed by Marseille et al (1999:803-9). The method assessed the cost effectiveness for a hypothetical cohort of 20000 pregnant women. It calculated the total programme costs, the cost per paediatric case, and calculated the cost per disability-adjusted life-year (DALY). Interpretation of their data concluded that there is a high cost-effectiveness in high sero-conversion areas but it may not be as cost effective in low-prevalence areas. Nevirapine as a single dose therapy, they concluded, could have a major public health impact at a reasonable cost.

Education versus medication

According to Sanderson (2001:12-13) antiretrovirals have benefits for those who are HIV positive as it lengthens their lives and provides them with temporary lifelines until a better regime of therapy is developed. However, he points out that the widespread use of antiretroviral drugs could undo the educational effects that have been done thus far. A population-forecasting model has been developed at the International Institute for Applied Systems Analysis in Austria. In view of this he discusses two approaches to the HIV/AIDS problem behavioural change resulting from education and a medical treatment approach. It is predicted that in a “behavioural change scenario” there is a 40 percent reduction rate for new infections for each age, for each gender and separately for people in 3 education groups. In a “medication scenario” there is an assumption that 50 percent of all people who have symptoms of AIDS will receive and tolerate the medication. In the “medication scenario” the death rate falls drastically in 2004, levels out in 2006 and increases

thereafter. By 2012 there is a prediction of more deaths in the medical scenario than in the behavioural scenario.

This mathematical model approach, discussed by Sanderson (2001), also predicts that short-term gains by medication will be short lived and concentrating on behaviour change will bring greater long-term benefits. Sanderson goes on to explain that medication programmes compete with education programmes in two ways. There is competition in terms of resources, where medication programmes require more money for medicines and for monitoring of patients. This places burdens on two resources in short supply in poor countries namely skilled labour and money, where education programmes running concurrently would be unlikely. The psychological aspect that Sanderson points out is that in the presence of medication, the attitude to risk behaviour may be minimised.

Drug resistance

Dr Zweli Mkhize, MEC for Health in KwaZulu Natal, emphasised that the problem of extending the existing pilot sites of the MTCT had much to do with financial aspects, logistical and human resources. With antiretroviral treatment there is a high risk of developing drug resistance. HIV-1 drug resistance is more common in mono therapy and may cause treatment failure, the cause of which could be multi-factorial. Viral susceptibility may only be one part of the problem while other factors such as medication adherence and continuity may be the other (Euro Guidelines Group for HIV Resistance, 2001:309-320).

Adherence, or treatment compliance, described by Bekker et al (2002:191-2) is a major obstacle that needs to be overcome in antiretroviral (ARV) programmes. They say that aside from the treatment itself, adherence is dependent on the individual support the ARV programmes offer. Therapeutic Counselors (TC) are used as buffers between clinical staff and patients. TC's and patients are to be in an alliance for enabling a quicker response when detecting and reporting any serious side effects.

Feeding Methods

Breast-feeding

Initial trials to assess the risk of breast-feeding by HIV infected mothers concluded that this method practiced exclusively did not significantly protect children from common childhood illnesses or delay the progression to AIDS (Bobat, Moodley, Coutsooudis and Coovadia 1997:1627-33). HIV transmission in developing countries is a risk in settings with poor resources where breast-feeding is preferred to other feeding options which run higher health risks due to lack of infrastructures such as piped water.

A Malawian study, headed by Miotti et al., (1999:744-49) endeavoured to show that HIV transmission by breast-feeding is highest in the early months. Six hundred and seventy two babies who were born HIV negative were monitored and tested by Polymerase Chain Reaction (PCR) to ascertain the exact time of sero-converting to HIV positive. To qualify for the trial, breast-fed babies had to be HIV negative at their first 6-week visit after birth. Results revealed that, 47 children became HIV positive during breast-feeding but not after they had stopped breast-feeding. This research concluded that HIV infection is more likely in the early months of breast-feeding.

As early as 1993, Dunn and Newell (1993:134-5) theorised on the need to quantify the risk of transmission via breast-milk. Comparisons were used where exclusively breast-fed versus exclusively bottle-fed infants were discussed and the problems of finding equal numbers of participants in each group in either developing countries or in developed countries. The latter encouraged HIV positive mothers to refrain from breast-feeding and the former only breast-fed their infants.

In a significant Durban study, Coutsooudis and co-researchers (2001:379-87) undertook to determine the risk of HIV transmission by infant feeding methods. The study included 551 pregnant HIV positive subjects. After appropriate counseling, where mothers were informed of the risks of exclusive breast-feeding as opposed to

exclusive bottle-feeding and that of mixed feeding, the subjects had to choose which method of feeding they preferred. They also had to attend follow-up sessions at 1 week, 6 weeks and 3 months. All mothers were then interviewed and asked about their feeding practices, and this was recorded. On conclusion of the trial it was established that the exclusively breast-fed babies were no more at risk to HIV infection than the non-breast-fed infants, but were significantly lower for susceptibility than the non-exclusive breast-fed infants. Coutsooudis explained (cited in Retzlaff 2000) that mixed breast-feeding “introduces allergens and foreign contaminants causing irritation of the gut mucosa which is hypothesised to increasing the chances of MTCT”.

Embree et al. (2000:2535-41) pointed out that a Kenyan study showed that in addition to antiretroviral therapy, public health policies should pay attention to prevention of maternal nipple lesions, mastitis and infant thrush and the reduction of the breast-feeding period in all HIV positive mothers. These factors increased the risk of virus transmission. It was also emphasised that breast-feeding should be avoided absolutely in high-risk individuals.

In a qualitative study in Durban, it was discovered that at no stage during their pregnancy were 13 HIV positive women given any information about the risks of breast-feeding for promoting MTCT (Seidel et al. 2000:24-33). It was further found that only one of the women had any awareness of the danger to the neonate and this awareness was due to her own information resources. Only two of these women learned of their infection through their baby becoming sick, (Sewpaul and Mahlelela, 1998, cited in Seidel et al. 2000). The authors highlight the plight of women who do not disclose their status but refrain from breast-feeding and are then subjected to much speculation and questions.

The formula food option

Alternative infant feeding strategies are argued against by Baggaley and van Praag (2000:1036-42) they stressed that when formula food is unavailable, mothers should breast-feed for as short a period as possible to provide the child with its nutritional

needs. Cautions about the need to educate mothers on the preparation of formula food and in understanding the correct proportions were highlighted. Due to the complexity of preparing and administering formula food, the advantages of breast-feeding are beneficial as a contraceptive as well as it's built in nutritional value and availability.

Practical problems related to formula food

“For infected women who are aware of and accept their sero-positive status and chose not to breast-feed, even when infant formula food is provided for them, can be particularly difficult, especially in societies where breast feeding is the norm” (Baggaley and van Praag 2000:1039). In Uganda less than 1 percent of women opted to bottle-feed despite the provision of free infant formula.

The interim findings of the current National MTCT sites recommended that the current policy to provide free formula for infants should be revised (McCoy et al. 2002). It was reported that higher rates of mortality and morbidity through illness and high rates of mixed feeding might mean that the usefulness of providing free formula is counterproductive. Public health specialists are divided on the current social, economic, environmental and cultural circumstances in areas where the bulk of the MTCT sites are situated. Many think that only those who can afford formula food should choose that option.

Some specialists in the report, argue for the provision of free formula to communities and households that would be able to exclusively formula feed safely (McCoy 2000: 41). Water-borne diseases including cholera and other enteric pathogens may cause severe protracted diarrhoea. In the absence of piped water and sanitation populations in poorly developed areas are extremely vulnerable to these diseases. Current AIDS prevention initiatives should sensibly address poverty alleviation, which also include budgets for essential infrastructure (Matchaba 2001:20).

Other issues that the interim report suggests is that policy makers need to address increased accessibility of formula. Dilemmas regarding a time frame for the supply of formula are a contentious issue. Questions were raised in the report as how long

would be long enough? Would more damage be done to a developing child when the programme reaches its last supply at six months by which time the mother's own breast-milk has long since dried up? All the complexities, the commission decided, surrounding the supply and delivery of formula should be considered within the broader contexts of current child poverty, mortality, food insecurity, poverty alleviation, access to social grants and orphan care (McCoy 2002).

Maintenance factors that hinder smooth delivery of MTCT intervention programmes, besides the cost of providing formula feeding options, includes “counseling and continuous support for the HIV positive mother long after delivery” said Mkhize (2002 public address). Infrastructure and capacity development should be in place before the drug becomes universally available. He was sceptical about operational issues that include testing, counseling and monitoring processes.

Women’s experience and response to feeding options

Child feeding practices in rural areas of Zimbabwe is a far cry from many of the envisaged urban realities where there are high levels of malnutrition and surprisingly low levels of child mortality. Cominsky et al (1993:937-47) examines infant and child feeding customs and practices of rural dwellers where even though women recognise the benefits of breast-feeding, the period is limited to when she falls pregnant again as it is believed that then the milk becomes bad for the baby. If breast-feeding has been stopped for a day or two, it cannot be resumed, as the milk is again considered to be bad.

Termination of breast-feeding has important cultural implications, one of which is that the grandmother or aunt has to sanction the parent's decision. If a woman terminates breast-feeding while her husband is away and without the mother-in-law’s endorsement, it may be interpreted to mean that she is involved in other sexual relationships, which could lead to a divorce. Breast-feeding is also used to measure a married woman's chastity and fidelity and this implies that when the infant accepts the mother’s breast, it is proof of legitimacy. The opposite effect could mean the mothers infidelity and result in physical abuse by her spouse (Cominsky et al. 1993:937-47).

Women who are HIV positive were interviewed and they spoke of inhuman stories when their status was revealed through their infant feeding choices. Happiness, one of the participants in a study conducted by Seidel et al, (2000:24-33) was married and disclosed her status to her husband when she decided to bottle-feed her child. She hid the bottles under the blankets in the ward at King Edward Hospital in an effort to keep her status secret from other patients. When she was found out she was obliged to reveal her status to the rest of the women in the ward.

Patience, another participant, said that because she would not breast-feed her baby her boyfriend was cross with her and accused her of trying to look younger and not feeding in order to stop her breasts from sagging. Grace, who also participated in the study and decided against breast-feeding, was subsequently subjected to violence from her brother. She reported that “he used to beat me and forced me to put hot towels on my breast when I told him I had no milk” (Seidel 2000:28).

Women in the study revealed that there were various responses to not breast-feeding. One woman said that it breaks the bond between mother and baby. Another said that she was now free to leave her baby with others to look after and that she had other things to do in her life. It was also described as painful by another respondent who said she felt that not breast feeding would mean he (the baby) would be more prone to diseases and infections (Seidel 2000:29).

Mothers responses to bottle-feeding according to Seidel et al (2000), was unanimous in that no consideration was given to their financial position when a feeding option was raised. Only two doctors who attended to the women made any attempt to help them to access formula through the social services. One unemployed woman was obliged to feed her child Rooibos tea between feeds, to make sure the short supply of formula food lasted longer (Seidel 2000:29).

Nursing staff abuse

Jewkes et al (1998:1781-95) discusses treatment meted out to mothers in maternity wards by the people who are intended to be supportive and caring. The cruelty of nurses, found in Kwazola and Groendal hospitals in the Cape Province, stemmed mainly from problems arising whilst booking-in for delivery when the staff were abusive and unconcerned with the patient's problems. Women who were chosen for the interviews were between 17 and 40 years old, from low socio-economic background and were predominantly Xhosa speaking. Women reported that they were shouted at, beaten or neglected.

The women were told to be at the hospital early and many lived far way with transport problems. Teenage mothers were humiliated by staff and told that they were dirty and stupid. Two teenagers delivered their babies with the help of other mothers, as they could not find a midwife. The mothers who assisted them were then scolded. Two women reported being slapped in the face and one woman who could not manage to climb back onto the bed delivered her baby on the floor. Staff justified their actions by saying that patients had unpopular practices, they were motivated by concerns for the baby and that they were attempting to teach mothers proper practices. These findings suggested that abuse of patients is widespread. Devaluing or dismissal of patients' knowledge, punishing of patients by making them wait or regarding them as stupid was a serious concern for the nursing profession.

Mixed reactions to VCT

HIV counseling and testing of pregnant women was assessed for acceptability in Tanzania. From June 1996 to May 1998, HIV testing was offered to a total of 10,010 pregnant women. Approximately 74 percent agreed to be tested but only 68 percent of these returned for their test results. Kilewo et al (2001:458) indicate that several similar studies have not been able to establish exact reasons why people agree to pre-test counseling, but then refuse testing or do not return for their test results once they have been tested. Other studies (Cartoux 1999; Ladner 1996; and Temmerman, 1995 quoted in Kilewo et al. 2001) have suggested the counseling techniques, suspicion of already being infected and fear of having to cope with a positive result are reasons for

differences in levels of acceptance of HIV test results. Group pre-test counseling has also been reported as yielding higher compliance to being tested and returning for results. The reason that this method is often used is due to the shortage of trained counselors in many districts. In the Petra trial, of the 27 percent of respondents who agreed and qualified to take part in the study, it was found that only 16 percent revealed their HIV status to their sexual partners. Reasons for this were attributed to the fear of violence, stigma and divorce (Kilewo et al. 2001:458).

Provincial health departments, in order to promote the fight against AIDS, provide VCT guidelines. VCT starts by counseling to help individuals to make an informed choice to be tested for HIV. The objectives of VCT programmes are for VCT to become the accepted thing to do and therefore help reduce the stigma. Other secondary functions are to learn more about the virus and its effects on the body. Healthy living is also promoted to ensure longevity. Information and counseling for positive people would mean acceptance, access to emotional support, development of healthy eating habits, controlling stress, controlling the possibility of re-infection and gaining knowledge of opportunistic diseases. Other advantages are to network with other HIV positive people as a support and to find out about resources to manage the disease. Information for medication for the control of opportunistic infections and for preventing MTCT can also be obtained. Most importantly is to be able to contain the disease and not to spread it to significant others (VCT guidelines KwaZulu-Natal department of Health 2000).

Sangiwa et al (2000:25-35) conducted a study of client's perspectives on the role of VCT in Tanzania. VCT as an important HIV prevention tool is used to reduce risk behaviours, is also cost-effective and provides support and care for people living with HIV. Results of this first ever efficacy study revealed that this client-centered model was positively received and could play a significant role in the future of VCT. Comments from participants showed that VCT helped them to assess their own risk, helped them to engage in risk reduction strategies, change lifestyles and adjust their relationships in line with their own capacity.

The cost-effectiveness was placed in the context of poverty and this freely available service empowered HIV positive individuals to have control of their own lives where ownership meant self-management in many cases. This study was unique in that it reports that participants were keen to learn their status and therefore made a greater effort to have access to blood results. Survey data and qualitative interviews showed that there were very few negative responses to receiving VCT.

Balmer et al. (2000) discussed the effectiveness of VCT in a study in Kenya where individuals and couples seeking HIV prevention services were monitored. Between June 1995 and March 1996 a total sample of 1,515 participants were recruited for the study. Ninetyfive percent of the participants agreed to be tested for HIV. It was ascertained that 32 percent of the sample had at least one STI. Most of the candidates were recruited through community outreach and were supported by friends and relatives who were made aware through presentations, schools and community leaders. This success should prove that community outreach programmes carry a highly effective response rate. Conclusions made from the study found that condom use was low, birth control use was low and the only low risk strategy employed was predominantly one partner sex. Over all findings suggested that in a low income area such as this, where condoms, contraceptives and treatment for STIs is in short supply, there is a high demand for VCT services (Balmer 2000:15-23). Kalichman (cited in Galloway, 2001:28-30) discussed 3 effective HIV risk reduction interventions. He said that education which provides information, tries to get people to recognise their own risk and includes the provision of skills building which people could use in their daily lives to reduce their risk of HIV.

It is also important to distinguish counseling from advice and instruction, which is discussed by Stein (1994:12-3). In HIV counseling, the client's concern is to make decisions concerning their own HIV testing, safer sex practice, disclosure etc. and in this case the counselor is only a facilitator who cannot make those decisions. If the client cannot make a decision the counselor may be able to point out various options and could advise on a course of action. Advice and instruction differs from counseling

(which is always non-judgmental and values-free), the latter enables ownership and autonomy.

Social and cultural consequences

Violence against women

Violent sex acts against women is on the increase and although originally rape was associated with the common image of a violent sexual attack by a stranger, in reality, the victim, often knows these offenders. Sexual violence that is non-consensual may involve physical force or may include trickery, blackmail and threats (Watts and Zimmermann 2002:1232-7).

In three Cape Town municipalities it has been documented that sexual and physical violence against women has accounted for a staggering 43 percent where men had admitted to beating up their partners in the last 10 years. Many African women, who have little financial resources of their own, either have to live with the threat of abuse or secretly sell sex favours to support their children (Wojcicki 2001: 8-13). Women are victimised into earning a living and face conflicts over the costs and benefits of risking HIV infection or saving their starving children.

Acceptance of violence and rape against women has become “a national sport” according to Malegapuru Makgoba, cited in Wojcicki, (2001). It is recommended by the author that violence against women should become a high priority in the fight against AIDS. A key issue remains to protect the vulnerable position of women in society and ensure that discrimination is eradicated and that they are able to take effective measures in protecting themselves against infection of HIV.

“In many communities women can expect a beating, not only if they suggest condom usage but also if they refuse sex...” (Leclerc-Mdadlala 2000:27-30). The author highlights “transactional sex” in the face of poverty, which has caused financial dependence on men, where women are placed in a position to accept whatever treatment men choose to mete out to them.

Findings of a longitudinal study done in Tanzania revealed how little women could do to prevent HIV/AIDS infection. Lugalla et al. (1999) reported that women are accused of bringing AIDS into the family if they show signs of the disease before their husbands do and in this case they are thrown out of the household and sent back to their parents. Marriage for women is passive and for men it is active which means that men usually initiate sexual activity and this renders women powerless in matters relating to sex and reproduction. Women may use the resources of their husbands but in return they may not refuse sex and should give him children. In the study a Tanzanian woman stated, "Even if your husband is promiscuous you have to tolerate it, if you desert him where will you go? How are you going to survive? Who else will marry someone with children already?" (Lugalla et al. 1999:377-397).

Lugalla et al (1999) discusses condom use and reactions to it, which included, "you cannot enjoy the taste of chewing gum if you do not remove its cover," or "you need to peel a banana in order to enjoy eating it". Comments from other sub-Saharan countries quoted in the study, reflected similar sentiments "Sex without additions", or "Sex with a condom feels worse" or "when you are using a condom you cannot feel anything, you may as well abstain". (Lugalla et al. 1999:87) Most men preferred "dry sex" and many women said that secreting too much during sex was shameful and men accused them of being useless or wet and cold. Men can easily socialise with other women and adultery on a man's part does not constitute grounds for divorce. Widows are retained, in the family, after the death of her spouse by other male members and if she does not produce children she can be rejected.

Poverty

AIDS as the poverty-facilitating link is discussed by Whiteside (2001:1) where exposure for the compromised immune system due to malnutrition for instance, may mean a higher risk of transmission of HIV. Poverty may also be an obstacle in acquiring knowledge about HIV/AIDS when illiteracy is high and communication, such as television, is often not available. Whiteside (2001:1) argues that future plans

are hindered by shortages of assets and money and may spill over into risk behaviours.

Stigma

“HIV/AIDS affects and infects the body politic just as it infects the bodies of individual citizens,” said Thomas (2001:7-10). The HI virus, which can be passed from mother to child, causes people living with the virus to be perceived as not only a threat to themselves but to the future of the nation and they are also regarded as an economic burden and a threat for the future. The irony of the political dilemma with regards to AIDS in South Africa, where a social message imploring the need to “break the silence” persists, is the government’s own lack of response to the urgency of the AIDS epidemic.

Seidel (1996:422) blames the culture of silence on organisations such as the National AIDS Convention of South Africa (NACOSA) where slogans such as “your status is your secret” did untold harm to future prevention programmes. Communities were previously unused to not sharing information and the code of silence reinforced the stigma that is still firmly associated with the disease.

“AIDS-related stigma is defined as prejudice, discounting, discrediting and discrimination directed at people perceived to have HIV/AIDS and the individuals, groups and communities with which they are associated” claims Herek (2002:1106-20). Herek (2002:1108) also says that as a disease AIDS manifests four different characteristics that are likely to evoke stigma. Firstly, the cause of the disease is the responsibility of the bearer and is associated with voluntary immoral behaviour. Secondly, there is a greater stigma attached to degenerative and unalterable illnesses as the diagnosed person may represent a constant reminder of death. Thirdly, stigma, in the case of AIDS, carries strong perceptions of fear and danger of contagion. Finally, AIDS is more stigmatised when it is apparent to others to whom it appears as ugly, repellent or upsetting.

Women bear the brunt of stigma whereas men as role players in society should contribute their part in choices of infant feeding. Men, in their roles as husbands, sexual partners and community leaders should be informed about best feeding practices and the implications and risks involved with infant feeding choices. All too often women reveal their status as a result of pregnancy and are therefore stigmatised, and labelled as bad mothers that are harmful to their children. Options around breast-feeding are often given by ill-informed health care workers who are not wholly aware of the complexity of the mixed feeding problem and the importance of sustainable adherence to exclusive breast-feeding or bottle-feeding (Galloway 2000:35).

Findings of the national prevention of MTCT study

Socio cultural factors discussed in the "Interim Findings on the national PMTCT Pilot Sites" (McCoy et al. 2002) included issues such as mixed feeding which in many cases is a cultural norm and enforced by mothers-in-law. Women are seldom afforded a choice in the matter as they are subjected to these cultural pressures. Another variable that hinders exclusive bottle-feeding is the maternal instinct to provide an unhappy child with "breast comfort". As mentioned previously the difficulty of preparing safe formula for the baby is often compounded by lack of fuel for fire and drinkable water and therefore the breast option is the most convenient.

Formula cost and availability

The very reason for the supply of free formula to poorer mothers may also be the reason why they are the subjects who may not manage to produce safe bottles for their babies. Although formula may be provided free other costs such as water collection, fuel and sterilising may be added financial burdens to the mother. Women may be under a false sense of security in believing that free formula is a solution and in fact may choose this option for the wrong reasons. Mixed feeding is, as the literature suggests, an added risk for MTCT and it is likely that a combination of formula, breast and porridge may be used to satisfy cultural norms (McCoy et al 2002). Non-exclusive breast-feeding is thought to be damaging for the immature intestinal mucosa of the baby leading to opportunity for the virus to cross the mucosa.

Other real challenges to government and society is the financial burden of providing formula which is roughly estimated at US\$72- US\$120 for a supply lasting for 6 months in 2000. The other contentious issue is how long to provide the formula for, should it be for 3 or 6 months. If a child has been formula fed for 3 months and is suddenly taken off the feed this could mean malnutrition for the baby (McCoy et al. 2002: 31-32). Overall the programme would like to provide more good than harm and these are the practical problems with delivery of formula food that are facing policy makers.

Cape MTCT programme

Chopra et al (2000:298-302) conducted a qualitative MTCT study in Khayalitcha in the Cape Province, where infant feeding practices were analysed to show how these affected the MTCT programme. Seventy caregivers with young children were asked to participate in structured interviews, 11 health care providers were interviewed as well as 11 HIV positive mothers who were asked to participate. The researchers found that disclosure of an HIV status is a very isolating experience and many people reported that the community was afraid of HIV positive people. Some of the partners of HIV positive mothers left them as a result of the revelation of their HIV status. Breast-feeding practices, which were on average agreed on for a duration of 2 years, also included other options such as tea, water, and gripe water. "Exclusive" breast-feeding was interrupted due to factors such as a discontented baby, rejection of the breast or crying.

Knowledge about the transmission of HIV was well known and it was seen that most people understood how to protect themselves. Sixty two percent of the women also understood that a baby could become infected through breast milk. It was found that many of the subjects did not believe in breast-feeding when HIV positive.

General findings suggested that there was a need for accurate information about MTCT, which included risks during pregnancy, childbirth and breast-feeding. Training for health care staff and support groups was also recommended. Breast-feeding options were not well understood by health care workers or mothers.

Women who chose breast-feeding should be monitored and counseled in their local language. Bottle-feeding options should be explained and education on preparation was also important as there was mixed ideas of the quantity and amount of feeds needed per day. Overall the study suggested similar studies should look closely at local problems where cultural differences should be addressed.

Conclusions

In summary, the literature has provided insight into the current status of the HIV epidemic and the South African government's response to it. The cost effectiveness of intervention strategies are addressed by various authors who agree that prevention without the necessary extensions services such as VCT would be fruitless.

Practical prevention methods have been given by documented publications where certain procedures are damaging and others are helpful for preventing MTCT. The literature that supports behavioural changes does not lose sight of medical interventions that may also assist in reducing the risk of MTCT. Other issues that are relevant to the study are the use of antiretroviral therapy and the risk of drug resistance that is imminent in the absence of careful monitoring.

Finally social and cultural factors have intensified the complexity of preventing MTCT, where women are abused both physically and sexually. Amidst poverty and dependence, choices are often not theirs to make and the community in which they live dictates to them what is expected of them. Practicalities and rural realities are some of the lessons learnt at the MTCT experimental sites and these are laced with intricate complications that can hinder a smooth roll out of MTCT prevention.

The literature provided has highlighted some major issues, but there exists gaps in women's own perspectives of the choices open to them regarding best feeding options for their children. It can be seen from the literature that there is a serious lack of information for both the health care worker and the mother who should be able to make an informed choice. Nurses are often the first contact with HIV positive mothers

and should be encouraged to be supportive and empathic. The Khayelitsha study provides a wealth of information for future studies but, as various authors suggest, local studies would be able to pave the way for addressing locally experienced problems. Local mother's perceptions of the information open to her and the experiences she could expect to encounter by her choice would add a source of wealth to the study and fill the gaps in the literature in this regard.

Chapter Three

Research Methodology

Introduction

In depth interviews were held with two groups of subjects, the pregnant antenatal women and the counselors involved with VCT. The sites chosen for interviews were antenatal sites used for the pilot phase of the provincial department of health's Nevirapine MTCT programme.

Women interviewed in this current study had not necessarily agreed to participate in the MTCT programme. The selection criterion was pregnancy and not their HIV sero-status. This became evident as some women had not been counseled and had no intention of seeking VCT. Results of in-depth interviews at two separate urban MTCT sites and one rural site were analysed. The focus of this study was to link the responses to the aims of the study. Firstly, attention was given to women's informed feeding choices both within the household and outside of it, but more specifically their immediate community and health care support systems.

Secondly, feedback from both the women interviewees and the health care workers was intended to identify the choices of women with regard to their knowledge of MTCT and their understanding of the different modes of HIV transmission. This was to establish circumstantial best feeding practices to enable their children to continue being HI virus-free.

Setting

KwaZulu-Natal is situated on the eastern seaboard of South Africa and it is neighboured by Mozambique and Swaziland to the North and Lesotho to the South. The province borders on the Indian Ocean to the East and extends inland towards the Drakensberg mountain range. Deep in the heart of the midlands, Tugela Ferry a small

town situated on the Tugela river can be found. The Church of Scotland hospital and clinic serves as a MTCT site for this extremely rural part of KwaZulu-Natal (Figure 1).

Figure.1 Map of Church of Scotland Rural Clinic.

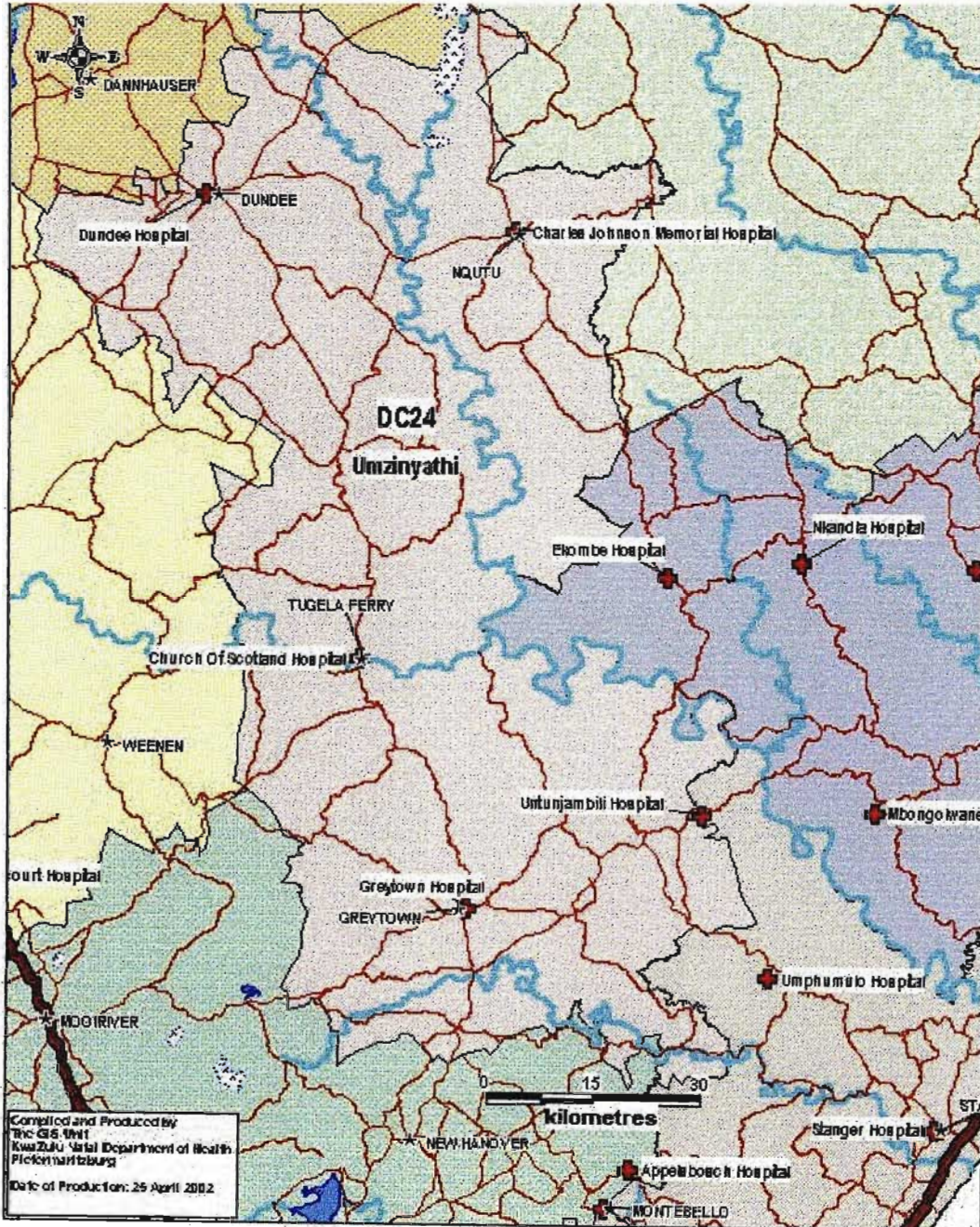
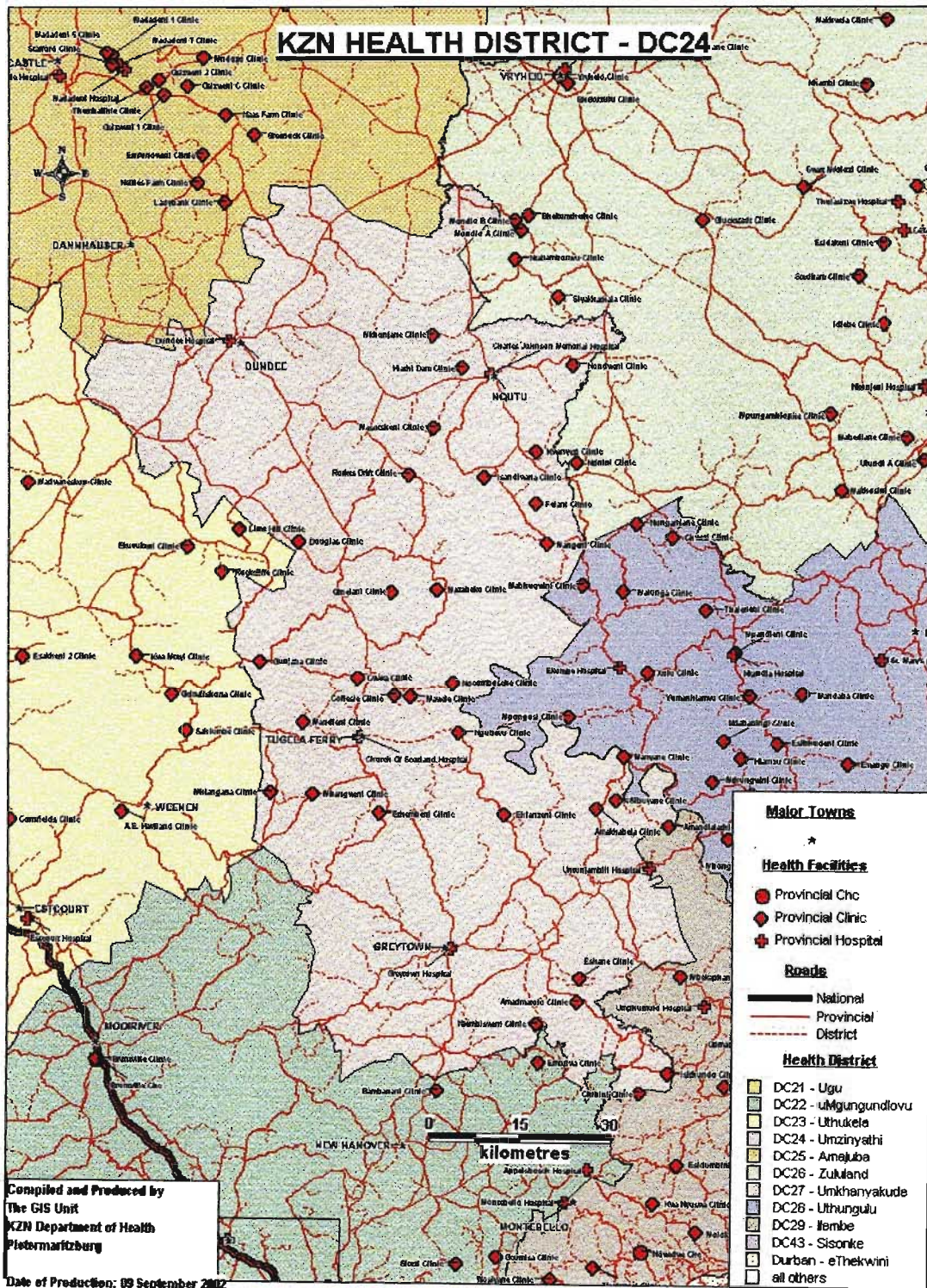


Figure 2 The Clinic Map of KwaZulu-Natal



As illustrated in figure 2 the KwaZulu-Natal health clinics are distributed throughout the province. The urban sites are in Durban and Pietermaritzburg which are separated

by approximately 80 kilometres. The N3 highway links the cities and the various extended sites described previously are meant to service these two major cities with MTCT treatment.

The present study took place, after the National pilot study was conducted at the end of 2000, this mainly measured the feasibility and efficacy of such a programme in this province (Mc Coy et al. 2002). The research and evaluation was meant to cover VCT for pregnant women, Nevirapine provision to HIV positive women, provision of counseling, feeding support and follow-up of mother and baby pairs after delivery.

The local provincial health committee elected to sub-divide their designated two MTCT sites into various smaller sub-sites to cover more of the representative population and area. The Durban sites consisted of King Edward V111 Hospital, Kwamashu polyclinic, Prince Mysheni Memorial Hospital, and smaller feeder clinics in section D and K in Umlazi. The Pietermaritzburg site was sub-divided into Grey's Hospital, which included Northdale hospital, and the Sabantu and Northdale clinics. Edendale hospital, included the Imbalenhle and Taylor's Halt clinics and Church of Scotland Hospital.

This exploratory study had as its focus Durban's KwaMashu polyclinic, Pietermaritzburg's Grey's hospital antenatal clinic and The Church of Scotland's antenatal rural clinic, set in the midlands of the province. The chosen sites covered sufficient urban and rural areas for estimated representation of most of the populations in the areas.

Existing MTCT programmes reported that the urban sites were being facilitated and managed by the Department of Health. (Moodley, 2002.). At the Durban site 9086 pregnant mothers had been pre-test counseled and 4718 at Pietermaritzburg between June 2001 and February 2002. The number of women, who presented themselves for HIV testing, was considerably less, only 81 percent in Durban and 70 percent in Pietermaritzburg. The rural MTCT site at the Church of Scotland (COSH) pre-test counseled 2211 for the same trial period, but only tested 86 percent of these (Table 1).

Other data from these sites are the number of mothers who chose to breast-feed and the number who chose formula. This information only becomes relevant when the HIV status of the participants is known, however their status is not relevant in this study.

Table 1 - Derived from MTCT programme in KwaZulu-Natal (June 2001-February 2002)

	Durban	Pietermaritzburg	COSH	Total
Pres-test counseled	9086	4718	2211	16015
Tested	81%	70%	86%	76%
Breastfed	39%	22%	68%	38%
Formula	39%	78%	74%	48%

At some sites, such as Pietermaritzburg and Durban in KZN, Rietvlei and East London in the Eastern Cape senior doctors are actively involved with the delivery of information and counseling and yet at others medical staff have been excluded from this educational and psychological service. Some sites are experiencing staff problems where lay counselors are often volunteers and do not receive any remuneration this may affect the quality of their work (McCoy 2002:12). Health care helpers who are classed as lay counselors are paid very little and are excluded from performing rapid saliva tests and this translates into a work overload for the nursing staff.

Significance of this study

The MTCT programmes were structured to firstly, pre-test counsel a pregnant mother, and then, to ascertain her HIV status, if she so wished. She could then return to be post-test counseled once she had receives the result of her test. According to the minimum standards for counseling each session should last 30 minutes and then there should be two 30-minute antenatal follow-up sessions (McCoy 2002:11). At the onset, there were problems with availability and access to counseling services. The poor quality of service and lack of encouragement by counselors was perceived as an added disincentive to return for results and there were also the perceived community problems. HIV positive women were faced with discrimination and isolation due to the stigma attached to the disease. The shortage of skilled counselors was only one

small part of the problem. The broader issues hinged on the individual's ability to be bold enough to be tested and consequently to be sufficiently empowered to return for their result. The success of MTCT programmes rests on what precautions are taken with a positive result for the sake of saving the baby.

This exploratory investigation seeks to explore some of the complex issues that prevent pregnant mothers from returning for their HIV test results. More importantly, once the HIV treatment has been accepted for the child it is often taken for granted that the HIV pregnant mother is empowered to keep her child uninfected. As other studies (McCoy 2002 and Chopra 2002) have indicated there are intricate dynamics being uncovered. Feeding methods, are secondary modes of infecting children and these are important life-saving decisions. Community, family and nursing influences and support systems play significant roles in the mother's choice.

In the pilot study of 2000 (McCoy 2002:78) 65 percent of the Pietermaritzburg's urban women opted to bottle-feed and 35 percent chose exclusive breast feeding. In the rural area, however, due to unsafe water and other influences 76 percent of women chose to breast-feed. Although training programmes are currently underway to facilitate an informed feeding choice, social setbacks such as influences on mothers by health care workers and by their family and friends, need to be investigated as this may threaten the smooth delivery of MTCT prevention services.

Methodology

The research methodology is a description of the procedures and methods that are used to gather data for processing and interpretation. The methodology selected for this study follows a qualitative research paradigm where rich experiences in real life can be transformed into meaningful assumptions and conclusions.

The qualitative approach, used in this study, requires the researcher to get to know a social context and to share the feelings and interpretations through the eyes and ears of the subjects and to attach purpose to the behaviour or social action. Qualitative methods assist the researcher in identifying local concerns, opinions and beliefs,

which helps in the provision of details for important topics (Rifkin and Pridmore 2001:31).

A qualitative method that is used in this study is inductive and seeks to attach ideographic meaning that provides a “symbolic representation or thick description of something else” (Neuman 2000:73). Some of the crucial advantages of using this approach are that it provides the reader with another's social reality. Reality is mapped out as it exists for the participants and the reader gains an in-depth understanding of the localities, activities and constraints experienced in others' daily lives.

Exploratory research as a basis for this study was essential, as gaps were found to exist where very little was known about the social occurrences that presented stumbling blocks for sustainable MTCT programmes. Similar studies have been conducted in different social contexts, (Chopra et al. 2002) political climates and geographical settings and have had different focal points.

“HIV and Infant Feeding” was a study undertaken by Chopra et al (2000) in collaboration with the Western Cape Health Department in Khayelitsha near Cape Town where women participating in the programme were told not to breast-feed. Between September and December 1999 the University of the Western Cape, in collaboration with other agencies, identified feeding practices in Khayelisha. Attempts to learn of experiences of women on the programme and use that information to extend the programme to women in other under-resourced areas in South Africa was part of the main objectives.

One such study sought out HIV positive women's breast-feeding experiences in an urban hospital (Seidel 2000). Incidental findings were more related to feeding options as a short-coming on the part of the nurses and stigma attached to feeding methods rather than an absolute exploration of social, cultural and economic set-backs. Exploratory research seeks to lay foundations for future studies when enough information and understanding is gained about these occurrences that may be explored at a greater depth in the future. “Exploratory researchers are creative, open

mindful and flexible: adopt an investigative stance and explore all sources of information” (Neuman 2000: 21).

Methods used in this study aimed to explore the realities behind some of the anecdotal feedback that has been received from the existing MTCT sites in KwaZulu-Natal. Reports such as mothers sharing out formula food to babies other than their own and other incidents of dumping of formula food may be lone occurrences. Interviews with mothers may assist in evaluating existing knowledge of HIV and also serve to remind researchers of the level of absolute poverty and the extent of stigma attached to mother's choices. Gaps in a mother's knowledge and information together with knowledge on feeding options by nursing and health carers and how this is disseminated, was captured by feedback from the patients and staff themselves.

The purpose of the in-depth interviews was to explore areas where gaps in knowledge of populations exist and this method brings the individual's situation to the attention of researchers and policy makers. Listening to and understanding what the interviewee is explaining is vital and therefore probes are necessary to delve deeper than the surface of a problem.

Research design

Sample selection

The sample selection was based on non-probability sampling. This method limits generalisation to the rest of the population, as it is not randomly selected. This purposeful selection was also limited by its availability and volunteer aspect which was a prerogative of the participants. The selection process included the first available patients of the day. The respondents, who had to be pregnant as the only prerequisite, needed to be willing to participate. Anyone who was attending at the time of the study was eligible to be a subject regardless of whether they had enrolled with the MTCT programme or not. The selection of nursing or VTC staff was based on availability. Discussions already indicated that skilled staff was limited and therefore the researcher made use of those willing to be interviewed.

As the MTCT prevention Government-run pilot study had already found, there was a population bias at these sites. Not only was there a higher rate of attendance, but also a greater number of positive patients. Reasons for this was that there were only a few clinics with supplies of MTCT prophylactic treatment and that may have attracted people who suspected that they were positive to travel long distances to these sites. Another bias was that many women being tested may have been tested elsewhere and were only trying to confirm their result. The purpose of this exercise though, was not to seek out HIV positive respondents but rather to include all the attendees at the clinic for selection.

Sample population

One part of the population was made up of pregnant women who were attending the rural antenatal clinic at the Church of Scotland hospital at Tugela Ferry in the KwaZulu-Natal Midlands. This was a non-probability sample as it was not representative of the whole rural population due to the limited size of the sample. The other sample was made up of a combined urban sample of pregnant women from Grey's hospital clinic and the KwaMashu polyclinic which was meant to be a non-representative sample of the urban sector of this population. Personal information from interviewees demonstrated the age-group distribution in the various areas where this study took place. Feedback was provided of their residential origins and number of pregnancies (Table 2).

Table 2 Personal data, comparison of urban and rural samples.

Clinic	KwaMashu	Greys	COSH	Total
No of women	5	5	8	18
Range of ages	19-36 years	20-39 years	16-30 years	
1 st pregnancy	3	0	1	4
Employed	0	1	1	2
Live in area	4	3	8	15

Sample size

The sample size was limited to 8-10 women at the rural site and the same number from the urban sites. The rural sample was collected at the Church of Scotland and

comprised of 8 respondents. The urban sample was made up of 5 respondents from each of the two urban sites. Increasing the sample size may have made the sample more representative and increased its reliability but transcribing large amounts of data would have become time consuming and laborious.

The secondary source of data, was obtained from the health care workers or nurses involved with VCT who were willing to participate. Special efforts were made by the researcher to reduce pressure on the staff. Where possible prior arrangements were made to ensure availability of staff.

Three women counselors were interviewed at the Church of Scotland clinic. The interviews were conducted between counseling sessions owing to the large number of women waiting for the counseling services.

One woman counselor and one male counselor were interviewed at Grey's Hospital clinic. On the day of the interviews the third counselor was not available. The situation at Grey's hospital clinic was much the same as at the Church of Scotland clinic, where a private cubicle was used for the interviews.

KwaMashu clinic provided 3 of their counselors, all of whom were women, for the interview. The counselors were housed in separate units outside the clinic. This was a very busy clinic and here, as with the Church of Scotland, there was a queue of people waiting for the counseling services. One of the counselors at KwaMashu felt at a disadvantage because she lived in the area and this, she felt, imposed limitations on her when imparting an HIV positive message to a mother so she delegated this task to one of her colleagues.

Data collection tools

The Interview

In-depth interviews were conducted with pregnant women and health care workers/counselors. An interview guide was used to ensure overall coverage of all the

relevant topics. (Appendix 3 & 4). The interviewer was schooled in addressing the participants in an open and unthreatening manner. Interviews were conducted in private to avoid fear of intimidation and stigmatisation if others perceived the person as being HIV positive. Tables 3 and 4 show the distribution of participants by area in the antenatal and health care workers sample.

Table 3: Number of interviews of pregnant women.

Sample 1: Antenatal patients		
Rural	Church of Scotland ANC clinic	8
Urban	Grey's ANC clinic	5
	KwaMashu ANC clinic	5
Total		18

Table 4: Number of interviews of health care workers/counselors.

Sample 2: Health care workers/counselors		
Rural	Church of Scotland VCT section	3
Urban	Grey's Hospital VCT section	2
	KwaMashu VCT section	3
Total		8

The interviewer

The interviewer was trained in interviewing techniques. Prior practice sessions were arranged to familiarise the interviewer and the researcher with all the questions and their probes. By repeatedly role playing the interviews they became fluid and conversational.

Interview guided questions

For this study, where sensitivity concerning AIDS was obvious, the researcher concentrated on avoiding threatening questions that may have resulted in embarrassment and cause inaccurate responses. The questions and probes, which were guided by an interview guide that allowed for different phrases, was designed to

explore the knowledge of both the pregnant mothers and the nursing staff to ascertain gaps in either one of these groups. These could contribute to short sighted choices on the part of the mothers.

Questions were categorised into a general section where the age, working status and residential area were recorded. Questions such as these were used to place each respondent into a contextual position. Feeding options for the mother was another category that was explored. Personal information as a category clarified the mother's own preference for a particular way of feeding her baby. Perceptions of other people in the community, family and friends in relation to feeding choice, was another topic for exploration. The next section was to evaluate the mother's knowledge and how this had been acquired. This section was concerned with breast-feeding in relation to HIV. Lastly, the questionnaire probed the uptake of VCT services and perceived reasons for non-return following testing and why some people declined to know their test results.

Questions were guided by an interview guide to enable the researcher to explore all the core issues which would otherwise be omitted by an over zealous interviewer. This was essential to create complete coverage of all the research questions and the open-ended nature of the questions allowed for individual comments and opinions. In this study, consideration was given to introducing probes where necessary to allow respondents to clarify certain issues. Another advantage of in-depth interviews are that they prevent misunderstandings and misinterpretations as these may be clarified by the interviewer at the time. Disadvantages were that these interviews could infringe on privacy and absolute anonymity of the respondents, which is seen to be threatening by face-to-face communication and may inhibit spontaneity. Personal interviews are costly, time consuming and often involve transcribing and translation.

The data collection process

The researcher and interviewer set a day for a visit to each of the MTCT sites. Pregnant mothers who consented to be interviewed were taken to a private room and the interview was conducted. Care was given prior to conducting the interview that the respondent signed a written information/consent form. (Appendix 5) This form was designed to assure the validity of the study and that it complied with the research ethics committee's requirements. The respondent was assured of absolute anonymity and confidentiality and was assured that the interviews were only being used for this research project.

The researcher then became the interviewer for the health care workers and performed a similar procedure. The health care workers or counselors were assured of anonymity and confidentiality and were given a consent form to sign (Appendix 6).

The interviews were conducted using the guided interview and when the respondents gave their permission a tape recorder was started. This was essential for the Zulu speaking respondents where it would be extremely time consuming to take notes of all the answers during the interview. Although the use of a tape recorder may have inhibited responses, attention was given to creating a relaxed environment so that the technology was forgotten.

Ethical considerations

Informed consent was received from each of the respondents. There was no pressure on any of the respondents to participate and this was voluntary. Owing to the extreme sensitivity of this study, ethical approval was essential (Appendix 7). This was subject to permission from hospital superintendents or site managers to conduct the study (Appendix 9). Health care workers and pregnant mothers were assured of confidentiality and anonymity. Assurance was also given that the information was to be used for research purposes only. Health care workers were also be assured that their responses would not effect their employment in any way.

Data analysis

Data was analysed by transcribing and translating the tape recordings into English from Zulu. The raw data was read and sorted several times to familiarise the researcher with similar and different responses. Data analysis was a way of forming patterns and the use of qualitative methods depends on finding recurrent behaviours, events or occurrences from which themes can be formed. Thematic analysis as a method of analysing data was used. This is when a pattern is sought in the collection of information that becomes a way of seeing, making sense, analysing systematically, observing and converting qualitative raw data (Boyatzis 1998).

Thematic analysis was useful in this research where the interpretative method of the researcher required social construction of meaning to be couched between consistent reliability and consistent judgement. Thematic codes were developed to enable the researcher to classify themes and here a hybrid approach was needed. This approach combines a theory driven, prior research-driven and data-driven approach but, essentially there is more reliance on the researchers thoughts, ideas and perceptions.

When developing themes and codes there is a need to reduce the raw data, and then to summarise each section (in this case responses to a question) of the data.

The questions in this study were divided into various areas of investigation. Questions for the pregnant mothers firstly sought to place her at ease with some general background questions. This was important contextual information where age (inexperience) and number of previous pregnancies (experience) may have made a difference to feeding option. The next broad outline was personal choice and this allowed the respondent to voice her first preference.

The following section asked about perceptions of influences of peers and family and how this affected the level of the woman's autonomy. Here some of the deep set cultural beliefs, societal and family obstacles were uncovered. Knowledge of HIV/AIDS was then explored and here questions probed the source of knowledge and information.

The literature has given strength to this investigation where emphasis was placed on the low social status of women, and power relationships from health care workers and family members (Mager 2000, Seidel 1993 and Jewkes 1998). The latter theme was explored more when the health care workers as a secondary source of data were questioned about their knowledge, practices and perceptions. These were important themes that were pursued when the data was analysed.

The next step was to compare summaries within the samples in search of similarities and patterns. Creating a code is a method of constructing statements that differentiate by means of editing, rewriting and reconstructing. The codes and themes drove the data towards a comprehensive reliable analysis and conclusion. An identification code was developed to identify responses of pregnant individuals who participated at the MTCT sites as volunteers for the study. The alpha-numeric codes readily identified the site location of the respondent, for example Church of Scotland clinic is identified as "COS", KwaMashu clinic as "KM" and Grey's hospital as "G" (Appendix 8).

Limitations of this study

Many people regard HIV as a reprehensible infection related to personal behaviour because it is an STI. This may cause respondents to fear that they are blamed. Other envisaged limitations was the language barrier, where the use of an interpreter may have not captured all of the rich expressiveness and non-verbal communication in the transcribing and translating process.

Bias may have been introduced in the recording process, Bless and Higson-Smith (1998:126) point out that this can be caused by a lack of information or the way that that the information is recorded. The interviewer may also unknowingly introduce a bias through his/her interviewing style. When the recorded data was translated from Zulu and transcribed into English, an independent Zulu person was employed for the purpose. Reliability was thus increased.

This study was limited by its size and geographical coverage. The most impoverished remote areas that border with neighbouring states may provide different problems, which this study may have excluded. Future studies may be extended to these isolated areas where illiteracy rates are high and information is scarce.

Conclusion

An overview of the research methods that were used in this research project attempts to show that through qualitative research methods existing MTCT sites can be revisited with a view to identifying some of the core concerns for the continuity and expansion of the programme.

Pilot studies in the past have mainly been concerned with the feasibility and efficacy of the programme and no effort has been made to ascertain the mother's own perceptions, attitudes and knowledge. This study investigated the social and economic complexities in three clinics in KwaZulu-Natal with an optimistic vision of reaching some of the focal concerns of the participants of the study.

Resistance from the community was felt when mothers chose not to breast-feed but this has been ascertained mainly by anecdotal feedback. With the use of in-depth interviews with pregnant women, this study may provide future researchers with enough knowledge of the problems involved with feeding options and influence policy makers to promote informed choices and to minimise other influences.

Chapter Four

Findings

Introduction

Information gathered from three MTCT pilot project sites in KZN are discussed in this chapter. For the sake of clarity the findings will be discussed according to the two groups of subjects, pregnant antenatal women and counselors involved with VCT. Interviews were conducted at antenatal clinics in urban and rural areas. In this chapter responses from interviewees with regard to breast versus bottle and the problems with each are identified.

Breast-feeding is perceived as the norm but to prevent MTCT, formula-feeding has to be considered. Some of the problems with bottle-feeding included costs of formula milk, difficulties with ensuring a clean bottle and warming the milk.

Antenatal women

Choice of feeding option

It became evident, as will be discussed, that there are several factors influencing the mother's choice between breast and formula feeding. It would appear that although some of the women interviewed claimed to have autonomy in making their choice nevertheless there could be considerable pressure placed upon them to make the approved choice.

These pressures included partner pressure, family pressure from in-laws, mother and other immediate family, peer pressure and the community. Perceived ideas of the norm within the context of culture and the community to gain approval was apparent in some cases as a subliminal influence affecting their choice.

Breast-feeding was the choice of the majority of the women interviewed. The reasons given varied and are elaborated upon in this section of the chapter. A modest number declared their intention to bottle-feed and another wished to use bottle-feeding but feared she would not be able to afford the formula milk. Younger women were more likely to bottle feed than older women. One was experiencing her first pregnancy, others had one or more children and a few had previously breast-fed their babies.

One young woman appeared to prefer bottle-feeding so that others could help her care for the infant. She appeared to consider the care of the infant a shared responsibility for when asked for the advantages of bottle-feeding she responded that her mother and her sister would also assist her with her baby.

“Anyone can feed the baby” and named, “my mother and sister” as being partly responsible.

rural woman # COS 7

As this was her second child, at the age of 16, it appeared to be the responses of a very immature juvenile.

Another young woman had decided to bottle feed, but gave no reason for this choice. She was the only one of those opting for bottle-feeding who came from an urban area all the others came from rural areas in or near Tugela Ferry. She was not concerned with the many pressures experienced by other rural women interviewed at this clinic.

One of the women reported bottle-feeding met with her family’s approval which at first sight appeared contradictory, but as she explained:

“They like it because I am always sick. You can leave your child with anyone if you are sick”.

rural woman # COS 5

She therefore wished to bottle-feed and she had bottle fed her previous babies too. Although she expressed opinions favouring breast-feeding, when asked how she made the choice of how best to feed her child she responded:

“I do not like it (bottle-feeding). You have to do it yourself (prepare the food) because of health reasons. It is the germs that the child can easily get if the bottle is exposed to germs”.

rural woman # COS 5

This woman was aware of the additional responsibility imposed by bottle-feeding in respect of hygienic needs and appeared to use the bottle only because of her own ill-health.

Another rural woman said that although she had previously breast-fed her babies and despite the fact that she was unemployed she still wished to bottle-feed her new baby. She acknowledged that there were family and community pressures for her to breast-feed but she emphasized her intention to make her own choice:

“I am going to bottle-feed it is fine, I like it. It is good when you are working and won't be around to feed the baby.”

rural woman # COS 2

Of the mothers opting for breast-feeding, which formed the majority, only one, expressed a preference for bottle feeding and had tried to use this method with her previous babies. She gave as her reason for choosing the breast due to the high cost of formula milk.

“I am going to breast-feed because I am not working. I would have liked to bottle-feed but because of financial constraints I cannot. It happens that while you are still breast-feeding the breast develops some sores then I cannot breast-feed. I have to buy milk for the baby.

Its good for the baby because it is not mother milk, so it cannot harm the child so the child can be protected.”

urban woman # KM 2

The younger women were determined to complete their education. However, they expressed their intention to breast-feed. Several women expressed their opinion favouring breast-feeding because it was cheaper and best for the baby.

“I hear breast-feeding is the best so I use it because I want the best for my baby”.

rural woman # COS 4

“I am going to breast-feed. The baby who is bottle-fed is usually sick and it is expensive”.

urban woman # KM 3

Older women opting for breast-feeding were firm in their intention to breast-feed. Overall the women expressing the choice of breast over bottle when viewed from their place of residence, urban or rural, fell in a ratio of 9:5. The overall residential distribution of the 18 women interviewed was 10:8 indicating in this small group of women that breast feeding as an option over formula was favoured equally by both urban and rural women even though those in town had better facilities such as safe water and electricity.

Women cited a number of advantages for breast-feeding. Several confirmed commonly accepted reasons such as the sterility of breast-milk, nutritional value, its availability and its consistent body-temperature, which reduces fuel costs for heating and laborious sterilising processes required by bottle-feeding. These are illustrated in the following comments

“It’s good for both the mother and baby and mother’s milk has got the antibodies to protect the baby from diseases”.

urban woman # KM 4

“because the child does not get germs from the breast. There is nothing good about the bottle, it carries a lot of germs”

urban woman # KM 5

“It is the best because it keeps the baby fresh. For me there is nothing nice about bottle-feeding because you have to be extra careful with it”.

rural woman # COS 5

All of these responses, and others, gave a clear indication of the health department’s efforts over the years to promote breast-feeding as the option of choice, mainly to reduce diarrhoeal disease. It is also an indicator of the difficulties that will be experienced if the health authorities decide to promote bottle-feeding as part of their strategy to reduce mother to child HIV transmission.

Employment influences

Women who were currently employed chose to breast-feed despite the greater convenience of the bottle for unspecified reasons, these may include the perceived greater nutritional advantage and pressures to conform. The women opting for formula feeding were all unemployed so it would appear that employment status does not play a major part in the choice between breast and bottle. The woman who was teaching, which meant that she was away from home during the day, opted for breast-feeding. This choice was the same for her previous babies, although she admitted it was necessary to resort to the bottle whilst she was working,

“I will hire someone to look after my child. If I am at work I have to rely on bottle-feeding. They will have to bottle-feed and give some solids when she is old enough”.

urban woman # G 2

“The bottle is good only if you work and you want to leave your child with someone. I will hire someone or my sister can help”.

rural woman # COS 8

From these responses it might appear that the use of exclusive breast-feeding is not considered to be important by these women. This was confirmed by some of the other responses when asked how their careers would affect the feeding of their child.

“During the day she would eat porridge and in the afternoon when I come back I can breast-feed”.

urban woman # G 1

Although exposed to information regarding vertical transmission of HIV, including viral passage in breast milk, and the use of Nevirapine they still took the pragmatic approach of day-to-day practicalities and opted to breast-feed.

Other pressures

There was some evidence of perceived autonomy on the part of some of the women. When asked who helped them with their choice of a feeding option several women, both in the rural and the urban samples, asserted that they made their own decision, as is illustrated in the following comments.

“It’s me, I make the decision”, another woman said, “Its me the mother, my husband is working he cannot help me decide”.

urban women # G 2 & 3

Although many of the women questioned confirmed this, there were others who indicated that there was influence from close family. Despite asserting that the choice to breast-feed was her own decision one rural woman when asked directly for her partner's opinion admitted:

“My boyfriend wants me to breast-feed, nothing else he says I must breast-feed because it does not cost nothing”.

rural woman # COS 8

Several others admitted to pressure from mothers or partners to breast-feed, if not from family, then from friends or the wider community. These responses illustrated the fact that the pregnant women do not have autonomy with regard to this important issue of feeding choice but are influenced by other members of the family.

Referring to general reactions to a mother not breast-feeding this rural woman replied, Zulu people only accept bottle feeding as an option if the mother is sick.

“for us Zulu we believe in breast-feeding unless you are sick.. they will say you are stupid for not putting your child's health first.”

rural woman # COS 8

Another said

“They disagree and force you to breast-feed. They want to know the reason for not breast-feeding”.

rural woman # COS 1

It would seem, from several of these responses that although many women consider that their decision to breast-feed is their own, it may, in fact, be subliminally influenced by others and the mother's wish to do the accepted thing in the eyes of the family, friends and wider community.

This view is partly supported by one forthright urban woman who responded to the question what do the in-laws say if mothers refuse to breast-feed?

“I do not know and I do not care”

There was a suggestion of assertiveness and independence in this reply that was further confirmed by disinterest shown when asked to how members of her family viewed bottle-feeding. The demeanour of this well-spoken and articulate woman gave support to the interpretation that her responses were spoken with conviction.

“I do not know.”

urban woman # G 2

Her responses indicated a resistance to outside influences and suggested that the apparent autonomy with regard to choice might be weighted by the need for peer approval. As this respondent was a 39 year old teacher, married but involved with her own career it would appear that she had a degree of self-sufficiency and a sense of personal worth that helped her to distance herself from the views of other members of the community.

Age

It appeared that the age of the subject had some bearing on the type of response elicited although the counselors did not regard age as being relevant. The younger women were more likely to be influenced by parental and other family pressures in their choice of feeding option or to have expectations of maternal support in the care of the child. When asked “who makes the decision on how best to feed the baby?”

The following response was elicited from a young woman who explained that the father was also involved in decision-making regarding the baby.

“it is the father of the baby. Yes, he is playing a major role in this”.

She had responded to an earlier question are there others in the family who helped you choose how to feed, with the response that her mother also helped her to reach a decision.

Older women tended to be more assertive as all of the women declaring the decision on feeding option to be their own were of mature age, range 24 years to 39 years except one, a 19-year-old in grade 12. When asked who will care for your child when you are at school? Her reply:

“my Aunt whom my stepmother hired”.

urban woman # KM 4

Two of the women whose choice was assisted by their mother also claimed their partner’s influence. All these were young, aged 17, 18 and 20 years. Some reported being influenced by other family members but did not specify relationships except one who did explain that her older sisters influenced her choice.

Cultural autonomy

All of the women interviewed considered breast-feeding to be the norm and perceived this to be the accepted norm both within the family and the community.

When this question was probed more deeply the perception was, that in most cases when a woman chose the bottle rather than breast, it was because of sickness, either of the mother or the baby. One of the mothers opting for formula feeding stated,

“I am sick, I cannot breast-feed the child, I have one option”

rural woman # COS 5

It was a universal response that failure to breast-feed brought pressure from the partner and in-laws as well as other immediate family. Friends and family would regard one as lazy resisting breast-feeding,

“Some say you are lazy for not breast-feeding and they want to know why”.

rural woman # COS 2

Sickness of the mother, as a reason for choosing the bottle rather than the breast, was acceptable as it was linked to a concern for the welfare of the infant.

A rural woman confirmed this:

“The nurses said if you are HIV positive you must not breast-feed, but use bottle-feeding to avoid infecting the child”.

rural woman # COS 3

One woman responded to the question “How do friends react if you bottle-feed?” with the response,

“Some do not support you and some do as they are concerned with the welfare of the child. Some complain and just accept your decision. Some just leave you like that and some help you with the buying of milk”.

rural woman # COS 5

It appeared that the responses regarding the perceived norm in the Zulu culture was the same in rural and urban groups, sickness is the only acceptable reason for not breast-feeding.

Mother’s health and previous experience

Of the women who had previously breast-fed few opted to use bottle-feeding, only a 24-year-old who had opted for formula due to sickness had also used bottle-feeding previously for the same reason. One other, a 39-year-old woman, who although opting for breast-feeding on this occasion, claimed:

“they all had both breast milk and formula, I prefer to breast-feed but if I am at work I have to rely on bottle-feeding”.

urban woman # G 2

A few who had breast-fed previously, had supplemented the breast with solids either porridge or vegetables with purity foods.

Convenience

The employed woman as well as the younger women were more likely to bottle-feed because it was more convenient and enabled the employment of surrogate carers, when the mother was away as expressed by a rural woman,

“the bottle is good only if you work and you want to leave your child with someone”.

rural woman # COS 8

Another woman also commented on the convenience of the bottle as compared to the breast when in mixed company to avoid the embarrassment of exposing the breast. Despite the ready availability of breast milk to meet the infant’s demands and its greater safety self-consciousness on the part of some women when feeding their child in public was evident.

At KwaMashu clinic all the women, with the exception of one, intended breast-feeding their child although this person stated that this was the expensive option. One young woman said,

“I was told that breast-milk is good for the baby’s health. The baby grows up healthy”.

urban woman # KM 4

“The milk is full of nutrition, it is cheap and always warm. (Bottle-feeding) helps when the mother is not around so they (anyone) can feed the baby in your absence”.

rural woman # COS 4

Most of the women agreed that breast-feeding carried advantages of cleanliness, ready availability, the correct temperature, prevention of infant infections and the fact that there was no cost attached.

Comments such as:

“it is full of nutrition and antibodies to protect the child from harmful bacteria’s”.

urban woman # G 3

A different view was that,

“Sometimes you want to breast-feed but the baby does not like it, so you have to buy the milk to feed the baby”.

urban woman # KM 4

Convenience was one of the priorities for mothers when deciding how best to feed her child and although this was more evident in terms of saving time and “readiness” there was a definite concern overall for safe, germ-free feeding.

Cost

All of the respondents were attending public sector clinics and it was safe to assume they were of the lower socio-economic sector of the community. They were therefore very conscious of expenses attached to bottle-feeding their child.

When asked for her views on bottle-feeding a 36-year-old urban woman expressed her concerns regarding the expense of buying formula milk, although she wished to be

able to bottle-feed she explained that as she was presently unemployed she found the cost of milk too expensive and beyond her financial resources.

“I would have liked to bottle-feed but because of financial constraints I cannot”.

urban woman # KM 2

She had previously tried formula feeds but this was not successful which was reflected in her reply;

“they all had breast-milk because they did not like bottle-milk”.

The expense of formula feeds was commented upon by many of the women. Most people were aware that the clinic’s supply of formula food was for a limited time only.

Stigma

The need to bottle-feed the baby when the mother is HIV positive is widely known irrespective of whether the mothers came from rural or urban areas. It follows that formula feeding will therefore be regarded with suspicion whenever stigma is strong. An example of the fear of stigma, was expressed by one woman,

“I think it is the fear that if they were found positive the man in her life would leave her”.

urban woman # KM 4

Another person admitted:

“if you do not breastfeed you are labelled as HIV positive by friends”.

rural woman # COS 4

There is suspicion attached to the person not conforming to the cultural use of breast-feeding. One respondent expressed the stigma attached to HIV/AIDS. When asked how friends reacted if the mother does not breast-feed in the context of HIV testing she replied:

“they say you are HIV positive”

rural woman # COS 6

This common suspicion within the community linking bottle-feeding with HIV status and adding to the stigma of the disease is evident in a number of responses to fairly innocuous questions, for example when asked if she knew many mothers who do not breast-feed their babies, one woman replied:

“yes, those who are HIV positive. They are protecting their babies from contracting HIV”.

rural woman # COS 1

There is perceived to be a need to explain why the baby is not being breast-fed so excuses such as the following were given:

“some say they have no milk so they cannot breast-feed.”

urban woman # KM 1

“they say if you breast-feed you will lose weight”

urban woman # G 3

Most of the women, except the one who would not tolerate any interference from family and least of all from her husband, admitted to pressures from their immediate family and friends. Part of the admissions reflected the underlying suspicion if women did not breast-feed the most likely reason was assumed to be because she was protecting her baby from the risk of HIV. Speculation on the part of peers or the mother-in-law either forced women to breast-feed thus dampening the suspicion of

HIV or in some cases this caused them to lie by saying that they had no milk or their breasts were sore.

Advantages and disadvantages of feeding options

Despite the fear of not conforming to the cultural norm of breast-feeding some women perceive certain advantages in bottle-feeding their infant such as freedom of movement, sharing the responsibility and availability of work opportunities should these arise. They are also aware of some of the disadvantages of bottle-feeding especially with regard to the baby's safety from intestinal infections. Some of these issues are illustrated below.

For some people the bottle-feeding option in the rural areas related to freedom of movement as the women have many domestic duties outside the house such as the collection of water and fuel they feel less restricted if others in the family can care for their baby whilst they are away.

“anyone can feed the baby and it is healthy”.

rural woman # COS 7

Another woman who chose this option said that it was good if she was working and wouldn't be around to feed the baby. Another response was,

“if I am at work I have to rely on bottle-feeding”.

urban woman # G 2

Risk of infection from contamination was acknowledge by some women, who were aware of the need for scrupulous cleanliness:

“the disadvantage of bottle-feeding are many, you have to wash the bottle”.

urban woman # G 2

Another rural person confirmed this by saying,

“the bottle attracts germs and flies”.

rural woman # COS 8

Reflecting on statements from all of the pregnant women, it is evident that most agree that bottle-feeding has risks and carries more disadvantages than advantages. Supporting the downside of formula feeding there was an impressive amount of knowledge both in rural and urban areas.

“I don’t like it, (bottle-feeding) a child that has been breast-fed has better chances of growing up healthy” (further probes) “It is best because it is full of nutrition... with the bottle the child does not grow well”.

rural woman # COS 1

Many women admitted knowing other women who did not breastfeed their babies. Reasons for not breastfeeding were different for many of the women and again suggested that there was a need for a ready reason for not breast-feeding to avoid the suspicion of being HIV positive. Some examples were:

“They are sick”, “Yes those who are positive”, “Some have no milk and some are HIV positive” “They have diseases” “She said her child is sick and that is why she is not breast-feeding it”. “They say the child does not like breast-milk”.

Some of the problems with bottle-feeding that were mentioned were that the milk is very expensive “while breast-feeding cost nothing and it is easy”. Somebody also explained that the bottle had to be washed or that the formula could get germs if the lid was not properly replaced and that the added burden was “that you cannot give it to the child without warming it up”.

Supplemented breast-feeding

It appeared from most of the responses that supplementing breast feeds with porridge, other solids and juice was accepted within the family and the general community as the norm. These supplementary foods ranged from Purity to mashed vegetables and juice. It should be noted that the status of the women is not known and that these supplementary foods should be considered the norm where there is an absence of a “positive status”.

When the concept “exclusive breast-feeding” was probed it was found that there was an exceptionally high rate of knowledge of what this concept entailed. It was widely understood that no other supplementary foods or liquids should be added to the child’s diet if a mother was on an “exclusive” breast-feeding programme.

“you breast-feed for six months or you don’t breast-feed at all for six months you use formula”.

urban woman # G 2

“they said I can breast-feed for six months and must not mix it”.

urban woman # G 3

“she must bottle-feed and not mix for six months”.

rural woman # COS 5

All of the other mothers knew that if Nevirapine was given to prevent HIV transmission the mother must breast-feed exclusively or bottle-feed only. A teenager’s response to the question was indicative of her awareness on how to obtain knowledge

“it is important so you don’t infect the child and you can get advice from the nurses on which feeding is the best if you are HIV positive”.

urban woman # KM 3

Exclusive breast-feeding options in both the rural and urban sample supported ‘no mixing’ with breast-milk for six months. This did not match with the women’s initial response when some of them named supplementary food mixed with breast-feeding.

Understanding of Nevirapine

Knowledge of MTCT of HIV is high among respondents and very few reported not knowing that the virus could be transmitted from mother to child. Rural and urban women alike were well informed about the meaning of exclusive breast-feeding as one of the reduction strategies of MTCT.

When asked about the information on MTCT given to mothers in the urban sample answers were varied. They ranged from one response to the question what do you know about Nevirapine? Being a disinterested “nothing”

“I do not know how is it given to the baby” “I do not know”

urban woman # G 1

One woman said she knew nothing about Nevirapine and had been told nothing although she had been tested. This suggested that she was disinterested as the education in all of the clinics was consistent and the counseling she received before testing would have included information on MTCT.

Others demonstrated knowledge and understanding, as follows:

“Nevirapine, it’s the pill that protects the child from HIV, the child gets two drops in her mouth when she is born”.

urban woman # G 4

“...they said if you tested positive you were going to be given Nevirapine just before you give birth so that your child will come out perhaps negative”.

urban woman # G 2

It was evident that much effort had been devoted to education regarding issues of MTCT and the need for mothers to accept responsibility.

“I do not know, I hear you cannot mix bottle-feeding and breast-milk. The nurses did not say anything, but some people come to us and counseled us and encouraged us to do the test... They said if you tested positive you were going to be given Nevirapine so that your child will be negative”.

rural woman # COS 5

Most of the rural women’s knowledge of HIV and MTCT was sound, as most of the women knew that Nevirapine only helped the child and not the mother. It helped to prevent the child being positive. Knowledge of feeding options for the positive mother were all for “bottle-feeding” and some said she is not supposed to breast-feed.

Acceptance of VCT

The failure of mothers to return for results at many VCT sites was thought to be related to the delays arising from blood specimens being sent to often distant laboratories and the long wait for results. This problem has been overcome in terms of “turn-around time” through the use of rapid test kits giving results, which are now available within 20 minutes. Despite this, women still have the right to their autonomy and can still decide if they want to know their HIV status.

One young mother admitted to being tested but stated that she did not want to know the result as she was afraid of her reaction if the test should prove positive.

“a positive result would send your blood pressure rising”.

urban woman # G 5

There was evidence of a more responsible attitude with regard to testing on the part of one woman who replied in the affirmative since she would not wish to infect others and would choose rather to live alone.

“Yes it is important (to know) so you would not infect other people and you must be alone at all times”.

urban woman # KM 2

Other women replied with regards to their possible emotional response if they tested positive with the following comments:

“it is very scary” and “that you would want to kill yourself”.

urban woman # G 4

“they do not want to be depressed, like me I would only want to know after I have give birth – right now I am scared because if I knew I would get sicker and have no one to talk to and that would eat me alive”.

rural woman # COS 6

These responses illustrate the depths of despair that many might feel in response to this disease, such responses might be very different if there was hope of treatment and support but unfortunately there is presently only fear and despondency, as illustrated by the following comment:

“some are afraid of how they are going to tell their husbands and some just do not want to know”.

rural woman # COS 5

VCT services appear to be successfully reaching out to many mothers but some reported that they did not want to know their HIV status and some were not interested in the VCT process.

“No. I do not want to know my status”.

rural woman # COS 4

There were women who responded more positively, they might have a more supportive partner, or have an understanding family structure or be more optimistic by nature. Alternatively it is possible that these women were confident of their negative HIV status.

“For me I would prefer to know because I hear if you are HIV positive you must not have sex, so to protect someone else its better to so practice sex safely”.

urban woman # G 1

Some people were blasé about the programme and even dismissive of its significance when asked had they tried it?

Only a small portion of the women had not been tested. Reasons given for not being tested were for one person was that she did not want to know her status. A few other people had not been in time for the session and one other person gave no particular reason. Some respondents thought that the VCT service was meant for ‘other’ people. Whilst others, it was encouraging to see, had “normalised” the service in their own minds.

One woman, who saw this as the same as any other life-threatening disease, reflected an exception to the range of normal responses to a positive HIV result.

“It’s because when they know they think they would have suicide thoughts and that would kill them, but for me I treat this disease just like any other disease, for example Cancer or TB, but all in all we all going to die and there is nothing we can do about it is just a matter of how or when”.

urban woman # G 3

One woman was adamant that people would want to know their results because she appeared to think that treatment would be available. This may be a reflection of mixed messages from the media and even the counselors.

“Yes they must prefer to know so they can get treatment. What is the point of having the test done if you do not want to know the result, I think they would like to know the results”.

urban woman # G 2

From the level of attendance to the VCT section, it can be suggested that it is seen to be favorable by most women.

Counselor helpfulness

It was evident that the counselor’s and the nurse’s helpfulness with regards to information and perceived levels of confidentiality were highly thought of by most of the women. This perception could, of course, be due to courtesy bias but during the time of the visits to the various clinics and the surrounding clinic areas an atmosphere of congeniality was apparent.

“All the nurses here are wonderful”. “yes they are friendly” other responses were “Yes they are helpful”.. “Yes they give us advice on how to protect ourselves”. “Yes they give you time”.

urban women # G 2, G 3, G 5.

Women attending the antenatal clinic were confident about sharing information with the counselors. However, some younger women felt that it was hard to share private information with strangers.

“no, I am scared” in response to do you feel comfortable in speaking about personal and sexual problems with them?

rural woman # COS 7

“no it is not easy, you get afraid. But they do have time for you”.

rural woman # COS 8

In summary, the women who were interviewed did not vary much in their feeding choices and those that chose the alternative of formula feeding found justification for that choice in the support of other care givers. Influences by peers and family were also evident. Acceptability of the VCT services appeared to be accepted for most people in this sample.

Counselors/health care worker opinions

Introduction

At the Church of Scotland Hospital, health care workers or counselors, (for the sake of simplicity) were provided with private cubicles where they could give pre-test counseling to pregnant women. Depending on the outcomes of the pre-test counseling session it was then decided whether an HIV test would be done by the normal rapid method which meant that the woman could return in a few hours for her result and to be given post-test counseling. This was also the routine at the remaining two urban sites visited where similar procedures were followed with only the physical infrastructure of the facility differing.

The findings discussed in this section are primarily to establish the feeding choices offered to women by the counselors. The age of the women, employment status, family and community pressures are other areas of the findings. Added to this is the relevance of previous child-rearing experiences. Another issue that may present obstacles for the pregnant woman and influence her decisions is her health status at the time of deciding. “The most convenient choice” responses are captured and also the perceived advantages and disadvantages from the counselor’s experience with women. The extent of stigma related to HIV is also explored. The findings are concluded with a brief description of responses pertaining to knowledge of

Nevirapine, virus transmission and the concept of exclusive breast-feeding, and their own views on the uptake of VCT among women.

Mothers choices

The health care workers at the voluntary testing and counseling sites offer women, who are attending, choices between breast-feeding and bottle-feeding with instructions for both methods if they are HIV positive. One of the counselors interviewed confirmed this,

“She can choose whether she is going to breast-feed or use formula feed but if she chooses to breast-feed she can do it for six months only and not mix”.

The counselors are trained to make sure that pregnant mothers are aware of the advantages of both bottle and breast-feeding. Some counselors who said that they do not tell the mother how to feed but usually outlines the advantages of both bottle-feeding and breast-feeding confirmed this. The information the mothers receives is given in full support of their feeding choice and this was illustrated by one of the counselor’s responses,

“The best feeding option depends on the mother and what feeding option she chooses, the mother can be HIV positive and if she chooses to breast-feed you can not say no, so you have to give the mother all the information”.

Age

The health care workers did not regard the age of the mother as of any importance when making choices for the best feeding option. Age, as perceived by the counselors was therefore not considered to be significant.

The health care workers at the voluntary testing and counseling sites offer women, who are attending, choices between breast-feeding and bottle-feeding with

instructions for both methods if they are HIV positive. One of the counselors interviewed confirmed this,

“If breast-feeding is not working we advise them to use Pelagon (dried milk) which we think is good for the child”.

The counselors are trained to make sure that pregnant mothers are aware of the advantages of both bottle and breast-feeding in order to make an informed choice. This objective was confirmed by some counselors who said that they do not tell the mother how to feed, but advises her on the advantages of both bottle-feeding and breast-feeding. It can therefore be concluded that the immaturity of the women is not considered to be of importance by the counselors, instead each person is treated equally and the ultimate responsibility of their feeding choice becomes part of their autonomy.

Employment

The health care workers confirmed that most of the women were unemployed and this did not mean that they needed to rely on other people to care for their children. One counselor did comment, in defense of working mothers, that you were not supposed to mix feeding methods and when one was working how did you explain this to your family. It was expected of her that whilst at home, she, the mother should breast-feed. Due to high unemployment in the sample of women, this may have meant housework, as opposed to formal employment. Widespread poverty is evident and to this end there is optimism among the counselors that women may find work after their confinement which may account for the abovementioned comment.

Peer pressures

It was found from the responses by health care workers, that pressures did exist within the community and family. This often influenced the choices that pregnant women made. In support of this one person contended,

“In our culture (Zulu) there is discrimination where you find that if a mother is not breast-feeding they quickly assume she is HIV positive especially the mothers-in-law, they put pressure on the mothers and you find that the mothers are afraid not to breast-feed”.

“I had a lady that chose to breast-feed, but after six months when she decided to bottle-feed her boyfriend did not like it, saying why she stop breast-feeding he would not buy milk. We have cases like that where your mother-in-law or boyfriend does not understand why you are bottle-feeding and they force you to breast-feed”.

Many of the counselors laid great emphasis on the importance of pressures within both the family and community to breast-feed but some counselors contradicted this and said that the family did not mind it was just the expense of formula milk that was the problem.

Previous experience

The health care workers did not find previous pregnancies were significant with regard to choice of feeding option. More reliance was placed on the present HIV status and the condition of the mothers' health. This opinion was confirmed by a counselor who said of a particular mother that:

“most of the time she is weak and cannot breast-feed the child”.

There was not much said about the number of pregnancies and how this influenced the choices of mothers.

Health

The health of the mother plays an important role and to this end counselors advised mothers to bottle-feed as a first choice. One person illustrated how she would react if she was HIV positive and had to make a choice,

“If I was HIV positive I would not breast-feed knowing very well there is HIV virus in breast-milk....”

Some counselors explained how they gave mothers' choices if she was HIV positive. It appeared as if the patient was confused because of the stress of learning that their test was positive, as can be seen by the counselors comment:

“Some of them seem confused and we ask them questions to see if they really understood what we were taking about and we make them feel at ease with deciding which feeding option is best..... ,because it is them who know their background of whether they can afford it, and it also depends on the mothers health”.

Some of the counselors felt that many of the pregnant women were very scared of breast-feeding their babies for fear of infecting their child. They tried to explain about the CD4 count and this was a good measure of how strong the immune system was:

“They are very scared that if they breast-feed they will infect the baby, we tell the there is this thing called CD4 count where you check how strong your immune system is so you can breast-feed easily but they were still scared and they do not want to take chances”.

The counselors explanation was often insufficient to reassure the women and they were still worried about HIV transmission through breast-milk.

Costs and convenience

Responses confirmed that convenience was a consideration when choosing infant feeding methods as this cut down on time, given that many of the households still had no access to safe piped water, sanitation and electricity. This was illustrated by a counselor who said,

“The best way is to breast-feed especially if you live in the rural area where there is no clean water”.

KwaMashu counselors confirmed the inconvenience of the bottle option:

“It is not in our culture to bottle-feed and bottle-feed is very expensive and some of the mothers are not working”.

In rural areas it was difficult to maintain the bottle-feeding instructions and working leaves no time for preparing formula.

Another counselor said that if she found a person was positive she advised the most appropriate option in view of her place of residence,

“We first ask where they live to establish whether it is safe and possible to formula feed because if the mother lives in rural areas it is not easy to get fresh water so they can not choose to formula feed”.

A more controversial view was offered by one respondent, with a more jaundiced view with regard to women’s ability to use bottle-feeding in the face of difficulties, it was not the view shared by most:

“What I think, some people are lazy and because first you have to prepare the bottle, for example boil the water and clean the bottle, that all takes time unlike the breast-feeding where you simply take out your breast to feed the baby”.

“Bottle-feeding is not recommended” one counselor conceded, but then added that if she (the mother) could sterilise the bottle and manage to bottle-feed the choice was hers. Convenience of bottle-feeding lags way behind that of breast-feeding which is always ready for the baby.

Advantages and disadvantages of feeding options

The counselors and health care workers had a different perspective on the subject of breast versus bottle. They were influenced by the extent of their knowledge on virus transmission via breast milk and so tended to favour bottle-feeding for the HIV positive mothers. However, they were well aware of the financial constraints faced by most of their clientele and knew that a further expense could not be borne. They were also aware of the difficulties regarding safe water, especially in the rural areas.

“Most babies get oral-thrush, they do not change the nipples in time. Some do not really boil the bottles and most babies who are formula fed get diarrhoea because they do not get this milk only and mix it with something else like porridge”.

It was also found that when a woman was sick or weak she could not manage to breast-feed the child as this was not only physically draining but also practically impossible as illness limited the amount of milk for feeding.

One counselor at an urban clinic responded an explanation that even if a mother is sick, she still counsels her with the same choices as everyone else, she commented,

“ Most of the time when a mother has been sick so I tell her that the choice is still hers and nobody else’s”.

Bottle-feeding had many disadvantages and as mentioned already the main one was the cost. “Many simply do not have the money” was the comment of one person. The problem of money when choosing an option for feeding was mentioned several times, although the formula milk is provided free for a limited time both the women and counselors are aware that when the free milk comes to an end the mother’s breast milk will not be available.

“The big problem is that they are not working and they have no money to buy the milk especially when the formula that is subsidised by the government has come to an end because you are only supplied for six months only”.

Another significant disadvantage for bottle-feeding was the cultural proscriptions and what was considered the norm within the Zulu culture, which is for a mother to nurture the child at the breast. Examples of these findings are relayed by several comments,

“It is not in our culture to bottle-feed..” “In our culture there is discrimination...”

It was found that the lack infrastructure with regard to water and other services played a significant role in restricting bottle-feeding and there were overwhelming responses to confirm this finding. One comment illustrated this concern,

“Most of the mothers can not afford the formula and some live in the rural areas where it is not easy to maintain the bottle-feeding instructions....”

Oral thrush was found to occur commonly when there was neglect of bottle cleanliness. Diarrhoea was also frequently cited as a health hazard. Some other health problems were the danger of bacterial contamination through neglect of washing and sterilising bottles thoroughly and the lack of running water for this purpose. Issues related to mother’s milk advantages over that of formula was that the former provided nutrients and therefore natural resistance to common children illnesses. Ignorance was another mentioned difficulty that health care workers posed as a problem and to this end there was this reference:

“Some mothers do not know how to prepare the formula, they do not clean the bottle properly and some live in rural areas where there it is

not easy to sterilise the bottles because there is no running water and electricity”.

Advantages for breast-feeding were found to outweigh those of the formula option and to this end concerns about unsafe drinking water, lack of electricity and the high costs of formula food were the most commonly cited problems.

Stigma

It was not surprising to find that stigma was also a major problem that posed obstacles for feeding choices of women for their infants. Several of the respondents in this sample explained that mothers were fearful of being stigmatised and therefore opted to breast-feed merely to retain their dignity:

“It is the stigma for example, if they choose the formula feed they have to come here to collect milk - they leave and people see them with this milk. People know they are positive, and also at their home if they say they are going to breast-feed only, they ask why because they suspect something is wrong with the mother”.

“Some, they have not revealed their HIV status to the family and are afraid of the questions that will come when they see her bottle-feed her first born and some just seems lost”.

It was firmly established by the counselors that in their work with pregnant mothers stigma was rife within the communities and very few women escaped criticism or discrimination if they were perceived to be HIV positive.

Exclusivity

All the healthcare workers understood exclusive breast-feeding and there was found to be no confusion of this concept. It was found that the pregnant mothers also understood this concept by and large, but that often they had little control over outside interference.

Many women thought that breast-feeding was still risky even with the exclusive breast-feeding option when a person knew that they were HIV positive. One counselor suggested a reason for this concern,

“We have a problem of mothers mix feeding the babies because of the pressure from the family. The other thing is that they never disclose their status to their family members so there is a lot of pressure”.

The pressure from the family, in the form of interfering with the mother’s care for her child, is obvious if the mother feels forced to hide her HIV status. It would be a natural action for a family member to pick up a crying infant and comfort it with juice, gripe water or such.

“I do not tell the mother what to feed her baby but advise her on the advantages of both breast-feeding and bottle-feeding. Some of the mothers choose breast-feeding and some choose formula feed ... You find that mothers are afraid to not breast-feed”.

A woman explained that once the mother went home, her mother-in-law would often give the baby other things to eat. One counselor conceded that many mothers were confused about the roles of the nurses and the counselors. They would ask the nurse what she thought that she should feed her child and then this was often conflicting with the “exclusive” breast-feeding option. It was best described as,

“It means nothing else except breast-milk, no water and no gripe water just breast-milk”.

Inclusive feeding as complementary feeding, that is additional feeding, was of different varieties. Some named ‘Nestum’, ‘Purity’, ‘umuthiwenyoni’ and gripe water as other inclusive feeding supplements besides the most common concept of “porridge”.

Nevirapine and virus transmission

The knowledge concerning the use and administration of Nevirapine for MTCT was of a high level among the counselors. To this end all of them knew that the medication was for the benefit of the child only. Most of the health care workers explained how they used their knowledge to explain this to the pregnant women. It was well understood that HIV is transmitted when the mother is still pregnant or when she is giving birth. Most counselors also know that transmission is also possible through breast-feeding.

“that is why in ratio’s they say that 30 percent of the children get HIV while inside their mother womb, and when the mother has not been tested and therefore has not received Nevirapine before giving birth and also when the mother is breast-feeding”.

If the mother is positive it means “she could go and disclose it to her husband so that they choose between breast-feeding and formula feeding”. But there were problems and another response to this probe was that it was dangerous for her because she can infect her unborn child with HIV. It was found that most of the responses confirmed that the minimising the chances of giving the virus to the baby meant, “taking Nevirapine”, protecting yourself from further infection and eating healthily. Other comments were to use condoms or abstain from sex altogether.

VCT services

Most of the comments from the counselors were supportive of VCT services. Reasons for this is that through the use of rapid testing it is possible for the client to return for the results after a few hours. This saved the inconvenience of coming to the clinic on many different occasions. A counselor recalled that previously money for a taxi posed a problem for women who wished to return for their results, whereas now this was unnecessary. The counselor confirmed that up to 85 percent of women return later in the day for their results and this does allow them a certain amount of autonomy in deciding whether they would prefer not to know.

Reasons for being tested was sometimes due to peer pressure as the women spent time together at the clinic whilst waiting their turn for attention and influenced each other to take the test. This was confirmed by one comment as illustrated by the following comment which shows the degree of group interaction between the mothers whilst in the clinic,

“Sometimes they do the test because they see others doing it, sometimes because you have been talking about HIV they want to finish everything and leave. They take the test and sometimes after thinking about it at home and hearing other people’s negative response to knowing your status she gets scared and never comes back”.

Reasons for not returning for the result was given by one respondent:

“I think some go home and tell their husband that they have had the test and the husband disapprove and they are afraid to come back for the results”.

This may be because the husband disapproves of the wife taking the initiative or because he fears the result.

Most of the counselors agreed that they try very hard to encourage the pregnant women to return for their results. Different comments confirmed these efforts. “We go inside the ANC clinic and remind them” a person commented and another said that she promises formula for the baby and the drug if the mother is positive.

VCT was found to be accepted by most women as part of the ANC process whereby they could either attend the service or refuse it which meant that their own autonomy was not jeopardized.

Helpfulness and empathy of counselors

Perceptions of helpfulness of the health care workers was universally agreed upon by all the responses where they saw themselves as helpful, patient and understanding to people's emotions and circumstances. They felt that they were trusted with private information of the women and that they always gave them the option to return with any further questions or problems.

Conclusions

In conclusion this chapter discussed the findings of the study of both the pregnant mothers and the counselors who were interviewed. Choices open to mothers for feeding her baby were limited by societal, economic and environmental constraints such as availability of safe water.

Overall it was found that knowledge of HIV and virus transmission was sufficient enough to allow an informed choice. VCT services were also found to be efficient, necessary and empowering for women.

Chapter Five

Discussion

Introduction

This section is devoted to combining the findings of both the antenatal women's views and that of the counselors. The sample of health care workers or counselors is compared to the comments of the pregnant women in order to clarify common understandings, misconceptions and consensual opinions.

The women and men counselors interviewed for this study were part of the MTCT staff employed by the province of KwaZulu-Natal. In addition to the nursing and medical staff known collectively as health care workers, the province also employs voluntary testing counselors. Their duties are to ensure that each woman is adequately informed about the risks of MTCT before giving birth and the precautions that can be taken to minimise this risk. Group counseling is also another activity at the MTCT sites.

A programme manager, who also monitors and evaluates the counselors' level of knowledge, supervises the training programme at all the MTCT sites. She also keeps them updated with any new developments regarding social developments such as the recent cholera outbreak and the latest research. An example of this was illustrated when research (Coutsoudis 2001) showed that there was a potential to minimise MTCT through exclusive breast-feeding this information was immediately used to educate counselors about best feeding options.

Choice of feeding options

Antenatal women predominantly chose the breast-feeding option regardless of their residential status. Rural women reiterated many of the counselors concerns of lack of clean water in the rural areas for enabling the bottle option. There was consensus between the women's responses and those of counselors that the mothers had the

choice. The counselors asserted repeatedly that they provided an environment for the mothers to make a free choice through information for both options.

Although the reasons for not bottle-feeding given by mothers varied from economic constraints to illness and convenience, the bottle-feeding choice appeared not to be the most favoured option of the counselors either since they pointed out the limitations of the state supplied free formula was only for six months.

Women who were working were more likely to leave their children with other people. Counselors commented on working mother's time constraints for preparing bottles of formula but this was not the same concern expressed by working women who decided that their babies would have to get used to both.

Although information on exclusive breast-feeding is perceived as being understood widely, these remarks may not be those of an HIV positive person but those of a busy mother. Counselors comments on the working person did not feature very much and this could be attributed to the high rate of unemployment currently.

Perceived autonomy was high on the part of the women who saw themselves as owners of their feeding choices. However, a later probe revealed conflicting responses suggesting the choices also relied heavily on partners, family and friends. Strong references such as "he says I must" and "they force" were made which suggests that absolute autonomy was camouflaged. Counselors collectively agreed that the culture and customs stood in the way of women's free choice and the larger community saw this as the norm. Another pressure was the assumption that one was HIV positive if one did not breast-feed and this invariably forced women to comply with breast-feeding options.

The counselors did not regard the woman's age as of any importance. This may well be due to their commitment to provide information and knowledge to everyone equally without weighing up the value of previous experience of feeding a baby. Age was most significant however when consideration was given to the quality and depth

of the responses. The young women who were still in their teens were more subjected to family, partner and peer pressures. Older women responded more assertively and responsibly about their choices of feeding, being tested and confiding in the counselors.

Many of these young women saw child caring as largely a duty of a mother or an aunt as they would be returning to school. With regard to knowledge of Nevirapine and its effects in HIV transmission it was found that age of the mother had significance and it was evident that most of the younger women had learnt more from their friends about HIV than the older women who seemed dubious about some of the procedures.

Sickness was the only acceptable reason not to breast-feed in the view of family and friends. This was the general consensus of both the women and the counselors. Breast-feeding was perceived as the custom and cultural norm therefore there was pressure from several sources to conform. Many women who found it hard to resist this demand experienced this. Counselors confirmed that when a woman does not breast-feed she is subjected to discrimination.

Experience with previous children was not highlighted by many of the counselors and this did not seem to feature in their assessment or advice to women. Women themselves who had other children felt comfortable with their previous choices and overall they opted to repeat those feeding experiences.

Mothers and counselors both agreed to maintaining breast-feeding unless a person was too weak to breast feed. Many women could not grasp the meaning of the “exclusive” feeding option when there was a positive HIV status. Additional feeds in the form of gripe water; juice and thin gruel are commonly used when breast-feeding. Cultural restraints complicate and confuse healthy feeding choices especially when a woman is not obviously sick but may have silent disease.

Convenience, it was found had many facets. Convenience of amenities such as safe water and electricity was a serious concern for the counselors who based the ethos of

their counseling on this convenience. Women, on the whole, were more concerned with the convenience of warm, safe and readily available food for their child. Nutrition and protection from harmful bacteria was also frequently cited. Although all the respondents mentioned various dimensions of convenience what was blatantly obvious is that the natural method of feeding, namely breast-feeding, is considered the best from all aspects and this includes economic, social and cultural.

The cost of formula impacted heavily on some women who would have preferred to bottle-feed. Counselors were sympathetic to women who could not afford formula food and many concerned themselves with the fate of babies who were on the MTCT programme and were given free formula for just six months. Many respondents concluded that this privilege would not assist the mother after the allotted time period when her own milk would have long since dried up. The risk of malnutrition would be substituted for the small chance of HIV transmission if the breast option had been maintained.

Not surprisingly, stigma occupied most people's thoughts when they made their choices of feeding their children. All the respondents agreed that being HIV positive labelled you either way whether the breast or the bottle option was chosen. A counselor who claimed that women suffered discrimination if they were seen collecting formula food from the clinic also voiced this opinion.

Mothers who chose exclusive breast-feeding did not escape the brunt of stigma. If this choice was the mother's preference she would no doubt have to explain to her family at home about her status to protect the child from receiving any other food supplements between feeds or in her absence. Covert feeding choices do not feature well in a community where cultural norms dictate openness so it seems that a mother may have to reveal her status early in her infection to ensure that her feeding options are respected.

Younger women in the sample shied away from knowing their status for fear of reprisals and rejection from their friends and family. One woman worried about her

partner leaving her if he knew her HIV status, another expressed her fears of loneliness and isolation if her status was known.

The advantages of breast-feeding as opposed to bottle-feeding were widely supported by advocates of breast-feeding. As the most popular choice both the counselors and the mothers recounted messages of nutritional benefits, convenience and costs. One or two people did admit that the bottle served a valid purpose when one was working, or in company. Babies who were bottle-fed were perceived as sickly and in danger of infections. Concluding remarks were most definitely in defence of the breast as the cheaper and safer option.

Exclusive breast or bottle-feeding was ambiguous among the women who thought that these two were interchangeable. Although, having made that statement it is vital to view this in the context of each particular woman and her HIV status. Without the presence of a disease such as HIV, this would be the norm. HIV positive people may have been more aware of the need to feed exclusively which means no mixing with supplements at all.

Exclusive breast-feeding, though perhaps not practised precisely, was well understood as a method of preventing mother to child transmission of HIV. Counselors commented to this effect and made the point that they could not monitor feeding practices at the women's homes and all they could hope for was that they would comply as far as they possibly could.

Both women and counselors in all the areas were well informed about nevirapine and virus transmission. Very few knowledge gaps were detected and even very young respondents were impressively knowledgeable.

Acceptance of VCT and the need to obtain results

Recipients of VCT services were found to be generally very accepting of the service. Some of the women appeared to regard the sessions as being meant for others and this was often confirmed when asked if they had tried it. One or two people indicated that

they were not interested in knowing their status. Although this was later revealed as fear. This was often relayed, as others are afraid to know. Most people accepted that the VCT sessions were part of the antenatal service and it was therefore not regarded as an extra service.

Counselors were most enthusiastic about their work and all agreed that women benefited from it and felt that they were reaching out to most women and empowering them.

Recipients of the VCT praised the counselors and this was seen as spontaneous and genuine. There appeared to be no animosity towards counselors who had the difficult task to give bad news at times. One counselor did concede that a woman was very annoyed with her when she received a positive result but later apologised for blaming her. Youth once again featured here where a few young women who said that they could not trust others with their private problems displayed obvious shyness.

Conclusions

Finally, MTCT programmes were well received by the women who were attending the clinics. This discussion has attempted to combine responses of both the antenatal women and the VCT counselors. Although a few topics were not absolutely uniform there was an overall sense of conformity when attempts were made to tease out the main obstacles hindering women's choices of how best to feed their babies.

This study cannot be compared to the findings of the Khayelitsha study (Chopra et al. 2002) as only HIV positive mothers were targeted and all were instructed to bottle-feed in that small programme. The findings of the national PMTCT Pilot Sites (McCoy et. al. 2002) only addressed the structures and logistics together with health support systems and did not address the sociological problems related to mothers choice of feeding options. Anecdotal references were made regarding problems concerned with mothers choices but these were not investigated further.

Chapter Six

Conclusions

This exploratory study has attempted to illustrate that alternative ways of feeding infants such as formula-feeding can be an added obstruction to the rapid expansion of the MTCT programme. It has also sought to justify the significance of VCT services and to evaluate this service from the antenatal women's perspectives. Finally, and most importantly it has attempted to uncover the level of vital health care support such as VCT services through the views of both women clinic attendees and counselors.

The literature has provided evidence that antiretroviral treatment such as Nevirapine for the reduction of MTCT is both sustainable and cost-effective. Buy-in from both the state and the multinational pharmaceutical companies are essential prerequisites to achieve this end. Caution from the state was provided by the MEC for Health in Kwazulu-Natal who raised concerns about development of viral drug resistance (Mkize 2002).

Behavioural methods such as safe sex practices through condom use, exclusivity of sex partners, and treatment of STI's are other well-documented issues that contribute to this debate. These do not detract from the social and cultural consequences often resulting from trying to prevent MTCT. Issues such as violence against women, due partly to her low status in society, should not to be overlooked. Poverty, as an exacerbating factor and often facilitator for HIV, may result in sexual favours in exchange for economic gains to support an impoverished household. This would naturally increase vulnerability to HIV and STIs. Stigma is omnipresent in most of the facets of MTCT prevention.

Pertinent to this research are the vital concerns that surround the breast versus the bottle options that could tend to undo Nevirapine's salvation and result in negative children sero-converting after being breastfed or incorrectly exclusively breast-fed. Medical researchers are hypothesising that exclusive breast-feeding, especially in poorly resourced areas, can result in a minimal chance of transmission.

The conclusions discussed in this chapter aim to neither dispute nor support this claim, rather it seeks to explore the social constraints within urban and rural backgrounds that intricately dismantle a woman's free choice of infant feeding. In so doing, relevant conclusions that emerge could provide insight into common problems both within the family and community and outside of it. Economic constraints together with the difficulties of environmental underdevelopment such as availability of clean water and fuel for sterilizing bottles are essential for the formula option to succeed.

Women in this study were found to have an illusionary vision of autonomy. With the exception of one woman, it is fair to generalise this statement. Women perceived themselves as having a choice, but when probed further there were a fraction that could reflect true autonomy. A further factor inhibiting women's choices was the fact that not only did they lack autonomy due to the structure of the community where the mother-in-law becomes a self-imposed authority but also the women were doubly bound by cultural conscriptions.

Autonomy to choose a best-feeding option was therefore limited by the family hierarchy and then by the cultural necessity to breast-feed. Limitations were discovered for those few women who chose to bottle-feed. The only valid reason was illness which amounted to women who were reluctant to reveal their status being confined to the breast option anyway. The problems attached to revealing ones status are numerous as demonstrated in the literature. Women are discriminated against and as one woman put it "you must be alone". Stigma is therefore a dire limitation for women's autonomy. To this end it could become a financial disadvantage as one woman illustrated, "you are afraid your partner will leave you".

Autonomy is further constrained if one is forced into breast-feeding which requires exclusive breast-feeding, and this option is further jeopardised by interferences in feeding the infant. Many mothers said that when they were away, family or minders would look after their children and would feed them accordingly. Only a few people wanted to express their milk for their child in their absence.

Other supplementary foods were named as part of the feeding process, so unless a mother spelt out her HIV status, exclusive breast-feeding as part of the babies survival package, and as a prerequisite to keep her child virus-free, would not be obtainable and would prove to be fruitless.

Counselors appeared oblivious of the limitations of women's absolute choices and they too insisted that the mother reserved that right to choose and reiterated that they themselves never influenced the woman's decision. This was true in most instances, with the exception of known HIV positive women, where the counselor would advise her to bottle-feed unless she resided in a rural area with limited access to safe water.

Age of the mother presented another challenge. Although this sample was limited in its size, there was a significant representation in both the rural and urban sample of teenage interviewees. Their inexperience of decision-making was seen as a shared responsibility of parents, siblings and partners. Young women therefore had a limited vision of their participation in feeding options for their child and this was reflected in their consistent reliance on authoritative parental support. Age was also a limiting factor when previous experience, as a variable, was considered and more so than not women who had previous pregnancies where more assertive in their choices.

The expense of formula food surfaced many times throughout the interviews. A few women expressed desires to bottle-feed but were economically limited as they did not work and could not afford this luxury. Women were continuously reporting being criticised for wasting money on formula food by family members and their partners.

Counselors at the clinic expressed concerns for infant's dependence on the state provided formula for only six months. This concern was once again locked into the financial constraints of unemployed women.

Although inconvenience, particularly of the formula option, were named issues, the lack of safe water and electricity to heat bottles were decidedly the most pressing issues and this presented serious challenges to women who were aware of the dangers to the health of their children.

In essence comments such as breast-feeding was always ready, always warm and cheaper all led to the conclusion that underdevelopment posed genuine concerns for both counselors who sought to establish the residential setting and pregnant mothers who sought the safest method. Most importantly was the high degree of awareness of unclean water among women responders, which suggests that their experiences with diseases like cholera and diarrhoea run deep.

The overwhelming responses from women, was for the acceptance of the voluntary testing and counseling services. It was perceived from the physical appearance of these establishments and the women who sat readily waiting to support them, were not coerced against their will. Although there was a sense of over support for these services this could be due the limitations of MTCT services. These clinics were attracting people outside of their area. This does highlight that accessibility to MTCT services are still limited.

A few of the younger women were coy, and not able to trust strangers with their private problems. In spite of support for the VCT services there was a distinct perception that some woman had not endorsed this programme as an extension of the antenatal clinic service but instead saw it as a function for "others" to utilise.

References to "others" occurred regularly in the interviews and some seemed to distance themselves as outsiders who were trying to view the service through the

window. It was strikingly obvious that a few women denied having been counseled and participating in any of its auxiliary services such as the group counseling sessions.

Contradictions were seen when many of the women were found to be extremely knowledgeable about the Nevirapine function and others claimed to be unsure about small practicalities. This was unsupported by the results received from counselors.

The counselor's knowledge was sound, considering that the MTCT programmes have only been operational for a short time. To this end it can only be concluded that denial is rife within communities for fear of reprisals and discrimination. There were also alternative contradictions to this conclusion, where the majority saw this as an extra arm of the antenatal programme and seemed happy about its existence.

Most of the women saw value in knowing their status and only a few of the younger women adhered to the notion of not knowing for fear of death. Only one person was determined not to know her status although some of the others thought others would not want to know, but agreed it was important for the life of the child.

Counselors insisted that most of the pregnant women returned for their results, usually available the same day. They did however, generally support issues relating to stigma and peer pressure that paradoxically forced them to do the test and then fear of stigma dissuaded them from returning.

Limitations of this study

Most prominently, was the limitations of the size of the sample that prevents it from being generalised to the whole population and thus limiting it to a non-probability study. Having said that, it is essential to remember that this was intended as an exploratory study with the hope for further research at these sites.

Another limitation worth mentioning is the difficulty of interpretation from Zulu to English. Certain words may lose their meanings in the translation process and limits

the colloquial richness of verbal expression. Therefore every precaution has been taken to ensure verbatim language.

Most conclusively, this study found that women are limited in their autonomous choices for feeding their children because of family, culture, economic and environmental limitations. Double binds for women are their inferior social status, unemployment and dependence on extended family for moral and financial support. Counselors at VCT sites have encouraged women to practice safe sex, choose a manageable feeding-option both practically and financially, but realise that this may fall outside the client's capacity.

Ways forward

Women who seek to protect themselves and their unborn children need to have autonomy in their feeding options. Achievement of this goal, may become an over ambitious objective of my own as the researcher. Self-reliance and less dependence may be a way forward towards reaching autonomy. Without an income, family support and government commitment this too may seem to be a pipe dream.

An absolute commitment is essential by the state for both the supply of MTCT prevention drugs and formula food, if the mother so chooses. Extension post-natal services should ensure that impoverished mothers are protected by the state until the vulnerable child is fully integrated on to solid food. Breast-feeding choices, which are supported by the majority as the norm, should also solicit a high priority. Many women were seen to be confused with the term exclusive breast-feeding so more education needs to be done to make the choice between breast and bottle more meaningful. Communal awareness of the risks of MTCT and its disastrous effects on a neonate should promote, "mom knows best" community slogans and in so doing empower mothers to make their own choice and also have the effect of minimising stigma.

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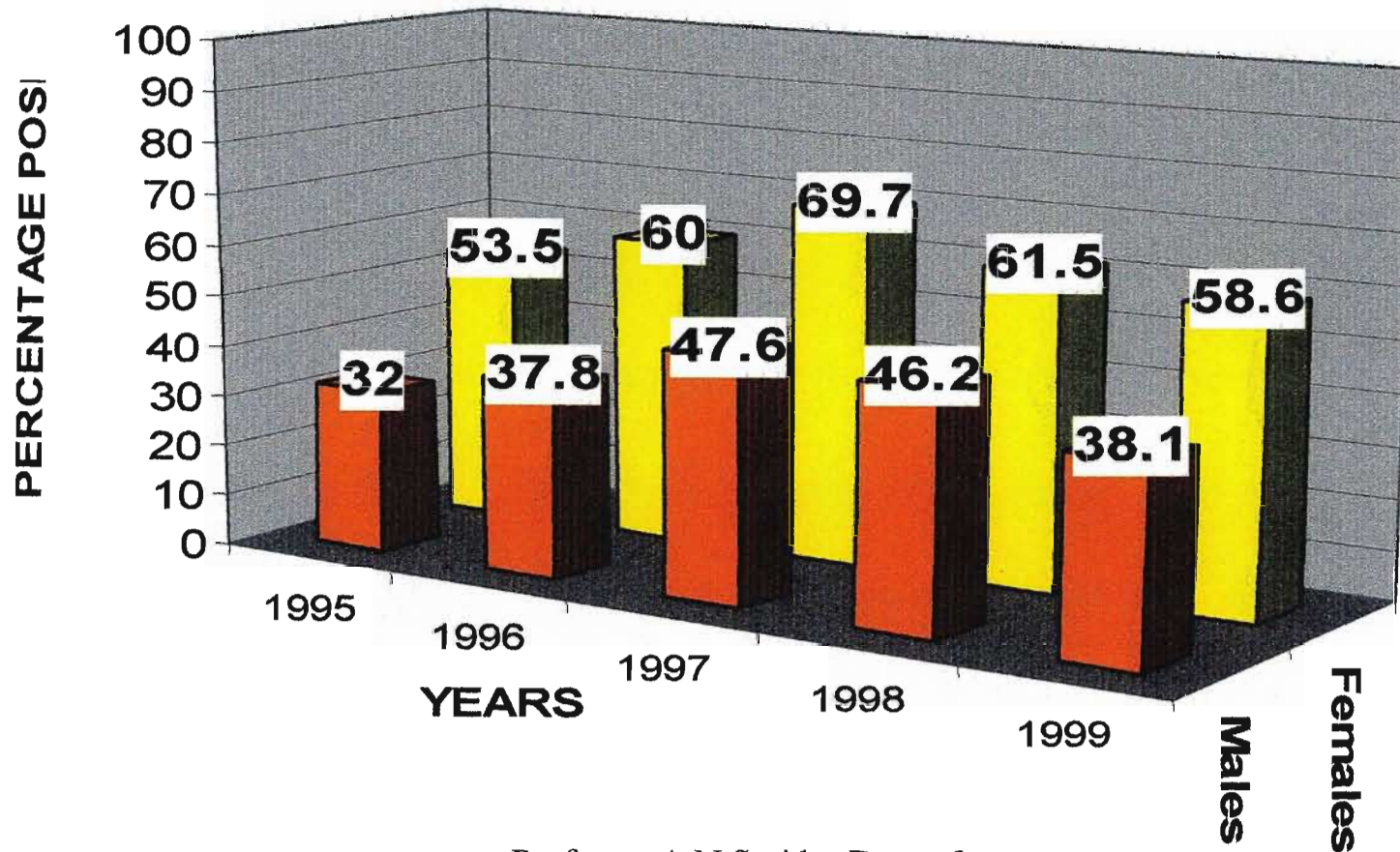
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DURBAN STD CLINIC 1995...1999

PATIENTS LESS THAN 25YRS OF AGE



Professor A.N.Smith - Dept of
Virology - UND

The New York Times

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A SUBSTITUTING OF DRUGS

A Cheaper Therapy Than AZT
Would Be Most Beneficial
in Developing Nations

By LAWRENCE K. ALTMAN

In an advancement that promises to significantly reduce the incidence of AIDS in children in developing countries, American and Ugandan scientists have found a simple new way to prevent mother-to-child transmission of the AIDS virus that also is less costly and markedly more effective than the standard therapy in the third world.

The more practical therapy comes from substituting one marketed drug, nevirapine, for the standard drug, AZT. The cost for the two doses of nevirapine was \$1, compared with \$268 for the AZT regimen now used in developing countries and \$815 for the much longer and more complicated course used in the United States and other developed countries, federal health officials said in releasing the findings yesterday.

The new treatment calls for both a mother and her infant to take nevirapine just one time—a mother takes a pill once during labor, and her baby is fed the drug as a syrup once during the first few days of life.

Nevirapine, a drug used in combination "cocktail" treatments, has been marketed since 1996 in the United States for treatment of H.I.V., the AIDS virus, and it was remarkably safe in the study that was conducted by American and Ugandan researchers. As babies reached 3 months of age, nevirapine had cut the risk of mother-to-child transmission of H.I.V. to 13 percent from the 25 percent for the standard course of AZT in developing countries, a reduction of 47 percent, United States and Ugandan health officials said.

Monitoring will continue for 18 months to determine adverse effects that might show up later in infancy. The monitoring will also help to determine how many babies will still become infected through breast-feeding in the first months of life, when such transmission is highest.

H.I.V. can be transmitted during pregnancy or during delivery when bleeding occurs. Nevirapine is believed to be able to block transmission of H.I.V. during the delivery, and further studies will be needed to determine if transmission can be stopped during breast-feeding.

Nevirapine targets the same enzyme in H.I.V. as AZT, but it is a different class of drug.

The low cost of nevirapine makes it feasible for wide-scale use in many developing countries, Dr. Anthony S. Fauci, who heads the National Institute of Allergy and Infectious Diseases, predicted in an interview. His Federal agency paid for the study.

Dr. Peter Piot, who heads the United Nations AIDS program in Geneva, said the nevirapine study was "a major gain" because it "approaches ideal prevention therapy" for developing countries, where 95 percent of the H.I.V.-infected people live.

But Dr. Piot said it was "unrealistic to introduce it on a large scale in developing countries without first using pilot programs" because drug therapy is only one part of a complex effort to prevent H.I.V. Such pilot studies will begin soon in developing countries, he said.

Most women in developing countries do not know that they are H.I.V.-infected because testing programs are scarce. "It is still a logistical, economic and cultural challenge to develop programs to encourage H.I.V. testing, counseling and baby formula as a substitute for breast-feeding for infected mothers," Dr. Piot said in an interview.

American and Ugandan scientists plan another study to see if it would be more effective to give nevirapine to mother and infant for longer periods. Also, a continuing study in the United States and Europe aims to determine if adding nevirapine to standard regimens will further lower the transmission rate of H.I.V. from mother to child. Dr. Fauci said there was no need to change the United States recommendations until more studies are completed.

The United Nations AIDS group estimates that 1,800 babies are born H.I.V.-infected every day in developing countries where most women do not receive prenatal care. In some areas of Africa, up to 40 percent of pregnant women are H.I.V. infected, and from 25 percent to 35 percent of their infants will be born infected if therapy is not provided.

Wide-scale use of nevirapine in developing countries "could potentially prevent 300,000 to 400,000 newborns each year from beginning life infected with H.I.V.," Dr. Fauci said.

AZT and other anti-H.I.V. drugs have drastically reduced mother-to-child transmission of the infection in the United States since 1994, when a federally sponsored study showed that AZT, taken for several weeks, could stop mother-to-child transmission of H.I.V. The American regimen calls for the pregnant woman to take AZT five times a day beginning as early as the 14th week of pregnancy and continuing until labor, when an intravenous injection of AZT is given. At birth, the baby takes AZT four times a day for six weeks.

Because the American regimen was impractical and too costly for third world countries, scientists sought a more affordable therapy.

Researchers initially intended to enroll 1,500 women in the study, conducted at Mulago Hospital and Makerere University in Kampala, Uganda, beginning in November

1997. One part of the study was dropped in February 1998 after another United States-financed study conducted in Thailand found that AZT used for a shorter period than in the United States was effective in preventing mother-to-child transmission of H.I.V.

The Ugandan study then involved 618 women in their ninth month of pregnancy who had not taken anti-H.I.V. drugs and their 631 infants. Of the 618 women, 308 took AZT and 310 took nevirapine. Enrollment stopped at the end of last April.

The women agreed to accept by random selection either of two drug regimens. One regimen was single dose nevirapine therapy for mother and infant. The other regimen involved taking two AZT pills at the onset of labor and then one pill every three hours until delivery. Infants born to mothers who took AZT were given AZT twice a day during the first week of life.

After two months, 59 infants born to mothers who took AZT and 35 infants born to mothers who took nevirapine were infected. Statistical tests projected the 25 percent and 13 percent infection rates, respectively.

The three deaths that occurred among mothers who took AZT were due to AIDS and not the drug, the researchers said. No deaths occurred among the mothers who took nevirapine.

Infection was the most common cause of adverse effects and death among the infants whose mothers took the two drugs. The adverse effects and deaths were not deemed drug related.

Scientists learned the findings on Monday at a meeting of a committee that oversees the safety and effectiveness of such studies.

Appendix 3

Interview Guide for mothers

General details : Ice breaker, purely putting the person at ease but important to categorise the interviewees.

What is your age?
What work do you do?
Is this your first pregnancy?
Do you live in this area?

Feeding options of mother: These questions will find the mother's choice of feeding options.

How do you intend feeding your baby?
Are there any others in your family that help you decide how to feed your child?
What are your views on bottle-feeding?
How do people in your family view bottle-feeding?
What is the usual method of feeding babies?
What other substances are given to babies together with the breast?

Personal information: These questions will give the reasons for her choice.

If you have had any other babies, how have you fed them?
What are the advantages of breast-feeding?
What are the advantages of bottle-feeding?
What are your views on bottle-feeding?
What restricts you when making a choice of how best to feed your child? - Reasons for those restrictions?
What is cheaper?
If you work, does this make a difference, if so how?
Who will care for your child if you are working?
How will they feed your child?

Perceptions of people in the community: These questions probe the peer pressures on the mother.

Do you know many mothers who do not breast feed their babies?
If yes, do you know why?
What do the in-laws say if mothers refuse to breast-feed?
Are there any other reasons why mothers do not breast feed?
What are normal family reactions when a mother refuses to breast-feed her baby?
How do friends react?
Does your husband/boy friend help choose?

Knowledge of HIV: These questions will probe the mother's understanding of the problem and the basis for her choice.

If a mother is tested positive for HIV can she give her baby the virus?

If yes, how?

Why is it important to choose a certain method of infant feeding when a mother is positive?

What has the clinic told you about voluntary testing and counselling?

Will you/have tried it? Why not?

What have you been told about Nevirapine?

What do you know about Nevirapine?

What does Nevirapine do for the positive mother?

How is it given to the baby?

If the baby receives Nevirapine what feeding options does she have to keep the baby negative? Where did you receive this information?

Are the Counsellors and nurses helpful with information?

Who makes the decision on how best to feed the baby?

Do you feel comfortable to speak about personal sexual problems with them?

If not, why?

Are they prepared to spend time to listen to problems?

Probing reasons for non return.

Do you think that women would prefer not to know if they are HIV positive?

If you think that does it matter if they don't know that they may be infecting the baby?

If a person has an HIV test is it likely that she will not want to know the result?

Why do you think that some mothers do not want to know?

Interview Guide for mothers

General details : Ice breaker, purely putting the person at ease but important to categorise the interviewees.

What is your age?
Uneminyaka emingaki?

What work do you do?
Usebensa msebenzi muni?

Is this your first pregnancy?
Ingabe ukukhulelwa kwakho kokuqala lokhu?

Do you live in this area?
Uhlala kulesigceme?

Feeding options of mother: These questions will find the mother's choice of feeding options.

How do you intend feeding your baby?
Uzimisele ngokumondla kanjani umntwana wakho? (Ukumncelisa ibele noma ibhodlela)

Are there any others in your family that help you decide how to feed your baby?
Bakhona yini abanye emndenini wakho abakusiza ngokukubonisa ukuthi umondle kanjani umntwana wakho?

What are your views on bottle-feeding?
Ingabe imibono yakho ithini ngokuncelisa ibhodlela?

How do people in your family view bottle-feeding?
Ngabe emndenini wakho bakubona kunjani ukuncelisa ngebhodlela?

What is the usual method of feeding babies?
Iziphi izindlela ezejwayelekile zokuncelisa umntwana

What other liquids are given to babies together with breast milk?
Yikuphi okunye okuphuzwayo ongakunika umntwana wakho kanye nobisi lwebele?

What other solids are given to babies together with the breastmilk?
Yikuphi okunye okudliwayo ongakunika umntwana wakho kanye nobisi lwebele?

Personal information: These questions will give the reasons for her choice.

If you have had any other babies, how have you fed them?
Uma unabo abanye abantwana, ingabe wawubondla (ubancelisa) kanjani?

What are the advantages of breast-feeding?
Ingabe yikuphi okuhle ngokuncelisa ibele?

What are the disadvantages of breast-feeding?
Ingabe yikuphi okubi ngokuncelisa ibele?

What are the advantages of bottle-feeding?
Ingabe yikuphi okuhle ngokuncelisa ibhodlela?

What are the disadvantages of bottle-feeding?
Ingabe yikuphi okubi ngokuncelisa ibhodlela?

What are your views on bottle-feeding?
Yimiphi imibono yakho ngokunceliswa kwebhodlela?

What stops you when making a choice of how best to feed your child? - Reasons?
Yini ekuvimbayo uma wenza isinqumo sokondla kangcono umntwana wakho - Izizathu?

What is cheaper?
Yikuphi okungambi eqolo?

If you work, does this make a difference, if so how?
Uma usebenza, kuyawenza yini umehloko?

Who will care for your child if you are working?
Ubani ozonakekela umntwana wakho uma wena usemsebenzini?

How will they feed your child?
Bazomondla (mupha kanjani ukudla) kanjani umntwana wakho

Perceptions of people in the community: These questions probe the peer pressures on the mother.

Do you know many mothers who do not breast feed their babies?
Bakhona yini abanye omama obaziyo abangabancelisi abantwana babo ubisi lwebele?

If yes, do you know why?
Uma kunjalo, ingabe uyazi ukuthi kungani?

Are there any other reasons why mothers do not breast feed?

Ingabe zikhona yini ezinye izizathu ezenza abanye omama bangancelisi ubisi lwebele?

What do the in-laws say if mothers refuse to breast-feed?
Bathini abasemzini uma umama engafuni ukuncelisa ubisi lwebele?

What are normal family reactions when a mother refuses to breast-feed her baby?
Ingabe ngokwejwayelekile imindeni ivame ukwenzenjani uma umama engafuni ukuncelisa umntwana wakhe ubisi lwebele?

How do friends react?
Ingabe abangani benzenjani?

Does your husband/boy friend help choose?
Ingabe umkhwenyana noma isoka lakho liyakusiza ukuthi ukhethe?

Knowledge of HIV: These questions will probe the mother's understanding of the problem and the basis for her choice.

If a mother is tested positive for HIV can she give her baby the virus?
Uma umama ehlolwe watholakala enegciwane lengculazi angamuthelela yini umntwana wakhe?

If yes, how?
Uma kunjalo, angayithelela kanjani?

Why is it important to choose a certain method of infant feeding when a mother is positive?
Kubaluleke ngani ukukhetha indlela ethile yokuncelisa umntwana uma umama enengciwane lengculazi?

What has the clinic told you about voluntary testing and counselling?
Ingabe emtholampilo bakutshela ukuthini ngokuzinikela uhlole igciwane lengculazi nokwelulekwa ngalo na?

Will you/have tried it? If not, Why not?
Ungakwenza yini / sewuke wazama na? Uma kungenjalo, Kungani ungazamanga?

What have you been told about Nevirapine?
Watshelwani nge Nevirapine?

What do you know about Nevirapine?
Wazini ngeNevirapine?

What does Nevirapine do for the positive mother?
Ingabe iNevirapine imenzelani urname onegciwane lengculazi?

How is it given to the baby?
Inikezwa kanjani kumntwana?

If the baby receives Nevirapine what feeding options does she have to keep the baby negative? Where did you receive this information?

Uma umntwana esethole INevirapine yiziphi izindlela umama okufanele amncelise ngazo ukuze avikeleke egciwaneni? Walutholaphi lolulwazi?

Are the Counsellors and nurses helpful with information?
Ingabe abeluleki nabahlengikazi bayasiza ngolwazi?

Who makes the decision on how best to feed the baby?
Ingabe ngubani othatha isinqumo sokuthi angondliwa kangcono kanjani umntwana?

Do you feel comfortable to speak about personal sexual problems with them?
Ingabe uyaye uzizwe ukhululekile ukuxoxa nabo ngezindaba zakho eziyinkinga kwezocansi?

If not, why?
Uma kungenjalo, kungani?

Are they prepared to spend time to listen to problems?
Ingabe bayaye bazinike yini isikhathi sokulale izinkinga?

Probing reasons for non return.

Do you think that women would prefer not to know if they are HIV positive? Why?
Ingabe ucabanga ukuthi abanye besifazane bangancamela ukungazi ukuthi banalo yini igciwane lengculazi? Kungani?

Is it important to know your HIV status if you want to keep your baby HIV negative?
Ingabe kubalulekile yini ukuzazi ukuthi unalo noma awunalo igciwane lengculazi ukuze uvikele umntwana wakho?

If a person has an HIV test, is it likely that she will not want to know the result?
Uma umuntu hlolelwe igciwane lengculazi, ingabe kuyenzeka yini angathandi ukuyazi imiphumela na?

Why do you think that some mothers do not want to know the results?
Kungani ucabange ukuthi abanye omama abafuni ukwazi imiphumela?

Appendix 4

Interview guide for health care workers and counsellors

Knowledge

What is HIV?

What does a positive result mean for a pregnant woman?

What precautions should she be taking?

What are the ways the virus is transmitted to the baby?

How can she minimize her chances of giving the baby the virus?

In the case of an HIV positive mother, what is the best feeding option and why?

If that option is not possible what is the 2nd possibility?

What does exclusive breast-feeding mean?

From your experience what are the dangers of formula food?

How is information/ choices given?

If a pregnant mother is positive what options *do you* offer her to choose from when she would like to know how best to feed her child? Please explain?

What information do you give mothers about Nevirapine?

When you explain feeding options are most mothers receptive to the information?

How do you deal with mothers who are not receptive and appear confused?

What percentage of pregnant mothers return for testing after pretest counselling?

How many return for their test results?

Why do you think some do not return.?

How do you encourage them to return?

Personal opinions

Why are mothers reluctant to bottle feed their babies?

What obstacles do they encounter when they choose this option?

What are some of the family pressures?

What is the most common problem for HIV positive mothers, when choosing a feeding option?

What complementary foods are included in most of the babies diets?

Do you think these choices of complementary feeds is always the mother's?

Do many pregnant mother feel they can trust you with their information? If not why?

G.8 INFORMATION GIVEN TO SUBJECTS

Title of study:

An exploration of emerging problems for infant feeding options and HIV testing which may present as obstacles for the rapid expansion of the mother-to-child transmission prevention programme - The Kwa Zulu Natal experience

To Whom It May Concern:

I am doing a survey to explore the options that are open to mothers for HIV testing and of how to feed their babies. Another reason is to find out why they choose these options and what are mothers' perceptions and ideas about their social environment and how this effect their best feeding options.

I thank you for volunteering to participate in this study. The information that you provide will only be used for research purposes. There is no obligation to complete the questions if you do not choose to do so. Complete anonymity will be ensured throughout the questionnaires.

I will be asking nine other pregnant mothers from this site to answer the same questions. These will be done on an availability and voluntary basis. These questions will be asked in a private place and you will not be asked to supply your name.

You will be asked a number of questions which will be recorded on a tape recorder. This is only to ensure that the answers are correctly noted and will be used by the researcher for record purposes only.

The questions should not take more than one hour to complete.

Thank you for your kind co-operation.

Elaine Smith

Information for Nurses or Health Care Workers

An exploration of emerging problems for infant feeding options and HIV testing which may present as obstacles for the rapid expansion of the mother-to-child transmission prevention programme - The Kwa Zulu Natal experience

To whom it may concern

I am doing a survey to explore the options that are open to mothers for HIV testing and how best to feed their babies. Another reason is to find out why they choose these options and what are mothers' perception ideas and feelings are about their social, cultural and economic environment and how these affect their best feeding choices. In order to establish some of these facts, your valuable input is required as advisors and informants to mothers.

I thank you for volunteering to participate in this study. The information that you provide will only be used for research purposes only. There is no obligation to complete the questions if you do not choose to do so. I do not require a record of your name and this survey will not effect your terms of employment in any way. I will be recording the conversation, but this is for data analyses only.

I am also interviewing 4 other nurses or health care workers at this site and these will be like yourself selected on a volunteer and available basis.

This brief questionnaire will not take up more than an hour of your time.

Thank you for your kind co operation.
Yours truly,

Elaine Smith

NB: A TRANSLATION INTO THE HOME LANGUAGE OF THE SUBJECT MUST BE PROVIDED AFTER A FINAL ENGLISH VERSION HAS BEEN APPROVED.

MEMORANDUM

To : Mrs E D Smith
Development Studies
HOWARD COLLEGE

From : Cheryl Borresen
Medical Research Administration
Nelson R Mandela School of Medicine

14 October 2002

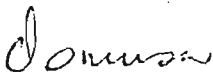
PROTOCOL: An exploration of emerging problems for infant feeding options and HIV testing which may present as obstacles for the rapid expansion of the mother-to-child transmission prevention programme - The KwaZulu-Natal experience. E D Smith, Development Studies. Ref.: H128/02.

The Research Ethics Committee considered the abovementioned application and made various recommendations. These recommendations have been addressed and the protocol was provisionally approved on 14 October 2002 subject to:

- a) the submission of a Zulu translation of the short form patient information sheet with amendments. Please note, checking of the Zulu translation will no longer be the responsibility of the Postgraduate Office. Your submission must contain a statement to the effect that 'this is a true and accurate translation of the English version and has been checked by a Zulu linguist'. The name, position and contact number of the translator must be clearly indicated at the foot of the translation.
- b) Approval from Hospital Manager.

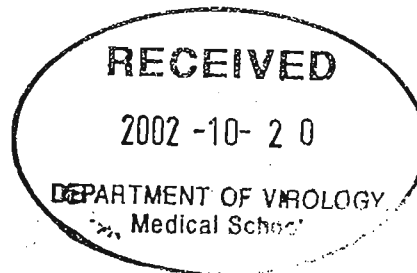
Please refer to attached document "Permission to Conduct a Research Study/Trial". This must be completed and submitted to the Medical Superintendent/s / Hospital Manager for signature.

Once the document has been signed it should be returned to this office so that full and final ethical approval can be granted.



Cheryl Borresen
Medical Research Administration

Hdeg/SmithEDH128.02



KwaMashu antenatal MTCT site coded as # KM1 – 5

Grey's hospital MTCT site coded as # G1 – 5

Church of Scotland antenatal MTCT site coded as # COS 1 – 8

Appendix 9

Elaine Smith
Department of development
Studies in collaboration with
Department of Obstetrics and
Gynaecology
University of Natal
Durban
4001

29th August 2002

The Superintendent
Church of Scotland Hospital
Tugella Ferry

Dear Dr van der Merwe

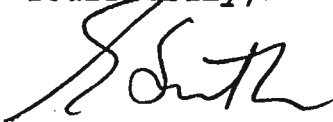
I am doing a sociological study as part of the requirement for the degree Masters of Social Science. My dissertation will address the problems facing mothers with regards to their choices for feeding their baby after confinement.

Dr D Moodley is co-supervisor for my study and my work will have relevance to her pilot study of Nevirapine to reduce the risk of Mother-to-child transmission of HIV.

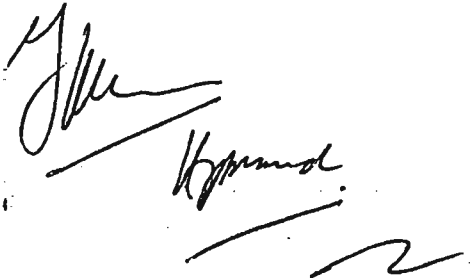
I wish to ask your permission to interview staff and patients in the ANC at your hospital. I will discuss this project with the clinic Sister to ensure that I do not interrupt the work of the clinic.

My husband Alan Smith of the department of Virology sends his regards.

Yours truly,



Mrs E D Smith





TEL : 033 - 8973321
FAX : 033 - 3422324

OFFICE OF THE HOSPITAL MANAGER

PRIVATE BAG X 9001
PIETERMARITZBURG
3200

Enquiries :	Date :	Reference :
From : DR R YU	Usuku : 30 AUGUST 2002	Inkomba :
By : vrae :	Datum :	Verwysing :

FOR ATTENTION:-

Elaine Smith
Department of Development
Studies in collaboration with
Department of Obstetrics & Gynaecology
University of Natal
URBAN
3201

Dear Elaine

RE: SOCIOLOGICAL STUDY :

With regard your request dated 28 August 2002,

you are hereby informed that you are given permission to interview staff and patients, provided the following persons are informed provisionally:-

T.R. Moodley (Chief Specialist- Obstets & Gynae) ext:- 3292
Miss H.M. Findlay (Nursing Manager) ext:- 3322
Mr W Hoosen (Human Resource Department) ext:- 3362

you are also requested maintain patient confidentiality (patients rights) and obtain patient's consent prior to your study.

Thanking you

Yours faithfully

R YU
HOSPITAL MANAGER
GREY'S HOSPITAL

Elaine Smith
Department of development
Studies in collaboration with
Department of Obstetrics and
Gynaecology
University of Natal
Durban
4001

29th August 2002

Matron Mthalane
KwaMashu Clinic
KwaMashu

Dear Matron Mthalane

I am doing a sociological study as part of the requirement for the degree Masters of Social Science. My dissertation will address the problems facing mothers with regards to their choices for feeding their baby after confinement.

Dr D Moodley is co-supervisor for my study and my work will have relevance to her pilot study of Nevirapine to reduce the risk of Mother-to-child transmission of HIV.

I wish to ask your permission to interview staff and patients in the antenatal clinic. I will discuss this project with the clinic Sister to ensure that I do not interrupt the work of the clinic.

Yours truly,



Mrs E D Smith

AB. Mthalane Assistant Director