

# **Paediatric Access To ART in KwaZulu-Natal, South Africa**

**R. Phili**

## **DEDICATION**

This work is dedicated to my wife, Annarose Phili, for her support and understanding, and the academic staff of the Health promotion Department for their support and encouragement.

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## **ABSTRACT**

South Africa and the province of KwaZulu-Natal (KZN) has one of the greatest HIV burdens in the world with an estimated 5.7 million people living with HIV/AIDS. One of the interventions that the government introduced to address this situation was the provision of antiretroviral treatment (ART) to those individuals that are eligible for HIV treatment in order to reduce the morbidity and mortality. Despite widespread availability of ART in KZN, children do not access ART to the extent that adults do, and therefore continue to die because of HIV and AIDS. This qualitative study explored the psychosocial and health system factors that influence paediatric access to ART in KZN from parents and caregivers perspectives. The ecological theory and the social cognitive theory was used to formulate an interview schedule used in conducting the in-depth interviews with adults (parents or guardians) who were bringing their children for ART-services and those attending these services themselves and not their children at Edendale and King Edward Hospitals in KZN. Purposive sampling was used to select clients for interviews and thematic was done in accordance with the aims and objectives of the study. A total of 42 participants were interviewed in this study. The low uptake of child ART was found to be influenced by several psychosocial and economic factors such as the poor knowledge about ART, stigma and disclosure associated with HIV, extent of support provided by parents/caregivers, parent's own ART was a determinant for bringing children for ART, use of traditional / alternative medicines, disintegrated families, especially the issue of multiple caregivers, complexity of paediatric ART, poor referrals of children from community institutions, unsatisfactory service at clinics, and some health policy and legislation with respect to health care for HIV-infected children

that had an unintended effect of restricting child access to ART as well as poverty related issues.

Improving knowledge and self-efficacy related to ART, prevention of mother to child transmission of HIV, re-training of health workers on child issues and addressing stigma and discrimination and other psychosocial and institutional problems and logistics could help to improve the low paediatric uptake of ART.

## **GLOSSARY / ABBREVIATIONS**

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy / Anti-Retroviral Treatment
ARVs	Anti-Retrovirals
ASSA	Actuarial Society Of South Africa
CCMT	Comprehensive care, management, and treatment
KZN DOH	Department of Health KwaZulu-Natal
HIV	Human Immuno-deficiency Virus
PMTCT	Prevention of mother to child transmission (of HIV)
SCT	Social Cognitive Theory
SITE	Hospital or Clinic, or Community Health Centre
USAID	US Agency for International Development
VCT	Voluntary Counseling and Testing

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## **CHAPTER ONE**

### **Background To The Study**

This chapter deals with introducing the general problem area, definition of research question, explanation of why the topic is important, research approach of the dissertation, key assumptions and contribution to be made by this research

#### **1.1 Introduction**

##### **Burden of Disease**

South Africa (SA) bears one of the greatest HIV burdens in the world with an estimated 5.7 million people living with HIV/AIDS (Department of Health, 2008). This means that the country accounts for 13% of all people living with HIV in the world. The life expectancy at birth is expected to reach a low level of 46 years in the period 2005–2010 with the current HIV prevalence situation, which is 22 years less than it would have been in the absence of AIDS (Rehle and Shisana. 2003).

Most of the data regarding prevalence rates is obtained from antenatal surveys that the government undertakes periodically. The province of KwaZulu-Natal (KZN) is disproportionately afflicted with HIV/AIDS when compared to the rest of South Africa (Figure 1). The antenatal clinic HIV surveillance for 2006 showed that KZN had a HIV prevalence of 39.1% (Department of Health 2007). KZN is the most populous province in South Africa and is made up of 10 259 230 individuals compared to 48 502 063 individuals (21.1%) making up the total SA population (Statistics SA community survey, 2007). This is despite being the country's third smallest province (Shisana and

Simbayi, 2002). The province has an unemployment rate of 29.9% (KZN Health Annual Performance Plan, 2007) with only 79,4% of households accessing piped water when compared with 88.6% of households accessing piped water in SA (Statistics SA Community Survey 2007).

KwaZulu-Natal (KZN) province is made up of 11 health district health services (Figure 2). About half of the population in KZN province lives in the districts made up of eThekweni, Ugu and Ilembe. The province has 554 primary health care clinics, 17 community health care centres, 72 hospitals, and 207 mobile clinics (Service Transformation Plan (STP) for MTEF 2007/08). As at the middle of 2007, about 1 540 183 people were HIV infected in KZN. About 12 00 babies are infected perinatally on a yearly basis in KZN [Actuarial Society of South Africa (ASSA) ASSA 03 for 2007]. The infant mortality ratio currently stands at 99.4 per 1000 live births and the child mortality ratio at 103 per 1000 live births (Department of Health KZN). Accompanying the HIV epidemic is the TB epidemic and its multi-drug resistant strains (MDR), with a mortality rate of 75%, and the extremely drug resistant form; XDR with 82% mortality rate. The total AIDS sick population in the middle of year 2007 stood at around 193 028 (ASSA) 03 for 2006.

### **Government response**

As one of the responses to the HIV and AIDS pandemic, the cabinet of the Republic of South Africa approved the Comprehensive Plan for Care, Management and Treatment of HIV and AIDS (CCMT Plan) in 2003 as means of providing a holistic response to the problem of AIDS. This includes Antiretroviral Treatment (ART) as part of a package of services in combination with interventions such as improved nutrition and access to traditional medicine. The Antiretroviral Therapy programme (ART) has dramatically altered the natural history of HIV disease for those for whom potent combinations of antiretroviral agents are made available. The primary goals of antiretroviral therapy are to reduce HIV related morbidity and mortality, suppression of the viral load to low or undetectable levels (to minimize the degree of viral replication), restoration and preservation of the immunologic function and improvement of the quality of life.

The initiation on antiretroviral therapy is based on clinical and immunological (CD4 count) assessments. The lower the CD4 count, the higher the risk of AIDS, and the more urgent the need for treatment. There are set guidelines for eligibility criteria for both adults and children, and these are considered along with an individual's readiness for starting treatment (Department of Health Antiretroviral Treatment Guidelines, 2003). One of the critical considerations prior to starting therapy is the patient's commitment to taking drugs appropriately and lifelong. This requires appropriate patient education to gain an understanding of the potential side effects and the importance of adherence to treatment (ARV drug literacy training). Another important

element in patient education is the emphasis on psychosocial support to overcome fears. It is argued that well-informed and engaged patients are the most successful with adherence to therapy (Furber, Hodgson, Desclaux, and Mukasa, 2004). Decisions on whether to initiate therapy are therefore taken once patient readiness have been assessed and patient education has been conducted. The provision of ART to patients is therefore a team centred approach, each member of the health care team is crucial to the success of patient care, which implies that decisions should be made about patient care as a team, rather than a doctor led care system. The ART site team consists of a doctor, nurse, pharmacist, a social worker, a dietician /nutritionist and the administrative staff that includes the data capturer and a clerk.

Initially district and regional hospitals were selected as ART service points. This was based on the fact that there were already in place certain basic requirements such as:

- 24-hour patient access
- Clinician availability
- Laboratory and diagnostic capability, either on-site or linked by a transportation system
- Pharmacy capability to secure and safely dispense ARVs
- Logistical support for regularly scheduled outpatient clinics
- Clear consultation and referral lines both up to the reference hospitals and down to primary care facilities

Figure 1. HIV Prevalence in South Africa, 2003 (Pre ARV Rollout)

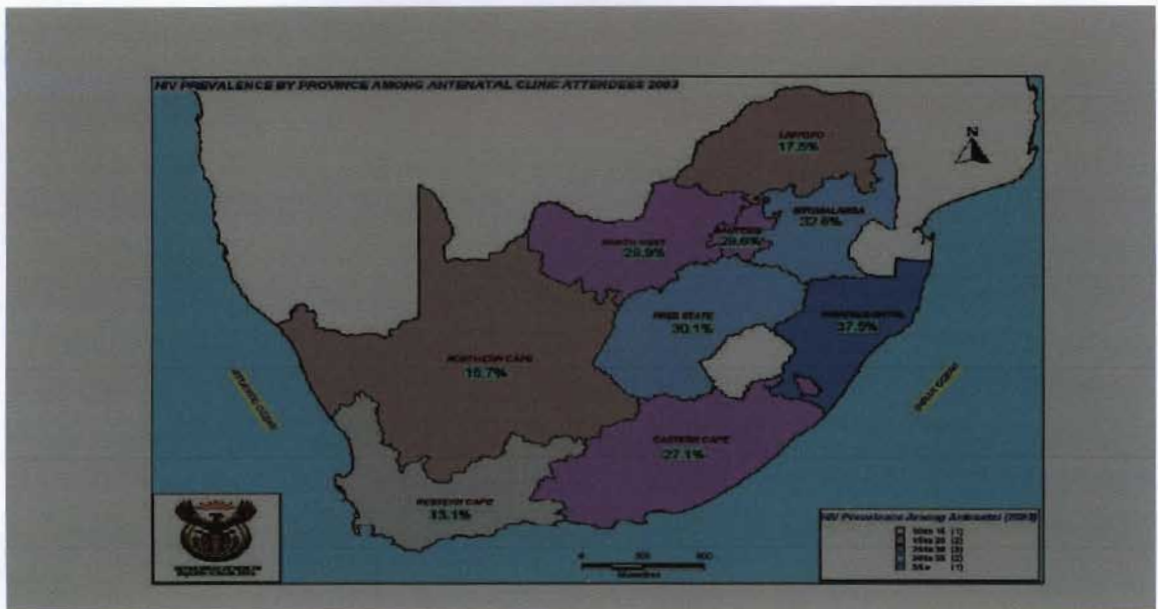
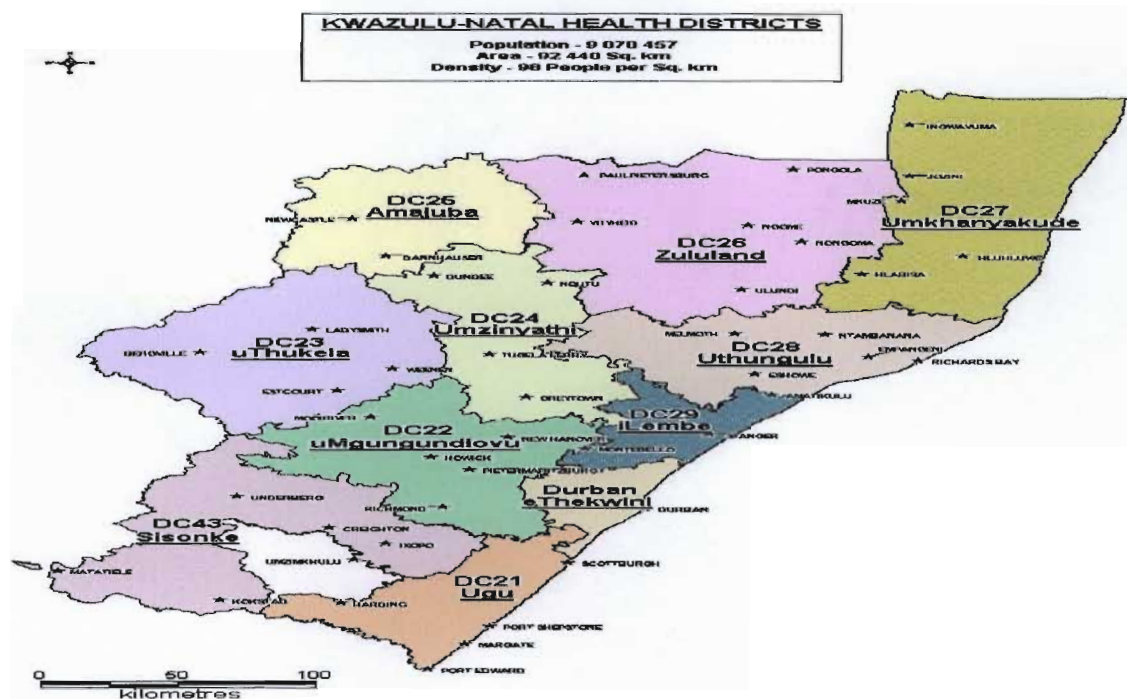


Figure 2. KwaZulu-Natal Health Districts (Source Department of Health KwaZulu-Natal).



### **Challenges and progress in the implementation of ART in KZN**

The provision of ART to those eligible for it, places extensive demands on the health care system in terms of administration, health systems management and ensuring equitable access for all patients to this service. Other challenges include (Attawel and Mundy, 2003):

- Low knowledge about ARV treatment, especially about newer regimens and effective monitoring of resistance to antiretroviral drugs amongst health workers.
- Ensuring uninterrupted drug supplies and other support services.
- Inadequate laboratory and pharmaceutical service capacities
- Severe shortage of trained people, especially doctors, dieticians and pharmacists.

The reasons for these challenges stem from the chronic under-resourcing of health systems, the underdevelopment of strategic public health leadership, the attrition of health personnel, and the high prevalence of poverty (Personal communication with KZN ART Manager). These are also limiting factors for the delivery of many less complex primary health care services.

The ARV rollout in KZN started in March 2004 with only a few hospitals being able to fulfill the accreditation criteria of becoming ARV sites. The programme is now being offered at more than 80 accredited sites throughout KZN. Currently, the programme is undergoing rapid expansion into primary health care clinics and other facilities with the capacity to provide ART.



### **Paediatric uptake of ART.**

Most of the 2.3 million children currently living with HIV in developing countries became infected through mother-to-child-transmission. With ARVs and other interventions, the risk of a HIV-positive mother passing infection on to her child can be minimised, but most HIV-positive mothers in developing countries are still not benefiting from these interventions. Reducing the rate of mother-to-child-transmission would decrease the global burden of HIV-infected children in need of treatment. Therefore, efforts to improve paediatric treatment ideally need to run parallel with campaigns to reduce mother-to-child-transmission.

In light of the fact that young children have rapidly progressing diseases and might be very sick or even die before HIV-diagnosis (Belzer, Fuchs, Luftman, & Tucker, 1999), it is of great concern that the provision of ARVs to children is still lagging far behind adult treatment. The number of adult clients in the programme increased rapidly since the inception of the CCMT plan in 2004, and is now one of the world's largest treatment programs with more than 154 000 clients on ART as recorded at the end of June 2008 (Department of Health KwaZulu-Natal). The national norm stipulates that at least 10% of people on ART should be children. According to the South African Comprehensive plan for Care, Management and Treatment of HIV and AIDS (CCMT plan), a child is someone who is of any age up to fourteen years (<14years). The operational definition of a child in this study was therefore in accordance with this description. In order for a child to access ARV-treatment, parental or legal guardian consent is required. It should be noted that the KZN province, along with the rest of the

country, barely meets 10% of children in their programmes. The reasons for the low uptake of ART service by children are largely anecdotal, and may include

- Inadequate referrals by institutions to paediatric ARV treatment resulting in the exclusion of a significant numbers of children in need.
- Insufficient training to health personnel on paediatric ART.
- Shortage of healthcare professionals, especially in rural areas.
- Lack of ART integration into the management of childhood illnesses.
- Stigma associated with HIV means that parents might be unwilling to get their children tested for HIV because of fear that this would also reveal their own status.
- Specific psychosocial vulnerabilities related to HIV/AIDS such as having sick parents who are themselves suffering from HIV and AIDS complications, the absence of parents and or guardians and in some instances belonging to child headed households.

Given the fact that these factors are not only unique to KZN-province, the question remains as to what accounts for the poor uptake of ART services among HIV-infected children in this province? It appears that there are specific constraints to the accessing of this service by children in this Province that needs to be investigated and documented. As of November 2007, there were just more than 10 000 children on ARV treatment in KZN province, in comparison with the more than 100 000 adults. At some facilities there are no children on ART at all. It has been noted that despite parental participation in the adult treatment programmes many eligible children seem not to participate in the ART programmes.. This points to the fact that certain obstacles

prevent some parents /guardians from ensuring that their children access this service, even though they fully understand the need for it themselves. It is therefore of great urgency to explore possible factors that influence the low paediatric uptake of ARV-treatment.

#### **Problem statement**

The enrollment of children into the ART programme has been slow in KZN. It appears that children are not being brought to the ART facilities in order for them to receive this therapy. What are the factors that influence this situation in KZN from the parents and caregivers perspectives?

#### **1.2. Aim**

The aim of this qualitative study is to explore the psychosocial and health system factors that influence paediatric access to ART-services as reported by parents and caregivers of HIV-infected children. Furthermore to investigate parents and guardians/caregivers perceptions about current practices relating to the treatment of children with HIV and AIDS with a view to making recommendations regarding the provision of ART services to children. Both adults, who bring their children for ART services and those who only access ARV-treatment themselves, but not their children, will be interviewed.

### 1.3. Objectives

- Explore the psychosocial factors influencing access to treatment and adherence for children from their parent's and /or guardian's perspectives
  - Perceptions, beliefs and socioeconomic factors influencing paediatric access to ART
  - Role of HIV/AIDS stigma and discrimination as a barrier to treatment
  - Support by parents/guardians to children pertaining to ARV treatment
- Investigate parents/guardians' views regarding ART service delivery to children (Service delivery factors).
  - Appropriate identification and referral of children for ART-services
  - Satisfaction with current service delivery
- Determine the convergence of practice and national policy and legislation with respect to health care for HIV-infected children
  - Client's perceptions regarding the ability of facilities to implement national and provincial protocols for the initiation and management of children in the ART-programme
- Propose recommendations to improve paediatric ART-access and to enhance national and provincial treatment guidelines.

#### **1.4. Chapter Outline**

This study is presented under the following headings:

**Chapter One:** An introduction and the rationale of the study presented.

**Chapter Two:** The literature review is presented and the theoretical frameworks for the study are discussed.

**Chapter Three:** Research methodology is described; the research process, structure and function are explained. The methodology is discussed in terms of the sampling technique, the collection of data and the development of the research instrument, the data analysis process and ethical considerations.

**Chapter Four:** The findings of the study are presented. In keeping with qualitative paradigm, 'thick descriptive' data was used to substantiate the findings.

**Chapter Five:** The discussion of the findings is presented. The findings are integrated and discussed in terms of the themes based on the objectives of the study and the theoretical frameworks and compared to findings of previous studies discussed in literature review.

**Chapter Six:** Conclusions and recommendations are presented. The contribution of the study is presented followed by recommendations as well as suggestions for further research.

## **CHAPTER TWO**

### **Literature Review and Theoretical Frameworks**

This chapter provides a discussion of the literature that is relevant to this study and will conclude with a conceptual outline of the theoretical models that will guide the study.

#### **2.1. Literature Review**

##### **2.1.1. HIV infection and paediatric ART**

Thousands of babies worldwide are born yearly with HIV, which they inherit from their infected parents. Whilst interventions to prevent or reduce mother to child transmission of HIV are in place in most countries, these interventions have had little impact in reducing congenital infection from their mothers (Attawell & Mundy, 2003; Peltzer, Skinner, Mfecane, Shisana, Nqeketho and Mosala, 2005). This has resulted in thousands of children acquiring the infection from their mothers and subsequently suffering from AIDS, and therefore in need of ART.

The goal of ARV therapy is to reduce the mortality and morbidity related to HIV and AIDS. Infant and child mortality is a major problem for developing countries, and paediatric AIDS account for the bulk of this problem (National Department of Health Antiretroviral Treatment Guidelines, 2004; National Department of Health Saving The Mothers Report). According to targets for the Millennium Developmental Goals (MDGs), it is critical that infant mortality be reduced drastically by 2015 (National Department of Health Saving The Mothers Report). Ensuring that children, especially in worst affected areas access and are maintained on ART, will greatly address the

problems of infant and child mortality due to HIV and AIDS. When taken as prescribed, ART significantly reduces the HIV viral load in a person's blood and increases the number of CD4 T-cells, which results in a rejuvenated immune system that is able to fight infections, thereby slows the progression to AIDS (Arnsten, Demas, Gourevitch, Buono, Farzadegan, & Schoenbaum, 2000; Bangsberg, Hecht, Clague, Charlebois, Ciccarone, Chesney, & Moss, 2000; 2004; Roca, Gomez, & Arnedo, 2000). ART requires strict adherence to the treatment schedule. Even the slightest digression from one's prescribed regimen can make treatment benefits temporarily or permanently unattainable (Amico, Toro-Alfonso, & Fisher, 2005). ART adherence rates that fall below 80% have been associated with the development of antiretroviral drug resistant strains of HIV (Bangsberg et al., 2000; Ickovics & Chesney, 1997; Knobel, 2002; Walsh, Horne, Dalton, Burgess, & Gazzard, 2001). Furthermore it is often cross-resistant to ART medications falling in the same drug class, quickly exhausting all potential treatment options. Adherence rates below 90-95% have been associated with rises in viral load (Blaschke, 1997; Knobel, 2002) and significant decreases in CD4 counts (Singh, 1999) and subsequent increases in mortality rates.

It should be noted that children respond differently to HIV-infection as their immune systems are still developing (New Mexico AIDS Info Net, 2005). Their CD4 cell and viral load counts are normally higher than in adults and are very diverse. Their viral loads usually decline up to the age of 4 or 5 before it stabilise. Without treatment, about 20% of children die or develop AIDS within one year (New Mexico AIDS Info Net, 2005).

### **2.1.2. The problems of paediatric ART access, care and support for children**

It is noted that ART access for children is poor when compared to that of adults. Currently children constitute about 11% of the patients on ARV treatment in KwaZulu-Natal (Department of Health KwaZulu-Natal). Children may face additional problems (psychosocial and logistical) that adult patients do not experience and these may play a role in their limited access to ART in KZN. However, most of the arguments offered in the literature in terms of low paediatric uptake of HIV services tend to be anecdotal or offered in communiqués or editorials in journals.

In 2006 there were 1, 2 million orphans living in South Africa (UNAIDS, 2006). Orphans are defined as those who have lost either one or both of their parents (Henderson, 2006). Poor access to HIV/AIDS related services in KZN is compounded by the growing problem of increasing numbers of AIDS-related orphans or children affected by AIDS. The HIV/AIDS pandemic compromises the basic rights of those children who themselves may be infected or affected by HIV/AIDS (UNAIDS, 2006). Many parents are dying due to the effects of HIV/AIDS, leaving orphans who often do not have relatives to care for them. (Richter, 2008). Furthermore, many of the ART-facilities have staff not adequately trained to assist these children as most lay counselors are not trained in child counseling skills. This results in these children not accessing the necessary services.

Older children are often forced to take care of their own younger siblings in cases where there are no relatives or extended families that are willing to take care of them



(Foster & Williamson, 2000). When children become the head of households and have the responsibility to raise younger ones, it is often done without the necessary skills, training or financial support (Nemapane & Tang, 2003). These child headed households represent an important sector of child deprivation of HIV and AIDS services, as the basic life priorities such as access to food and shelter tend to take priority. The loss of important documentation during parent bereavement may also impact negatively on the child's ability to access necessary financial needs to survive. Without special efforts made to identify these children and their needs, without acquiring identity documents, orphans and vulnerable children could remain unseen by institutions that could have provided necessary support (Lusk et al, 2003) including HIV-testing and access to ART. The death of one or both parents due to HIV and AIDS further raises issues about child care and who should be responsible for offering this care. There is an increasing responsibility placed on grandparents to care for their grand children (Seeley, Grelier, Barnett, 2004; Akintola, 2006). In some cases, these deaths have resulted in the shifting of traditional roles played by men and women in child care, with some men taking over the responsibility of caring for the child's day-to-day needs when the partner dies (Seeley et al, 2004). This could imply that these children may not have adequate access to services such as ART if these males are also working. Their care given role would thus be compromised.

Family disintegration is another factor limiting child access to health services including ART. The impact of the death of a breadwinner on some families result in children being left behind to be "adopted" by relatives and other family members who are able

to look after them. Often the health priorities of these children in their “new” families are not a priority (Le Marcis & Ebrahim-Vally, 2005). Therefore ART access for these children may be denied, even though their parents could have died of HIV and AIDS related conditions.

In a study conducted by the Population Council in collaboration with the University of Cape Town (Horizons Program and UCT, 2005), some of the current understandings of paediatric ART are discussed. One of the major issues was the poor referral rate of children to ART by various institutions. While this was found to be predominantly a health systems problem, this explanation is however insufficient to explain the extent and nature of the problem in KZN as it wasn’t covered in detail in this project. In addition, other factors such as health policies and guidelines have been shown to influence access to health services in general due to documentation requirements that may not be in the clients’ possession such as the child’s birth certificate or the parent’s identity document (Kruger et al, 2007). More specific and relevant studies are needed in this province to demonstrate the extent to which these apparent constraints have on the access to ART services by children. This study will seek to explore some of the factors that influence access from the ART client’s perspectives. As this is a relatively new programme in KZN province, there is little information available on the reasons for the low numbers of children in this programme. Many administrators tend to focus on administrative/logistical issues that hinder the progress, but this approach often downplays the relevance of psycho-social and contextual factors influencing the slow progress in this area. Most of the published literature has identified specific factors

contributing to the slow uptake of HIV and AIDS services by children as discussed in the next sections.

### **2.1.3. Stigma and disclosure related to HIV and AIDS as barriers to treatment access.**

Almost all literature that looks at the constraint to HIV and AIDS services, either by children or adults has found that HIV and AIDS stigma and discrimination is the largest contributing factor to people's reluctance in accessing these services (Mokoae, Greef, Phetlhu, Uys, Naidoo, Kohi, Dlamini, Chirwa, & Holzemer, 2008; Phaswana-Mafuya and Peltzer, 2006; Qwana, Mkaya, Mwamburi, Dladla, Lurie, 2001; Nguyen, Oosterhoff, Ngoc, Wright, & Hardon, 2008; Otolok-Tanga, Atuyambe, Murphy, Ringheim, & Woldehanna, 2007; Newman, Grusky, Roberts, & Rivkin, 2002) The word "stigma" is a Greek term denoting a mark that, in ancient times, was burned or cut into the flesh of an unsavoury character — a traitor, criminal, or slave (Harvey, 2001). Goffman (1963, p3) defined it as an "attribute that is deeply discrediting within a particular social interaction", as a spoiled social identity and a "deviation from the attributes considered normal and acceptable by society" (Harvey, 2001, p. 175). There are numerous other definitions of this term in the literature; however, Goffman's concept of stigma is the one most widely accepted (Harvey, 2001). The use of this term has been extended to describe this apparent discrimination to those infected with HIV and those with AIDS. In this context AIDS stigma means prejudice, discounting, discrediting, and discrimination that is directed at people perceived as having HIV or AIDS, and at individuals, groups, and communities with whom they are associated.

People with HIV or AIDS may not have any visible signs of the disease, yet they are more likely to be stigmatised because others may view them as “contributors to their own problems and unworthy of the care directed to more legitimate victims of illness” (Holzemer & Uys, 2004, p166). Stigmatization of HIV/AIDS is associated as is other STIs, to sexual excess and low moral character (Phaswana-Mafuya and Peltzer, 2006). In certain communities, the belief that migrant people are responsible for spreading HIV influence the amount and nature of stigma associated with HIV (Calin, Green, Hetherton, & Brook, 2007). Furthermore, HIV/AIDS stigma increases the likelihood to deny the presence of HIV and AIDS in one’s own community (Phaswana-Mafuya and Peltzer, 2006).

Those who experience stigma view it differently than those who stigmatise (Herek, Capitanio & Widaman, 2002). The two types of stigma referred to in the literature are felt stigma and enacted stigma. Felt stigma relates to the fear of being discriminated against whereas enacted stigma concerns the actual experience of a prejudicial effect (Daftary, Padayatchi, & Padilla, 2007). Felt stigma typically precedes and can exceed enacted stigma (Scambler, 1998). Felt stigma often leads to unwillingness to seek help and access resources (Jillings & Alexis, 1991). Enacted stigma has been shown to result in discrimination on the basis of HIV status or association with someone who is living with HIV/AIDS. The reasons for stigma are vast, with most authors arguing that it is fuelled by fear of infection, moral outrage, and shame, leaving those living with HIV and AIDS shunned and thus act as a barrier to timely care and support (Meyer-

Weitz, Makhaya, Frohlich, Mboyi & Abdool Karim, 2008; Otolok-Tanga, Atuyambe, Murphy, Ringheim, & Woldehanna, 2007; Phaswana-Mafuya and Peltzer, 2006).

Closely related to stigma as a barrier to access HIV and AIDS services, is disclosure of one's status to others. HIV stigma has been identified as a key factor inhibiting disclosure (Hereck and Capitano, 1993). In certain communities in KZN these factors have been measured, showing that disclosure patterns may depend on anticipated stigma and discrimination, and thus impact on ART-access, care and support (Abdool Karim., Maarschalk., Werner., & Swart, 2007). Meyer-Weitz, Makhaya, Frohlich, Mboyi & Abdool Karim, unpublished manuscript) found that the decisions to disclose one's HIV status stemmed from the view that some individuals felt that "there is no point in hiding" and that AIDS is a disease like any other, and therefore no shame needs to be attached to it (p5). Stigma results in various forms of discriminatory practices to those who are infected. Most people living with HIV and AIDS have been found to be exposed to stigma at community and family levels as well as from health care workers (WHO/UNAIDS 2000; Qwana, Mkaya, Mwamburi, Dladla, Lurie, 2001). Most HIV infected people are fearful of the result and of other people knowing their status and believe that if they are found to be positive, that their test result will not remain a secret (Nguyen, Oosterhoff, Ngoc, Wright, & Hardon, 2008). Such fears have stigma origins and result in people providing false names and addresses to avoid identification when having to test for HIV. Others are reluctant to access the necessary health services due to stigma. It was found that HIV related stigma override the potential benefits of treatment as many patients were found to be afraid of being seen at HIV clinics

(Daftary, Padayatchi, & Padilla, 2007; Meyer-Weitz, et al, unpublished manuscript). There have been cases where even hospital linen that had been used by infected people had been incinerated, and utensils thrown away after use (Mahendra, Gilborn, Bharat, Mudoi, Gupta, George, et al, 2007). Fear about AIDS stigma and discrimination that hinders disclosure has been shown in other studies not to only affect the individual, but can sometimes affect the rest of the family as they would be viewed as having HIV/AIDS (Meyer-Weitz, et al, unpublished). Stigma appears to also mediate the relationship between misconception about HIV/AIDS and willingness to disclose HIV status. Misconceptions are closely related to stigma, stigma is negatively associated with a willingness to disclose and vice versa (Yang, Li, Stanton, Fang, Lin, & Naar-King, 2006). In a case study at Manguzi Hospital (KZN) described by Dr Colin Pfaff, (2004), a mother tried to convince her child that he had TB, while he overheard that both of them had HIV/AIDS. On further investigation as to why the mother was lying to the child, it was discovered that the child was not living with the mother, but with the aunt, along with eight of the aunt's children. In fear of being ostracized and prevented from attending school by the aunt, it was deemed necessary to lie about the child's HIV-infection. It has been observed in some studies that the child's biological parents are less likely to disclose the child's HIV status to other children or health workers (Lesch et al, 2007). This could mean that children whose parents have a problem with revealing their own or their children's HIV status will have difficulties in taking their children for ART services.

It is clear that stigma can have a variety of negative effects on health behaviour, such as seeking voluntary HIV-counseling and testing (VCT), accessing health care timely, and willingness to disclose a HIV-positive status (Abdool Karim et al, 2008; Makoae et al, 2008). Disclosure of HIV status to others confers benefits both to the infected person and to those disclosed to (Calin. Et al, 2007). This is because disclosure to sexual partners gives those partners the opportunity to make informed choices regarding HIV-related risk behaviours (Greene, Derlega, Yep, Petronio, 2003). Disclosure has also been found to be linked to increased adherence to ART (Adam, Maticka-Tyndale, Cohen, 2003), as well as to seeking medical treatment generally (Bartlett and Gallant, 2001). In some studies, the fear of HIV stigma resulted in people seeking the services of traditional practitioners, who they regard as being able to provide health services in a more discreet manner and whose services are readily available (Masauso Nzima, Romano, Anyangwe, Wiseman, Macwan'gi, Kendall & Green, 1996). Where there is a low disclosure of HIV status by individuals, there is an accompanying low uptake of services including ART. Disclosure is associated with higher satisfaction with social support, lower levels of anxiety and lower ratings of stigma (Calin et al, 2007).

The process of disclosure is not uniform, it is a multi faceted behaviour, e.g. disclosure may be between parent and child, child and siblings, parent and family, sibling and the school and so on. Many authors have studied the reasons for disclosure between different parties, and found that these are very complex in different situations. Calin et al. (2007) found that reasons for disclosure to the family were the most complex. Disclosure to friends for example, was predominantly motivated by obtaining social

support; to partners the motivation was the availability of treatment of HIV. Mokoae et al., (2008) found that disclosure was used in certain instances as a coping strategy, depending on whether it was judged to make things better or worse. Some people would feel better if they disclose their HIV-status, especially to a spouse or family members, and some would not disclose for fear of rejection. It has been found that HIV-positive adults were likely to disclose their status to family and friends in order to preserve the honesty in relationships, to gain social support, and to avoid the anxieties of concealing their HIV status (Lam, Naar-King & Wright, 2007; Lam et al, 2007; Simoni, Mason Marks, Ruiz, Reed, & Richardson, 1995). Youth on the other hand, were less likely to disclose to friends who may be less supportive and acceptive of the diagnosis but would rather disclose to family members (Lam et al, 2007). In most cases mothers are likely to disclose their HIV-status to some of their children or, not at all (Ostrom et al., 2006). The uncertainty by parents about when to disclose their own or the child's HIV status seems to be one of the factors that contribute to the low uptake of health services by children as these parents may be unwilling to have their children tested for HIV and then subsequently accessing ART ( Mellins, Brackis-Cott, Dolezal, Richards, Nicholas and Abrahams, 2002). In this study, the most common reasons for non-disclosure was the thinking that a child deserves to have a carefree childhood, not wanting to scare the child and not wanting the child to worry about the mother. Disclosure to children may also be influenced by pressing societal and personal issues for parents, e.g. a women who is infected by a husband who had been having premarital affairs may find it difficult to disclose to children by virtue of having to explain to them this particular situation (Ostrom, Serovich, Lim and Mason, 2006). Research indicates



that in general, parents avoid disclosing to their children for a very long time, with some delaying disclosure until the school years, with most disclosure occurring to adolescent children, and many parents decide not to tell their children at all (Abadia-Barrero and LaRusso, 2006). Vallerand et al. (2005) found in their study regarding the disclosure process of HIV-positive mothers to their HIV- negative children, that the reasons why mothers chose to disclose to children was because they wanted to protect their children from the same fate. This was however done with full consideration of whether the child was developmentally ready for disclosure. This is in keeping with the fact that most child disclosures are normally done with older siblings. In some cases parents are obliged to disclose their status to children because of their poor health. Forced disclosure also occurs in situations where children receive information about parental HIV-status from other sources and when children confront their parents about the information they received from the community (Vallerand et al, 2005).

Generally, non-disclosure has been associated with various other psychosocial consequences such as negative mood, avoidant behaviours i.e. social withdrawal and increased alcohol consumption, as well as other risk taking behaviours (Mokoae, et al, 2008). Some studies have suggested that children who were aware of their own HIV-status had higher self esteem than children who did not know their status, and that parents who had disclosed the HIV-status to their children experienced less depression than those who did not (American Academy of Paediatrics, 1999; Lesch, Schwartz, Kagee, Moodley, Kafaar, Myer, & Cotton, 2007). The disclosure process can only be

understood with adequate consideration of the cultural and family contexts and prevailing HIV-related stigma (Pfaff, 2004).

Children in need of HIV and AIDS services depend on adults to gain access to these services. Therefore, all of these factors invariably mean that children whose parents or guardians anticipate or experience HIV/AIDS-related stigma might have difficulty with HIV-disclosure therefore are unlikely to access appropriate support and care including ART for themselves and their children. In some instances they might access it for themselves but due to the complexities of disclosure to their children and other relevant stakeholders such as the school, parents might be reluctant to access paediatric ART for their children.

#### **2.1.4. Economic factors**

The physical access to a health facility is another factor that limits the attendance of services. Access to health facilities is a problem especially in geographically dispersed communities such as rural communities. In a study by Peltzer et al., (2005) conducted in the Eastern Cape, regarding the factors influencing the utilization of PMTCT, it was found that the majority of women did not access this service due to a lack of money and transport. Poor access to transport and affordability of transport to and from the clinics seemed to impede the utilization of the PMTCT-services (Peltzer et al, 2005). Poverty and unemployment are factors that are rife in KZN, as evident in the 25% reported unemployment rate (Statistics South Africa). This implies that access to ART services by children could be negatively influenced as parents might be unable to find money to

travel to health facilities. Furthermore other priorities such as buying food and clothing could get preference to attending health services in most of these poor families. In some cases the grandparents who receive old age grants were tasked with the responsibility of taking children for health services when they receive their grant payments (Appleton & Hunter, 2000).

#### **2.1.5. Health systems: Access to services**

The historical weaknesses in the health systems of underdeveloped countries have been viewed a major reason for the apparent ineffectiveness of global HIV and AIDS interventions (Coovadia and Hadingham, 2005). This contributes to bottlenecks in service delivery initiatives. Health systems constraints have multiple causes, both within and external to the health system itself, which in turn could be interdependent. This aspect is true for SA institutions, where despite the availability of government and donor funding, patients struggle to obtain services. The bureaucratic processes involved in the disbursement of funds for infrastructure, information systems, drugs, logistics and human resources that are required to provide HIV and AIDS services impact negatively on the effectiveness of delivery. In South Africa, problems like staff shortage, poor delivery of medication, lack of proper consultation and counselling rooms, are experienced in several health institutions throughout the country (Peltzer et al, 2005). The shortages of staff at health institutions are associated with long waiting times and reluctance of people to return for the same services. Similarly, the Ugandan / Ethiopian project (Racalbuto et al, 2006) found that the overload due to HIV/AIDS on the fragile health care systems, ill-equipped for the management of paediatric AIDS,

accounted for the poor paediatric uptake of ART. Furthermore, services such as obstetric care, child immunisation, diagnosis and treatment of malaria also proved to be of a higher priority in these countries than paediatric ART, a situation that is different to KZN province. In addition, many African countries are also not ready yet for the complexity of ARV-treatment (Racalbuto et al, 2006). In all these studies, inadequate investigation was done of client factors restricting paediatric access to ART, an area in urgent need of exploration due to the paucity of available literature. The basic underlying understanding is that more effective and more appropriate processes between providers and patients will improve health outcomes which in turn are determined by improved facilities, equipment, staffing, and training (Wu, Gifford & Asch, 1998).

The clinic operating times may be another factor that may specifically restrict child access to ART services. This is because most children are normally at school during the clinic operation times, and may not always be able to skip lessons to go to the clinics. It is therefore important to investigate the extent to which the opening and closing times of the ART clinics impact on children accessing ART services.

#### **2.1.6. Health worker's attitudes towards HIV and AIDS**

It is a widely acknowledged phenomenon that the treatment clients receive by staff at health institutions have a bearing on their future health behaviours including health care seeking behaviours (Fransman, McCulloch, Lavies, & Hussey, 2000). The major motivation for clients to return to a clinic for services appeared to be the attitudes of

health workers found in a study by Peltzer et al., (2005). This phenomenon is not unique to health institutions only, but to other service based workplaces as well. Negative attitudes of health care workers might impact negatively on people accessing HIV/AIDS-related services generally. It should also be noted that because nurses often work at the frontline of health service delivery, that negative attitudes towards patients might be a reflection of their general work dissatisfaction rather than towards the patients per se.

As in the wider community, misconceptions and myths about HIV and AIDS are held by a sizable group of health workers at health care facilities where some still believe that sharing a meal with someone who has HIV/AIDS could be a route of HIV transmission (Phaswana-Mafuya and Pelzer, 2006). Clients have reported experiencing negative attitudes from nursing personnel at health institutions (Deetlefs, Greef and Koen, 2003). Communication of client's HIV status to other staff members or other people without client consent can result in clients avoiding the health services, which means that they will be unlikely to access the continuous treatment, care and support that they need (Nguyen, Oosterhoff, Ngoc, Wright, & Hardon, 2008). Health workers (nurses) judgmental and prejudiced views are manifested in blaming the infection on specific group attributes such as low social class, occupational status and behavioural practices (Mahendra, Gilborn, Bharat, Mudoi, Gupta, George, et al, 2007). Nurses and other health workers who care for persons living with HIV/AIDS have their own emic view of stigma that may lead them to promulgate prejudice and discrimination toward their patients. These health care workers are themselves sometimes the recipients of

stigma from their families, friends and patients. It is unclear how such stigma affects the quality of work life for HIV/AIDS care providers. (Holzemer & Uys, 2004). Some newer studies have established that factors such as health worker stress could contribute to the low uptake of services by children. The amount of stress that caregivers experienced has been identified also as having an effect on the quality of care delivered in specifically childcare centres (Hogenkamp, 2008).

An increase in the level of stress that caregivers experience will lead to a decrease of the quality of care they deliver. In a study conducted by Mahendra, Gilborn, Bharat, Mudoi, Gupta, George, et al, (2007) to understand and measure AIDS related stigma in health care settings in India, it was observed that health practitioner's negative attitudes resulted in some discriminatory practices. Amongst these were testing of patients without counselling and informed consent, disclosing of patient's results to others without patient consent, improper disclosure of results to patient's families, and the use of gloves when assisting patients whose files were marked 'HIV positive'. In other studies the effect of health worker stigma resulted in clients not returning for scheduled follow up visits for themselves or their children (Nguyen, Oosterhoff, Ngoc, Wright, & Hardon, 2008).

It is possible that some of the negative staff attitudes towards clients may be due to the ever increasing work pressures emanating from overcrowded clinics because of the high demand for HIV and AIDS services. This may result in the nursing staff trying to offer a service to as many clients as possible within the limited time period. This may

impact negatively on the quality of service they are able to offer with consequences for their client relationships and client satisfaction pertaining to the ART service. These practices by health care workers will impact negatively on general client access of HIV/AIDS related services as these messages would reach others in the community who may be dissuaded from utilizing the formal health care system and therefore rather seek alternative or traditional health services.

## **2.2. Theoretical Frameworks**

The ecological theory (Bronfenbrenner, 1996) and the Social Cognitive Theory of Bandura (1986) will guide the study. Both these theoretical perspectives emphasise the interaction of individuals with their social environment and conceptualise behaviour to result from this reciprocal and dynamic relationship.

### **2.2.1. Ecological theory (Bronfenbrenner, 1996)**

A more holistic approach to the factors influencing paediatric ART-access was considered for this study, hence the ecological theory of Bronfenbrenner (1996) was considered in conjunction with the Social Cognitive theory to be most appropriate in order to emphasise the influence of contexts on behaviour. The ecological theory was only used to guide the **broad framework** of the study as the influential factors in ARV access to children seem to stem from personal, interpersonal and environmental factors. The term ecology refers to the study of the relationships between organisms and their environments (Stokols, 1996). This theory allows for the investigation of people's behaviours through the interaction of individual, family and community level factors including health systems. Ecological theory stipulates that health and behaviour are influenced at multiple levels, including interpersonal, sociocultural, policy, and physical environmental factors, and that these influences interact with one another (Bronfenbrenner, 1981; Bronfenbrenner, 1989; Hawley & Amos, 1986; Stokols, 1996). The ecological model includes an emphasis on characteristics of the built environment, such as architecture and community design, access to elements important to behaviours such as health seeking behaviours and adherence to medicines. All of these are



elements that require investigation as the possible contributors to the poor access to ART. At the largest level, this model recognises the effect of natural environmental factors such as geography, weather, and climate on health behaviour. This theory provides a good guide on questions that need to be asked to the participants during the interview as it will assist in understanding the role of these issues in affecting paediatric access to ART. The ecological theory therefore would reflect not only on behavioural and environmental change but also the interplay between persons, groups, and their social, physical, and cultural milieu, which are hallmarks of what this project aims to investigate, namely factors influencing the apparent reluctance to enroll children on ART by the parents. These are integral in identifying intervention points for health promotion interviews (Kar & Alcalay, 2001). This study will focus on communities affected by problems of HIV infections, stigma and poverty that may influence the decisions to seek ART care, and are in turn also influenced by these problems. The complex multidimensional interplay between socio- economic and political factors requires a multidimensional approach to this problem of paediatric access to ART. In ecological theory (Bronfenbrenner, 1996), the behaviour of individuals is described by five levels of influence or concepts:

- **Intrapersonal level:** Individual characteristics that influence behaviour (knowledge, attitudes, self-concept, skills, and development history, attitudes, beliefs, personality traits). These will be established in clients.
- **Interpersonal level:** Relationships with primary social groups (family, peer networks, and the workplace) that provide social identity, support, and role confusion. Also this concept can be employed in this study to

establish constraints at social family and organisational level with all the participants.

- **Community level concepts:**

- Institutional factors- social institutions with organisation characteristics, such as economic and social resources. In this project, the role of these determinants will be looked at, e.g. the economical factors will dictate if there are any issues relating to unemployment that determines whether children are able to access services. The presence or absence of community social workers is another possible factor influencing the referral of eligible children to services.
- Rules, regulations, policies, and informal structures, which may constrain or promote behaviour, will be established. The issue of the new Child Act for example is likely to play a significant role in this area.
- Community factors- primary social groups to which an individual belongs, such as families, friendship networks, and neighborhoods, and relationships among social groups and organisations within a defined boundary. This is an area where the role of religious groupings and schools is critical, as these may provide relief to overburdened health institutions.
- Public policy- local, state, and national laws and policies that regulate or support healthy actions and practices for disease

prevention, early detection, control, and management. The child act also fits in this area.

Unlike many theories or models of behaviour that focus on one dimension of health promotion, such as knowledge attitudes, or skills that do not necessarily result in desired behavioural change, the strength of the ecological theory lies in that ecological models provide a mechanism for linking health promotion and health protection emphasizing a shared framework for change targeted at individual behaviours and the environment (Patrick, Intille, and Zabinski, 2005). This may lead to improved program effectiveness. Its weakness tends to be its strengths – too many levels of focus make it cumbersome to formulate strategies at all levels. At the community level, it tends to overlap with suggestions at the interpersonal level. It is a theory that is basically made up of other theories.

### **2.2.2. The Social Cognitive Theory (SCT).**

The SCT of Bandura (1986) underlies the interaction and reciprocal determinism between the individual and the social environment. While many theories have been used to help explain health behaviour, Bandura's social cognitive theory (SCT) (Bandura, 1986) is considered one of the primary cornerstones of research into the determinants of health behaviours such as that of ART behaviour. SCT has also served as the basis for a large proportion of individual-level health behaviour interventions (Airhihenbuwa & Obregon, 2000). This theory explains how people acquire and maintain certain behavioural patterns, while also providing the basis for intervention strategies. Human behaviour is explained in terms of a triadic, dynamic, and reciprocal model in which behaviour, personal factors, and environmental influences all interact

(interaction among cognition, behaviour, environment, and physiology) (Bandura, 1989). An individual's behaviour is uniquely determined by these interactions. A key mechanism through which the individual contributes to this triad is personal agency or self efficacy (one's perceived ability to adopt a recommended behaviour). Key to human agency is the person's belief in their personal efficacy. This means that unless people believe they can produce desired results to their actions they have little incentive to act or to persevere in the face of difficulty. The two primary domains widely used in HIV/AIDS programs are modeling (imitation of the behaviour of a role model) and self-efficacy. Both these domains are extensively covered by this theory. These attributes were viewed as relevant for this type of study, where the theory was expected to provide guidance on analysis of issues influencing ART seeking or constraining behaviours. The other attributes of environmental issues and physiological issues were viewed as important consideration in determining the social aspects influencing children's access to ART. According to this theory, the personal factors that influence behaviour include having the capability to:

- Symbolize behaviour
- Anticipate the outcomes of a behaviour
- Learn by observing others
- Have confidence in performing a behaviour (including overcoming any barriers to performing the behaviour)
- Self-determine or self-regulate behaviour
- Reflect and analyse experience

The major constructs of SCT and their implications for interventions are:

*Environment:* This construct looks at factors physically external to the person. The environment is composed of the social environment such as family, friends, peers at work or in the classroom and the physical environment.

*Situation* refers to the perception of the environment. It is important to correct misperceptions and promote healthful forms. Changing the environment implies a change in situations.

*Behavioural capability:* This refers to the knowledge and skill to perform a given behaviour. Promotion of mastery learning through skills training is a recommendation for intervention. If a person is to perform a behaviour he or she must know what the behaviour is (knowledge of the behaviour) and have the skills to perform it. A person can also develop a behavioural capability through observational learning from others.

*Expectations:* These are anticipatory outcomes of a behaviour. The implications for an intervention would be to model positive outcomes of healthful behaviour. Expectations guide behaviour and are learned in four ways according to this theory:

- Performance attainment
- Vicarious experience
- Hearing from others or social persuasion
- Physiological arousal

*Expectancies:* These refer to values that the person places on a given outcome, incentives. The suggestion is to present outcomes of change that have functional meaning. Generally a person will choose to maximize a positive outcome over a

negative outcome. This is key in intervention for motivating adoption of new behaviours such as seeking ART.

*Self-control:* Personal regulation of goal-directed behaviour or performance. It is advisable that an intervention should provide opportunities for self-monitoring, goal setting, problem solving, and self-reward. The key is the ability of the individual to engage in behaviour to achieve a goal.

*Observational learning:* this refers to behavioural acquisition that occurs by watching the actions and outcomes of others' behaviour and the reinforcements associated with those behaviours. Interventions should include using credible role models of the targeted behaviour. Observational learning occurs when a person watches other people's behaviours.

*Reinforcements:* These are responses to a person's behaviour that increase or decrease the likelihood of reoccurrence. Interventions at this level include the promotion of self-initiated rewards and incentives. Reinforcements are applied to reward positive behaviours and sanction negative behaviours and can be

- Direct reinforcement
- Vicarious reinforcement
- Self reinforcement

*Self-efficacy:* Bandura used the term self-efficacy to refer to a person's belief that he or she can successfully carry "courses of action required to deal with prospective

situations containing many ambiguous, unpredictable, and often stressful elements" (Bandura & Schunk, 1981: p.587). Therefore, self-efficacy is a person's belief that they have behavioural competence in a particular situation. The suggestion is to approach behavioural change in small steps to ensure success.

*Emotional coping responses:* These are strategies or tactics that are used by a person to deal with emotional stimuli. Provision of training in problem solving and stress management is the recommended intervention. Excessive emotional arousal however inhibits learning.

*Reciprocal determinism:* Refers to the dynamic interaction of the person, the behaviour, and the environment in which the behaviour is performed. It is advisable to consider multiple avenues to behavioural change, including environmental, skill, and personal change.

Some authors have argued that the social cognitive theory is an individual psychological model of behaviour change (Yoder, Hornik, & Chirwa, 1996). Bandura (1998) advocates the need to focus on collective efficacy if the theory is used in communities characterized by communal values and norms. The limitations of Social Cognitive Theory include: difficulties in disproving it, difficulties in using it to deal with non-linear relationships, multiple concepts can be difficult to implement in an intervention and it also does not give a clear direction in mechanisms to sustain change (Bandura, 1989). Furthermore, behaviour has been found to be more consistent than is argued by Bandura's theory which focuses a great deal on the situation. Some researchers have argued that the theory lacks attention to biological or hormonal

processes (Pervin & John, 2001). Of most significance is the criticism that the theory is not unified. Concepts and processes such as observational learning and self-efficacy have been highly researched but there has been little explanation about the relationship among the concepts.

This theory was used to discuss the results as it combines well with the ecological model (complimentary role). Some limitations inherent in theories based on cognitive processes are covered by the comprehensiveness of the ecological model, as it is more inclusive of the many environmental factors that may affect health behaviours. Therefore the combination of the two theories was viewed having the potential of providing a comprehensive coverage of all issues influencing the barriers to ART access by children. It should however be noted that this qualitative study does not attempt in any way to test these theories but rather use these theories to ensure adequate exploration of paediatric access to ART.



## **CHAPTER THREE**

### **Research Methodology**

#### **3.1. Introduction**

This chapter provides an overview of the research design and the methods used in exploring the factors influencing children's access to ART services from parents' and guardians' perspectives.

#### **3.2. Research Design**

##### **3.2.1. Qualitative design**

A qualitative study was conducted in which in-depth interviews were conducted with both adults (parents or guardians) who bring their children for ART-services and those attending these services themselves, but not their children to explore factors influencing paediatric access to ARV-services. A qualitative study was chosen based on its suitability for this exploratory investigation. Qualitative research, broadly defined, means "any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification" (Strauss and Corbin, 1990; p17). Quantitative research tends to seek causal determination, prediction, and generalization of findings whereas qualitative research seeks instead illumination, understanding, and extrapolation to similar situations. Qualitative analysis results in a different type of knowledge than quantitative inquiry. It further allows for greater insight into a particular phenomenon (Trochim, 2006).

A qualitative design was therefore preferred for this study because of its ability to explore social issues influencing participant's behavioural perceptions and decisions pertaining to paediatric ART at a deeper level. As the concept of paediatric access to ART is relatively unexplored, it can be argued that inadequate experience and insight into this phenomenon exist. This makes qualitative research into this subject of special value as it provides a potential for revealing some complex and sensitive issues pertaining to paediatric access to ART that are not known or inadequately understood. It furthermore allows for the description of the phenomena of interest in great detail, in the original language of the research participants. The issue of HIV and access to ART pertains to parts of an individual's life story best understood through qualitative methodologies (Le Maric and Ebrahim-Vally, 2005).

Another basis for selecting the qualitative method for this study was that previous researchers on similar projects primarily utilised qualitative research methods in order to effectively establish participant's opinions in similar matters (Le Marcis and Ebrahim-Vally, 2005). If quantitative methods had been used, participants may not have presented a deep insight into their thoughts and feelings that an in-depth face-to-face interaction can generate.

There is however a disadvantage of qualitative methods as they may provide extensive detail that results in difficulties in determining what the generalisable themes may be for the subject under investigation. This is why some authors have suggested that there is a great value in mixing qualitative research with quantitative research in the same project (Strauss and Corbin, 1990; Patton, 1990). Quantitative research excels at

summarizing large amounts of data and reaching generalizations based on statistical projections. Qualitative research excels at "telling the story" from the participant's viewpoint, providing the rich descriptive detail that sets quantitative results into their human context (Lincoln and Guba, 1985). Some aspect of this study were analysed quantitatively, e.g. some participant's demographics as these are better expressed in figures.

Qualitative research can be emotionally taxing and also time consuming. These research methods can also be used to gain new perspectives on things about which much is already known, or to gain more in-depth information that may be difficult to convey quantitatively. Thus, qualitative methods are appropriate in situations where one needs to first identify the variables that might later be tested quantitatively, or where the researcher has determined that quantitative measures cannot adequately describe or interpret a situation. All of these attributes were relevant for this topic of poor paediatric access to ART, hence the choice of this method.

The ability of qualitative data to fully describe a phenomenon is an important consideration not only from the researcher's perspective, but from the reader's perspective as well. It provides readers with information in the form in which they "usually experience it" (Lincoln and Guba, 1985). Qualitative research reports, typically rich with detail and insights into participants' experiences of the world or the topic under investigation. It is also viewed as epistemologically in harmony with the reader's experience (Stake, 1978) and thus more meaningful.

### **3.2.2. Study Setting**

The study was conducted at two hospitals offering ART services in the district of EThekweni and Umgungundlovu in KZN, i.e. King Edward hospital (KEH) and Edendale hospital (EDH) respectively. Both districts have the highest number of people residing in KZN with EThekweni district having the most people. These districts were selected because they are easily accessible to the researcher and because the health facilities cater for a mixture of patients from all walks of life reflecting the different dynamics of the population of KZN.

King Edward hospital has a significant number of children in its programme, is not badly resourced as specialists-paediatricians, nurses and other support staff and services are available. It is centrally placed in Durban, serves communities from diverse backgrounds e.g. urban and informal settlement dwellers, and also receives referral clients from other institutions from as far as Eastern Cape. This was viewed as an important mix of the population of KZN in view of revealing information reflective of the diverse background of people living in KZN.

Edendale Hospital is slightly less resourced than King Edward, but also has child specialists, social workers, and nurses. The hospital serves a largely semi-urban to rural community and a significant number of informal settlement dwellers. It also serves as a referral hospital for the Midlands region and the northern parts of KZN. Being the major referral institution for the central and northern parts of the province, it was viewed as important in getting the views from this section of the KZN population.

There is a high activity of traditional practitioners around the vicinity of Edendale hospital with some traditional medicines on sale just outside the hospital premises, indicating a possible high demand and use of traditional medicines in the communities in which the study was performed. These settings were assumed to yield information valuable in understanding paediatric constraints to ART within KZN.

### **3.2.3. Sampling**

Purposive sampling was used to select clients for interviews. Purposive sampling can be defined as the selection of information-rich cases which can be studied in depth (Patton, 1990). Individuals are selected because they meet specific criteria. It is also regarded as a very flexible method of sampling for interview purposes. Despite the apparent flexibility in purposeful sampling, it is noted that there can be some sampling errors that can arise in its use in qualitative research. These include the distortions caused by insufficient breadth in sampling, distortions introduced by changes over time, and the distortions caused by lack of depth in data collection at each site (Patton, 1990). All of these factors were considered during the sampling and data collection process.

Two criteria were used to select the participants. They had to be adults who were bringing children for ART services, and adults who were attending ART services but who did not bring their children for this service. The parents or guardians (clients) were selected for the interviews with the aim of establishing the social constraints that restrict access to ART by children. Parents who brought children for ART were included in the study in order to establish reasons that compelled them to bring their

children for this service, despite the possible constraints or hardships that they may have faced when they realized that their children were in need of this service. The parents who were attending adult clinics and did not bring their children were included in order to elicit reasons for not bringing their children for ART even though they were on ART themselves and to explore possible problems associated with having to access ART for themselves and their children on different days / times for those who had children but who accessed this service at different times; and in the case of adults who did not have children at all to give information on their feelings about bringing children if they had them or what they considered would be constraints. The caregivers who brought children who were not their own were also included to document their perspectives on the dynamics involved with caring and bringing children for ART. A total of 42 participants were interviewed in this study. Twenty two (22) participants were interviewed at Edendale Hospital and twenty (20) at King Edward Hospital. At each site, 11 and 10 participants respectively were purposively selected from parents/ caregivers who bring their children for ART, and another 11 and 10 respectively were participants who access the adult ART-services but who do not bring their children for ART. The initial approach to the participants was through the nursing staff at these facilities as some clients are considered too unwell to participate, especially at the adult clinics. The nursing sister in charge assisted with the selection of clients, and lay counsellors assisted in approaching clients. The interviews were conducted in the designated counselling rooms at these facilities, which are designed for one on one interview, thereby preventing other patients and staff from hearing the discussions.

#### **3.2.4. Research Instrument and Data collection**

Qualitative interviewing utilizing open-ended questions that allow for individual variations have been shown to be beneficial in similar studies. Patton (1990) writes about three types of qualitative interviewing;

- Informal conversational interviews,
- semi-structured interviews, and
- standardized, open-ended interviews.

In this study the latter option was employed to conduct in-depth interviews with participants. All questions asked were open-ended in order to stimulate trains of thoughts from the participants (Morgan, 1993). An interview schedule was developed for this purpose. An interview schedule can be described as a list of questions or general topics that the interviewer wants to explore during each interview. Although it is prepared to ensure that basically the same information is obtained from each person, there are no predetermined responses to the questions asked, and the interviewer is free to probe and explore within these predetermined inquiry areas. The interview schedule also enables the researcher to probe on issues that emerge during the interview, thus allow for great flexibility during the interview process. Interview schedules ensure good use of limited interview time and make interviewing multiple subjects more systematic and comprehensive. They also help to keep interactions focused and allow people to openly elaborate on issues that they felt were important to mention without restriction. In keeping with the flexible nature of qualitative research designs, interview schedules can be modified over time to focus attention on areas of particular

importance, or to exclude questions the researcher has found to be unproductive for the goals of the research (Lofland and Lofland, 1984). The interview schedule for all participants was developed with consideration of the literature review, the theoretical frameworks and the objectives of the study (Annexure 1). The interview schedule was used in order to assist the researcher when conducting the interview to allow for adequate probing and exploration of issues that arise, to allow the interviewer to adapt to the interaction that unfolds and to control the time factor, as participants were likely to have limited time to answer questions due to transport times, and having to attend clinic proceedings. In addition, the interview schedule aids in recording of answers. Thus all potential items (ideas, concepts) for inclusion into the interview schedule were selected with the goal of tapping into important categories or themes suggested by the research questions and in particular to identify gaps in information pertaining to paediatric ART.

Patients attending adult and paediatric ARV services were interviewed to establish some personal, interpersonal, and environmental issues regarding bringing children for ARV treatment. Treatment history in case of parents who were bringing their children for treatment was also investigated; personal factors which influenced them to bring their children onto the program, and beliefs and attitudes of their families and community members about having their children on treatment were all aspects that were explored. For adult patients on ARV treatment, they were asked whether they have children who have been tested, and on ART, and the reasons for bringing or not bringing their children to access ART.



Consideration was also given to provide a personal and non-threatening context to learn from people about their lives, particularly events, behaviours and attitudes related to HIV and AIDS and paediatric ART. It was necessary to ensure that the participants felt that they were listened to, understood and that they were considered with unconditional positive regard.

The interviews were recorded through written notes rather than tape recorded. It was felt that using a tape recorder would be intrusive and possible technical failure of the recorder influenced the decision not to use recorders. During each interview the researcher wrote down notes to serve as a memory aid when full notes were constructed soon after the completion of the interview. Interviews lasted for approximately an hour. The length of the interview was determined in due consideration of the available time as some participants had to travel long distances to their homes after the clinic visits.

Participants were approached during visits to the ART clinics while waiting to see health staff. They were informed about the study and if they were interested, informed consent was explained to them outlining the consequences of participating in the study including the voluntary nature of participation. It was pointed out also that there was no remuneration involved when participating, and information and their identities would be kept in the strictest confidence. Additional data was collected through discussions with policy makers and programme managers at the interview sites but does not form part of the formal study. In most cases these additional sources were used to verify information already collected.

### **3.2.5. Data analysis**

Data analysis on the findings was done using thematic analysis that was guided by the interview schedule in accordance with the aims and objectives of the study. Thematic analysis means that the data that is generated from the interviews is organised, broken down into manageable units and synthesised. Thereafter the data is searched for patterns - discovering what is important and what is to be learned, and deciding what will be disseminated (Bogdan and Biklen, 1982). Inductive analysis of the data is then performed, where the critical themes emerge out of the data (Patton, 1990).

There was some creativity used in this study to place the raw data into logical, meaningful categories and examining them in a holistic fashion. Analysis began with identification of the themes emerging from the raw data, a process that is sometimes referred to as "open coding" (Strauss and Corbin, 1990). During open coding, conceptual categories into which the themes observed were to be grouped were identified and tentatively named. The goal was to create descriptive, multi-dimensional categories which form a preliminary framework for analysis. Words, phrases or events that appeared to be similar were grouped into the same categories. These categories were gradually modified or replaced during the subsequent stages of analysis that followed.

It is a recommendation by some authors that as the raw data are broken down into manageable units, the researcher must also devise an "audit trail"—that is, a scheme for identifying these data units according to their speaker and the context. The particular identifiers developed may or may not be used in the research report. The next stage of

analysis involved re-examination of the categories identified to determine how they were linked, a complex process called "axial coding" (Strauss and Corbin, 1990). The discrete categories identified in open coding were compared and combined in new ways to understand the "bigger picture". The purpose of coding is to not only describe but, more importantly, to acquire new understanding of a phenomenon of interest. Therefore, causal events contributing to the phenomenon; descriptive details of the phenomenon itself; and the ramifications of the phenomenon under study were identified and explored. During axial coding a conceptual model was built and the data was examined whether sufficient to find support for the specific interpretations. Although the stages of analysis are described here in a linear fashion, they tended to occur simultaneously and was repeated. The study supervisor assisted in coding and where discrepancies occurred, this was discussed and clarified.

### **3.2.6. Ethical approval**

Ethical approval for the study was obtained from the Higher Degrees Committee of the Faculty of Humanities, Development and Social Sciences and the Ethics committee of the University of KwaZulu-Natal for the Protection of Human Subjects. Written informed consent was obtained from participants after carefully explaining the study to them and their options regarding participation. The consent form (Annexure B), covered the explanation of issues such as the purpose of the research, description of the research project, confidentiality of information collected, risks and discomforts of the research, voluntary nature of participation and withdrawal of participation as well as contact details of the researcher responsible for the study and the study supervisor. There was strict adherence to correct ethical procedures. The basic rights of participants were respected. Participation in the study was completely voluntary, and participants were allowed to withhold information that they did not feel comfortable in disclosing.

## **CHAPTER FOUR**

### **Results**

#### **4.1. Introduction**

In this chapter the findings of the study is presented in terms of the themes that emerged from the data and new themes that emerged from the interviews. The themes include socio-economic, psychosocial factors that influence paediatric access to ART, ART service delivery factors, and the policy and legislation aspects that influence ART- service.

##### **4.1.1. Demographic characteristics of participants**

A total of 42 participants were interviewed in this study. Twenty two (22) participants were from Edendale Hospital and 20 were interviewed from King Edward Hospital. Most of the participants (76%, N=32) were females, and 24% (N=10) were males. Participants ranged from age 21 to 74. All participants interviewed were Zulu speaking. Of the 42 participants, interviewed, 6 were couples. These were couples that were attending adult clinics; none of the participants attending paediatric clinics were couples. All of the paediatric clinic participants were accompanying children who had come for ART service (eleven (11) out of 11 at Edendale hospital; and ten (10) out of 10 at King Edward Hospital. Two of the parents at Edendale had more than one child attending this service, the rest were bringing only one child for the service. The majority of clients interviewed at the adult clinics [19 out of 21, (10 at KEH and 9 at EDH)] did not bring children along. Others in this group did not bring children because the clinic visits for children were on separate days (7). Eleven

(11) of the participants in this group indicated that they had children but that these children were not on ART for various reasons. One (1) participant indicated that she did not have a child of her own or that she was caring for. There was reluctance from the participants to give information on their educational status, therefore this information was not asked from the participants. However some of the elderly participants voluntarily stated that they had no formal education.

Figure 3: Age and gender of participants.

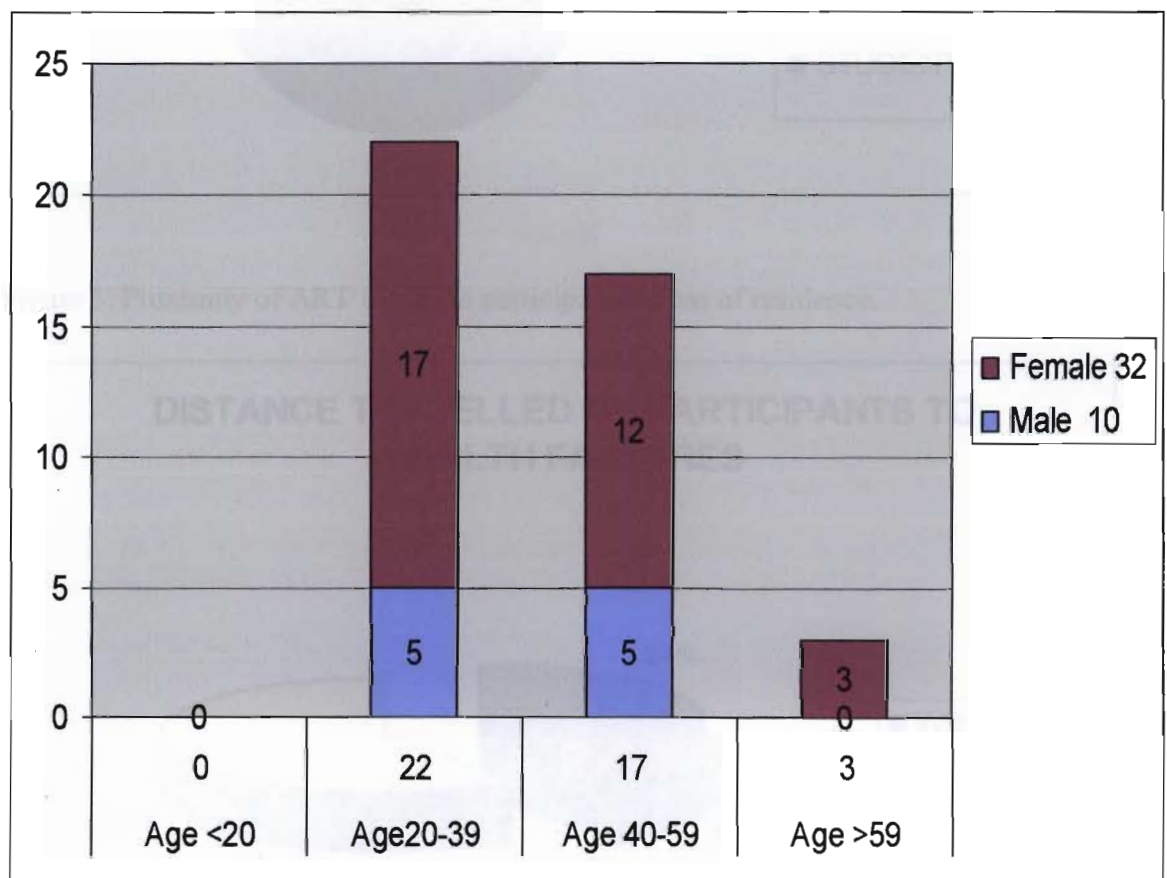


Figure 4: Employment Characteristics of Participants.

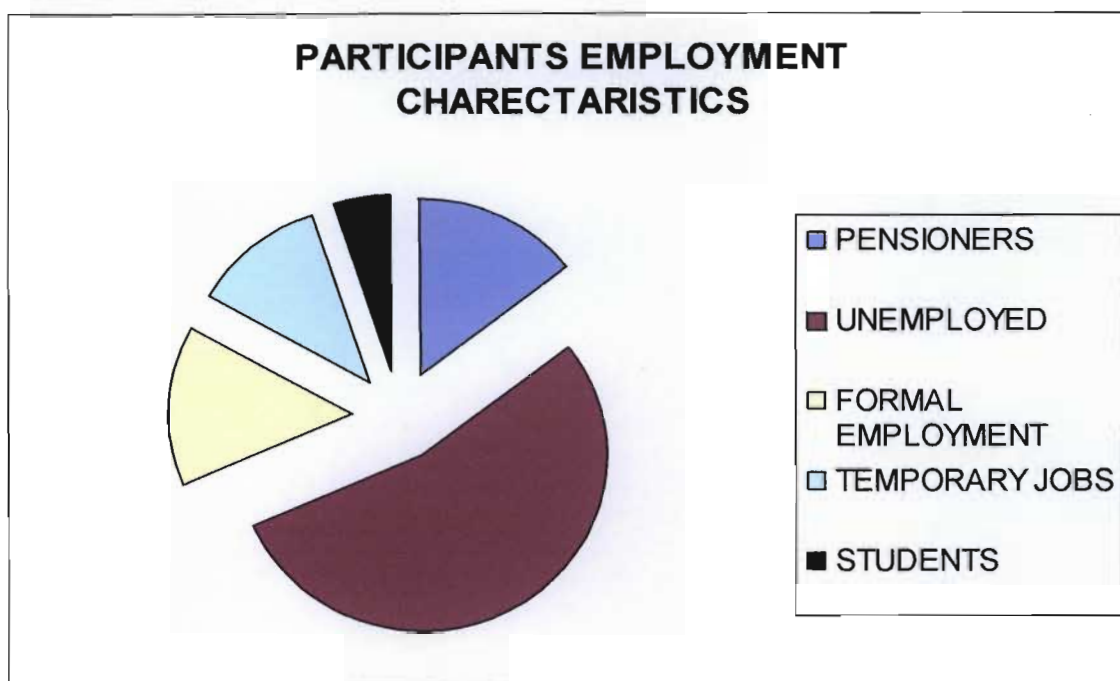


Figure 5: Proximity of ART clinics to participants' areas of residence.

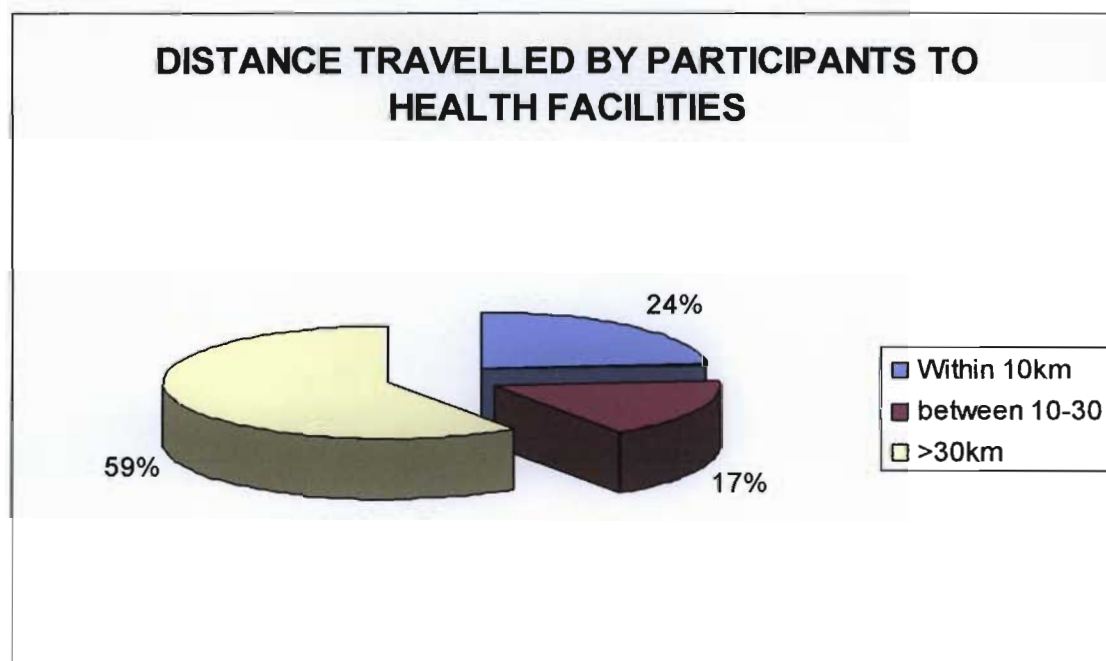
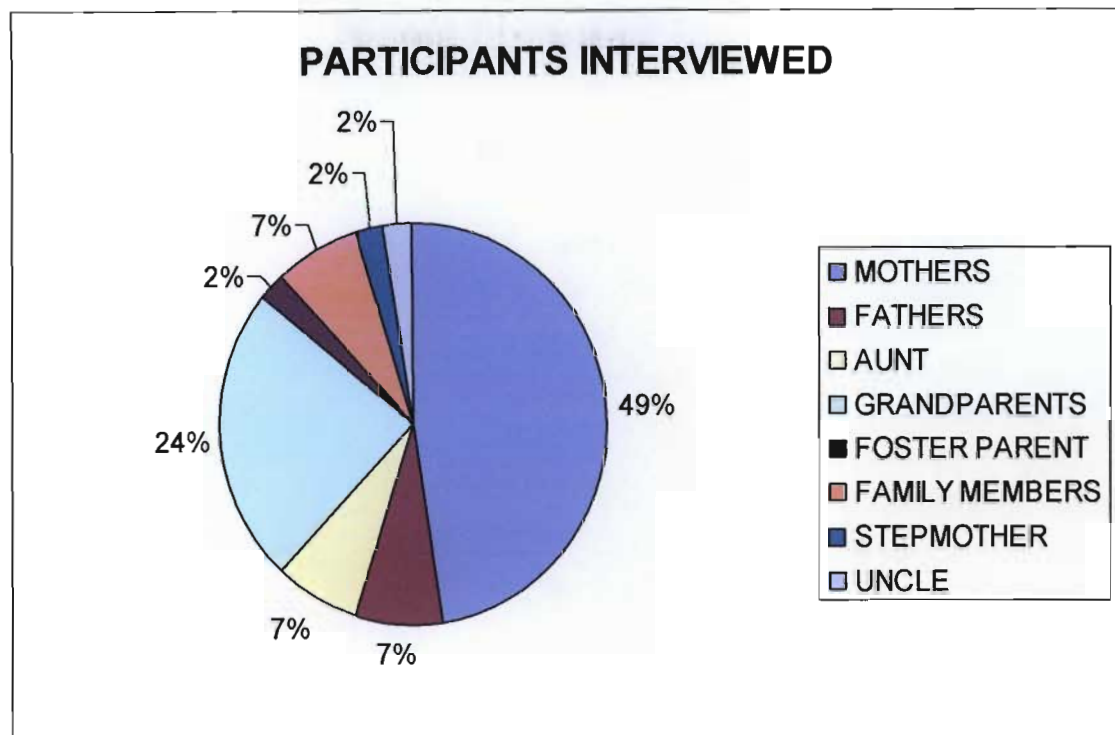


Figure 6: Relationship of participants interviewed to the children.



Most of the participants were unemployed and had to travel long distances to the ART sites. The mode of transport used was mainly minibus taxis. Many of the participants were biological mothers of the children that were attending ART services.

#### 4.2. Socio-economic factors influencing paediatric access to ART

Poverty and related limitations seem to play a major role in ART-access for both the parents and their children. Poverty was a significant factor that contributed to poor uptake of ART by children. There was a feeling that it was not a priority to have children on ART when in need of food, clothing and school fees. Many breadwinners seemed to have already died due to AIDS or were too poor to cope with the clinic requirements for ART.



#### **4.2.1. Unemployment and transport costs are the main constraints.**

All of the participants mentioned that the issue of transport costs and unemployment was by far the most restricting factor that prevented adults and children from accessing this service. Most clients seen appeared to come from very poor and disadvantaged backgrounds, with 52% of the participants indicating that they were unemployed. None of the participants were professional employees or were involved in any business practice. This can indirectly imply that this category of clients either attend private facilities or choose to send caregivers or their helpers to attend clinic services for their children.

Most of the participants revealed that they did not live close to the hospitals where ART is delivered. The long distances that they had to travel meant that more money should be obtained to pay for transport costs than previously (Figure 5).

Participant: *"..You know...I live in Umbumbulu, the nearest ART clinic is in Prince Mshiyeni hospital, and it is always full there, and I often have to sleep on the bench overnight to get attended to first in the morning... It's better here (King Edward Hospital), as there are plenty of doctors, but I have to take three taxis to get here..."*

*- 31 year old female, Umbumbulu, King Edward Hospital*

It appeared that many people were not accessing ART services closer to where they lived. Umbumbulu is a rural area, and no clinics offer ART in that area. In such settings, if clients want to be assisted they need to visit hospitals in another area, and

this is costly. There were even cases referred to where some patients died because of the unavailability of transport money:

Participant: *"My neighbour's child died because they had taken his blood for a CD4 count. He later got sick himself, and was unable to fetch the results. My father went to get the results for him, but they refused and said they wanted the parent to collect the results. The child died after that because his father was unable to walk, and we did not have transport to help him collect his results".*

*- 25 year old male, Edendale Hospital*

The most important issue reflected in the above quotation refers to the inflexible health services - the fact that the health providers demanded the parent to collect the results himself, possibly due to issues of confidentiality, and then secondly the implied financial costs that other community members accrue when they want to assist. Linked to their difficult financial situation, is the fact that most of the participants seemed to be eligible for social grants that would enable them to get money to attend ART services, but were not accessing these grants due to implied financial costs and various other reasons.

Participant: *"...I have given up about that, they keep asking me for an identity book, I don't have one... the Home Affairs office is in town... I don't have money to go there"*

*- 61 year old female caregiver, King Edward Hospital*

Participant: *"Even if you go there you wait in the queue forever and nobody bothers (about you), as they want you to bribe them for an ID..."*

*- 29 year old student, Smero Township, Edendale*

Participant: *You don't only need an Identity book and child birth certificate for these grants, I live in a farm....they want me to produce proof of residence. Only the chief can give me a letter. It cost R40 for a taxi to his office, and R66 to go to town (Home Affairs Office), and there is no guarantee that I will be assisted at Home affairs... ..Where must I get all this money... ”*

*- 44 year old male, Eston Farm, attending Edendale clinic*

The major constraint about the access to grants was obviously the difficulties in obtaining identification and insistence of health institutions and social welfare services on identity books. These identification problems are exacerbated by the traveling costs to home affairs offices.

#### **4.3. The influence of psychosocial factors on the uptake of paediatric ART**

The psychosocial factors that seemed to influence paediatric access to ART include knowledge about ART and its complexity, HIV and AIDS stigma and discrimination, traditional/cultural understanding of HIV and AIDS and female responsibility for health care.

##### **4.3.1. Lack of knowledge about ART and complexity of ART.**

Participants felt that while there is a lot of information available on HIV and AIDS and TB everywhere, messages about ART were very rare and inadequate. Some of the grandparents interviewed indicated that they were illiterate and poorly informed of the ARV-programme procedures and details of how the treatment worked and its implications on the future of their grandchildren.

Participant: “.. *there is poor communication in terms of disseminating the information on ART, unlike HIV and AIDS. Most of the people are illiterate, both adults and young people. They find it difficult to use pamphlets and posters. There are many posters here, but it doesn't help them. Perhaps having campaigns in the community and talk about ART will be better*”

*- 43 year old, female, Edendale*

According to them, their illiteracy also presented challenges when they had to attend the preliminary HIV literacy training prior to starting ART. The clinics were viewed as doing their best to explain the procedures in simple language, but this was insufficient at some stages.

Participant: “*the nurse taught us for two weeks about ARV treatment before my child started, but you cant remember everything...some of the things are difficult to understand, and you cant keep asking questions and delay other people who want to go home during these trainings.*”

*- 33 year old female participant, King Edward*

Many participants viewed paediatric ART as very challenging specifically because of the complex regimens and dynamics involved in its administration, such as food-drug interactions and drug-drug interactions with ARVs.

Participant: “... *There are just too many things to remember about this treatment. You have to go to remember all the clinic schedules for your child, know what you are eating, and always remember the time for pills!*”

*Mother (33), Machibisa, Edendale*

For some participants, this was even more of a challenge when children are on ART.

Participant: *"I know of someone whose child stopped taking ARVs because it was hard for her (mother) to cope with adherence to ART due to her busy schedule, and the fact that she was forever attending meetings. Eventually she started giving the child immune boosters"*

*33 year old caregiver, Chesterville, attending King Edward Clinic*

#### **4.3.2. Stigma and disclosure as a barrier to paediatric treatment.**

Stigma associated with HIV and AIDS seemed to be amongst the biggest factors that contributed to the limited numbers of children being brought to the health services for ART-service. Participants indicated that it had taken them a lot of effort to be able to undergo HIV testing themselves and their children, and that they knew of many people who feared to seek voluntary counseling and testing (VCT) for HIV/AIDS. Stigma was perceived to be present everywhere, within the family (husband, wife, and other children), the community and in the work setting.

Participant: *"I have this child from my ex-boyfriend, my current boyfriend doesn't know that we are both on ART.....he would definitely leave if I told him."*

*-29 year old parent, Smero Township, attending Edendale Hospital*

Participant: *Some families don't even want us to visit them anymore. They would rather hide and pretend that they are not at home ... "*

*- 34 year old caregiver, King Edward*

The above view illustrate that stigma resulted in people hiding from others in their community because of their HIV-infection. HIV and AIDS stigma was presumed to be

evident even amongst religious groupings, schools and community structures. Whilst most participants indicated that they had disclosed their HIV status to their families, many of them felt that this was not possible with religious groupings such as churches. It was much harder to discuss these issues within these contexts.

Participant: *“Not at all, I would never discuss my child status with the schoolteacher for my boy’s sake. As for the church (laughs), no, people will laugh, and start gossiping amongst themselves”.*

*-39 year old mother, King Edward*

The stigmatisation extends to those children who are on ART already. Some participants indicated that it was a fortunate matter that the timing of ART drugs was in the morning and afternoon, and therefore their children would not have to take the drugs at school as other children would come to know their children’s status.

Because of generalized AIDS stigma and discrimination, denial of AIDS seemed to be used as a way to manage HIV/AIDS related stigma.

Participant: *“Others choose not to believe that HIV is there, because people will know, like my husband. He died, not believing”*

*-34 year old female, Botha’s Hill, attending at King Edward*

Stigma was also a major issue when it came to the feelings of parents about disclosing their children’s HIV status to others and in particular to other children. Many said that it was not possible to disclose to other children as it may result in unfair treatment of their children by other children and their parents. For these reasons, they preferred to keep it “*a secret*” that their children were HIV-infected or on ART.

Participant: *"I fear that other people will know about the status of the child and prevent their children from playing with my infected child..."*

*23-year-old female, Pata, Edendale.*

Uncertainty about when and how to disclose their own and the child's HIV status to the child were a central concern among all the participants. AIDS-stigma appeared to be at the root cause of this dilemma. This appears to result in some parents' inability to seek VCT for their child, disclose their child's status and access paediatric ART-services.

Participant: *"It's unthinkable at the moment. I cannot even start to think how I will be able to tell her of my status"*

*39 year old participant attending adult ART clinic.*

The main concerns were around the "unpredictable" response and behaviour of the child as soon as they were old enough to understand the full implications of being HIV-positive and being on ART for the rest of their lives. Other related concerns that were raised include the impact of this knowledge on their social lives and interaction with peers, as well as whether they would be able to cope with this situation or comply with treatment once the implications are understood.

Participant: *I live with my daughter who is five years now and is on ART for the last two years. I keep telling her she is taking vitamin medicines because her body is weak, I don't have people to share my problem with. There are times when I don't know what to do, because I feel its unfair not to tell her, but what will she do, What will she tell her friends? It is very tough for me ... "*

*42 year old participant who brought child for ART, King Edward*

Many of the caregivers indicated that the children they were accompanying knew of their HIV status. This was mainly due the fact that when the child biological parent died, the families often suspected AIDS, and would get the child tested.

Participant: *"my sister was sick for a very long time before she passed away. Everybody knew that she had AIDS, and the child was often admitted to hospital, so its obvious that she got it(HIV) from her.... The doctor advised us to do an HIV test, and it was positive. We told her because the community would have told her anyway.."*

*36 year old caregiver (aunt), King Edward*

Most of those who indicated that their children are not on ART stated that their children had not been tested for HIV because of fear for the possible consequences of testing HIV-positive.

Participant: *" It's very hard-my daughter is thirteen now. I was never offered HIV testing or knew anything about nevirapine (PMTCT) when I gave birth. Now she has a lot of friends and is not sick, how do I begin to tell her that she may be positive?"*

*29 year old mother, Chesterville, attending King Edward Clinic*

#### **4.3.3. Traditional understanding of HIV/AIDS and related practices.**

Traditional understanding of HIV and AIDS and the use of traditional medicines and remedies were often mentioned as a reason for not bringing children for HIV testing or ART when they were sick. This was stated by some participants who admitted to be taking traditional remedies concurrently with ART. Some clients whose children were



not on ART, indicated that the role of traditional medicine was still an important way of treatment that prevented some children accessing the ART services.

Participant: *"There are some traditional healers who say that they cure HIV and AIDS, and people believe them"*

*33 year old, KwaMpande, attending at Edendale Hospital*

There were also some very strong beliefs that traditional medicine works just as well as most of these parents *"grew up with it"*, and therefore no need exist to consult the clinics. Some cultural ideas that could relate to stigma also emerged that made it a taboo for children to *"grow up on pills"*.

Participant: *"Some people preferred to consult traditional practitioners as means of avoiding stigma as well as an excuse not to go to clinics"*.

*23 year old participant, King Edward.*

A large number of respondents indicated that many people still believe that their children have been bewitched when they became ill, and thus only have to consult with the traditional practitioners.

Socio-economic conditions i.e. problems of unemployment and transport costs also influence people to seek help from traditional healers, who are operating within their communities and therefore are easily accessible.

Participant: *" .... the reason for them using traditional medicine instead of ART is that traditional healers are in the community compared to the money that they have to spend on transport to the hospital"*.

*62 year old grandparent, Cato Manor, who brought a child to King Edward Clinic*

Cultural beliefs and practices were offered as contributing to the “silence” around HIV as it was viewed culturally inappropriate for parents to discuss HIV and sexual issues with their children.

The overemphasis of ART related side effects also resulted in some people opting for traditional remedies.

*Participant: “Look at that guy who developed breasts.... What do you call that?”*

*33 year old, Edendale – referring to a picture of an article in the Daily Sun newspaper about a man who developed gynaecomastia while on ART*

And

*Participant: “My friend was sick, but when he started taking ARVs, he started complaining of numbness in his fingers and feet, and eventually he couldn’t walk. You don’t get that with imbiza (traditional remedy)”*

*23 year old, Azalea, Edendale*

#### **4.3.4. Parental / caregiver ART-access and support.**

Issues pertaining to parental support for eligible children to access ART were revealed. Many of the parents who were bringing children for ART indicated that starting ART and experiencing the results of improvement of their own health in turn motivated them to have children tested for HIV and to access paediatric ART.

*Participant: “I nearly died, then I started taking ARV’s, now I am as healthy as everyone else...I would never risk my child life by not giving her ARVs as well”*

*22 year old female, Imbali Township, Attending Edendale Clinic*

Some parents who were attending adult ART-clinics, but who did not bring their children for the same services offered several justifications for their behaviour. The main reason being the fact that they were still healthy and believed the same to be for their children.

Participant: *“At the moment, my CD4 count is still above 200, so I am not on ART...I haven't really checked my children as yet”*

*29 year old male, King Edward*

The child's general wellbeing appeared to be used as an indicator of whether children would be taken for ART.

Participant: *“If she (the child) had AIDS, she would have died a long time ago.. she is 12 now and I think she's fine”*

*31 year old female, at adult ART clinic, King Edward*

Other reasons offered as to why ART was not necessary were that the parents were able to take control of their lifestyles by engaging in activities such as good nutrition, regular exercise, and timely treatment of opportunistic infection amongst others, and were doing the same for their children.

It was noted that a significant number of caregivers were elderly citizens. Those who responded to the questions as to why this was the case responded that it was easier for grandparents to take children to ART clinics because most of them were pensioners and had time available, and that some were attending health services anyway on a routine basis.

Participant: *"It is much easier that I bring my grandson here. His mother is always working, and does not have time. I also collect my BP (hypertension) drugs at this facility at the same time"*

*62 year old grandparent, Cato Manor, who brought a child to King Edward Clinic*

#### **4.3.5. Disintegrated family systems.**

Most of the children who were attending ART-services were in the care of their mothers or female caregivers, with very few being brought by males (it should be noted that only a small group of the participants were males - only 7%). The only males who accompanied children tended to be siblings of the children rather than parents.

Participant: *"Most men are supposed to work, and don't have time for all these visits..."*

*21year old male student*

Many single mothers or care givers were concerned about the sustainability of the children's ART-treatment schedules if they initiate new relationships with new partners or when they get married. They were concerned that the change in their life circumstances may make it difficult for them to continue caring for their own or the children in their care, in the same way as before the new relationship.

Participant: *"I don't know how long my (current) boyfriend will tolerate all of this. I have to take my sister's child to the clinic every now and then."*

*32 year old caregiver attending paediatric clinic at Edendale Hospital*

A considerable number of the elderly caregivers stated that the children that they accompany are under their care as their parents had died due to HIV and AIDS complications and in some situations simply abandoned their children. This often results in the problem of children having multiple guardians. Multiple caregivers seemed to pose a major problem to paediatric ART-access. Some of the children lived with aunts, uncles and biological parents at irregular intervals; therefore, it was not possible to have one caregiver responsible for the child's needs at all the time. The other issue was that children do not stay permanently with one care giver and move around making continuous care and treatment highly impossible.

Participants: *I am currently taking care of my grandson because his father has disappeared. He was retrenched last year and went to look for work in Johannesburg...*

*52 year old male, Dambuza, Edendale*

Some of these guardians have been quoted not to care or consider the child's needs.

Participant: *"At the moment the child is staying with an uncle. Once the child starts ART, he will be taken care of. However, when the child goes to his biological mother, he will be taken care of by an aunt from the mother's side. Those people don't care"*

*64-year-old Cato Manor resident*

The devastating implications of HIV and AIDS on families also emerged as a restricting factors on child ART access.

Participant: *"At home my child and I, as well as my two brothers are infected (with HIV). All of us are not working, so it is difficult to get money for all of us to come to the clinic on different days. Sometimes I don't bring the child for follow up checks...."*

*29 year old female, Edendale*

Participants felt that it was difficult for children from households where alcohol and drug abuse were prevalent to access services such as ART.

Participant: *It is very hard for these children... ..my neighbour owns a shebeen, the only thing they do is drink, smoke and make noise there ...I wonder how the children manage to do their homework.'*

*49 year old male, Machibisa, Edendale.*

The issue of child –headed households was indicated as one that required attention as well.

Participant: *"There are children who live on their own and rely on neighbours for support. Government must look after them; nobody cares what happens to such children.."*

*59 year old grandmother, Edendale*

#### **4.4. The influence of ART-service delivery factors on paediatric ART-access**

Service delivery factors influencing access to treatment and adherence for children from parent's and /or guardian's perspectives were investigated. The data suggested the presence of some challenges with regard to the identity books, overcrowding at clinics and issues relating to staff attitudes as possible contributors to ART seeking behaviours of clients.

##### **4.4.1. Identification and referral of children for ART**

There were a considerable number of participants who knew of eligible children who could not attend child care services due to lack of identification (birth certificates). Some of these children were also experiencing difficulties at schools because they could not be registered. Most of their parents also did not have identity books. Problems were attributed to bottlenecks at the Department of Home Affairs offices and the costs involved in acquiring the documents as discussed previously.

*Participant: "It takes a lot of money to travel to these centres, and often one would have to attend a few times in order to successfully apply for an identity book. Some people had to wait for periods up to a year to get their documents, and some never received them at all".*

*53 year old grandfather, Ntuzuma Township, attending at King Edward*

The people mentioned that voluntary / home based care workers and social workers within the communities played a role in advising families and referring some children for care. Inadequate and uncoordinated efforts around HIV/AIDS within communities seemed to impact negatively on children accessing ART. The main reason for poor or

uncoordinated referrals by community based institutions was that many of the institutions in the existing referral networks do not have paediatric HIV care, thus inappropriate referrals for the level of care often occur. Participants also pointed to a lack of linkages between home-based care groups working with orphans and vulnerable children, and other community organizations working on HIV care and support.

*Participant: We have a lot of these home based caregivers visiting households in our communities. The community health workers also visit our houses, but they don't talk about ART. They will ask you if the child has been immunized, but will never ask about the HIV-status"*

*53 year old caregiver (aunt), King Edward*

Many communities consult with social workers for different reasons, especially caregivers who are looking to adopt children whose parents may have died of HIV and AIDS conditions or who have been abandoned. Members of the public also utilise their services for other social issues pertaining to health, social grants and trauma counselling amongst others. The data suggest that a significant number of participants in the study had never consulted with social workers nor were they aware of the availability of these existing services.

*Participant: "I've never had a reason really to go to them"*

And

*"Lay counsellors are helpful; I do not really see a reason why I should see a social worker"*

*32 year old female student, Edendale Hospital.*



sector. Overcrowding resulted in long waiting times at clinics. This affected both the children and adults, and was a factor that contributed to a reluctance to attend clinics by both adults and children. This situation is worsened when parents and or children are sick and are not feeling well.

*Participant: I started by going to Prince Mshiyeni. I was on leave, and I decided to go for a HIV test with my daughter. The sister at the clinic told me to sit on the bench and wait as they were still busy. I waited till one o'clock, and they went for lunch. I took my child and we went to Commercial city...."*

*29 year old participant, Umlazi, attending King Edward ART clinic*

The clinic operating times also came up as one of the constraints that most parents identified as influencing their children's attendance of ART services. Many of the patients who had children who were not on ART indicated that they were unable to bring their children to the clinic due to awkward operating times and the fact that children were seen at different days.

*Participant: "My boss will never give me time off to go to the clinic. I have to take sick leave when I need to go there, because the clinic opens after I have gone to work and closes before I knock off. My child is also still at school during these times, and the teachers complain when I ask for him"*

*29 year old casual employee, Edendale*

#### **4.4.2.2 Health worker attitudes**

The negative attitudes of health workers towards people infected with HIV were an important factor referred to as restricting general access to ARV-treatment. The nursing personnel seemed to be the ones directly implicated when participants expressed concerns on the negative staff attitudes:

Participant: *“At the clinic, the nurses treat us so badly as if we all asked for HIV, some even tell us that they didn’t send us to get this disease; we got it on our own. The nurses treat us very badly”*

*23 year old participant from KwaMashu, Durban*

Concerns about confidentiality were raised as reflected in the following views:

Participant: *“the nurses who are working here are gossiping about people who come to the hospital. They even mention your name and say they saw you coming to the clinic to check that thing”*

And

Participant: *“The only reason I am here is because I don’t care what nurses say about me, this is my life, and I am doing this for myself”*

*29 year old female participant, King Edward Hospital*

#### **4.5. National policy and legislation with respect to ART-services**

The client’s perceptions regarding the new Child ACT were also explored in this study. This was done to gauge the client’s awareness of this policy and its implications with regards to ART access by children. Many participants were not knowledgeable about

this policy, and on explaining it, participants revealed some reservations about it. Some issues regarding the perceptions about the ability of facilities to implement national and provincial protocols for the initiation and management of children in the ART programme were apparent.

#### **4.5.1 The Child Act**

Participants who indicated support for the act felt that it was not necessary for children to have to wait for unsupportive parents or caregivers to access ART services and argued that this Act will result in more children accessing ART as it gives power to children as young as 12 to make their own decisions about HIV testing. Furthermore it allows for any adult who is a regular minder of the child to make such a decision even though they are not the biological parents of the child.

Participant: *“Why not, if the parents are undecided... the child must go for testing on his own”!*

*33 year old father, King Edward*

Some participants responded that they had concerns about the ability of a 12 year old child to make decisions about accessing ARV treatment.

Participant: *“A 12 year old cannot make such decisions on her own. That child is still very young. If there is no parent, community elders should be approached”*

*Caregiver (60), King Edward*

When further probed as to what the child should do in the absence of the parent or guardian, some cultural reasons given as to the inappropriateness of the Act.

Participant: *"That child must first consult with relatives or elders in the community before taking any action"*

*Caregiver (60), King Edward*

#### **4.5.2. ART-guidelines**

Many clients pointed out to the fact that whenever they went for ART services, the first question that was asked by health care workers was whether they had a green bar coded ID book. This was often followed by refusal by health staff to attend to their needs.

Participant: *"I tried to explain that I had lost my ID book, and that I am still waiting for another one....she would not listen, and told me to produce the temporary ID book.."*

*45 year old male, KwaMpumuza, Edendale*

The explanation offered by health workers was that the guidelines stipulated that a green bar coded South African ID book was a prerequisite for entry into the programme. The staff also seemed to have a lack of clarity regarding the requirement of identity documents for patients wishing to start ART. This was mentioned to be worse for refugees and illegal immigrants.

Participant: *"Look, I came to South Africa in 1997. When I showed them my refugee papers, the nurse said it was not acceptable.. She even said that they could be fake documents. I had to wait for 2 years to get a green ID book, only then was I accepted into the programme"*

*50 year old female immigrant, King Edward*

The duration of drug literacy training, a necessary prerequisite for ARV-treatment seemed to be problematic for some participants, especially for those who have financial difficulty and for those who are very ill and find it emotionally and physically demanding.

Participant: *"Look, I appreciate the information they give you at the clinic, but sometimes people are too sick, and they make you wait and wait while they go through the sessions"*

*43 year old female, Cato crest, attending at King Edward*

And

Participant: *"You run out of money trying to attend the scheduled trainings, some people never come back because the taxi fare is too much; they should do this in one day"*

*33 year old female, Edendale Hospital*

In the next chapter the above findings will be discussed.

## **CHAPTER FIVE**

### **Discussion**

#### **Introduction**

This chapter reflects and elaborates on the findings of this study. The discussion of the results is presented in terms of the themes presented in the results section. The discussion takes consideration of the theoretical framework of the study and implications that emerge from these frameworks.

#### **5.1. Participant's demographics**

It can be generally assumed that the participants who brought their children or children in their care for ART faced several obstacles but found ways to overcome them resulting in their children being able to access ART. The severity and nature of the obstacles, as well as issues pertaining to the awareness of ART service and its benefits resulted in some parents or members of the public not behaving in the same manner resulting in their children not accessing ART. This was evidenced by the numbers of adults attending ART services, who did not bring their children. There were no participants of the age group of less than 20 years of age in this study. It was observed that most of the younger clients were not willing to participate in the study. This could mean that this group either did not fully appreciate the severity of the situation quite like the older age groups and therefore did not think it was particularly important for them to participate in something that could benefit the broader community and the service as a whole. It is also possible that most of them were in a hurry to receive the service and leave the clinics. There was reluctance from many participants to reveal

their level of education; therefore this aspect was not pursued with those that declined. Most of the children that were brought for ART were below the age of 5 years, indicating a possibility that many of the eligible children were at school.

## **5.2. Socio-economic factors influencing paediatric access to ART**

The issue of poverty, unemployment and unaffordable transport costs was one of the biggest constraints in ensuring paediatric access to ART-services. Because most of the participants stated that they did not live close to the hospitals where ART-services are delivered, this implies that there were travel costs involved to and from institutions for ART services. Furthermore, about half of the participants interviewed were not employed or were involved in some unstable temporary/casual employment. This represents difficulties in terms of the accessibility of ART to clients in provinces such as KZN. Given the fact that the province of KwaZulu-Natal has eighty accredited ART facilities to date (Department of Health KwaZulu-Natal), and has an unemployment rate of around 25% (Statistics SA), it can be deduced that there is a lot more children who are not accessing this service due to high transport costs for traveling to these facilities. However, some participants and communities do find means to access this service despite adverse financial conditions. As suggested in SCT, the outcome expectations of ART and self efficacy could explain the motivation to take action despite such barriers. The ability to access social grants seems to have a beneficial effect on ART access, as people who depended on old age grants and pensions were found in abundance at the sites where the study took place, indicating that they were able to get money for travel to clinics. Furthermore clients needed to have identity

documents in order to access ART (Department of Health Antiretroviral treatment guidelines, 2003). Although the protocol states that treatment should not be denied if one is eligible but does not have an identity book, most facilities still insist on this requirement according to the participants. The process of applying for an identity book is costly for some people as it often involves a need to travel to the home affairs department to apply. Often the queues are long and the process of application cannot be completed in a single day, therefore more money is required to travel to these centres. It would thus appear that based on this study, inadequate ART-service delivery facilities exist and it is necessary to bring the service to the clients.

It can also be argued that ART services need to be more accessible because clients seek traditional services precisely because of inaccessible services. Those that seek traditional services might also be less likely to also seek ART. Furthermore for those that utilize both services simultaneously, there might be implications for the adherence to ART and the possible development of ART-drug resistance due to traditional medication that might interact with the ART-drug regime (Khomanani Information brochure- Department of Health).

Unemployment in this study was not only found to limit child access to ART-service, it also enabled unemployed parents who live close to the health care facility offering ART-services to bring their children for ART. It was normally the unemployed parents and child caregivers that were found to accompany children to the clinics. Care givers might have to bring children to the clinic in situations where the biological parents are



employed and therefore not always able to get days of work to bring their children to the clinic. Most of these elderly caregivers indicated that they were on chronic medications and had to go to clinics on a regular basis for their medicines. This provided the explanation for the many grandparents who accompanied children to the clinics.

In order for a child to be enrolled onto the ART programme, a stable guardian/parent is required, who will be able to attend the mandatory ART literacy sessions on behalf of the child as well as serve as the child's adherence supporter. A stable guardian is also required in order to monitor the child's progress and any possible adverse events that can occur as a result of the child being on ART. Therefore, the unemployed parents/caregivers were the ones who were able to get time to take children to clinics. It therefore appears that children whose parents are in full time employment are likely to face difficulties in terms of access to the ART service. The intergeneration support is noteworthy and the elderly should be acknowledged for their contribution to the care and support of children. The elderly often have to start afresh as breadwinners to look after the children affected by HIV and AIDS (Report, United Nations Office for the Coordination of Humanitarian Affairs, 2002). Their role as carers for children is well documented in literature (Appleton, 2000, Hunter, 2000).

### **5.3. The influence of psychosocial factors on the uptake of paediatric ART**

Several factors appear to influence the decisions about access to ART in this study:

#### **5.3.1. Inadequate knowledge about ART**

The findings in this study indicate that although general information is widely available on HIV and AIDS and TB in the media, messages about ART was not widely available in the media and huge uncertainties exists around ART. The overwhelming attention in the media towards VCT as a way to address treatment in the absence of media interventions directed at educating the public on ARV and treatment regimes might impact negatively on ART-access and wider community support to those who are on ART.

The general knowledge about HIV and AIDS has been found to be relatively high in most studies conducted in the southern African region (Jansen van Rensburg, 2007; Shisana, Rehle, Simbayi, Parker, Zuma, Bhana, Connolly, Jooste, Pillay, & Shisana, 2005). Although the knowledge of HIV and AIDS appears to be high in these studies, some myths and misconceptions about HIV and AIDS still remain in most communities, such as the belief that if one was overweight or obese, they were not likely to have HIV or AIDS (Abdool-Karim & Nkomokazi, 1991; Du Plessis, Meyer-Weitz & Steyn, 1993). As in other projects, the most common source of HIV information appeared to be radio and television (Shisana et al. 2005). It is therefore necessary to continue relentlessly with appropriate media interventions to improve knowledge about HIV/AIDS and also ART. Furthermore, the improvement of knowledge and in particular knowledge about HIV/AIDS transmission remains an

important strategy to address AIDS stigma and discrimination (Daftary, Padayatchi, & Padilla, 2007; Furber et al, 2004., Meyer-Weitz, unpublished). In the study, prevailing AIDS stigma impact negatively on adult and paediatric access to ART.

In addition to the inadequate exposure to media interventions regarding ARV, the inadequate knowledge about ART reported by the participants could partly be related to the low literacy levels among the participants, particularly among older caregivers who indicated their levels of illiteracy. Many children grow up in the care of grandparents who often have low literacy skills or are illiterate. Other studies found that low health literacy can also be found among the youth (Phaswana-Mafuya and Peltzer, 2006). Low literacy poses major challenges to the parents/guardian's of HIV-infected children to follow the ART-programme logistics. The challenges of illiteracy and poor ART knowledge seem to negatively influence the ART-self efficacy of clients. In terms of the SCT, clients have to know all the facts about treatment in order for them to successfully take it and achieve the positive treatment outcomes. If individuals do not feel that they can exercise control over their health behaviours (which in this case will be ART seeking behaviour), they are not motivated to act, or to persist through challenges. This means that they will be unlikely to seek ART care for themselves or their children. This places the issue of improvement of self efficacy through proper education and awareness about ART, especially for children amongst the critical issues that require attention at a public health level. Self-efficacy as suggested by the SCT of Bandura (1986) is thus critical in ensuring behaviours related to seeking ART.

The Department of Health has instituted a comprehensive client education programme with health staff doing their best to simplify the complex ART-messages with the use of pictures, where possible to illustrate some aspects of the programme. The issue of posters and leaflets that are normally used to inform communities appears to be insufficient according to some participants. This is a finding that has been demonstrated in other studies (Taha, 1997) mostly due to issues of poverty, and illiteracy taking priority in some communities. Generally people are more receptive and responsive to spoken messages on radio and television or through face-to-face interaction (Yang, Li, Stanton, Fang, Lin, & Naar-King, 2006; Jansen van Rensburg, 2007). As seen in the case with HIV/AIDS, an increased awareness due to the expansion of education, information and communication programmes can result in increased acceptance of the disease and its implications (Coovadia and Hadingham, 2005). It can thus be argued that in communities where knowledge about ART is low, there is generally a reciprocal low ART seeking behaviours among the communities leading to low paediatric uptake of ART.

Paediatric ART was considered to be complex and challenging for a multiple of reasons in this study. There appears to be difficulties around the areas of drug administration to children, adherence to treatment and the need for regular clinic visits. The aspect of ensuring that children took ART medication regularly and correctly was mentioned by several participants as very challenging. Similarly the fact that paediatric ART was viewed as technically complicated may be related to parents' and caregiver's level of self-efficacy regarding the understanding of procedures related to the ARV medicines.

It is a general problem among ART institutions that health care workers also find the ART-regime complex in terms of dosing to children (personal conversation with the paediatrician at King Edward). The importance of self efficacy in managing ART regime seems to be a central theme in paediatric ART access. Improved training and ongoing support will be needed to improve self efficacy (Feucht, Kinzer and Kruger, 2007). There are challenges of taste of syrups to children that make it difficult to administer them. Bad tasting drugs are a well recognized factor in treatment failures in children, and may lead to some practitioners in resource rich countries to resort to procedures such as gastrostomy tubes for medical administration, which are unaffordable for poor countries ( Shingadia, Viani, Yogev, 2000; Temple, Koranyi and Nahata, 2001). Sometimes children would vomit and parents were unsure of whether to readminister the drugs. The amounts of drugs to be taken are considerably much more than other medications and children possibly do not want to take all of them. TB is the most common opportunistic infection among HIV patients, and some children were on dual TB and ARV treatment (personal conversation with the paediatrician at King Edward). In such cases the complexity is enormous. The number of medicines that need to be taken is often more than children can tolerate and the times are very cumbersome. These factors and others such as difficulties with getting liquids out of the bottles and measuring them appropriately have also been documented in other projects to contribute to the complexity of treatment (Committee on Paediatric AIDS, 2007; Feucht, Kinzer and Kruger, 2007). Smaller tablets and co-formulation of ARV drugs into tablets that contain 2 or 3 different agents are some of the issues that require consideration especially in resource poor settings ( Pujari, Patel, Naik, 2004). As the

child grows or gains weight, doses of drugs need to be changed it therefore pose a challenge to most care givers to remember the correct dosage or to keep up with the changes. Furthermore, drug doses need to be carefully calculated based on either weight or body surface area (Ponnet, Frederix, Petdachai, Wilson, Eksaengsri and Zachariah, 2005). Because dosing is so complicated, there is a risk that children will be given too little or too much of a drug, which can lead to treatment failure (Weidle, Abrahams, Gvetadze, Rivadeneira and Kline, 2006). Lack of availability of appropriate ARV formulations that are inexpensive and easily usable is a major impediment to access to economical healthcare for children with HIV (Committee on Paediatric AIDS, 2007). The food that had to be avoided when their children are on ART drugs were also viewed as difficult to remember and to keep the right type of food at home all the time. This may also be a problem in poor households. The fact that some drugs were to be taken before food and some after food further complicated the situation, and this could lead to adherence problems with drug resistance implications.

The ability to cope with clinic follow up visits in cases where more than one family member was on ART, especially if they were accessing this service at different clinics is a difficulty that many participants indicated. Therefore it is likely that in families where more than one child requires ART, access by children to this service is likely to be interminant, resulting treatment lapses and the possibility of treatment failure and potential development of ART resistance. Such observations have been shown in similar projects (Coovadia and Hadingham, 2005; McConnell, Byers, Frederick, 2005). This is another example where the environmental conditions, i.e. the health service

delivery of ART services inhibit access. The dynamic relationship between environmental conditions and individuals determine their various options.

### **5.3.2 Stigma and HIV disclosure as a barrier to paediatric treatment.**

Stigma associated with HIV and AIDS appears to be the single biggest social factor that restricts children's access to ART and any other HIV related service as suggested by the findings of this study. AIDS stigma has been reported in various other studies to impact negatively on accessing the support and treatment services (Mehendra et al, 2007; Abadia-Barrero and LaRusso, 2006; Paswana-Mafuya and Peltzer, 2006; Le Macis and Ebrahim-Vally, 2007; Jansen van Rensburg, 2007). The negative effect of stigma on health seeking practices has been reported by various researchers (Guest, 2001; Lusk, Mararu, O'Gara, & Dastur, 2003; Calin et al, 2007). AIDS stigma brings secrecy and is the vehicle through which conditions such as AIDS proliferate. Besides restricting access to healthcare services, stigma has been shown to result in poor patterns of HIV status disclosure amongst the infected and affected individuals (Abdool Karim et al, 2008), poor adherence to treatment as a result of inadequate adherence support that is provided by treatment supporters, and increased risk of drug resistance due to improper administering of drugs as a result of possible defaulting due to adverse treatment taking circumstances that may arise when ART is taken secretly (Van Der Meij & Heijners, 2004). Most research studies also confirm the major role that stigma plays in decisions about disclosing one's status ( Abdool Karim et al, 2008; Moneyham, Seals, Demi, Sowell, Cohen & Guillory, 1996; Ostrom, Serovich, Lim and Mason, 2006).

Stigma was apparent at all levels in this study; from the family (husband, wife, and other children), work colleagues, religious groupings, schools and community structures. There were many participants who indicated that they attended church services, and felt that they could not disclose to church members in this study. Even though most participants had revealed their status to close family members, and that these members knew their children's status, there was a significant portion that hadn't because of HIV stigma. Most participants who had disclosed indicated that their work colleagues were often supportive.

While disclosure of one's status is generally encouraged by many health workers, it sometimes contribute to poor access to HIV services as negative social effects such as rejection, discrimination and violence (Gielen, O'Campo, & Faden, 1997). There are also effects of emotional unpreparedness that restrict disclosure behaviour (Kouyoumdjian et al, 2005). The fear of knowing one's HIV status was too great in communities, and this prevented people from seeking services and subsequently children being denied these services (Chesney and Smith, 1999). However, positive rewards do result from disclosure such as increased social support and intimacy with partners, avoiding of anxieties of concealing HIV status and reaffirmation of one's sense of self (Skogmar et al, 2006; Lam et al 2007). These factors may motivate some to disclose their status. Women faced a special challenge in this study when it came to disclosing status to partners, especially new partners. The fear of women that the partner will leave when finding out about HIV-status was of concern for most single



women, therefore indicating the problems of disclosure issues pertaining to partners and HIV prevention issues that still need to be addressed in society. Other studies have reported similar findings with some reporting several break-ups upon disclosure to sexual partners (Daftary, Padayatchi, & Padilla, 2007). It is possible that women's reluctance to disclose their own and their children's status is linked to their financial dependency in male partners rendering them and their partners vulnerable to HIV infection and re-infection.

Parents and caregivers simply choose to be secretive about their HIV status to children and not to get them tested for HIV in fear of AIDS stigma and discrimination. The disclosure to children about their parent or their own HIV-status was problematic in this study. It appears that the main concern around reluctance of parents to disclose their own status and their child's status to their children centered on possible AIDS stigma and discrimination that the child could face from other children and their parents once this was known. Similar findings have been reported by Ostrom, Serovich, Lim and Mason (2006). As seen in the study, the emotional overwhelming nature of parent-child disclosure resulted in parents' reluctance and even decision "never to disclose" an HIV-positive status. Other studies found that disclosure of the child's status was more likely if the caregiver was not the biological parent (Lesch et al 2007), as caregivers find it easier to talk to the child about his/her HIV-status than the biological parents. This could be due to the feelings of guilt and self blame that biological parents could be facing for their HIV status and for passing it on to the children, whereas caregivers have a

feeling of not being necessarily responsible for the child status, and therefore find it easier to talk about HIV issues to children and other family members (Pfaff, 2004).

Many of the children attending ART clinics with adults had been tested for HIV-infection early in life either because they were often sick and the doctors advised parents to test them, or in other cases some of the children's parents had died (mostly those accompanied by caregivers). The relatives who take over care for these children normally would have them tested for HIV as most suspect that their biological parents died from HIV and AIDS complications. These relatives seemed to find it much easier to tell these children of their status than the biological parents as reported by Lesch et al (2007).

The timing of the disclosure appears to be another critical dilemma for most adults when deciding to disclose to children. There is a general uncertainty about how the child will respond to the news that parents are being infected as well as being infected themselves. The age of the child appears to be a factor that many people consider when deciding to disclose to a child. Of great concern were those children above five years of age. Other studies e.g. Mellins, Brackis-Cott, Dolezal, Richards, Nicholas, & Abrahams, (2002) have also found that age was the strongest predictor of whether or not the child has been disclosed to. The fact that the child may be viewed as too young for HIV-disclosure influences most of the reasons offered for non-disclosure (Funk-Breattano, Costagliola, Seibel, Straub, Tardieu, & Blanche, 1997; Mellins, Brackis-Cott, Dolezal, Richards, Nicholas, & Abrahams, 2002).

The data suggest that the age of the child is an important predictor of disclosure as parents seem reluctant to discuss their status or that of their child once the child has reached early adolescence due to discomfort around the association of HIV with sexuality. Similar findings in this regard have been reported by Vallerand, Hough, Pittiglio and Marvicsin (2005). The other most strongly endorsed reason for non-disclosure to children is related to the notion that children deserve to have a carefree childhood and therefore not be burdened unnecessarily as supported by findings of Ostrom et al. (2006).

The uncertainty of the child's future behaviour as soon as they were old enough to understand the full implications of being on ART for the rest of their lives, their social lives and interaction with peers, as well as whether they would be able to cope with this situation or comply with lifelong treatment were also critical factors mentioned by participants that need attention in interventions directed at improving parent-child disclosure.

Among teenagers and children older than 10 years, the major determinant for HIV testing in most families appeared to be either because the child became sick or fell pregnant, as also reported by Lesch et al (2007). The reluctance to disclose increased where there were fears that if the children knew of their status this would expose the parent /caregiver's HIV-status to other family members (Lesch et al, 2007). Furthermore, the anxieties experienced by the disclosing adult centred around possible questions regarding the acquisition of HIV/AIDS, also reported by Ledlie (1999). The ability of children, aware of their status, to keep the diagnosis a secret, seemed to be an underlying reason for non-disclosure. Fear of perceived isolation that they are likely to

suffer from others when not able to keep the “secret” has also been reported in other studies (Moneyham et al, 1996; Murphy, Roberts and Hoffman, 2002). The fact that some women were concerned that their male partners would leave them should they disclose their own and child’s status, or that they were on ARV-treatment, is evidence of the generalized fear of stigma and discrimination surrounding HIV/AIDS. It is also a major concern that this fear of stigma and discrimination perpetuate unsafe sexual relationships and thus HIV-transmission. Similar findings have been reported in the studies of Skogmar, Shakely, Lans, Danell, Andersson, Tshandu, Oden, Roberts, & Venter, (2006).

In this study, most parents were concerned about the negative impact of HIV-disclosure on children specifically in situations where the child may tell peers about that status, and the resultant discrimination. It has been argued by authors such as Mellins et al. (2002) that there is no evidence to suggest that disclosure can negatively affect HIV-positive children. Lesch et al (2007) found that children whose status had not been communicated to them often became aware of their HIV-status from other people’s comments anyway. In these cases the children sensed that they could not openly discuss their new found information with their parents. The lack of parental disclosure to children could be psychologically detrimental to them (children). Children therefore need to be told of their own and parents’ HIV-status.

Many researchers have reported that disclosing HIV-status and maintaining open communication with children about their disease, resulted in better parent-child and family-health care institution relationships, less parental anxiety, and in children, better

psychosocial adjustment and coping as well as less behavioural problems and better preparation for safer sexual practices later (Abadia-Barerro and LaRusso, 2006). However, most of these findings are from studies in developed nations where children live within families, and have not acquired HIV through PTCT, a situation that is strikingly different from that in southern Africa. In this study as well as many others, the voice of the child remains silent in the disclosure debate. This is an area that needs further exploration (Lesch et al, 2007). On the other hand, parents who indicated that they had disclosed their status to children had different reasons for this behaviour, which was in keeping with some previous findings in other studies, (Vallerand., Hough., Pittiglio and Marvicsin, 2005) e.g. wanting the child to hear of their status from the parent themselves, not to be traumatised by learning this from strangers, and perception of being forced to disclose because of the child's poor health.

Related to this is the finding that clients hide the fact that they and or their children are on ARV-medication. Similar findings have been reported in other studies (Furber et al, 2004; Meyer-Weitz et al, 2008). Because of anticipated AIDS stigma and discrimination, parents and caregivers are often unwilling to make it publicly known that the child in their care is HIV-positive, and on ART which in turn may lead to adherence problems, as the taking of medicines would be avoided in the presence of friends and other family members who are not aware that the child is on ART. This also results in some parents and caregivers not making a child's school aware of their condition, which can lead to them missing drug doses during the school day if the children are being treated for opportunistic infections. For children who are old enough

to administer their own ARVs, it can be hard to fit their treatment routine in with their increasingly active social lives.

The data suggested that stigma was associated with denial about HIV infection and its consequences. Stigma was also linked with the use of traditional medicine, immune boosters and other concoctions. The illness representations that people hold of HIV/AIDS influence their health care seeking and coping behaviour. While there is the realisation that when one becomes sick; one has to take some form of medicine, but instead of going to health facilities, people resort to alternative practices when they suspect that they might have HIV/AIDS, which in turn promote secrecy around HIV/AIDS. One of the important finding in this study was the role of stigma as a catalyst to seek health care (ART). Contrary to most studies that concur on stigma being an inhibitory factor to health seeking behaviour, it was found that the experience of HIV and AIDS symptoms motivate health care seeking amongst some participants. The construct of SCT of behavioural expectations suggests that those that believe ARVs have positive consequences in addressing symptoms and in managing the immune system are likely to access ART. Observational learning also played a part of influencing ART access as participants who have observed the positive effects of ART are motivated to seek care and thereby avoid displaying symptoms that would reveal their HIV positive status. While stigma might prevent people from accessing ART it seemed also to facilitate seeking ART in order to prevent them from developing full blown AIDS.

Many of the children who were on ART in this study had been enrolled in the ART programme due to ill health, i.e. opportunistic infections that led to health worker

initiated HIV testing and ART enrollment. Had it not been for ill-health, the children would not have been tested or would have been given other forms of therapies (Holzemer and Uys, 2004). Taking a child for ART was deemed to be necessary in order to avoid increased attention on the child's frequent illness and the possible suspicions of HIV infection.

The death of other children and family members proved to be another strong factor that prompted people to seek ART services. It was an observation that in many instances, family members who had passed away often had never disclosed their status to other family members, and where this was the case, the cause of death aroused suspicion and prompted those left behind to seek HIV testing. A result facilitated ART access. AIDS stigma and discrimination might have played a role in facilitating ARV treatment. In terms of the ecological model and the SCT the social environment is characterized by generalized HIV/AIDS stigma and discrimination that play a central role in shaping decisions about HIV testing, disclosure and behaviour such as seeking of ART and also traditional treatment.

### **5.3.3. Use of traditional medicines, alternative therapies, alcohol and cultural concepts**

It appears that the use of traditional medicine impact on decisions pertaining to accessing ART in communities. The role of traditional medicine is clearly significant and seems to prevent some children from accessing the service. Some parents preferred to consult traditional practitioners as means of avoiding stigma as well as an excuse not

to go to clinics. This behaviour may be due to several reasons that range from the traditional understanding of illness (Masauso Nzima, Romano, Anyangwe, Wiseman, Macwan'gi, Kendall and Green, 1996) and economic circumstances. Because of the difficulties in accessing ART, some communities are forced to look for traditional medical care and other forms of therapy. This means that efforts to bring ART services closer to the communities (such as at primary healthcare level) need to be scaled up. The promotion of alternative healthcare and the integration of traditional healers in the healthcare system could facilitate health care seeking from traditional practitioners. Messages of the efficacies of alternative therapies and traditional medicine were frequently being disseminated by some health officials and politicians, and this possibly contributed to the confidence of communities in alternative therapies.

The unavailability of transport money to travel to clinics was another factor mentioned that forced some individuals to seek traditional medicines, especially in cases where there are strong beliefs that traditional medicine works just as well, and therefore no need to consult the clinics. The popularity of traditional medicine is further advanced by claims of some traditional healers that they are able to cure HIV and AIDS. Other studies have found that many of the traditional healers themselves hold this view about their own practices (Masauso Nzima et al, 1996; Burnett, Baggaley, Ndovi-Macmillan, Sulwe, Hang'Omba and Bennett, 1999). Furthermore beliefs that children are bewitched when they became ill seem to fuel beliefs that only traditional healers need to be consulted. There were many testimonies about people who were still stuck with beliefs that traditional medicine was the answer to their children illnesses, even though



others were aware that the child was HIV positive. However, as the children's conditions worsened, they would then take them to a doctor who would prescribe ART. It can be argued that the vulnerability experienced by an HIV-infected person will make it easy for them to believe the claims by traditional practitioners as they are often better able to address the emotional and coping needs of their clients when having to come to terms with the reality of their HIV-related illness than the formal health care system. With presumed possibility of complete recovery, more of PLWHA are turning to alternate medicine or spirituality for help and hope. Over time this area has become lucrative and competitive market, and many HIV/AIDS sufferers are drawn to them (Le Marcis and Ebrahim-Vally, 2005)

These aspects justify clients seeking alternative traditional medicines and spiritual healing services. Furthermore, the accessibility of traditional healers in communities emerged as one of the reasons why traditional medicines are often first sought. It should be noted that while most health facilities are closed in the afternoons, traditional healer facilities are known to be open at all times, including at night time and thus their medicines are always available. While it might not be possible to dissuade clients from seeking traditional health services, it might be necessary to seek greater cooperation with healers around ART. The training of traditional health practitioners on HIV and AIDS issues, especially around ART would enable them to assist in the recognition of AIDS symptoms and thus ART eligibility in their clients, and the subsequent referral to health care services to access ART. Similar reports have been made by other authors, where a high level of preparedness to refer clients to health practitioners by traditional

practitioners were observed (Peltzer, Mngqundaniso and Petros, 2006; Nakyanzi, 1999). However it is a finding other studies that this high level of preparedness to refer clients for ART was not accompanied by the actual referrals of clients to health institution in provinces like KZN (Peltzer, Mngqundaniso and Petros, 2006). This could be due to the absence of formal referral systems between the traditional health practitioners and health institutions and the fact that some clients were happy to receive the services from the traditional health practitioners. The training of both traditional health practitioners and health care workers has been shown to improve this situation, resulting in changes in relationship and interreferrals between the two fraternities (Homsy and King, 1996). This was further evidenced by some of the traditional healers offering condoms in addition to their services (Nakyanzi, 1999; Homsy and King, 1996; Burnett et al, 1999).

The highly publicised side effects of ART also contribute to the use of traditional medicines as many participants considered them not to have side effects yet effective against HIV as also found by Piscitelli (2000). This was a consistent finding in this study, where those who admitted to be using traditional medicine indicated that the absence of side effects were the reasons for them to use traditional medicine. Similar findings have been reported in other research studies (Bodkin, undated).

With many families living in adverse socioeconomic conditions the problems of alcoholism and drug abuse amongst families was cited by participants as one of the reasons for the poor uptake of ART services by children. Other studies found that many

children born to parents with alcohol problems could be exposed to HIV infection through its association with high risk sexual behaviours because parents with alcohol problems often abuse their children and pay inadequate attention to their children, their health needs are most often not attended to (Phorano, Nthomang, & Ntseane, 2005). Phorano et al (2005), found in their study on gender based violence and HIV/AIDS in Botswana that an overwhelming majority of child abuse cases (that presumably would include neglect to seek health care for children) had direct and indirect links to domestic violence caused by the husband's or wife's heavy drinking habits. In this study, heavy drinking habits were also viewed as one of the ways that some people dealt with the stress of living with HIV.

#### **5.3.4. Parental or caregiver ART- access and support.**

The data illustrate traditional notions about female responsibility for caring and especially in health care. Very few men brought their children to ART-services. This could also be a cultural problem in the study population, where there was a general feeling that taking care of child health was basically a woman's job, and males did not see themselves having to play a lead role in this aspect. There are still cultural beliefs that exist where men are expected to play a productive role whereas women are expected to model reproductive roles. Care giving and the persistent confinement of women to the domestic sphere still exist in most societies (Seeley, Grellier and Barnett, 2004). The productive role of men was evidenced by the response from some participants who stated that it was the men's role to work and women's one to care for children. This has negative implications for those children who are under male

supervision, as it means that they are unlikely to receive health services in these situations. The situation may be changing currently, as AIDS deaths are resulting in role changes, e.g. grandparents taking care of orphans, and males being forced to care for children when the female partners die (Seeley, Grellier, Barnett, 2004; Strebel, Crawford, Shefer, Henda, Kaufman, Simbayi, Magome, & Kalichman, 2006; Akintola, 2006). Most female participants indicated that their concerns were more about the uncertainty about what would happen when their own health status began to deteriorate as they felt that their male counterparts were not committed enough to their children's health issues.

The fact that some female participants indicated that they were unsure of what their partners would do when they found out that they were caring for children on ART further illustrate the perceived irresponsibility of males towards caring for children in need. The lack of support from the male counterparts has been observed in other studies (Daftary, Padayatchi and Padilla, 2007), where there were cases where women sought their male partner's consent to test for HIV. It was a general feeling that males would not cope with the dynamics involved in caring for these children. In some programmes, up to 90% of people who attend HIV and AIDS services are females (Department of Health KwaZulu, Natal VCT statistics, 2008). This reflects the general low HIV-related health care seeking behaviours of men, a situation that can possibly be the same for children under their care.

The fact that the parent or caregiver was on ART themselves appears to be one of the determinants for parents / caregivers to bring children for ART in this study. The benefits that these parents had seen on their own lives when they began ART motivated them to ensure that their children accessed ART services as well. This finding is also consistent with what has been found in other studies, for example the micro-economic study in Kenya, where adults on treatment were able to resume working resulting in children benefiting from nutrition, reduction in child labour and some children returning to school and others accessing ART – all due to parents being on ART (Kimou, Kouakoa and Assi, 2008). The clients who attended adult clinics but whose children were not on ART revealed some reasons for their inability to bring their children for ART. These ranged from the fact that children's immune status were still good based on their CD4 count (CD4 above the threshold of value for beginning ART), to the facts that the children were generally well and not showing symptoms of illness. Some of these reasons could possibly be excuses because of HIV-related stigma. The stigma can be a contributing factor to this behaviour as children were viewed as likely to talk about their conditions to others in this study, therefore parents could choose to ignore ART aspects unless the child's health status deteriorated. In a study on HIV-testing and disclosure amongst TB patients in KZN, Daftary, Padayatchi and Padilla (2007) found that experiences of stigma and discrimination by adults were clear barriers to VCT. It appears also that children are sometimes used as proxy to judge the parent's HIV status and the child's own HIV status. There may be a general perception that if a child has reached a certain age, therefore it was likely that they were not

infected, and therefore no need to get them tested for HIV, and subsequently these children would never access ART.

It should be noted that healthy lifestyle activities that adults easily engage in to prolong their HIV positive status without requirement for ART, e.g. regular exercise, access to ongoing counseling, good nutrition and regular treatment for opportunistic infections are not always possible with children. This shows a gap in terms of healthy lifestyles programmes aimed at children and youth who are HIV-infected., as most focus is on adults. It is also an indication that some adults do not apportion the same level of concern for their children as they place on themselves, but can also be a behaviour that is influenced by AIDS stigma and a multitude of socio-economic factors. The care of children with HIV/AIDS makes a shift from only caring to caring, education and raising (Hogenkamp, 2007). For some parents, it was a matter of sensitization to the issue of paediatric access to treatment that was needed. This places the importance of adequate counseling of adults at adult clinics amongst issues of high priority for health institutions. After the interviews, many parents who were not having children on ART from the adult clinic indicated that they would be willing to bring their children given the benefits of ART that they had experienced themselves, but had not really viewed their children's need in the same light as that of their own. This means that there is a possibility there could be many parents and caregivers who could be waiting and observing from those who brought children in order to 'benchmark' if they would be able to cope with doing the same or to observe as to how other clients coped with the operations. Once they are able to observe positive results, they might be more likely to

bring their own children. Thus the observational learning of construct of the SCT (Bandura, 1996) plays a role in seeking ART. This behaviour also could still be some level of denial or inability to face the probability that children could be infected. It also means that the knowledge of one's HIV status alone did not appear to influence the decision to take children for HIV service. An experience of some form of life threatening AIDS condition or own benefit of ART and from others tend to motivate ART seeking behaviours. These dynamics would subsequently motivate people to seek ART care for their children.

#### **5.3.5. Disintegrated families**

The issue of family disintegration emerged as another major contributing factor restricting the number of children being enrolled onto the ART-programme. Many children do not live with biological parents for various social and economic reasons. This is more pronounced in rural areas where parents are often migrant workers as also found in the study of Pfaff (2004). Although migrant labour is predominantly believed to be a male concept, this is not always the case. The economic crisis that rural villages face tends to force women to also seek employment in nearby towns and cities (Le Marcis and Ebrahim-Vally, 2005). This migrancy of parents results in the breakdown of family structures and further results in reconfiguration of family life, prompting the creation of multiple households. Multiple households take different forms; from a group of women from the same village, from the same family or just friends staying in the same squatter camp, who decide to appoint one among them to become the caregiver for the children of another women who are in employment or seeking

employment away from home (Le Marcis and Ebrahim-Vally, 2005). The impact of HIV-deaths exacerbates family disintegration, as most families often disintegrate when the breadwinner dies. These circumstances result in children living with relatives that are unable to give them the same attention that their biological parents might have given them.

Family disintegration often implies that decisions about the child's health are taken by people who may not have the child's interest at heart, in some cases even though the biological parents may still be alive. It was a finding in this study that child caregivers were sometimes switched from time to time resulting in multiple guardians, due to social changes (e.g. change in employment status or when there were family feuds), and that this contributes to children being caught in-between these situations which in turn impact negatively on the management of their ART. The inconsistent "parental care" means that the ART issues may not be viewed with the same level of importance in different households that the child finds himself at different stages. This aspect may be totally neglected in some households because of different dynamics playing out in the different households. Many single mothers were concerned about the sustainability of their children's treatment schedules if they engaged with new partners or when they got married, as they thought that circumstances may change, and it would not be easy to care for their children the way they did at that time. The fact that some women were single parents who indicated that they were not sure of how long their current relationships with their partners would remain posed problems for children under their



care. This means that the child is likely to face the ever-changing family dynamics that may not be conducive to his/her ART care as women engaged on partner relationships.

The child headed households that some participants referred to also pose a strong inhibitor to ART access by children, as it does with regards to other health care services (Hogenkamp, 2008). These are households where parents have died and children live alone, normally with the older child assuming the role of a parent for their siblings. The absence of a stable guardian in these situations means that there is no one to attend to the children's ART needs. There is also difficulties in these households with regards to the obtaining of required identification that would enable them to access ART (ID books) resulting in their exclusion from these services (Lusk et al, 2003). In sub-Saharan Africa, it is estimated that 12 million children have lost one or both parents to AIDS, a figure which is expected to increase to 18 million by 2010 (Coovadia and Hadingham, 2005).

#### **5.4. The influence of ART-service delivery factors on paediatric ART-access**

Several service delivery issues were found to play a role in restricting access to ART by children. These included problems regarding the identification and referrals of children for ART, human resources challenges, clinic infrastructure and operational dynamics.

##### **5.4.1. Problems of identification and referral of children for ART**

It appears that there are poor child referral systems between health institutions and community based groups when it comes to children. Where referrals do occur, this

seems to be done in an uncoordinated manner. The main reason for this is possibly related to the fact that few of the institutions in the existing referral networks do not have paediatric HIV-care, thus inappropriate referrals for the level of care often occur (Quality Assurance Project, USAID, and Unicef, 2008). In South Africa, hospitals are often overburdened and thus children with HIV may be directed to the community for care. As a result, non-professional caregivers are a predominant source of care for children living with HIV, therefore it is important that efficient and formal referral systems exist between health institutions and the community based organizations (Van Graan, Van der Walt and Watson (2007). Inadequate referral of children also happen within the health institutions themselves. While immunization issues are discussed regularly at clinics when a mother brings their children, HIV-issues are not (personal communication with the King Edward paediatrician). This approach is indicative of a silo-based approach to interrelated diseases resulting in children who are eligible for ART not being referred for this service even though they have presented at the clinic. This situation is further exacerbated in that the treatment of children is often provided at a different clinic than where the mother received antenatal care or delivered, therefore children exposed to HIV often go unrecognized when they present for early care e.g. for their first set of immunisations (Unicef Report).

The community social workers are also a category of health workers who are ideally placed to identify childhood problems and other health conditions that require referral to health institutions. Communities consult with them for various reasons, especially caregivers who are looking to adopt children whose parents have died of HIV and

AIDS conditions. Members of the public also utilise their services for other social issues pertaining to health, social grants and trauma counselling amongst others. Many participants indicated that they had consulted social workers at some time in their lives. However issues of ART were not emphasised. This could mean that the social workers were aware of their obligation to counsel on HIV care, but did not refer clients adequately for this care due to the limited referral networks. So the responsibility would still rest with the client to pursue the service further with their local clinics. The perceptions by some clients that social workers are located somewhere in urban areas is an issue that require addressing through effective communication with the communities, as it creates a perception that one needs transport money to receive their services. The major sources of support for children and families still come from civil society organisations (Richter, 2008). Many of these are faith groups operating in circumscribed areas. Even if these are expanded, they still cannot cope with the required needs of children, therefore institutions such as social workers can play an major contributory role in expanding these services.

The lack of linkages between home-based care, groups working with orphans and vulnerable children, and other community organizations working on HIV-care and support is another visible shortcoming of the current system. This is supported by the current estimation that fewer than 15% of households supporting children orphaned or made vulnerable by HIV and AIDS are reached by either community-based or public sector support programmes (Richter, 2008). This occurs despite the fact that the Department of Health has an active cadre of home based caregivers and community

health workers who visit households on a regular basis. Other studies that reported similar poor links between health institutions and community-based organizations found that in most cases, the community-based organizations were viewed by health facilities as more accessible and more supportive to clients. However they were regarded as unable to guarantee the follow-up of clients, as many of them tend to lose patients (Furber, Hodgson, Desclaux and Mukasa, 2004). It was established in this study that even though many participants had at some stage been in contact with the home and community-based health workers, issues of HIV and AIDS were hardly discussed, and in most instances, ART was not discussed at all. This may be due to the stigma issues, but may also be due to the scarcity of referral points for children to these services. The role of HBC programmes has been predicted as likely to increase in South Africa as the HIV epidemic becomes an AIDS epidemic (Willis, McGilvray, McNally, Defilippi and Pawinski, 2004). However, carers frequently report they do not have the skills to give optimum care for children infected with HIV (Willis et al, 2004). Other authors found that HIV and AIDS furthermore erodes social safety nets that are important for the care of the sick children and for their protection (Seeley et al, 2004).

#### **5.4.2. Client satisfaction with service delivery**

The satisfaction with ART service delivery at the study sites was generally good as some of the participants felt that they would recommend that other people bring their children for treatment as well. However, there were some service delivery issues that were found to pose constraints to this service.

#### **5.4.2.1 Overcrowding and clinic operation times**

The problem of overcrowding in paediatric clinics was one of the issues identified as causing dissatisfaction. It is an issue that can be directly attributed to the chronic shortage of staff at these clinics and generally within the health service (Travis et al, 2001). Generally in provinces with high burden of disease and where demand for services such as ART is high, it is not unusual to find overcrowded facilities. The few staff members that are available often have to cope with high patient loads resulting in the overcrowding. High staff turnover at most facilities exacerbate this situation of overcrowding, as the demand for the service is more than what the few experienced staff members available can cope with (Peltzer et al, 2005). New staff needs to be exposed to the ART service over time in order to be fully efficient. The increasingly complex standards of care also create a significant knowledge and experience gap between HIV-experts and those without years of experience (Khalsa, Gates, Jacobson, Katsufakis and Lerner, 2004). Being a newer service and somewhat specialised, it is not easy for inexperienced staff to fully adapt to the complex service standard required and to cope with high patient loads. The issue of inexperienced staff dealing with specialised care has been shown to result in missed opportunities for access to services, e.g. missed opportunities for counselling potential ART clients from other clinics (Nguyen, Oosterhoff, Ngoc, Wright, & Hardon, 2008). This problem reduces the speed with which ART programme can expand. Even the experienced staff who are permanently employed at these institutions frequently have to be rotated to other departments, leaving these ART clinics manned by junior or inexperienced personnel. This is often due to the need for the same experienced staff in other departments within the

institution and due to the fact that the staff members themselves are affected by HIV and AIDS and TB and may be absent due to illness (Wilkinson and Gilks, 1998). The situation is further fuelled by the requirement at many facilities that specialists need to deal with children's illnesses (Personal conversation with a paediatrician, King Edward Hospital).

However, there were attempts by the health department to mitigate the problem by allocating community service personnel to facilities that are hard hit with staff shortages (Personal communication with provincial ART manager, Department of Health KZN). The reality is that most of these graduates normally leave after the end of their community service (Hall et al, 2004). Some of the doctors at the facilities where the study was conducted were foreigners and only providing services for a short period. In rural sites staffing problems tend to be the norm. It is difficult to recruit health professionals to work in some of the rural sites because of the challenges faced by these facilities such as limited accommodation and inadequate schooling for staff's children, and poor resource availability in these areas (Travis et al., 2001). This results in fewer sites in rural areas being able to be accredited to provide ART-services as they often are unable to meet accreditation criteria to provide ART. As accreditation is the only means through which sites can provide ART, this invariably means that children in rural areas are at a greater disadvantage than children elsewhere. Of the 80 accredited ART sites in the province, only 68 have in their registers children on their ART programme (Department of Health KZN). This means that while adults are free to access the service widely, children have to compete for access at fewer sites.

The physical separation of paediatric and adult services at clinics was also shown to influence specifically access by children. It was often difficult for working parents to attend clinics in certain cases for themselves, and still have to wait the whole day for their children in cases where the parent / guardian and the child are affected. Clients indicated that there were fewer waiting problems at adult clinics as there were more doctors and nurses available to assist them. This was more the case with paediatric clinics. The long waiting hours at health institutions has also been reported as one of the inconveniences of ART in other studies (Furber, Hodgson, Desclaux and Mukasa, 2004)

The clinic operating times came up as one of the constraints that most parents identified as influencing their children's attendance of ART-services. Many of the patients who had children who were not on ART indicated that they were unable to bring their children to the clinic due to awkward operating times as these times seemed not to correspond to that of adult service delivery times. Most ART clinics operate from 8am to 4.30 pm, when parents are still at work or the children are still at school. Some clients stated that they often had to take a day's leave to come to clinics, as their employers were not willing to release them during working times. Schools also complain about the interruption of school activities (sometimes parents leave coincides with exams/tests) to attend a service where there is no guarantee that they will succeed on that day as clinics were often congested, and they had to often come back for several times. These factors result in low numbers of children who have access to these

services during normal operational hours. The clinic times could also be a contributing factor to limited HIV testing. It has been reported that only about 8% of infants in low and middle income countries are tested within two months of their birth (WHO et al, 2008).

Addressing health system constraints alone has been shown not to constitute a comprehensive solution to the management of the epidemic; it is however one of the critical steps for consideration in attempts to improve the health services (Travis et al, 2001). It is important to note that the mitigation of risk factors is an integral part of the response to health systems constraints and therefore relentless efforts in HIV/AIDS prevention are required (Coovadia and Hadingham, 2001).

#### **5.4.2.2 Health worker attitudes**

Negative staff attitudes appear to be another factor that discourages people utilising services at health institutions. Negative attitudes of staff have been found to impact negative on service delivery (Phaswana-Mafuya and Pelzer, 2006; Nguyen et al, 2008). The healthcare setting is a particularly conspicuous context for HIV and AIDS related stigma and discrimination. It is where people living with HIV and AIDS often discover their status and receive information on treatment and care. However, as is observed in other studies, due to stigma from health workers, some of them receive inferior care or are denied care altogether (Ogden & Nyblade, 2007). In this study, the inferior care and negative attitudes were attributed mainly to the nursing personnel. The nurses are accused of not displaying 'professionalism' when dealing with clients. Some



participants in this study even mentioned that they had overheard them discussing their conditions with friends. Such findings have been reported in other studies, especially when health workers knew the clients from outside the health service (Mahendra et al, 2007; Bharat, Aggleton and Tyrer, 2001). Confidentiality seemed to be of prime importance with the clients as HIV status was viewed as a private matter. While it can be argued that the nurses are subjected to such criticism because they are in the frontline of ART-service delivery, it is an established fact that the strenuous working conditions of nurses make them prone to developing negative attitudes towards patients (Deetleefs et al, 2003). Nurses coped with the discomfort of their working conditions by using defence and coping mechanisms that hamper the development of a therapeutic relationship between them and HIV positive patients (Phaswana-Mafuya and Peltzer, 2006). Nurses themselves can also be recipients of stigma because they care for PLWHA. They require knowledge, support, and understanding of the illness in order to cope with the stigma associated with the care they provide (Mokoae et al, 2008). The selective bad management of those who are HIV infected has been well documented in other settings (Mahendra, Gilborn, Bharat, Mudoi, Gupta, George, et al, 2007). The selective treatment of infected patients has been shown to result in patients being tested without informed consent when they were suspected based on symptoms, labeling of their belongings, and unwarranted use of universal precautions when handling them (Mahendra, Gilborn, Bharat, Mudoi, Gupta, George, et al, 2007). Negative staff attitudes were not only displayed by nurses, there were also some complaints about the lay counselor's attitudes as well. This is a finding by other authors as well (Nguyen, Oosterhoff, Ngoc, Wright, & Hardon, 2008). It seems that staff with the highest

workload are often to blame for negative attitudes towards clients. In a study in Vietnam that looked at barriers to access to the PMTCT service by women, Nguyen, Oosterhoff, Ngoc, Wright, & Hardon, (2008) found that many women expressed their dissatisfaction with the way that they are treated by some counselors. This resulted in some women avoiding the health services, which means that they were not able to access continuous treatment later and post delivery service that would ensure that their children receive appropriate HIV-care. Given the fact that the majority of children who are HIV-positive are infected through mother-to-child transmission (Richter, 2008), this factor deserves urgent attention.

#### **5.5. National policy and legislation with respect to ART-services**

Some legislative matters and policy guidelines tend to have unintended consequences of restricting access to services. The knowledge and application of the new child Act and issues relating to the national ART guidelines appear to have unintended constraints to the provision of ART service to children.

##### **5.5.1 The Child Act**

The study took place around the period when the new child Act had been passed. Given the fact that the new act makes some special allowances for children from the age of 12 to make some health decisions and confer rights to decide on certain health matters about the child on the regular caregiver, participants awareness of the act and its implications was assessed. The inadequate awareness and understanding of the act that was found amongst participants shows the low level of communication that has been

done about this matter. This could be the case of the communities not speaking the same language on health matters with the government and also indicates the failure of communication at local level between officials and their constituencies.

Once the Act was explained, different views were expressed about this act. The basis for support of this act was that it will increase access to ART, as children do not have to wait for adult decisions and it gives power to the children in child-headed households. As this act is new there are currently no studies or reports demonstrating its effectiveness in facilitating paediatric ART access.

Amongst the disagreements with this Act stands the cultural notion that stems from the fact that children cannot make important decisions on their own. The potential risk of exploitation of the act to suit caregivers' needs seems to be of concern. In some studies, it has been shown that some health care providers are of the view that a child is an autonomous individual who has the right to know about their health status (Pfaff, 2004); therefore the Act would be welcomed by those of the same view at health institutions. However other studies have demonstrated that such differing views between health providers and some community members may result in negative attitudes towards each other (Mahendra, Gilbom, Bharat, Mudoi, Gupta, George, et al, 2007).

The new child Act appears to be the solution for the children who currently are prevented from seeking health care that they are entitled to because of cultural views about the position of the child in the family. As was indicated by some participant that

the child needed adult consent to make important health decisions about their own lives, this Act will give power to children to access life saving interventions that would have not been possible without adult consent. This appears to be a welcome development as long as it is backed by adequate counseling and support given to those children by the health care system.

#### **5.5.2. ART-guidelines**

The current ART-guidelines stipulate that identification in the form of an ID book or birth certificate is required for entry into this programme. This requirement had long been identified as a constraint, as some patients were in need of treatment, but did not have ID books and would therefore be denied access. These difficulties are not unique to ART, as schools and other government institutions demand the same forms of identification for registration. According to participants, there were generally delays at the department of home affairs offices which, coupled with travelling costs resulted in many patients not being able to get their ID books. Children and adults were being turned away at some facilities due to the lack of the required documentation. There is also lack of clarity regarding the requirement of identity documents for patients wishing to start ART, as according to the Department of Health protocol, the unavailability of an ID book is not an exclusion criteria. Clients are supposed to be assisted in this regard. However, they need to in the course of time obtain an ID book. This should be emphasised to clients according to the KZN Health Department.

Refugees, illegal immigrants and asylum seekers then become completely excluded as the processes of getting identification are of long term nature. Therefore children of these vulnerable groups face almost certain exclusion despite the fact that they live in the country and some even might have spouses and partners locally. Refugees are known to remain in South Africa for periods of up to 17 years (personal communication with Lawyers for Human Rights organisation); therefore exclusion on the basis of identification has a reciprocal negative implication of fuelling the spread of HIV in South Africa. The requirement of an ID book for ART-access is one of the difficult issues for the South African government because it has advantages and disadvantages. On one hand, if this requirement is not enforced, it might contribute to a mass influx of HIV-positive people from other countries to seek costly ART in South Africa. This presents a dilemma for the government as this service is funded by the taxpayer who is already overtaxed. The ID book also confers some benefits for the healthcare worker and clients. It contains information such as the correct birth date, age and gender of the client which are important in the management of clients at health institutions. It is also the only reliable unique identifier of a person. Hospital numbers and other forms of identification can sometimes be similar, and this has severe implications on the management of these clients, e.g. failure to separate clients test results, difficulties with clinical monitoring in cases where the clients names and hospital numbers are the same, etc. The use of an ID number also makes it easier to refer clients for other services such as grant applications, where ID numbers are used. It also makes it easy to track patients as they move from one facility to another thereby preventing duplication of services that have already been done where there are electronic patient management systems in

place. Using any other identifier could pose problems if such numbers are the same. However, exclusion of eligible clients due to the absence of the ID book equally has negative consequences such human suffering, further spread of HIV and further fuelling of xenophobia as immigrants and refugees are denied access to ART. Also contributing to exclusion is the fact that health workers are ignorant about the legal status of refugees and asylum seekers. According to the National Department of Health policy, refugees and asylum seekers qualify for the same health benefits as South African citizens.

The ART-literacy sessions are prescribed requirement for any patients that needs to start ART. In these sessions, clients are taught the basics of HIV and AIDS, disease progression, how ARV-drugs work, different classes of ARV drugs, why clients need to take them for the rest of their lives, issues of drug resistance, drug-drug, and drug-food interactions. This is done to ensure that clients understand fully the implications of ART and to ascertain that they are ready and willing to comply with ARV treatment. While some insight into this requirement was evident, some saw it as a constraint for people who need to start treatment immediately as this delay the commencement of therapy, especially when initiating treatment at a late stage. It would appear that efforts need to be made about encouraging people to bring children early or get them tested before they fall very sick. It is thus important to address AIDS stigma to facilitate early treatment but also educate all HIV-positive adults with children about the importance of timely HIV testing and treatment for their children. However, it is evident that some parents might ignore signs of HIV/AIDS, possibly because of denial and being unaware

of the severity and others will embark on the use traditional medicines until the child became very ill before taking them to health institutions. In a study conducted in Kalafong hospital in Pretoria by Kruger et al (2007), it was observed that there were other important clinical guideline reasons for treatment delay in children such as co-infection of children with tuberculosis (as TB needed to be treated first), and incorrect disease stage classification by clinical staff that also contributed to delays in ART for children. However, as this study was focusing on the patient factors, these could not be established, although they were likely to prevail in the institutions where the study was conducted. It seems that the pre-training is successful in creating awareness around the importance of ART adherence despite the various challenges clients are faced with. The positive experiences with ART may further reinforce their treatment behaviour and influence their outcome expectations.

In the next chapter the conclusion and recommendations that emerged from the study will be presented.

## **CHAPTER SIX**

### **Conclusion and recommendations**

Paediatric ART-access seemed to be limited by various obstacles as emerged from the data. However, despite these obstacles, some clients were able to overcome them to improve the livelihoods of their children. They had to accept their HIV positive status as well as their children's status, and possibly had to deal with adverse conditions that accompany their HIV-infection, especially HIV/AIDS stigma related factors. This points to the presence of positive outcome expectations of ART and high self efficacy of the participants that motivate them to access ART even when faced with various obstacles. These factors pertaining to ART seemed to have prompted them to bring their children for ART as well as comply with the ART protocols.

Amongst the myriad of socioeconomic and psychosocial problems the participants faced were the predominant issues of poverty and social stigma that played a significant role in limiting paediatric ART-access. Because of the multiple constraining factors, some individuals seemed overwhelmed, and unable to exercise control over some or all of these constraining factors, resulting in them not bringing their children for HIV-testing and ART services. This lack of motivation contributes to the low numbers of children that are sent for HIV and AIDS services including ART. These parents represent a sector of the community that is aware of the severe impacts of HIV and AIDS in their own lives and that of others. These people might have witnessed deaths due to AIDS in their families and society and are motivated to seek the benefits of ART. As a person adopts new behaviours (in this case accesses ART), this causes changes in both the environment and in the person (reciprocal determinism) resulting in



the motivation that other community member's gain through observing these individuals' behaviours and the positive effects of ART. Therefore the more participants are encouraged to access ART services for their children, the more other people are going to be motivated, resulting in more children being initiated in the ART programme, that will ultimately result in the decline in cases of paediatric AIDS.

The anticipated stigma and discrimination from the broader community and even religious groupings such as churches tends to determine the rate at which people who belonged to these groupings would disclose their status and the extent to which they will take positive action towards HIV/AIDS services. The secrecy created by stigma because of AIDS fuel high infection rates as people refrain from talking and engaging openly on issues of HIV and AIDS and also continues to engage in high risk sexual partnerships. In these contexts, discussion of ART and the need to access these services timely might be limited or viewed as a subject better ignored.

Parents concern for the psychological well-being of their children, i.e. to prevent them from being subjected to possible AIDS stigma and discrimination hamper paediatric ART access. This is not only because of the child's status, but also parental status. Difficulties for parents around HIV disclosure issues and the association of HIV with sexuality is another factor limiting ART-access. Concerns about children's ability to manage their HIV-positive status in a responsible manner and to accept lifelong treatment were major concerns that need to be addressed in order to facilitate ART access.

Counsellors are not trained to deal with issues pertaining to these children, and therefore such children are likely to be turned away from institutions due to failure to comply with certain requirements. The issue of unstable parents and guardians also poses challenges with the behavioural capability of participants and therefore communities, as children sometimes swopped relatives resulting in the inability for one person to take care of the child. The study has also revealed some service delivery and policy constraints that needs to be urgently addressed by the health department if paediatric ART-access is to be improved. It must be noted that some of the constraints stem from the factors that are outside of the health service (poverty, unemployment, morality factors). A more integrated approach from other departments may then be necessary to address these challenges.

The ecological model of Bronfenbrenner and SCT of Bandura (1986) has been useful in understanding paediatric access to ART. Both models make it clear that the environment in which individuals are based is characterised by poverty and AIDS stigma and discrimination that influence decisions and practices regarding ART-access, and particularly paediatric access, i.e. limit access. The health system characteristics impact on parents decisions and behaviour pertaining bringing their children for ART-services. The restrictions of the health care delivery system seem to limit access.

The constructs of the SCT that seemed to play a significant role in paediatric ART-access include self-efficacy in seeking ART-care and the ability of parents and caregivers to overcome the multitude of psychosocial and economic barriers.

The positive outcome expectations of clients regarding ART seem also to facilitate ART-seeking behaviour while the positive experiences of parents / caregivers regarding ART motivate them to seek treatment for their children. Observational learning also seems to play a role in motivating paediatric ART. While it may be difficult to address contextual issues of poverty and AIDS stigma in the short term, the study suggests that paediatric access can be improved by focusing on clients self efficacy and outcome expectations of ART. In this regard positive role models who have experienced the positive consequences of ART on their own and children's lives will be valuable in advocating for paediatric ART.

From the results of the present study a number of priorities for ART programme improvement emerged. It is suggested that the following areas are further researched and /or prioritized for programme improvement:

**Recommendations regarding the socioeconomic factors that inhibit ART access.**

- The improvement in the provision of child support grants and the old age grants will foster ART-access it would enable communities to afford the transport costs to the clinics.
- Intensification of the decentralization of ART care to primary health care clinics to increase accessibility and also to eliminate the need for transport money to travel to the few ART sites that are available.

Some important factors need to be considered when implementing these recommendations, such as the cost of decentralizing ART services. It may also not be feasible to decentralize all activities rapidly, given the fact that almost all of the constraints that exist at accredited hospitals currently, also exist at a clinic level. Therefore these processes may prove to be lengthy, but are still critical in attempts to improve the access of ART to children.

**Recommendations regarding psychosocial factors that impact on paediatric ART.**

- The general knowledge about ART should be improved through intensive community education about ART with a special focus on paediatric ART to strengthen general understanding. This would result in behaviour change among the communities (more ART visits). Education and motivation of people to test for HIV could stimulate internal reinforcement and convince them to test and thereby access ART.
- Intensification of community education programmes aimed at stigma reduction, and to promote HIV status disclosure.
- Improved ways to communicate and educate parents / caregivers regarding ART, especially when they are illiterate.
- Urgent provision of guidelines and support to HIV positive parents / caregivers on how and when to disclose HIV status and ART status to children, and to assist in the development of skills in this regard.

- Integration of ART services into mainstream medical services may also help in reducing stigma that may be associated with attending HIV or ART only clinics.
- Involvement of child minders and domestic workers as in the support system for children in need of ART. This is beneficial to those parents who cannot find time to attend to child health issues adequately due to work commitments. Also the strengthening of initiatives that focus and encourage men as partners in the maintenance of child health will be beneficial.
- Greater involvement of community health workers and home based carers as child treatment and adherence supporters in cases where parents are too sick to take children to the clinics or for children from child headed households and other disintegrated families needs to be investigated. This strategy will also alleviate the plight of other vulnerable children.
- Utilization of parents / caregivers as role models and ART training supporters to assist in explaining and supporting the complex ART regime would be a useful strategy to extend ART- service. Possibilities of employment could be explored.
- Provision of customized assistive devices, such as pillboxes, and cell phone reminders so that client's self-efficacy be improved, e.g. taking of medicines at the correct time.

- Training of traditional healers on HIV and AIDS and ART aspects in order to increase their capacity to identify and refer children in need of ART services and to address some problems of concomitant use of traditional remedies and ARVs.
- Identifying and addressing the problem of alcoholism at a community level with relevant authorities and NGOs in order to alleviate the plight of children in the care of the families that are negatively affected by alcohol abuse.

Most of these recommendations can be done at minimal cost, however some, e.g. provision of information materials and community based training have significant cost implications but are critical prerequisites for accessing ART. This can be overcome by involvement of donors and private organizations, so as to minimize the cost of implementation and to ensure accountability for addressing the HIV and AIDS problems across all sectors including business/ employers. A multisectoral response and approach will facilitate community acceptability and feasible implementation of these recommendations.

### **Recommendations regarding service delivery factors**

The problems of identification documents, identification of eligible children and referral of children can be addressed through:

- The provision of services such as applications for identity books and the child support grants on site (at ART clinics) would remove barriers that

are caused by the unavailability of these services for some individuals, and would also help with transport costs and the need for clients to come back on another day. Alternatively, computerised links to these departments could be made available to expedite the grant and identity document applications.

- Training of teachers at schools on HIV and AIDS issues and ART to assist teachers in referring children that might be in need of ART-services from educational institutions. This may be beneficial in situations where parents may be lacking knowledge about ART, as it would provide an additional point of identification of eligible children.
- Intensification of counselling of adults at adult ART clinics on the importance of bringing children for HIV testing and screening for eligibility for ART. This can be further strengthened by routinely asking all adult clients by staff if they have children or care for children who have not been tested and then to recommend HIV-testing.

Problems of overcrowding and clinic operation times:

- Since the in-facility drug literacy training appears to be strong enough in ensuring compliance amongst the clients, community based HIV testing and drug literacy training is needed in order to influence ART seeking behaviour at community level and to ease the workload of staff at ART clinics, which in turn would result in more children being initiated on ART at clinics.

- Extension of ART clinic operating times or possible introduction of shift work in order to allow the working public and school children to attend these services after hours without having to disrupt work and schooling activities.
- Offering of customized training for all doctors on paediatric ART so that the reliance on specialists is minimized.
- Consideration of task shifting strategies in order to remove the workload from scarce skills personnel, and allow the lower level workers to carry out some of their tasks to free up time of health workers qualified to offer ART-services and thus enable greater access to ART.
- Intensified training of health workers on HIV and AIDS and ART, with special focus on stigma reduction in order to improve their attitudes to clients and to increase their ability to identify and refer children appropriately.
- Integration of paediatric and adult ART services so that parents and children can make one visit to the clinic rather than coming at different days. This may improve attendance of scheduled visits and adherence to treatment as there is less money spent on traveling. The possibility of integration of chronic medical services could also be considered as there are cases where multiple family members need to access different medicines for various conditions so that they can all attend clinics at one time.



- Designing of tailor made ART literacy training for illiterate individuals; this could be done in the form of picture-based materials.
- Pharmaceutical companies need to be engaged on the possibility of making child syrups that are tastier and therefore easier to administer to children (flavours).
- Intensive training relevant health care workers on paediatric ART and drug dosing so that they are capacitated to dispense drugs for children. The training of nursing staff on this will take the load off the doctors who can then attend to other pressing work.

The above recommendations are feasible to implement as there are currently existing bodies that are tasked with implementation of related issues and who receive a budget for conducting their activities. What seems to be required however, is a readjustment and realignment of targets and activities in future plans in order to accommodate some or all of these recommendations. The acceptance by communities will not be problematic as there will be a direct improvement in the access to services if the recommendations are implemented, e.g. extension of clinic operating times will not benefit ART clients only, but also access to other clinic services as well.

### **Recommendations on policy and ART guidelines**

- Embarking on community information campaigns about the new Child Act and its implications for HIV treatment, care and support to generate understanding of the Act and its intended benefits.
- Efforts should be directed at addressing misconceptions about the national guidelines, and the provision of information for health workers on identity documentation, the rights of children of refugees, illegal immigrants and asylum seekers, to rectify their exclusion from available ART services.

The feasibility of implementing these recommendations is evident as it involves mainly the revision of guidelines to address constraints, and the training of relevant staff on the proper use and interpretation of the guidelines. The cost of implementation should also be minimal as the same budgets that were allocated for these functions can be used.

### **General recommendations**

While a reduction in the rate of mother-to-child-transmission of HIV would decrease the need for paediatric treatment, it is unlikely in the near future not to have children living with HIV, and thus subsequently AIDS. As long as this is the case, testing and treatment facilities for children need to be improved, and paediatric ART needs to be scaled up. Because the majority of HIV-positive people are adults, medical interventions such as ART have not really been focused on children. Children in need of ART seem more vulnerable than adults because they face some special psychosocial

problems as well as institutional and logistical problems resulting from their drug regimens, their dosing and follow-up visits. Every health worker needs to understand HIV and AIDS management not only for adults, but for children as well. Furthermore, positive adult experiences with ART seemed critical in ensuring paediatric ART-access.

This study has highlighted some often ignored social constraints to paediatric ART, and shown that there cannot be significant strides in the provision of services to children unless the psychosocial, service delivery and policy challenges related to ART are addressed. The tendency to over-medicalise HIV and AIDS programmes will limit the success of these programmes. Greater consideration of what works and what does not work regarding ART service delivery to children from the parents and guardians perspectives will result in more parents bringing their children for ART. Greater paediatric ART-access is a critical milestone in the achievement of the millennium developmental goal of reducing infant and child mortality in developing countries.

### **6.1. Limitations of the study.**

Despite assurances that participants were free to express their views openly and honestly without fear or risk of being identified, the fact that interviews were carried out by a health official in the health facilities possibly might have prompted some participants to give socially desirable responses to the questions posed. Furthermore, the qualitative nature of the study and the fact that the clients attending the clinics at Edendale and King Edward hospitals might not be representative of the broader community as those seeking ART-services might be biased towards those in favour of seeking ART-services. Also self reported behaviour is subject to reporting bias (Skogmar et al, 2007); therefore some behavioural responses that were reported by participants may not be a true reflection of their daily lives.

It will be important to follow this study with a quantitative study to determine how widespread the reported findings are in the general communities. A further study will also be important to fully understand the paediatric ART-service from a health systems and health worker's perspective.

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## **ANNEXURE A: INTERVIEW SCHEDULE**

Title: Access to antiretroviral treatment by children in KwaZulu-Natal Province: A qualitative exploratory study into factors influencing poor access.

### **Parent/ Caregiver Interview**

#### **Section A (Demography)**

**Client's name**

**Age**

**Gender**

Marital Status

Occupation

**Address**

**Hospital name**

Languages:

#### **Section B (Client's perspectives)**

To probe information about factors (psychological, psycho-social and demographic) that make them to bring their children to ARV clinics or that prevent them from doing so.

All questions to be open-ended questions

### **1. For participants attending paediatric ARV clinics**

#### **Intrapersonal factors**

What is your relationship with this child?

Are you taking ARV drugs yourself?

How long have you or your child been on ARVs?

What are your feelings about ensuring that your child takes medication regularly, and attends all scheduled visits, do you find it an easy/difficult task?

Do you sometimes feel that it is too much burden, or it's something you must do?  
Do you feel that this treatment is too complex; there are many things to remember?  
Socioeconomic and psychological issues, such as unemployment, traveling problems,  
Was there a time when you considered discontinuing this service?  
Are you satisfied about the service that your child receives from this clinic?  
Would you encourage other people to bring their children for treatment as well?

#### Interpersonal factors

Do you have close members of family (e.g. husband, wife, and other children)?  
Does he/she/they know of your and your child status?  
Is anyone of them taking ARV drugs?  
Do you belong to a community organisation / church, etc?  
Do other children know that your child is on ARVs?  
If no, what are your feelings about them knowing?  
Do you think that this will promote /inhibit HIV positive children from taking ARV treatment?  
Are your friends/family/work colleagues supportive?  
What do you think makes other parents/guardians not take their children for ART?

#### Community level concepts:

Institutional factors to be investigated such as the availability of social workers and their role in referring children for ART services.

- Have you or your child ever consulted a social worker?
- If not, what are the reasons for this?
- If yes, was ART ever discussed

Rules, regulations, policies, and informal structures, which may constrain or promote behaviour to be established

- The new child act stipulates that children of 12 years can make own decisions about accessing services such as ART, do you think that this is good idea?

Public policy- issues relating to laws and policies that regulate or support healthy actions and practices for disease prevention, early detection, control, and management are to be investigated

- Are the opening times of the clinics convenient for you and your child?
- How do you manage to keep with appointments for your child?
- How does the school feel about your child missing some lessons to be at the clinic?

## **2. For participants attending the adult clinics (in addition to above)**

To probe for information around knowledge about paediatric services available and issues preventing them from bringing their children if they have them.

### **Open-ended questions**

Do you have children of your own or any that you are supporting?

Have you ever considered having them tested for HIV / take ART?

To probe for reasons for both a positive (YES) and a negative (NO) answer

For participants with no children, to find out what their feelings would have been in bringing their children for treatment, given their own experiences with ARVs

Do you think that the health institutions make it easy for parents to bring their children forward?

Do you think that other institutions such as schools, churches and employers make it easy for parents to bring their children forward?

## **ANNEXURE B**

### **Access to antiretroviral treatment by children in KwaZulu-Natal Province: A qualitative exploratory study into factors influencing poor access.**

#### **PARTICIPANT INFORMATION**

**Investigators:** Prof Anna Meyer-Weitz, Mr R Phili

#### **Greeting & Introduction:**

Hello, my name is Roger Phili. I am from a University of KwaZulu-Natal and doing research on factors that influence access to antiretroviral treatment by children in KwaZulu-Natal Province, in particular those that are influencing poor access.

#### **Why are we doing this study?**

Research is a process to learn the answer to a question. In trying to promote access to children to antiretroviral treatment services, it is necessary to know as to what are the factors that influence the poor access of children to antiretroviral treatment in KwaZulu-Natal. We need to understand social and environmental factors that influence decisions to allow children or not to allow them to obtain this life saving intervention. In this study we are looking at those reasons with an aim of informing policy on the improvement of child access to antiretroviral treatment.

#### **Invitation to participate:**

We will be asking about 20 people from two ARV treatment sites, Edendale Hospital and King Edward Hospital to participate in this study and are inviting you to be one of those participants. You are completely free to decide whether or not you want to take part. If you do not want to participate you will not suffer any penalties. If you do decide to take part, we will ask you to sign a consent form. If you sign this form, it means that you agree to take part in the study. You have a right to stop taking part at any time, and you will not suffer any penalties if you decide to do so.



### **If I take part in the study, what will happen?**

After you have had a chance to ask any questions you want to about the study, we will ask you to sign a consent form. We will then ask you some questions about your views to what the constraints to children's access to ARV treatment are. There are no right or wrong answers. We want to find out what you really think. If you give permission, I will start to tape record and document the interview. If you don't want to give permission, we will make notes about what you say on paper. You can stop the interview at any time or not answer any questions that make you feel uncomfortable. The interview will take about thirty minutes. After we have finished the research, we will write a report so that other researchers can learn from our study, and we will use the results to better promote the enrolment of children to HIV treatment programmes. A research report will be made available at our offices at a later stage.

### **What are the risks and benefits of taking part in the study?**

There is no risk to you for taking part in this study. Information that we get from people taking part in this study will be kept securely stored. I will not take down your name or any of the participant's names. Any reports that we write about this study will not reveal names, or who said what.

Instead, you will help us by providing important information about what you view as constraints to children enrolling for these services in this province, which is something that we don't know much about.

### **What can I do if I want to ask more about this study?**

If you have any questions about this study, you can ask me now. I will also give you a copy of this sheet that explains the study, to take away with you. If you have questions later or if you want to know what the research found you can visit my work office at Department of Health, 230 Prince Alfred Street, Pietermaritzburg; or phone me at 033 341 4000. You can also fax me at 0866 102 012 or email at [roger.phili@kznhealth.gov.za](mailto:roger.phili@kznhealth.gov.za). A research report will be made available at a later stage and a copy would be available at my office.

The committee that gave ethical approval to this study was the Research Ethics Committee of the Faculty of Humanities, Development and Social Sciences, University of KwaZulu-Natal. If you have any questions or worries about your rights as a person taking part in a research study, you may contact Ms Phumelele Ximba at telephone 031-260-3587, or email her at [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za).

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## **PARTICIPANT CONSENT**

**Study title:** Access to antiretroviral treatment by children in KwaZulu-Natal Province: A qualitative exploratory study into factors influencing poor access

**Investigators:** Prof Anna Meyer-Weitz, Mr. R Phili

I have read the information sheet about this study (or the information sheet has been read to me). I understand what will be required of me, and what will happen to me if I take part in the study.

\_\_\_\_\_ has answered any questions I have about the study.  
(name of study staff member)

I understand that:

- If I agree to participate, I will be given a signed copy of this document and the participant information sheet which is a written summary of the research.
- I may visit the Department of Health offices at 230 Prince Alfred Street, Pietermaritzburg; or contact Roger Phili at 033 341 4000 any time if I have more questions about the research.
- I may contact the Research Office at the University of KwaZulu-Natal 031-260 3587 if I have questions about your rights as a research subject.
- My participation in this research is voluntary, and I will not be penalized or lose benefits if I refuse to participate or decide to stop.
- My contribution if I participate in this research will be kept confidential.
- I may withdraw from the study at any time without giving a reason.

Therefore:

1. I agree to take part in the study:

YES / NO (circle answer)

2. I agree that I can be tape recorded:  
answer)

YES / NO (circle

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Witness  
(Where applicable)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Translator  
(Where applicable)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## **ANNEXURE C**

### **EXAMPLE OF THE INTERVIEW**

Title: Access to antiretroviral treatment by children in KwaZulu-Natal Province: A qualitative exploratory study into factors influencing poor access.

#### **Participant attending the adult clinics**

Aim: To probe for information around knowledge about paediatric services available and issues preventing them from bringing their children if they have them.

#### **Open-ended questions**

**Interviewer:** Do you have children of your own or any that you are supporting?

**Participant:** *Yes, I have a child a I am caring for my sibling as well*

**Interviewer:** Have you ever considered having them tested for HIV / take ART, whether your own child or your siblings?

**Participant:** *Yes, when the clinic offered to have her tested. I agreed.*

**Interviewer:** Were you not scared?

**Participant:** *I was even though I had been tested; the fact is I tested very late and got my results and took nevirapine, but I wasn't sure if it worked.*

**Interviewer:** What were the child's results?

**Participant:** *Fortunately the child tested negative. I was very relieved.*

**Interviewer:** Had the child tested positive, would you have considered having her take ARVs if eligible?

**Participant:** *It would have been a difficult thing.*

**Interviewer:** Why

**Participant:** *Because people would know that I am positive, and people would no longer like my child and would not even want to play with her. They would keep saying "Shame, Shame" all the time.*

**Interviewer:** Therefore you would not have your child take ART?

**Participant:** *Not necessarily, I wouldn't have liked my child to die.*

**Interviewer:** What about your sibling?

**Participant:** *I advised her to get tested when she was eight months pregnant because I had learnt that you don't leave it till late.*

**Interviewer:** Why didn't you tell her to get tested earlier than that?

**Participant:** *We didn't know that she was pregnant, she hid it.*

**Interviewer:** And will you advise her to have her child tested, and possibly take ART if needed?

**Participant:** *I will accompany her to the clinic, but she will be on her own in the consultation room, so I don't know what she will do.*

**Interviewer:** Do you think that the health institutions make it easy for parents to bring their children forward for testing or to get ARVs?

**Participant:** *Not really, firstly the nurses shouting at us all the time, and having to sit on the bench the whole day is not encouraging. Sometimes you arrive late at the clinic because of transport delays, and the nurses will shout at you for arriving at that time.*

**Interviewer:** What other things do you think makes it hard to take children to the clinic.

**Participant:** *I have to wake up at 5am, and if you are 5 minutes late you are asked to go back. There was even my neighbor child who had asthma. When her mother arrived with her at the clinic, she realized that she had forgotten the child's card. The nurses sent her back, and the child died afterwards.*

**Interviewer:** Do you think that other institutions such as schools, churches and employers make it easy for parents to bring their children forward for HIV services including ART?

**Participant:** *No, look at the schools; they don't even want condoms at schools... how much more then if the child is sick. It's not easy..teachers are people too. They also have their own stigma towards HIV. So you are stuck if you have HIV.*

*Employers are worse because we don't even speak about HIV at work at all. It's like you are boasting that you are negative if you talk about HIV. People look at you funny..*