NIGERIAN HEALTH WORKERS' VIEWS CONCERNING PAEDIATRIC ADHERENCE TO ANTI-RETROVIRAL THERAPY

by

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DECLARATION

I declare that **NIGERIAN HEALTH WORKERS' VIEWS CONCERNING PAEDIATRIC ADHERENCE TO ANTI-RETROVIRAL THERAPY** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

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NIGERIAN HEALTH WORKERS' VIEWS CONCERNING PAEDIATRIC ADHERENCE TO ANTI-RETROVIRAL THERAPY

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ABSTRACT

This study sought to explore the views of healthcare workers regarding paediatric anti-retroviral therapy (ART) adherence in Nigeria. An exploratory descriptive qualitative research design was used to identify and describe healthcare workers' views in Kano and Lagos, Nigeria. Three focus group discussions were held. The transcribed data was analysed using the framework approach of data analysis.

Healthcare providers perceived poverty, illiteracy, stigma and discrimination, inappropriate care approaches, and parental dynamics as factors influencing ART adherence.

Recommendations for enhancing paediatric ART adherence levels in Nigeria included: mainstreaming adherence counselling in paediatric ART and adopting a comprehensive family centred care approach were identified as measures for improving paediatric ART adherence. Other measures included free ART services, quality improvement in paediatric ART services, parental empowerment and stigma and discrimination reduction programmes.

KEY TERMS

Anti-retroviral therapy (ART), ART adherence, Nigeria, paediatric Auto-Immune Deficiency Syndrome (AIDS)

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DEDICATION

This work is dedicated to my children,
Changhenfemi, Changhieco and Changwami

TABLE OF CONTENTS

CHAPTER 1
ORIENTATION TO THE STUDY

CHAPTER 3

RESEARCH DESIGN AND METHOD

CHAPTER 4
DATA ANALYSIS AND DISCUSSION

CHAPTER 5
CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

LIST OF TABLES

LIST OF DATA DISPLAYS

LIST OF ANNEXURES

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

This study sought to explore the views of healthcare workers in Nigeria regarding treatment adherence in children with human immunodeficiency virus (HIV) infection. The study specifically focused on determining the views of healthcare workers regarding children's adherence to antiretroviral therapy (ART), received free of charge through subsidisation in Nigeria, and factors influencing paediatric patients' adherence to ART.

1.2 BACKGROUND INFORMATION ABOUT THE RESEARCH PROBLEM

1.2.1 The source of the research problem

This section highlights the core issues that stimulated the researcher's interest to investigate this topic.

The Federal Government of Nigeria, in response to the human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) has since 2004, financed one of the largest government funded antiretroviral treatment (ART) programmes in Africa. The programme aimed at reducing the burden of AIDS on individuals and families. However, specific challenges remain inherent in the programme, including the initial absence of paediatric anti-retrovirals (ARVs), ongoing shortages of paediatric drugs due to poor supply chain management, limited facilities and capacities to provide ART, shortage of paediatric specialists in public health facilities and insufficient training of healthcare personnel about paediatric ART care.

The World Health Organization (WHO 2004:44) reports that studies of drug adherence in the developed world have suggested that higher levels of drug adherence are associated with improved virological (reduced viral load) and clinical (increased CD4 counts) outcomes. The adherence rates that exceed 95.0% are desirable in order to maximise the benefits of ART (Shah 2007:55). In Nigeria, it has been difficult to achieve rates this high over a long period of time, since 2004 when the ART programme had been scaled up.

Numerous approaches to improving adherence have been investigated in the developed world and have been explored in the developing world, including Nigeria. Viral load testing is being explored in Nigeria, but will not be widely introduced in the near future because of costs and technical considerations (high sophistication of equipment, poor infrastructure, inadequate health systems and limited capacity of healthcare workers). Consequently, while there is a need to focus on maximising adherence in order to avoid drug resistance and ensure the durability of the effect of ARV regimens, adherence in children is a special challenge, particularly if the family unit is disrupted as a consequence of adverse health or economic conditions (WHO 2004:45), including HIV/AIDS deaths.

Malta, Maya, Clair, Freitas and Bastos (2005:1424) conducted in-depth interviews with 40 physicians treating people living with HIV/AIDS at six public reference centres in Rio de Janeiro, Brazil. Barriers to ART adherence were perceived by the physicians as being mainly related to poor patient-worker relationships. Other barriers were related to “chaotic” patients’ lifestyles, and inadequate knowledge and/or negative beliefs about HIV/AIDS and ARV effectiveness. To improve adherence, Malta et al (2005:1424) recommended networking between services, establishing effective referral systems, and improving health professionals’ interprofessional collaboration.

Brackis-Cott, Mellins, Abrams, Reval and Dolezal (2003:252) report medical workers’ views from two primary care programmes regarding adherence to ART among HIV-infected children in New York, in the United States of America (USA). Workers believed that the limited treatment options available to HIV-infected children presented families with adherence challenges. Most prescribed paediatric ART regimens were difficult to maintain and could become increasingly complex for possible future successful treatment, with increased demands on adherence issues. Although workers were able to identify several

helpful communication strategies in theory, they were unable to consistently implement these strategies in practice. Many families also struggled with poverty, mental health and substance abuse problems, additional HIV positive family members, and disclosure issues (often involving stigmatisation).

Shah (2007:55) and the Federal Ministry of Health (FMOH 2007:136) maintain that optimum paediatric ART adherence is critical to successful treatment outcomes. At least 95.0% adherence to ART is optimum (Shah 2007:55) and studies have shown that <95.0% adherence is associated with virologic failure rates of >50.0%. However, a study in more than 90 countries across Europe (including Israel and Argentina) by Reekie, Mocroft, Sambatakou, Machala, Chiesi, van Lunzen, Clumeck, Kirk, Gazzard and Lundgren (2008:2381) showed that patients who spent more than 80.0% of their time on combination ART (cART), with fully suppressed viraemia prior to baseline, had a 38.0% reduced risk of treatment failure. Another study (Horberg, Silverberg, Hurley, Delorenze & Quesenberry 2008:301) investigated the impact of prior ARV experience on adherence and clinical outcomes. This study was conducted among patients initiating new ART regimens in Kaiser Permanente Northern California from 1997 till 2002. Reportedly years of ART experience did not affect adherence or any other outcome measures. Thus, ARV naïve patients had improved ART adherence, HIV ribonucleic acid (RNA) control, and CD4 T-cell count increases, compared to ARV-experienced patients, irrespective of years of ARV experience.

In New York City, maintaining adherence was reportedly an ongoing challenge and strategies had to be evolved as children matured (Merzel, Van Devanter & Irvine 2008:977). Regimen fatigue and resistance to taking medications were major challenges to maintaining adherence among the older children. In other cases, caregivers developed a kind of partnership with the children for administering the medications. Disclosure to the child of his or her HIV status to promote adherence seemed to be effective only under certain circumstances. Social support appeared to have an indirect influence on adherence, primarily by providing caregivers with temporary help when needed. Health

care professionals were important sources of disclosure and adherence support for parents. The study illustrated the interplay of maturational issues with other contextual psychosocial factors as influences on adherence among older children and adolescents.

Important factors that influenced ART adherence such as regimen-related complexities, patient/family-related issues and factors related to the healthcare delivery system also affected HAART adherence challenges. Most ART adherence research focused on ART adherence among adults. ART data about children are limited in Nigeria. Therefore, in order to facilitate adherence and improve outcomes of ART in the paediatric population, it is necessary to understand factors influencing adherence and interventions that can improve children's ART adherence.

Family Health International (FHI 2008) piloted family-centred AIDS care programmes in two hospitals in Nigeria during 2007. One of the approaches for addressing children's health, included ART adherence. Children's ARVs are supplied free of charge at these two facilities, through subsidisation by the United States (US) President's Emergency Plan for AIDS Relief (PEPFAR). At the programmatic level, strategies are in place to ensure adequate stocks and storage of ARVs and to provide resources for culturally appropriate ART programmes.

This study attempted to identify healthcare workers' views at these two facilities about the perceived

- impact of free paediatric ARVs on these children's ART adherence rates
- factors militating against ART adherence
- patterns of ART adherence observed in children accessing ART services through the family-centered model of care.

1.2.2 Background to the research problem

Nigeria is the most populous country in Africa and the eighth most populous country in the world, with a population of over 140 million. The first case of AIDS in Nigeria was reported in 1986. Since then, the National Agency for the Control of AIDS (NACA 2008:6) reports

that HIV prevalence has steadily increased from 1.8% (1991) to 5.8% (2001) with a slight decline to 4.4% (2005). NACA (2008:6) shows that although the prevalence rates appear low, Nigeria ranks third in terms of the actual number of people infected with HIV after India and South Africa.

The drivers of the epidemic, according to NACA (2008:7), have been linked to poverty, negative peer influences, poor access to health services and poor health seeking behaviours of Nigerians. The existence of some religious and socio-cultural practices also contributed to the increased prevalence of HIV/AIDS, particularly those that reduce the status of women in the Nigerian society.

Variations in HIV prevalence exist across Nigerian states and between rural-urban localities suggesting that there are sub-epidemics within an epidemic. NACA (2008:10) maintained that the results of the HIV/STI Integrated Biological and Behavioural Surveillance Survey (IBBSS 2007) among high-risk groups in Anambra, Cross River, Edo, FCT, Kano and Lagos States showed an average prevalence of 37.4% among brothel based female sex workers (FSWs). The result for non-brothel based FSWs, from the same study, was 30.2%. The prevalence rate among members of the armed forces, police and transport workers were 3.1%, 3.5% and 3.7% respectively. The prevalence rates among men who had sex with men and intravenous drug users were 13.5% and 5.6% respectively.

According to NACA (2008:8), about 3.2 million people lived with HIV in Nigeria, of whom 136 284 were girls and 142 639 were boys aged 0-14 years. Approximately 507 440 of these persons (adults and children) needed ARVs.

Nigeria's free ARV provision since 2006 increased the access and uptake of ARVs (NACA 2008:17). The annual cumulative number of clients on ART increased from 50 581 at the inception of ART in 2005 to 269 859 at the end of March 2008. Out of this number 15 345 children aged under 15 years received ART (Epidemiological Fact Sheet on HIV and AIDS 2008:12). This was greatly facilitated by the PEPFAR and Global Fund Round 5 (GFR5) supported ART programmes in Nigeria.

United Nations Children's Emergency Fund (UNICEF 2005:4) estimated that children under 15 accounted for 1:6 global AIDS-related deaths and 1:7 new global HIV infections during 2004. A child under 15 dies of AIDS-related illness every minute of every day, and a young person aged 15-24 contracts HIV every 15 seconds.

HIV/AIDS is ravaging the lives of children, especially in Nigeria where resources are limited and poverty eats deep into the lives of the majority of families. Among the infected and affected families, children are worst hit by the epidemic, and more needs to be done to salvage this situation.

In Nigeria, most HIV infections in children are mother to child transmissions (MTCT). The Epidemiological Fact Sheet on HIV and AIDS (WHO 2008:14) reports that of the 240 000 HIV positive pregnant women who needed ARVs for PMTCT in Nigeria, about 10.0%, or 12 278, received ARVs in 2007. Although it is an increase from less than 1.0% in 2005 and about 5.0% in 2006, increasing numbers of children are being born infected with HIV, diminishing their chances of survival. Likewise, increasing numbers of adolescents and young people are contracting the virus every year, impacting on their quality of life and on the global economy.

AIDS has left no country untouched. In the 54 countries where adult HIV prevalence has reached more than 1.0% in the general population, HIV/AIDS directly affects millions of children, adolescents and young people. In the hardest hit countries, UNICEF (2005:4) asserted that health systems were increasingly losing their capacities to treat and care for children and their families. The children of sub Sahara Africa (SSA) account for more than 85.0% of all children under 15 living with HIV (UNICEF 2005:4).

Children affected by HIV/AIDS might miss out on ART and the antibiotic cotrimoxazole that is effective for decreasing mortalities among HIV-positive children (UNICEF 2005:7). While UNICEF (2005:7) reported a global picture that less than 5.0% of young HIV-positive children in need of paediatric ART are receiving it, the case in Nigeria is worse – less than 1.0% of children have access to paediatric ART.

In SSA generally, and specifically in Nigeria, designated public hospitals for AIDS treatment are being overwhelmed with caring for AIDS-affected patients. This reduces the ability of health services to care for children with other life-threatening illnesses such as pneumonia, diarrhoea and malaria. Health systems are further undermined by the loss of staff. UNAIDS (2003:15) estimates that death rates among health workers in the most highly affected countries in Africa have increased five or six fold as a result of AIDS-related illnesses. UNICEF (2005:8) notes that in SSA, many doctors and nurses, faced with low pay and poor working conditions, are seeking jobs in industrialised countries. The undermined health system contributes to a total collapse of the quality of paediatric patient care, thus, leading to inadequate adherence counselling and consequent high losses to follow-up and threats to treatment outcomes of paediatric AIDS patients. In addition, children affected by HIV/AIDS are increasingly missing out on other measures – safe water and sanitation, proper infant feeding practices and nutritional support – to help them achieve better treatment outcomes, survive, develop and grow (UNICEF 2005:8-11).

In focusing on the drug adherence situation in Africa, Gill, Hamer, Simon, Thea and Sabin (2005:1243) assert that maintaining high ART adherence rates will likely prove to be a major challenge in Africa - just as it has been in developed nations. Early reports suggested that adherence would not pose a major barrier to treatment success. However, Gill et al (2005:1243) assert that more recent research shows that adherence rates in Africa are quite variable and often poor. In direct contrast to the assertion by Gill et al (2005:1243), Muller, Bode, Myer, Roux and Von Steinbuchel (2008) report that adherence to pediatric ART regimens in South Africa is not lower than in the developed world, yet not high enough to guarantee long-term treatment success rates. However, caregiver reports seemed to be unreliable in this setting.

In Senegal, Laniece, Ciss, Desclaux, Diop, Mbodj, Ndiaye, Sylla, Delaporte, and Ndoye (2003:S103) report that a cross-section analysis of 158 patients showed that the level of adherence was high: on average, patients took 91.0% of each monthly dose of their ARVs and full monthly doses during two-thirds of the months studied. Patients who made little or no contribution to the cost of their treatment had better adherence to ARVs than those who

fully paid for their ART services. Adherence was also better with efavirenz-containing regimens than with indinavir-containing regimens. Thus, Laniece et al (2003:S103) conclude that adherence to ART can be as high in Africa as that generally observed in industrialised countries, and that the cost and type of drug regimen must be taken into account when designing ART access programmes for poor communities.

Using in-depth interviews of 42 HIV-infected children taking ART and/or cotrimoxazole prophylaxis, and 42 primary caregivers, at a comprehensive HIV/AIDS clinic in Uganda, Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuza, Mermin, Malamba and Bunnell (2006:s85) report that complete disclosure of HIV status by caregivers to children and strong parental relationships were related to good adherence in children. Poverty and stigma were barriers to adherence even for children who had complete disclosure and a supportive relationship with at least one parent. For example, Greeff, Uys, Holzemer, Makoae, Dlamini, Kohi, Chirwa, Naidoo and Phetlhu (2008:96) note that because the status of PLWAs is known, they were denied opportunities like cooking for the family or to be part of community activities. They were also denied access to health services. Greeff, et al (2008:102) also add that the mere fact that a spouse, child or family member was related and associated with PLWA led to their being stigmatised. Children from other families were hindered from associating with those from the affected family, including playing together. To ensure adherence to life-extending medications, Bikaalo-Kajura et al (2006) underscore the need for workers to support caregivers to disclose, provide on-going support and maintain open communication with HIV-infected children.

In an ethnographic study conducted in Nigeria, Tanzania and Uganda, Ware, Idoko, Kaaya, Biraro, Wyatt, Agbaji, Chalamilla and Bangsberg (2009:0039) report that individuals taking ART routinely overcome economic obstacles to ART adherence through a number of deliberate strategies aimed at prioritising adherence: borrowing and “begging” transport funds, making “impossible choices” to allocate resources in favour of treatment, and “doing without.” Patients accomplish prioritisation of adherence through resources and help made available to them by treatment partners, other family members and friends, and healthcare workers. The helpers expect adherence and make their expectations known, thereby

creating responsibility on the part of patients to adhere. Patients, on the other hand, adhere to promote good will on the part of helpers; thereby ensuring help will be available when future needs arise.

There are a variety of other factors that influence the adherence patterns in children. The rates and determinants of ART adherence in Italian children (Giacomet, Albano, Starace, de Franciscis, Giaquinto, Gattinara, Bruzzese, Gabiano, Galli, Vigano, Caselli & Guarino 2003:1398) showed no significant difference between age and the stage of HIV infection in the determination of adherence. Children aware of their HIV status were less adherent to treatment. Individual drugs showed similar broad adherence patterns and children who received HAART were more adherent than those who did not. Children receiving therapy from foster parents were more adherent than those receiving drugs from biological parents or relatives. Thus, Giacomet et al (2003:1402) concluded that adherence is a major problem in children and psychological rather than clinical or socio-demographic features and types of drugs are major determinants of adherence.

In another study in USA (Marhefka, Farley, Rodrigue, Sandrik, Sleasman & Tepper 2004:323), significant regimen knowledge deficits were observed among caregivers. Inaccurate identification of prescribed medications was also significantly associated with low adherence levels in this study.

Other factors that reportedly affected ART adherence among adolescents in the USA are depression and active substance abuse (Chesney 2000:S171, Tindyebwa, Kayita, Musoke, Eley, Nduati, Coovadia, Bobart, Mbori-Ngacha & Kieffer 2005:171). Depressed individuals have little motivation for life's activities, including taking prescribed medications. Alcohol, cocaine, heroin, Indian hemp (marijuana) and other drugs of addiction make it difficult to adhere to ART. Alcohol use increases the likelihood of having serious side effects from some ARVs because both alcohol and ARVs are hepatotoxic.

Rosen, Ketlhapile, Sanne and DeSilva (2007:524) reported that South Africa is providing ART free of charge in order to increase access for poorer patients and promote adherence.

However, Rosen et al (2007:524) also stated that non-drug costs (such as transport) of obtaining treatment could limit access. To estimate the costs that South African patients incurred in obtaining ART, Rosen et al (2007:524-525) reported that patients had to visit a treatment clinic at least six times per year where they started ART. The average cost per visit was R120, plus travelling and waiting times. Patients and caregivers also spent considerable time and money between visits. Thus, patient costs should be considered in efforts to sustain adherence and expand access.

Despite the challenge of costs in poverty stricken SSA, various studies (Mills, Nachega, Buchan, Orbinski, Attaran, Singh, Rachlis, Wu, Cooper, Thabane, Wilson, Guyatt & Bangsberg 2006:679) provided hope for AIDS treatment programmes in SSA. For instance, in a study to evaluate the estimates of ART adherence in SSA and North America, Mills et al (2006:679) included 31 studies from North America and 27 from SSA. The research findings indicated that favourable levels of adherence (determined mostly by patient self-reports) could be achieved in SSA settings and that adherence remained a concern in both North America and in SSA. The ART retention rates, and responses to therapy in a severely resource-constrained setting in Kenya were investigated (Marston, Macharia, Nga'nga, Wangai, Ilako, Muhenje, Kjaer, Isavwa, Kim, Chebet, DeCock & Weidle 2007:106-112). This study evaluated patients enrolled between 26 February 2003 and 28 February 2005, in a community clinic in Kibera, an informal settlement, in Nairobi, Kenya. The study concludes that the response to ART in this slum population was comparable to that seen in industrialised settings. With government commitment, donor support, and community involvement, it could be feasible to implement successful ART programmes even in extremely challenging social and environmental conditions.

Despite the rapid expansion of ART in SSA hopes are still not dashed on compromising quality of care and retention of patients on treatment. Bekker, Myer, Orrell, Lawn and Wood (2006:315-20) compared mortality, viral suppression and programme retention for three consecutive years at a public sector community-based ART clinic in a South African township. Data were collected prospectively from the establishment of services in October 2002 to the censoring date in September 2005. While further operational research is required into optimal models of care in different populations across SSA, these results

demonstrated that a single community-based public sector ART clinic could extend care to over 1 000 patients in an urban setting without compromising programme performance.

Family Health International (FHI 2004:349) suggested, that to improve adherence and patient retention on treatment, the following intervention strategies should be applied in ART programmes:

- educate and motivate patients
- provide basic drug information
- discuss the importance of adherence, timing of medication and drug interactions.

Other suggested strategies included: simplified drug regimens, tailor-made treatment matching the patient's lifestyle, using an adherence team, addressing patient-related issues, recruiting an adherence monitor, providing adherence promoting devices, using home-based care staff to promote adherence and apply the principles of directly observed therapy (DOT).

Tindyebwa et al (2005:175-176) studied ART programmes in many SSA countries. This report indicates that health practitioners and health facilities, whether for children or adults, were inadequately prepared to address the needs of HIV-infected children, adolescents and young people, particularly those who had been diagnosed recently. Also, knowledge and experience of service workers about ART patients' mental and psychosocial needs (including the need for adherence to ARVs) of adolescents and young people were limited.

1.3 THE RESEARCH PROBLEM

Paediatric patients receive free ART at the two health centres that participated in this study. Nevertheless, paediatric ART adherence remained ineffective (80.0%) in spite of free ARVs. Paediatric HIV/AIDS morbidity and mortality rates might not decrease unless

adherence rates of at least 95.0% are maintained throughout these patients' lives. As ARVs were supplied free of charge, factors other than ARVs' costs, must have influenced paediatric ART adherence rates. Healthcare workers' perceptions about these factors that could influence paediatric ART adherence rates were addressed in this study. Identifying such factors, and addressing them, might help to enhance the paediatric ART adherence rates, to the benefit of Nigeria's HIV positive children.

1.4 AIM OF THE STUDY

The aim of the study is to identify factors, excluding the cost of ARVs, influencing paediatric ART adherence in Nigeria. This study attempted to answer the broad question:
"What factors, according to health workers' perceptions, influenced ART adherence rates among children aged five and younger at two healthcare centres in Nigeria?"

1.4.1 Research purpose

The purpose of this study was to

- identify and describe the perceptions of healthcare workers on factors that influenced paediatric ART adherence, at two healthcare centres where ARVs were supplied free of charge
- make recommendations to healthcare authorities for addressing the identified factors, to enhance the paediatric ART adherence rates (if implemented) at the two participating healthcare centres, and possibly also at other sites.

1.4.2 Research questions

In order to attain the purpose of this study the following research questions were posed:

- What were the health workers' views regarding paediatric ART adherence in children who received free ARVs from the two participating health facilities in Nigeria?

- What were the health workers' views regarding the ART adherence patterns of children receiving free ARVs from the health facilities in Nigeria?

- What were the healthcare workers' views regarding the factors affecting children's ART adherence in the participating health facilities in Nigeria?

- What, according to the healthcare workers, could be done to improve adherence to ART among children (at your clinics specifically and in Nigeria generally)

1.5 SIGNIFICANCE OF THE STUDY

The results of this study could add to the existing body of knowledge regarding paediatric ART adherence in SSA in general and Nigeria in particular. Policy makers could consider the results of this study to improve paediatric ART adherence in Nigeria. Health workers could utilise the results of this study to improve the overall quality of care rendered to HIV positive children. If paediatric ART adherence could be enhanced, paediatric HIV/AIDS mortality and morbidity rates should decline. Moreover the spread of potentially ARV-resistant strains of HIV throughout the communities could be contained.

1.6 DEFINITIONS OF KEYTERMS

1.6.1 Adherence

The New Webster's Dictionary (2004:10) defines adherence as the action of adhering or attachment. Family Health International (FHI 2004:348) defines adherence as the term used to describe the patient's taking of prescribed drugs correctly in terms of dose, frequency and time. The Oxford Advanced Learners' Dictionary (2006:17) defines adherence as the fact of behaving according to a particular rule, or of following a particular set of beliefs, or a fixed way of doing something. This is differentiated from compliance which means the patient does what he or she has been told to do by the doctor/health worker. Shah (2007:55) defines adherence to medications as the extent to which a patient follows medical instructions. Shah (2007:55) did not see any difference between adherence and compliance with medications, but warns that this does not mean that the patient is only

a passive receiver of medical advice and not an active contributor to the treatment process. The Dorland's Illustrated Medical Dictionary (2007:32) defines adherence as the act or condition of sticking to something. In this study, adherence was used as the pattern of compliance of children with their prescribed ART regimens.

1.6.1.1 Paediatric ART adherence

In this dissertation the term paediatric ART adherence refers specifically to the ART adherence levels among children aged up to five years.

1.6.2 Anti-retroviral therapy

ART, according to the WHO (2006:9) refers to the delivery of ARVs as part of care interventions, including the provision of co-trimoxazole prophylaxis, the management of opportunistic infections and co-morbidities, nutritional support and palliative care. ART involves more than merely the prescription for ARVs. ART includes the ARVs as prescribed, at the correct times every single day of one's entire life, adhering to food prescriptions, and taking generally good care of one's health. ART also involves keeping follow-up clinic visits and maintaining available supplies of ARVs.

1.6.3 Anti-retroviral drugs (ARVs)

Tyndyebwa et al (2005:137) refer to ARVs as drugs that suppress HIV replication and therefore prevent disease progression. ARVs are medications for the treatment of infection by retroviruses, primarily HIV. The drugs do not kill the virus. However, they slow down the growth of the virus. When the virus is slowed down, so is HIV disease. When several such drugs, typically three or four, are taken in combination, the approach is known as HAART.
In this study, ARVs were used as medications to reduce the morbidity of children and improve their quality of life.

1.6.4 Acquired-immune deficiency syndrome (AIDS)

In children, Tyndyebwa et al (2005:93) assert that AIDS is an immunosuppressive effect of HIV infection characterised by diarrhoea, acute lower respiratory tract infections, septicaemia, acute suppurative otitis media, sinusitis, and failure to thrive.

In general, AIDS is a complex where one must have tested positive on an HIV test and have another disease that is known as “AIDS defining disease.” These diseases include yeast infections (candida), cervical cancer, kaposis sarcoma, tuberculosis, cytomegalovirus, and pneumonia (Tyndyebwa et al 2005:93; WHO 2006:8; FHI 2004:42).

All children on ART in this study had AIDS.

1.6.5 CD4 count

Tyndyebwa et al (2005:28) view the CD4 count as a measure of specific level of immune suppression - the measured level of a type of white blood cells that fight infections (CD4 cells or T-helper cells). In this study, CD4 counts were the laboratory measurements done to determine CD4 levels, as a routine part of ART.

1.6.6 Children

The Oxford Advanced Learners’ Dictionary (2006:245) defines children as young human beings who are not yet adults. Sometimes children are defined as being aged up to 12 but in other cases up to 18. Studies, quoted in this dissertation, refer to children as being up to 12 years of age. For the purposes of this study, children were regarded as young human beings up to 12 years of age.

However, the children participating in this study were only those up to five years of age.

1.6.7 Determinants

The New Webster's Dictionary (2004:260) defines determinants as the act of being decisive, a determining factor, or element. The Oxford Advanced Learners' Dictionary (2006:399) defines a determinant as a thing that decides whether or how something happens. The Dorland's Illustrated Medical Dictionary (2007:290) defines determinants as factors that establish the nature of an entity or event or to be bound, limited or fixed. In this study, the term determinants denote factors, including predictors of barriers or facilitators, influencing ART adherence in children.

1.6.8 Healthcare workers

The Oxford Advanced Learners' Dictionary (2006:691) defines healthcare workers as people who are involved in the service of providing medical care - also known as healthcare workers or healthcare professionals. In this study, the term healthcare workers was used to refer to nurses and pharmacists who were trained on adherence counselling and who provided these services within a family-centred model of comprehensive ART services at the two participating centres in Nigeria.

1.6.9 Highly active anti-retroviral treatment (HAART)

Tyndyebwa et al (2005:137) refer to HAART as a regimen of ARVs, usually combinations of at least three ARV drugs, potent enough to reduce viral replication and prevent the emergence of resistance for a significant amount of time.

In this study, all references to ART encompass HAART as well.

1.6.10 Human Immuno-deficiency Virus (HIV)

HIV is a virus that attacks the immune system, the body's natural defence system.

1.6.11 Infection

The Oxford Advanced Learners' Dictionary (2006:763) defines infection as the act or process of causing or getting a disease, or an illness that is caused by bacteria or a virus and that affects the body. The Dorland's Illustrated Medical Dictionary (2007:949) defines infection as an invasion and multiplication of micro-organisms or parasites in body tissues.

In this study HIV infection referred to the situation where an individual had been diagnosed as HIV positive, implying that the HI virus was depleting the person's immune system, making him/her susceptible to other infections.

1.6.12 Treatment

The New Webster's Dictionary (2004:1051) defines treatment as the act or method or manner of treating someone or something; medical or surgical care. The Oxford Advanced Learners' Dictionary (2006:1576) defines treatment as something that is done to cure an illness or injury, or to make somebody look and feel good. The Dorland's Illustrated Medical Dictionary (2007:1983) defines treatment as the management and care of a patient for the purpose of combating disease or disorder. In this study, treatment was referred to as using prescribed ARVs to suppress the progressive deterioration of the HIV positive child's immunity. ARVs achieve this by enabling the person's CD4 count to rise and viral load count to decrease. In this study, the term ART will be used to include HAART.

1.6.13 Views

The New Webster's Dictionary (2004:1097) defines views as what one can see from one's position, a painting or photograph of a scene, visual inspection, or an opinion or set of opinions. The Oxford Advanced Learners' Dictionary (2006:1640) defines views as personal opinions about something, an attitude towards something or a way of understanding or thinking about something. In this study, views were regarded as the perceptions of healthcare workers regarding factors influencing paediatric ART adherence.

1.6.14 Viral load

Tyndyebwa et al (2005:81) refer to viral load as the viral ribonucleic acid (RNA) in plasma and other body fluids, detected through HIV RNA assays. Viral load is an important measurement of the amount of active HIV in the blood of some one who is HIV positive.

In this study, viral load refers to the quantitative RNA tests used to determine the risk of HIV disease progression and to guide decisions for initiating ART.

1.6.15 Caregiver

In this dissertation the term caregiver refers to the person(s) primarily responsible for the day-to-day maintenance of the child on ART. The caregiver can be the biological parent/s, guardian/s or any other person primarily responsible for the child's upkeep and adherence to ART.

1.7 FOUNDATIONS OF THE STUDY

1.7.1 Meta-theoretical assumptions

Assumptions are statements that are accepted as true without verification (Polit & Hungler 2004:13). The assumptions underlying this study are explained in sections 1.7.1.1-1.7.1.3.

1.7.1.1 Ontological assumptions

Ontological assumptions are statements about human nature, society, nature of history and material phenomena, causality and intentionality (Mouton 1996:46).

- Patients on ART understand the nature of treatment and its outcomes
- Poor family backgrounds impact negatively on children's ART adherence rates.
- Family-centred AIDS care programmes improve adherence to ART among members of the family, including the children.

1.7.1.2 Epistemological assumptions

Epistemological assumptions relate to assumptions about the nature of knowledge and science or the content of truth and related ideas (Mouton 1996:123).

- The diverse views of healthcare professionals assist in shaping the future of ART.
- Factors, other than free supplies of ARVs, affect children's ART adherence rates.

1.7.1.3 Methodological assumptions

Methodological assumptions relate to the nature of research processes and the appropriate methods for investigating the phenomena of interest to the researcher (Mouton 1996:124). Qualitative research enables the researcher to investigate the views of healthcare workers regarding factors influencing ART treatment adherence and its determinants in children aged up to five**.** A decision to use FGDs was driven by the need to experience albeit in an artificial setting, the experiences, views and perceptions of the participants.

1.8 RESEARCH DESIGN AND METHOD

1.8.1 Research design

A descriptive qualitative research design was used in this study. These concepts will be elucidated in Chapter 3 of this dissertation.

1.8.2 Research setting

The study was conducted at two public health facilities, located in the western and northern parts of Nigeria. These health facilities hosted FHI's project to pilot a family-centred model of AIDS care, and ARVs were provided free of charge. Consequently these two sites were suitable for this study attempting to identify factors (excluding ARVs' costs) influencing paediatric ART adherence.

1.8.3 Research population

The research population of interest to the study comprised all healthcare workers providing care to paediatric ART patients in Nigeria. However, the costs and time required to reach such a population were beyond the reach of the researcher. Consequently the target population for this study included healthcare workers in Lagos and Kano states of Nigeria, providing ART services to children. The accessible population included all healthcare

workers involved in the provision of paediatric ART services at the two participating study sites providing family-centred care in terms of the Family Health International (FHI) pilot project. The concept of the research population will be explained in Chapter 3 of this dissertation.

1.8.4 Data collection procedure

Focus group discussions (FGDs) were used to identify the views of healthcare workers regarding factors influencing paediatric ART adherence. Healthcare workers who had been trained by FHI and were involved in the day-to-day conduct of adherence counselling for children receiving ART were selected to participate in FGDs in each of these two facilities. FGDs were used to elicit information from the respondents until the point of saturation had been reached. The study explored the views of the healthcare workers regarding factors influencing paediatric ART adherence (receiving free ARVs). The data collection procedure will be discussed in Chapter 3 of this dissertation.

1.8.5 Data analysis

The analysis of this qualitative data began in the field, during data collection, using the unstructured FGD. The framework approach for qualitative data analysis was used, because it reflected the original accounts and observations of the participants (healthcare workers). The concept of data analysis will be discussed in detail in Chapter 3 of this dissertation.

1.8.6 Ethical considerations

The researcher ensured strict compliance with ethical standards, relevant to protecting the rights of the respondents, institutions where data were collected and scientific integrity were maintained throughout the study. Approval was sought and obtained from both the state health authorities in Nigeria and the Department of Health Studies, University of South Africa (Unisa) before data collection commenced. Details of these will be presented in Chapter 3 of this dissertation.

1.9 SCOPE AND LIMITATIONS OF THE STUDY

Two public health facilities that focused on paediatric care and the family-centred approach to ART participated the study. Consequently the results of this study might not be generalisable beyond these two participating sites.

Only the views of the healthcare workers were studied. Caretakers, parents and/or guardians of children might have different views about paediatric ART. Children might also have different views. However, due to time limitations the views of parents/guardians/caretakers were not obtained. Permission to conduct interviews with children up to five years of age, could pose numerous ethical challenges, requiring months to be granted.

The results of this study cannot be generalised to children who use ARVs that are not supplied free of charge, nor to children's adherence to any other therapeutic regimens.

1.10 LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral

cART	combination Antiretroviral Therapy
CLWA	Children Living With AIDS
DFID	Department for International Development (United Kingdom)
DOT	Directly Observed Therapy
FHI	Family Health International
FGD	Focus Group Discussion
FMOH	Federal Ministry of Health
GHAIN	Global HIV/AIDS Initiative Nigeria
HAART	Highly Active ART
HIV	Human Immunodeficiency Virus
IBBSS	Integrated biological and behavioural surveillance survey
NACA	National Agency for the Control of AIDS
PEPFAR	President's Emergency Plan for AIDS Relief
PMTCT	Prevention of Mother to Child Transmission of HIV
RNA	Ribonucleic acid
SSA	sub-Saharan Africa
STI	Sexually Transmitted Infection
UN	United Nations
UNAIDS	Joint United Nations programme on HIV/AIDS
UNICEF	United Nations Children Emergency Fund
USA	United States of America
WHO	World Health Organization

1.11 STRUCTURE OF THE DISSERTATION

This dissertation is presented in five chapters, organised in the following order:

Chapter 1: Orientation of the study, covering the background information about the research problem, definitions of key terms, statement of the research problem, aim of the study, significance of the study, foundations of the study, research design and method, scope of the study and the structure of the dissertation.

Chapter 2: Literature review, addressing determinants of paediatric ART adherence, views of healthcare workers regarding paediatric ART adherence, patterns of paediatric ART adherence, strategies for improving paediatric ART adherence and treatment outcomes of children on ART. As limited literature sources could be traced about paediatric ART adherence, specifically about children up to five years of age, some studies referring to ART adherence among young people and adults have also been included in this literature review.

Chapter 3: Research design and methods, including sampling, population of the study, data collection approach and method, data analysis, trustworthiness of the study and ethical considerations of the study.

Chapter 4: Analysis, presentation and description of the research findings

Chapter 5: Conclusions, recommendations and limitations are presented in the final chapter.

1.12 SUMMARY

Chapter 1 of this dissertation presented the basic research problem for investigation: “What factors influence paediatric ART adherence in Nigeria?” The purpose of the study was to explore and describe the perceptions of healthcare workers on factors influencing paediatric ART adherence at two health facilities in Nigeria. A qualitative descriptive research design was used, employing FGDs to obtain information from trained healthcare workers.

The next chapter will review literature relevant to factors influencing ART adherence levels.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The previous chapter addressed the research problem, aim and significance of the study, definition of key concepts, foundations of the study, research design, measures of ensuring trustworthiness of the study, ethical considerations and the scope and limitations of the study. This chapter will focus on the review of relevant literature on ART adherence generally, and on factors influencing children's adherence rates specifically. Steele and Grauer (2003:27); Van Dyke, Lee, Johnson, Wiznia, Mohan, Stanley, Morse, Krogstad and Nachman (2002:1), indicate that literature on paediatric ART adherence appears to be less available than literature on adults' ART adherence.

This chapter will examine previous studies, covering the period 2002 to 2009 regarding:

- The definition of adherence
- Needs of children on ART
- Treatment adherence in children
- Factors influencing paediatric ART adherence
- Healthcare workers' views regarding paediatric ART adherence
- Patterns of paediatric ART adherence
- Strategies for improving paediatric ART adherence
- Treatment outcomes of children on ART

2.1.1 Adherence

Different definitions of adherence have been provided in section 1.6.1 of this dissertation. Adherence has been used in similar and in different ways by researchers, depending on the situation or the purpose of their research. For instance, in a cross-sectional study aimed at estimating the prevalence of paediatric ART non-adherence in Brazil (Wachholz & Ferreira 2007:S424), adherence was defined as the situation when the child had taken more than 80.0% of his/her prescribed medication during the 24-hour period preceding the interview. In another cross-sectional study (Elise, France, Louise, Bata, Francois, Roger & Phillipe 2005:498) in Code d'Ivoire, adherence was determined by a 1-month recall by the child or caregiver, with full adherence signifying no interruptions in the prior month. Yet, in another cross-sectional study in Uganda (Nabukeera-Barungi, Kalyesubula, Kekitiinwa, Byakika-Tusiime & Musoke 2007:123), adherence was defined as taking at least 95.0% of prescribed medication. In a multi-site study in USA (Marhefka et al 2004:323), adherence was defined as maintaining at least 90.0% pharmacy refill rates, which in this study, was significantly associated with virologic responses.

2.1.2 Needs of children on ART

In SSA the provision of paediatric ART is influenced by limited resources and capacities to provide effective ART services at the lower levels of healthcare. UNICEF (2005:7) reported a global picture where fewer than 5.0% of young HIV-positive children in need of ART, were indeed receiving it. This is in line with the estimated 6.5 million people said to be in need of treatment in low- and middle income countries by the end of 2004. This number of 6.5 million people included 660 000 children under the age of 15 years. The mid-2005 estimate of 970 000 people receiving ART in low- and middle-income countries (with an uncertainty range 840 000-1 100 000) translated to a coverage of 15.0% of people in need of treatment (Boerma, Stanecki, Newell, Luo, Beusenberg, Garnett, Little, Calleja, Crowley, Kim, Zanrewski, Walker, Stover & Ghys 2006:148).

Luo, Akwara, Ngongo, Doughty, Gass, Ekpini, Crowley and Hayashi (2007:179) asserted that globally in 2005, 8.0% of all infants born to HIV positive mothers received ARV

prophylaxis for PMTCT, up from 5.0% in 2004. Also, 11.0% of HIV positive children in need of ARVs received ART in 2005. Zachariah, Harries, Luo, Bachman and Graham (2007:687) reported that out of an estimated 4 million children in need of co-trimoxazole prophylaxis worldwide (HIV-exposed and HIV-infected), only 4.0% were receiving ART.

2.2 PAEDIATRIC ART ADHERENCE

Shah (2007:56) asserted that factors influencing ART adherence included regimen or medication related complexities, patient/family related issues and healthcare delivery system factors. Although numerous interventions to improve adherence had been investigated in developed as well as in developing countries, the majority of work in this area focused on ART adherence among adults. In order to facilitate adherence and improve paediatric ART outcomes, it is necessary to understand the factors influencing paediatric ART adherence and interventions that can improve these adherence rates (Shah 2007:58).

Kloos, Assefa, Adugna, Mulatu and Mariam (2007:1) shared the Ethiopian Ministry of Health's (MOH's) experiences on the spatial, temporal and demographic patterns of ART in Ethiopia. A total of 101 public hospitals provided ART services and treated 44 446 patients while 91 ART health centres treated 1 599 patients during December 2006. The number of patients who received ART doubled between February and December 2006 and the number of female patients, aged 15 and older, surpassed the number of male patients. This might be attributed to increased awareness about HIV/AIDS and the provision of free ART. Of 58 405 patients who had started ART in December 2006, 46 045 (78.8%) were adhering to treatment during that month.

Ellis and Molyneux (2007:261) reported their experiences of a 12 months' free ART programme for HIV-infected children in Malawi, a resource-poor country in central southern Africa with an estimated 91 000 HIV-infected children. This programme indicated that even in a resource-poor setting with only clinical monitoring available, children can feasibly and effectively be treated with ART. Lack of appropriate laboratory facilities, staff shortages and the absence of paediatric drug formulations, should not prevent commencement of paediatric ART in such settings. Ellis and Molyneux (2007:261)

reported that after one year of treatment monitoring of a cohort of 238 HIV-positive children in Malawi, 194 (81.5%) were alive and adhered to ART, 20 (8.4%) had died, 19 (8.0%) were lost to follow-up and 5 (2.1%) had been transferred to other health facilities.

2.2.1 Factors influencing paediatric ART adherence

To investigate rates and determinants of ART adherence among Italian children (Giacomet, Albano, Starace, de Franciscis, Giaquinto, Gattinara, Bruzzese, Gabiano, Galli, Vigano, Caselli & Guarino 2003:1398) an observational, cross-sectional multicentre study was conducted. Caregivers of HIV-positive children were interviewed. Socio-demographic, clinical and psychosocial characteristics of children were recorded. The results showed that 129 children (median age 96 months) were enrolled, of whom 94 (72.9%) were on ART. Twenty-one (16.0%) had omitted more than 5.0% of their total doses during the preceding four days and were considered non-adherent, because their ART adherence rates were lower than 95.0%. However, only 11.0% of caregivers reported that therapy had been administered consistently at the correct times. No significant difference was found between the child's age and the stage of HIV infection. Giacomet et al (2003:1402) concluded that adherence was a major problem among Italian children and that psychological rather than clinical or sociodemographic features and types of drugs were major determinants of ART adherence. Although this study was conducted in Italy, which might differ from SSA countries in many ways, it identified paediatric ART adherence challenges that might be similar to those encountered in the SSA region.

Aboubacrine, Niamba, Boileau, Zunzunegui, Machouf, Nguyen and Rashed (2007:741) conducted a cross-sectional study in Bamako and Ouagadougou in East Africa. The sample comprised 94 men and 176 women on ART. Data were collected through questionnaires and chart reviews. Logistic regressions were performed to isolate determinants of adherence. Overall, 58.0% of the patients were adherent, but there were differences in the levels of adherence according to country and treatment site. Socio-demographic factors were not associated with adherence. However, social characteristics such as having children, in Ouagadougou, or being a housewife and not planning to have a

child in the next year, in Bamako, were associated with adherence. Time on ART was negatively associated with adherence in both countries with adherence levels declining later in Bamako. Levels of adherence were inadequate particularly among patients who had been on ART for longer periods of time. Aboubacrine et al (2007:746) concluded that scaling up ART access must build in long-term infrastructures to support ART adherence for the rest of the patient's life.

Mukhtar-Yola, Adeleke, Gwarzo and Ladan (2006:141) noted that ART has resulted in declining morbidity and mortality rates from HIV-associated diseases in Nigeria, but concerns regarding access and adherence were growing. The paediatric ART adherence levels and the reasons for non-adherence among children, at Aminu Kano Teaching Hospital in Nigeria, were studied by Mukhtar-Yola et al (2006:141). They conducted a cross-sectional study, using a self-report tool among 40 children who had been on ART for at least six months. Thirty-two patients (80.0%) were reportedly at least 95.0% adherent to their medications. The most common reasons for non-adherence were running out of medicines, inaccessibility of medicines, and the inability to purchase more medicines due to financial constraints. As many as 85.0% of the paediatric patients took ARVs at the same time everyday, and scheduled appointments were kept by 87.5%. The social class of the patients did not significantly affect adherence levels. The level of adherence to ART was comparable to levels reported from other developing and developed countries. Thus Mukhtar-Yola et al (2006:144) maintained that the adherence level of paediatric patients at the teaching hospital appeared to be comparable to that of developing and developed countries, despite the fact that patients in Nigeria faced huge structural and economic barriers to access regular supplies of ARVs. Mukhtar-Yola et al (2006:144) concluded that expanded access to subsidised ARVs should improve adherence and consequently treatment outcomes for patients in resource-poor settings.

Veinot, Flicker, Skinner, McClelland, Saulnier, Read and Goldberg (2006:261) investigated HIV-positive youths' perceptions and experiences of ART, using a community-based, participatory approach to conduct a mixed methods study. Thirty-four qualitative, in-depth,

semi-structured interviews were conducted with HIV-positive youths (aged 12-24) in Ontario, Canada. The major themes that emerged from the analysis of the interviews, included treatment knowledge, confusion and skepticism. Some participants did not understand or believe in ART's effectiveness (Veinot et al 2006:263). Some youths did not feel that they had any choice about ART, and others did not feel ready to make such decisions (Veinot et al 2006:264). Difficulties in taking medications were related to social routine disruptions, feeling "different" and experiencing side effects (Veinot et al 2006:264). Many viewed ARVs' costs to be a barrier to treatment.

Wachholz and Ferreira (2007:S424; 433) conducted a cross-sectional study to estimate the prevalence of paediatric ART non-adherence in Porto Alegre in Brazil. A total of 194 child caregivers were interviewed. Non-adherence was reported when the child had reportedly taken less than 80.0% of the prescribed medication during the 24-hour period preceding the interview. Although, in Brazil, there is a treatment policy that guarantees free access to ARVs, this study uncovered that the general paediatric ART non-adherence rate was only 49.5%.

Nabukeera-Barungi, Kalyesubula, Kekitiinwa, Byakika-Tusiime and Musoke (2007:123) conducted a cross-sectional study of 170 children aged 2-18 years in Uganda. ART adherence was defined as taking at least 95.0% of prescribed medication. It was determined using three measures: a 3-day self-report by the caregivers, clinic-based pill counts at enrolment and home-based unannounced pill counts 2-3 weeks later. The 3-day self-reports indicated that at least 95.0% adherence was maintained by 89.4% (n=170) of the children. Using clinic-based pill counts, 94.1% (n=170) maintained at least 95.0% ART adherence rates compared to only 72% (n=164) by unannounced pill counts at their homes. When the primary caregiver was the only one who knew the child's serostatus, he/she was three times more likely to be non-adherent (p=0.02, OR 3.34, 95% CI 1.14-9.82). Those who had been hospitalised at least twice before starting ART were more likely to have at least a 95.0% adherence rate (p=0.02, OR 0.44, 95.0% CI 0.20-0.92). Nabukeera-Barungi et al (2007:130) concluded that the majority (about 75.0%) of children

had good adherence levels of at least 95.0%, when estimated by unannounced pill counts. Disclosing the child's HIV serostatus only to the primary caregiver and having been hospitalised only once or not at all were associated with poorer adherence rates. Nabukeera-Barungi et al (2007:130) recommended that parents and caregivers should be encouraged to disclose the child's status to at least one additional person before starting ART. Other strategies such as home visits, peer counselling and community support groups should be incorporated into ART programmes to enhance sustained ART adherence rates of at least 95.0% (Nabukeera-Barungi et al 2007:130).

Williams, Storm, Montepiedra, Nichols, Kammerer, Sirois, Farley and Malee (2006:e1745) examined the relationship of self-reported medication adherence to health, demographic, and psychosocial characteristics of children and their caregivers in USA. These researchers used data from an ongoing multicenter prospective observational study of long-term outcomes of HIV paediatric patients. Child and caregiver characteristics were evaluated for association with adherence via univariate and multiple logistic regression models. Williams et al (2008:e1748) noted that out of the 2 088 children and adolescents, 84.0% reported ART adherence rates of at least 95.0% over the preceding three days. The median viral load was approximately 10 times higher among non-adherent than among the adherent children, and the strength of this association increased with age. Factors associated with increased ART non-adherence rates (Williams et al 2008:e1751) included increasing age, female gender, detectable viral load, recent stressful life events, repeating a grade in school, self-assessment of adherence by the subject, and diagnosis of depression or anxiety. Having an adult other than the biological parent as the primary caregiver, using a buddy system to remember to take ARVs, higher caregiver education levels, previous adherence assessments, and taking antipsychotic medications were associated with improved adherence rates. After controlling for these characteristics, there was no significant association of adherence with race, knowledge of HIV status, medication burden, CD4 count, or ART regimens (Williams et al 2008:e1745). These authors suggested that child and family characteristics should be evaluated before the initiation of paediatric ARVs to identify those at higher risk of non-adherence. This will allow interventions to be initiated in good time (Williams et al 2008:e1753).

2.2.2 Healthcare workers' views regarding children's ART adherence

Ten medical workers' from two ART programmes in the USA, (Brackis-Cott, Mellins, Abrams, Reval & Dolezal 2003:254) completed questionnaires (five physicians and five registered nurses). They worked with perinatally HIV-infected children. The questionnaire examined worker-patient/family relationships The medical workers also participated in individual qualitative interviews regarding workers' views on paediatric ART adherence. Workers believed that the limited paediatric ART options available presented challenges to ART adherence (Brackis-Cott et al 2003:258). Reportedly most children were on complicated ART regimens and needed even more complex regimens for success in the future, posing greater challenges for sustained adherence levels. Although workers were able to identify several helpful communication strategies in theory, they were unable to consistently implement these in practice. Many families reportedly experienced financial, mental health and substance abuse problems. ART adherence challenges were influenced by additional HIV positive family members, and disclosure issues. Brackis-Cott et al (2003:252) concluded that ART adherence is a long-term, ongoing problem that is directly related to the child's family life, with workers playing an integral part in this struggle.

A multi-site study documented caregivers' regimen knowledge; barriers to adherence; and the relationships between adherence, regimen knowledge and barriers in the USA (Marhefka et al 2004:323). Predominantly female, African American parents and caregivers of HIV-infected children (n=51) completed the Treatment Interview Protocol (TIP), a brief, structured interview designed to assess regimen knowledge and barriers to adherence. TIP data were compared to information obtained from medical records and pharmacy refill histories. Of children, 49.0% were considered adherent, defined as at least a 90.0% refill rate, which was significantly associated with virologic response. Significant regimen knowledge deficits were observed among caregivers, and inaccurate identification of prescribed medications was significantly associated with adherence. Caregivers identified 21 barriers to adherence, and poor adherence was significantly related to the number of barriers reported. Results indicated that the TIP was a successful tool for identifying regimen knowledge, potential adherence barriers and adherence problems. Marhefka et al (2004:335) suggested that the TIP could be integrated into clinical practice as a quick,

effective tool to identify poor adherers and guide interventions and treatment decision making.

Although parents and caregivers might have the primary responsibility for their children's medication-taking, few studies have examined caregivers' psychosocial correlates compared to children's ART adherence rates. Marhefka, Tepper, Brown and Farley (2006:429) used a cross-sectional, descriptive study to examine the relationship between caregivers' psychosocial characteristics and paediatric ART adherence in the USA. Fifty-four caregivers of children with HIV completed demographic questionnaires, the Parenting Stress Index, the Brief Symptom Inventory, the Family Support Scale, and the Support Functions Scale. Adherence to ART was compared to children's 6-month pharmacy refill histories. Children and caregivers were primarily African American, urban, and poor (63.0% reported <$15,000 annual household income). Univariate analyses showed that an adherent classification (at least an 80.0% refill rate) was associated with shorter duration of ART, nondisclosure of the HIV diagnosis to the child, lower caregiver income levels, having a non-biologically related caregiver, and less caregiver psychiatric distress. In a multivariate logistic regression, the duration of the child's ART treatment, the child's HIV disclosure status, caregiver income, and caregiver psychiatric distress accounted for 63.0% of the variance in adherence (Marhefka et al 2006:433). These authors implicated caregivers' psychological distress as a predictor of children's ART adherence levels. Interventions that could reduce caregivers' stress levels, addressing the context within which HIV affected families struggle to meet the demands of their stressful lives, might improve paediatric ART adherence rates.

The relationship between children's and caregivers' perceptions of medication responsibility, disease knowledge, regimen complexity and ART adherence was assessed in the USA (Martin, Elliott-DeSorbo, Wolters, Toledo-Tamula, Roby, Zeichner & Wood 2007:61). For this 6-month longitudinal study, Medication Event Monitoring System (MEMS) data revealed adherence rates of 81.0% at time 1 and 79.0% at time 2. Only 8.0% (n=2) of child-caregiver pairs reported complete agreement regarding who held

responsibility for medication-related tasks. Patients' reported responsibilities for medication correlated with the children's ages, but not their regimen knowledge. Greater regimen knowledge among caregivers and fewer child-caregiver discrepancies about medication responsibilities predicted better ART adherence levels. Martin et al (2007:66) concluded that paediatric ART adherence was lower than 95.0% required for optimal viral suppression. Thus responsibilities for medication-related tasks should be clarified among family members, regimen knowledge should be emphasised and caregivers should avoid assigning treatment responsibilities to children prematurely (Martin et al 2007:66).

To assess the level of paediatric ART non-adherence and to identify the main problems faced by caregivers when giving medicines to children, caregivers completed questionnaires (Pontali, Feasi, Toscanini, Bassetti, De Gol, Nuzzolese & Bassetti 2001:466). The respondents were caregivers of children who took combination ART in Italy. Of the children 20.5% and 31.8% had missed at least one dose of ARV drugs in the three days preceding the assessment and since the previous visit (1-2 months earlier), respectively. The main problems reported by caregivers included too many medicines/pills; (34.0%); difficulties in swallowing many pills (29.5%); taking medicines at school or outside the home (27.3%); child resisting/refusing therapy/spitting out (25.0%); and food interactions (22.7%). The systematic review of more than 50 studies by Simoni, Montgomery, Martin, New, Demas and Rana (2007:e1371), also indicated that the correlates of adherence were grouped as those relating to medication, the patient, and the caregiver/family.

2.2.3 Patterns of paediatric ART adherence

The evaluation reports of paediatric ART adherence vary. In a multivariate analysis (Wachholz & Ferreira 2007:S425) the education of caregivers had borderline associations with treatment outcomes. Reportedly, institutionalised children and those taken care of by people with higher educational levels, reportedly had lower ART non-adherent rates.

Albano, Giacomet, De Marco, Bruzzese, Starace and Guarino (2007:765) compared the evaluation of caregivers' reports and physicians' judgements in Italy. This was done by using two parallel structured questionnaires administered to caregivers of 129 HIV-infected children and to their physicians in seven different Italian reference centres. The results indicated that adherence was a major problem but there were discrepancies between caregivers' reports and physicians' judgment. Interactions between physicians and caregivers on specific ART adherence issues should be addressed (Albano et al 2007:766). A similar study could not be traced in the SSA context.

Byrne, Honig, Jurgrau, Heffernan and Donahue (2002:151) compared families' and clinicians' perspectives regarding ART adherence in New York, USA. Interviews (in Spanish or English) were conducted with 42 HIV-positive children's families, Chart reviews and visual analogue scales (VAS) were also used. Adherence was high by traditional markers of prescriptions filled (100.0%), doses reported taken (97.0%), and appointments kept (88.0%). Clinicians estimated slightly, but not significantly, lower adherence rates than families using the VAS. Of the families, 64.0% reported barriers to adherence, and 30.0% reported strategies that differed from those in the general adherence literature. For the purpose of increasing the quality of paediatric ART, Fraaij, Rakhmanina, Burger and De Groot (2004:125) suggested the use of a therapeutic drug monitoring (TDM) tool to assess ART adherence. However these authors cautioned about practices of basing assumptions on plasma levels alone because aberrant plasma levels may also be the result of other factors such as changes in nutritional habits, drug-drug interactions, or changing gastric motility.

A cross-sectional assessment of ART adherence was conducted among a group of children in Abidjan, Cote d'Ivoire (Elise, France, Louise, Bata, Francois, Roger & Philippe 2005:498). These authors reported that adherence was determined by a 1-month recall by the child or caregiver, with full adherence signifying no ART interruptions during the prior month. One-third reported less than full adherence. Undetectable viral load was associated with full adherence in a subset of children with a P value <10.0% (P = 0.098). Compared to

children with full adherence, those with less than full adherence were significantly older and more likely to be taking efavirenz. These findings underscored the necessity of assessing and supporting children's adherence routinely in AIDS care institutions. Elise et al (2005:499) concluded that this study demonstrated a lower adherence rate than those reported in clinical records (84.0%). This finding emphasised the importance of developing a cheap, high performance, easy to use tool to measure paediatric ART adherence specifically in SSA settings.

Farley, Hines, Musk, Ferrus and Tepper (2003:211) assessed the utility of the MEMS system in monitoring paediatric ART adherence and compared this with other methods of adherence assessment in the USA. Perinatally HIV-infected children (n=26), being treated with three or more ARVs, and their caregivers were prospectively followed-up for six months. Adherence was assessed using MEMS monitoring of one ARV, pharmacy refill records of all ARVs, a caregiver self-report interview, a physician/nurse questionnaire, and appointment-keeping behaviour. Viral loads measured at the end of the 6-month period were compared with the various adherence assessment methods. Adherence rates for the MEMS-monitored medication ranged from 12.7% to 97.9% (median = 81.4%), and 11 of the participants (42.0%) had less than 80.0% adherence using this method. A MEMS adherence rate greater than 80.0% was associated with a viral load below the threshold of detection six months after enrollment ($p < .001$). Although not as robust, pharmacy refill rates for all ARVs were also associated with virologic responses. The highest specificity was attained when both MEMS and pharmacy refills were combined. Physician assessment of the ART adherence rate as well as appointment-keeping behaviours were associated with virologic responses, whereas caregivers' self-reports were not (Farley et al 2003:217). A similar study assessed the MEMS and caregivers' self-reports by VAS of adherence in a paediatric HIV outpatient clinic in Cape Town, South Africa. Muller, Bode, Myer, Roux and Von Steinbuchel (2008:257) reported that for the 73 children, the median adherence by MEMS was 87.5%; median caregiver reported adherence was 100.0%. MEMS and caregivers' reports differed in reporting excellent (>95.0%) adherence, with MEMS classifying 36.0% of subjects in this category, whereas caregiver reports classified 91.0%. Overall, 65.0% of children achieved virologic suppression after the study period.

MEMS adherence was significantly associated with virologic suppression. The highest specificity was obtained when adjusting the data for doses taken at the prescribed time (91.3%). No predictors for the differences between MEMS and caregiver reported adherence rates could be identified. Muller et al (2008:261) concluded that paediatric ART adherence rates to regimens in South Africa were not lower than in the developed world, yet not high enough to guarantee long-term treatment success. Caregivers' reports seemed to be unreliable in this setting. MEMS was a feasible and accurate measure of adherence for children on liquid drug formulations.

To examine the extent to which ART adherence is related to social and psychological variables, Gauchet, Tarquinio and Fischer (2007:141) gathered data from 127 patients (aged 18-65 years) at their quarterly consultation at Metz Hospital (France). Respondents completed self-report medication adherence scales, the Illness Perception Questionnaire (IPQ), the Beliefs about Medicine Questionnaire (BMQ), a French Value System Scale, a treatment satisfaction scale, and socio-demographic measures. Data analyses revealed significant associations between adherence rates and patients' beliefs about treatment, satisfaction with treatment, confidence in their physicians, some values ("other people," "god and children"), and duration of treatment and illness severity. The data suggested that patients' beliefs about treatment were based on the patients' relationships with their physicians. Furthermore, adherence seemed to be related to personal values. Gauchet et al (2007:148) reported that confidence in the physician, moderated partly through patients' beliefs about treatment, predicted adherence to the ART regimens.

2.2.4 Strategies for improving paediatric ART adherence

Specific interventions for improving paediatric ART adherence include improvement of ARV formulations, better counselling for children and their families, and tailoring of ART according to specific children's needs. Generalising these results should be done cautiously due to the small sample size and to the heterogeneity of the cohort (Pontali, Feasi, Toscanini, Bassetti, De Gol, Nuzzolese & Bassetti 2001:466). Youths might need support for managing treatment difficulties, such as side effects, social impacts, and

adherence (Veinot, Flicker, Skinner, McClelland, Saulnier, Read & Goldberg 2006:266). Developmentally appropriate, empowerment-based treatment education might be helpful for HIV-positive children. The availability of social programmes to provide treatment access might not guarantee awareness. Byrne, Honig, Jurgrau, Heffernan and Donahue (2002:151), suggested that paediatric ART adherence strategies depended heavily on family support and the resolution of disclosure issues within the households.

The relationship of self-reported ART adherence to health, demographic, and psychosocial characteristics of children and their caregivers in the USA was studied by Williams et al (2006:e1745). These results highlighted the importance of evaluating and supporting the family environment to optimise ART adherence rates. Wachholz and Ferreira (2007:S424), emphasised the need for close surveillance of paediatric ART adherence in order to evaluate the effectiveness of ART.

Berrien, Salazar, Reynolds and McKay (2004:355) conducted a study to determine whether home-based nursing interventions improved ART adherence rates in Connecticut in the USA. Of the patients, 67.0% (37 out of 55) and their caretakers participated. Participants were randomised to either standard care or the intervention trial. The intervention was designed to improve knowledge and understanding of HIV infection and ARVs and to modify adherence barriers. Both groups completed pre- and post-intervention questionnaires, assessing their knowledge and understanding of HIV, ARVs and adherence to ART. Adherence was estimated objectively from medication refill histories and subjectively from self-report scores. Berrien et al (2004:355) also inferred adherence from pre- to post-test plasma viral loads and CD4 cell counts. The knowledge score ($p = 0.02$) and medication refill history ($p = 0.002$) improved significantly in the intervention group. The adherence self-report scores improved, although not significantly ($p = 0.07$). Berrien et al (2004:355) did not observe statistical differences in CD4 cell counts or viral loads between the two groups. Thus they concluded that home-based nursing interventions helped HIV-positive children and their families to adhere to prescribed medication regimens.

A study was conducted to describe the approach used to promote ART adherence in the first primary care public sector ART project in South Africa (Coetzee, Boulle, Hildebrand, Asselman, Van Cutsem & Goemaere 2004:S27). These researchers conducted a prospective open cohort analysis, including all adult patients naive to previous ART who received ART in Khayelitsha, from May 2001. Patients were followed up till 31 July 2003. Plasma viral loads were determined at 3, 6, 12, 18 and 24 months after ART had been initiated, and CD4 cell counts 6-monthly. Kaplan-Meier estimates were determined for the cumulative proportions of patients surviving, and patients with viral load suppressions and viral load rebounds (Coetzee et al 2004:S29). A total of 287 patients used triple therapy. The probability of survival was 86.3% at 24 months. The median CD4 cell count gain was 288 cells/microliters at 24 months. Viral loads were less than 400 copies/ml in 89.2%, 84.2% and 69.7% of patients at 6, 12 and 24 months, respectively. The cumulative probability of viral rebound (two consecutive HIV-RNA measurements exceeding 400 copies/ml) after achieving an HIV-RNA measurement below 400 copies/ml was 13.2% at 18 months (Coetzee et al 2004:S29-31). These authors concluded that with a standard approach to patient preparation and strategies to enhance adherence, a cohort of patients on ART could be retained in a resource-limited setting in a developing country. These results could be enhanced if the ideas of Chesney (2003:169) and Cunningham, Naar-King, Ellis, Pejuan and Secord (2006:44) on accommodating psychosocial factors and individual differences in HIV positive children's care (Coetzee et al 2004:S29-31) could be integrated into the home-based care proposed. Chesney (2003:174) asserted that patient-healthcare worker collaborations could result in the selection of a lifestyle-tailored regimen characterised by convenient dosing, low pill burden, and tolerable side effects that would enhance adherence, effectiveness, and the patients' willingness to remain on ART for the rest their lives. Cunningham et al (2006:49) noted that a multi-systemic therapy (MST), combined with an empirically supported intensive home-based treatment approach, proven effective with other chronic paediatric conditions, would be useful in HIV patient care. However, D'Oulx, Chiappini, De Martino and Tovo (2007:426) emphasised the need for an expert in paediatric and adolescent HIV infection to take charge of paediatric patient management. This warning corresponds with that by Cunnigham et al (2006:49) that MST has various limitations, including the absence of follow-up information to determine whether treatment gains were maintained over time.

A study to demonstrate that participation in pill-swallowing training is associated with improved medication adherence as documented by routine pharmacy pill counts, was conducted by Garvie, Lensing and Rai (2007:e893) in the USA. These authors retrospectively reviewed charts of 23 HIV patients, aged 4-21. These patients were referred for pill-swallowing training by an experienced paediatric psychologist for swallowing difficulties with prescribed ARV regimens and/or the desire to change the child's regimen. Patient demographics, reason(s) for pill-swallowing training referrals, number of pill-swallowing training sessions required, ART adherence rates, CD4 cell counts, and viral loads were abstracted at baseline and at 3 and 6 months post-training. The modal number of sessions required to acquire the pill-swallowing skill was one session. Younger children (aged 4-5 years) required a median of two training sessions, while older children required three or more sessions. Improvements in adherence from baseline to six months post-pill-swallowing training completion were significantly related to improved CD4 cell counts and decreased viral loads. Garvie et al (2007:e898) observed that participation in pill-swallowing training was related to improved medication adherence at six months post-training. Subsequent improvements in related CD4 cell counts and viral loads were noted over time, significantly at six months post-intervention. These preliminary findings indicated that pill-swallowing training potentially was a successful time-limited, cost-effective intervention to improve ART adherence (Garvie et al 2007:e899).

A qualitative study seeking to integrate adherence to ART into children's daily lives in Belgium, was conducted by Hammami, Nostlinger, Hoeree, Lefevre, Jonckheer and Kolsteren (2004:e591). Eleven primary caregivers were interviewed to assess their children's adherence and influencing factors. Adherence to treatment was assessed using caregivers' self-reports and laboratory results. Content analyses for common items were performed, and statements of adherent and less-adherent patients were compared. Three main factors influenced adherence. Adherent patients were found to internalise the medical information to a greater extent than less adherent patients. Adherent patients showed stronger motivation to adhere to the medical regimen on the basis of personal cost-benefit analyses, implying that perceived benefits outweighed the perceived costs or difficulties

experienced. Adherent patients developed greater problem-solving capacities, such as ways of dealing with practical complications of medication intakes. These interviews also revealed that knowledge, motivation, and capacities evolved in progressive ways, related to individual stages of coping with HIV. Hammami et al (2004:e591) suggested that coping with HIV and establishing good adherence might be interrelated. Caregivers who accepted the disease might be more likely to internalise the received information and thus develop a stronger motivation to fight for the child's life. Problem-solving skills sustained this adherence, and medication became a priority in the adherent caregivers' daily lives. On the contrary, less-adherent caregivers might be situated at less advanced stages of the coping process. Thus, tailor-made approaches, adapted to the individual's HIV-related coping strategies, need to be developed to improve paediatric ART adherence.

Havens (2003:269) explained that improving paediatric ART adherence required that practitioners with paediatric ART experience should be involved in all ART decisions. ART adherence is critical to regimen success and optimal treatment requiring careful use of potent combinations of drugs, with attention to adherence, palatability, toxicity, and pharmacokinetics. ART requires life-long therapy to attain durable suppression of HIV replication and prevent or reverse HIV-related symptoms or immune system dysfunctions. Combination therapy with three or more ARVs is widely recommended for treatment of children. While potent regimens can initially reduce virus loads to below quantification limits in the majority of persons, 30.0%-80.0% of children will have regimen failures and the return of detectable plasma virus within one year (Havens 2003:269).

Pontali (2005:137) asserted that the treatment ART requires sustained adherence to maintain efficacy. Paediatric ART adherence could present challenges for the children and for their caregivers and healthcare workers. Pontali (2005:139) pointed out that many factors could affect ART adherence including: factors related to the patient and his/her family; drugs/medications; and the healthcare system. Pontali (2005:141) remarked that different strategies could be employed to tackle specific obstacles identified in these three groups of factors to facilitate adherence. Among the key interventions, centred on the

patient and his/her family, are the tailoring of the ART regimen to the daily activities of the child and his/her family, and the implementation of an intensive education programme on adherence for the child and the caregiver, prior to starting ART (Pontali 2005:143). Specific medication-related problems (depending on drug pharmacokinetic and pharmacodynamic properties) taste, palatability and food interactions cannot be solved solely by clinicians or by families. Greater commitments of the pharmaceutical industry are needed, and innovative solutions have to be identified by clinicians in partnership with drug manufacturers. Furthermore, Pontali (2005:147) asserted that the development of an 'adherence strategy/programme' can be recommended to all paediatric HIV institutions. Pontali (2005:147) noted that most interventions included in such programmes could be easily implemented, but they require trained and committed staff members (and institutions), and time to be spent with patients and their caregivers.

The use of directly observed therapy (DOT) as an ART adherence tool has been advocated. A retrospective chart review by Purdy, Freeman, Martin, Ryder, Elliott-DeSorbo, Zeichner and Hazra (2008:158) identified five patients with vertically acquired HIV and plasma HIV viral load rebounds or non-responses on stable HAART regimens. They followed a period of DOT in a clinic or hospital setting with serial viral load measurements. Four participants had virologic responses (mean decline 1.15 log10) after DOT. A response to HAART could be seen, despite ARV resistance, using DOT. Treatment-experienced patients who are apparently unresponsive to HAART might be non-adherent even with reassuring adherence measures. A period of clinic-monitored DOT might allow diagnosis of non-adherence, discussion of medication barriers, and avoidance of unnecessary medication changes (Purdy et al 2008:158). The result of Purdy et al's (2008:164) study showed that treatment-experienced patients could experience virologic responses with DOT without changes in their ART regimens.

Psychosocial factors have been identified as contributing factors to the failure of children to adhere to ART. Mellins, Brackis-Cott, Dolezal and Abrams (2004:1035) suggested that efforts to improve children's adherence to complex regimens required addressing

developmental, psychosocial and family factors. This study examined biomedical factors, child psychosocial and caregiver/family factors influencing adherence to ART in perinatally HIV-infected children (Mellins et al 2004:1036). Seventy-five children (aged 3-13) on ART, and their primary caregivers were recruited from two urban paediatric HIV programmes in the USA. A battery of psychological assessments and self-report adherence data were collected from all caregivers and 48 children. Of the caregivers 44.0%, and of children 56.0%, reported having missed doses of medication in the past month. Families in which the caregiver or child reported missed doses (non-adherent) were compared with families who reported no missed doses (adherent). In univariate analyses, non-adherence was significantly associated with older child age ($P < 0.05$), worse parent-child communication ($P < 0.017$), higher caregiver stress levels ($P < 0.002$), lower caregiver quality of life ($P < 0.003$) and worse caregiver cognitive functioning ($P = 0.033$). Borderline significance was associated with increased child responsibility for medications ($P < 0.07$), HIV disclosure to the child ($P < 0.07$) and child stress levels ($P < 0.08$). In logistic regressions controlling for age, caregiver/family factors were the most strongly associated with non-adherence, including worse parent-child communication ($P < 0.03$), higher caregiver stress ($P < 0.01$), less disclosure to others ($P < 0.05$) and quality of life ($P < 0.01$) (Mellins et al 2004:1035).

Rueda, Park-Wyllie, Bayoumi, Tynan, Antoniou, Rourke and Glazier (2006:1) supported the view that patient support and education interventions improved ART adherence. Interventions targeting practical medication management skills, those interventions administered to individuals versus groups, and those interventions delivered over 12 weeks or more were associated with improved adherence outcomes. This evidence came from a systematic search of electronic databases from January 1996 to May 2005. The populations studied ranged from general HIV-positive populations to studies focusing exclusively on children, women, Latinos, or adults with a history of alcohol dependence, to studies focusing almost exclusively on men. Study interventions included cognitive behavioural therapy, motivational interviewing, medication management strategies, and interventions indirectly targeting adherence, such as programmes directed at reducing risky sexual behaviours. Ten studies demonstrated beneficial effects of the interventions on adherence. The researchers found that interventions targeting practical medication

management skills, those administered to individuals versus groups, and those interventions delivered over 12 weeks or more were associated with improved adherence outcomes. They also found that interventions targeting marginalised populations such as women, Latinos, or patients with a past history of alcoholism were not successful at improving adherence. The researchers were unable to determine whether effective adherence interventions were associated with improved virological or immunological outcomes. Most studies had several methodological shortcomings leaving them vulnerable to potential biases. Thus, the researchers suggested a need for standardisation and increased methodological rigour in the conduct of adherence trials (Rueda et al 2008:1).

Van Oosterhout, Kumwenda, Hartung, Mhango and Zijlstra (2007:1241) shared the experience of the Queen Elizabeth Central Hospital (QECH) in Blantyre (Malawi), where free ARVs provided to clients improved programme quality and reduction in ART defaulters. The ART clinic of QECH was established as a fee-paying clinic in 2000. Van Oosterhout et al (2007:1242) reported that in 2004, a successful transition to free-of-charge ART provision was made with the introduction of Malawi's national ART scale-up programme. Despite the human resource crisis in the healthcare system, remarkable improvements in the quantity and quality of care, a reduction of defaulters, favourable ART outcomes and better access to ART for the poor, women and children were achieved. The programme was, however, hit hard by the shortage of ART staff in relation to the ever-expanding patient population (Van Oosterhout et al 2007:1245).

Rigorous ART adherence is necessary to achieve and maintain undetectable viral load levels. The study by Reddington, Cohen, Baldillo, Toye, Smith, Kneut, Demaria, Bertolli and Hsu (2000:1148) interviewed the caregivers of HIV-infected children in Massachusetts, USA. They were questioned about their experiences with the administration of ARVs, opinions regarding medication-related issues and the potential usefulness of interventions to improve adherence. In the 90 caregiver interviews, 78.0% of the children were taking three or more medications, 17.0% missed a dose in the previous 24 hours and 43.0% missed at least one dose in the previous week. Children whose caregivers reported no

missed doses in the previous week (adherent) were more likely to have an HIV viral load <400 copies/ml (50.0% versus 24.0%, P = 0.04). Non-adherent caregivers (who reported one or more missed doses in the previous week) were more likely than adherent caregivers to agree with a statement that full adherence is impossible (44.0% versus 12.0%, P = 0.001) and expressed the need for more help with medication administration (26.0% versus 6.0%, P = 0.02). They were less likely to have informed the school or day-care centre about the child's HIV infection (42.0% versus 67.0%, P = 0.05) and were more concerned about the child's teachers and friends finding out that the child was HIV-positive (54.0% versus 31.0%, P=0.05). Out of 10 potential interventions, 6 were rated by the majority of respondents as being "very helpful"; better tasting medications (81.0%); longer dosing intervals (72.0%); medications that did not require refrigeration (63.0%); access to 24-hour telephone advice (62.0%); a follow-up call from a healthcare worker (57.0%); and a pill organiser (56.0%). Caregivers' perceptions indicated that adherence was difficult or that they were concerned about the loss of their privacy. These perceptions might have affected their abilities to adhere to complicated medication regimens. Caregivers felt that the most helpful interventions would be modifications to improve the convenience and palatability of medications and increased access to medical advice (Reddington et al 2000:1148).

Simoni, Frick, Pantalone and Turner (2003:185) evaluated four randomised controlled trials conducted with adequate methodological rigour. The findings of these studies included some effects of pharmacist-led individualised interventions, cognitive-behavioural educational interventions based on self-efficacy theory, and cue-dose training when combined with monetary reinforcement. They noted that 39 ongoing federally funded studies, offering superior methodological sophistication, included some innovative strategies, such as the use of handheld devices, two-way pagers, and alarmed medication vials, along with enhancement of social and emotional support (Simoni et al 2003:191). In their study to investigate nurses' perceptions about Botswana patients' ART adherence Kip, Ehlers and Van der Wal (2009) made recommendations for improving adherence. These include: provision of means of transport to enhance follow up care, mobile clinic services, telephonic contact tracking, use of peer adherence counsellors (especially, in every village), and improved quality of care, especially, record keeping, health education

and counselling services.

2.3 TREATMENT OUTCOMES OF CHILDREN ON ART

Shah (2007:55) maintained that ART is effective in suppressing HIV replication, decreasing morbidity and mortality associated with HIV and improving the quality of life in adults as well as in children. However, concerning ART, it needs to be emphasised that “drugs don't work in patients who don't take them”. Optimum ART adherence is critical for successful outcomes.

Few sources are available on the outcomes of paediatric ART in the developing world. In a study by Zhang, Haberer, Zhao, Dou, Zhao, He and Cao (2007:594), 83 children were followed prospectively in China from July 2005 to August 2006. These children received zidovudine/stavudine plus lamivudine plus nevirapine/ efavirenz. Of the children, 51 were ART naive at enrolment, and 32 were ART experienced. After 12 months, these children’s median weights increased by 0.3 weight for age z-score, median CD4 count increased from 116 to 340 cells/mm ($P < 0.0001$), and median viral load decreased from 5.53 to <2.60 log10 copies/mL ($P < 0.0001$) in the previously ART-naive children. In the ART-experienced children, the median CD4 counts increased from 193 to 318 cells/mm ($P = 0.13$), despite few observed changes in the median viral loads (4.85 to 4.58 log10 copies/mL; $P = 0.83$). The viral load was <400 copies/mL in 55.0% of the previously ART-naive children and in 16.0% of the ART-experienced children. Weight and CD4 cell counts improved, and more than half of the previously ART-naive patients had undetectable viral loads after one year. Zhang et al (2007:598) admitted that treatment of paediatric patients in developing areas was challenging, but the experiences in China indicated that children responded to ART (Zhang et al 2007:598).

Using a fixed-dose combination of Stavudine+lamivudine+nevirapine ('Triomune') as the first-line regimen in the scaling up of ART for HIV-infected patients in Malawi, TRSRMH (2007:511) noted that split tablets were given to children with doses according to body

weight. Transactions of the Royal Society of Tropical Medicine and Hygiene (TRSRMH 2007:514) reported that by March 2006, a total of 46 702 patients had been started on ART, of whom as many as 2 718 (5.8%) were children aged <15 years. In a subset of 935 children, comprising 486 boys and 449 girls, 1.5% aged less than one year, 26.0% were aged 1-4 years, 39.0% were aged 5-9 years and 33.0% were aged 10-14 years. Between July and September 2005, 7 905 patients started ART, comprising 7 469 adults and 436 children. Six-monthly cohort outcomes, censored on 31 March 2006, showed significantly more children to be alive and significantly fewer children dead or defaulted compared with adults. Between January and March 2005, 4 580 patients started ART, comprising 4 347 adults and 233 children. Twelve-month cohort outcomes, censored on 31 March 2006, showed significantly more children to be alive compared with adults (TRSRMH 2007:514). The results of this national study should encourage other programmes to invest in ART for children and particularly to monitor their treatment outcomes (TRSRMH 2007:515).

Despite the rapid expansion of ART in SSA, there are few studies using longitudinal data describing programme performance during rapid scale-up projects. Bekker, Myer, Orrell, Lawn and Wood (2006:315) compared mortality, viral suppression and programme retention over three consecutive years of a public sector community-based ART clinic in a South African township. Data were collected prospectively from the establishment of services in October 2002 to the censoring date in September 2005. Viral load and CD4 counts were monitored at four monthly intervals. Community-based counsellors provided adherence and programme support. Bekker et al (2006:315) reported that during the study period, 1 139 ART-naive patients received ART (161, 280 and 698 in the first, second and third years respectively). The median CD4 cell count was 84 cells/microl (interquartile range (IQR) 42-139), 89 cells/microl (IQR 490-149), and 110 cells/microl (IQR 55-172), and the proportions of patients with WHO clinical stages 3 and 4 were 90.0%, 79.0% and 76.0% in each sequential year respectively. The number of counsellors increased from 6 to 28 and the median number of clients allocated to each counsellor increased from 13 to 33. The overall loss to follow-up was 0.9%. At the date of censoring, the Kaplan-Meier estimates of the proportion of patients still on the programme were 82.0%, 86.0% and 91.0%, and the proportion that were virally suppressed (< 400 copies/ml) were 100.0%,

92.0% and 98.0% for the 2002, 2003 and 2004 cohorts respectively. While further operational research would be required into optimal models of care in different populations across SSA, Bekker et al (2006:319) demonstrated that a single community-based public sector ART clinic could extend care to over 1 000 patients in an urban setting without compromising programme performance.

Eley, Nuttall, Davies, Smith, Cowburn, Buys and Hussey (2004:643-6) reported on the early response of children to HAART in a South African tertiary referral hospital, where children were followed up at 4-weekly intervals. Monitoring included initial and yearly viral load measurements, baseline and six-monthly CD4 counts and four-weekly adherence checks. Between August 2002 and June 2003, 80 children were enrolled in the programme, representing a follow-up period of 23.9 patient-years. Seventy-five children had severe clinical disease and/or severe immune suppression. The response of children who had received HAART for at least six months (n=17) was assessed. There was no change in the mass z-score ($p = 0.11$) or in the length z-score ($p = 0.37$), but a significant increase in CD4 count ($p < 0.0001$) during the first six months of therapy. Six-monthly viral loads were available for 12 children. There was a significant drop in viral load ($p = 0.001$) and nine achieved undetectable levels after six months' ART. Most children achieved at least 85.0% adherence rates. By June 2002, 67 children (84.0%) were relatively well, one had B-cell lymphoma, seven (8.8%) had died, four (5.0%) were lost to follow-up and one had withdrawn from the programme. Out of 57 children who had completed three months' HAART, 12 had been admitted to hospital amounting to a total of 17 times for infectious complications. There were no severe drug reactions. Three out of seven mothers on HAART received treatment through the programme. These initial results suggested that many HIV-infected children in the public sector could benefit from ART. However, both ambulatory and inpatient facilities were required to manage these children comprehensively (Eley et al 2004:643-6).

A study demonstrated the durability of both clinical and biological responses to ART in African children. Survival and immuno-virological responses were assessed by Rouet,

Fassinou, Inwoley, Anaky, Kouakoussui, Rouzioux, Blanche and Msellati (2006:2315-9) for 78 children in Abidjan (Cote d'Ivoire). These children were enrolled on ART programmes from October 2000 till September 2004. Initial ART regimens consisted of two nucleoside reverse transcriptase inhibitors with either nelfinavir (NFV) or efavirenz (EFV). For the comparison of immunological and virological responses, CD4 cell counts and HIV-1 RNA viral loads were assessed by performing time-point specific and longitudinal data analyses. At baseline, the median CD4 cell percentage was 7.5% and the median HIV-1 RNA viral load was 5.37 log10 copies/ml. The survival probability was high (0.86 at month 42; 95% confidence interval, 0.77-0.92) with no difference according to whether the ART regimen contained NFV or EFV. At 36 and 42 months of follow-up, an immune recovery was observed with median CD4 cell percentages reaching 23.1% and 24.8%, respectively, with no difference according to the ART regimen (longitudinal data analysis). At the same time, sustained viral suppression was also obtained, with undetectable viral loads achieved in 46.5% and 45.0%, respectively, regardless of the type of ART regimen. Rouet et al (2006:2318) concluded that durability of both clinical and biological responses to ART could be sustained in African children. As in western countries, ART prolonged the survival of HIV-1-infected children (Rouet et al 2006:2318).

In children, reported adherence predicts the virologic response to ART and is a useful measure of adherence. Van Dyke, Lee, Johnson, Wiznia, Mohan, Stanley, Morse, Krogstad and Nachman (2002:1) found evidence that ART adherence was associated with virologic response. Full adherence and non-full adherence were defined as missing no doses and missing at least one dose, respectively in the last three days before the researchers' visits to the study sites. Adherence data from study week 48, or the most recent study visit, were available for 125 children (week 48 for 109 children). Overall, 70.0% of children reported full adherence and 30.0% reported non-full adherence. Adherence did not differ by treatment regimen, age, or the child's knowledge of his or her HIV-positive status. There was a suggestion that adherence was less for white than non-white children (40.0% versus 73.0% full adherence) but did not differ between black and Hispanic children. Rates of full adherence rates were 82.0% for d4T, 79.0% for 3TC, 83.0% for nevirapine, 84.0% for ritonavir, and 68.0% for nelfinavir. Despite similar rates of full

adherence, difficulties with taking specific medications were reported most frequently for ritonavir and nelfinavir. These included poor taste, patients' refusal, and scheduling problems. Van Dyk et al (2002:6) concluded that self-reported adherence, when collected in a standardised manner, could be a useful measure of medication-taking behaviour predicting the virologic reponses to ART.

The use of the combination of at least three different ARV drugs for the treatment of HIV-1 infection, has greatly improved the prognosis for HIV-1-infected patients. Van Heeswijk, Veldkamp, Mulder, Meenhorst, Lange, Beijnen and Hoetelmans (2001:201) provided evidence for the efficacy of a combination of a protease inhibitor (PI) plus two nucleoside analogue reverse transcriptase inhibitors established over three years. However, virological treatment failure had been reported in 40-60.0% of unselected patients within one year after initiation of a PI-containing regimen. This observation might be attributable to the poor pharmacokinetic characteristics of the PIs. Given as a single agent the PIs could have several pharmacokinetic limitations; relatively short plasma-elimination half-lives and a modest and variable oral bio-availability. The latter, for some of the PIs, could be influenced by food. To overcome suboptimal pharmacokinetic properties, high doses (requiring large numbers of pills) must be ingested, often with food restrictions, complicating adherence to the prescribed regimen. Positive drug-drug interactions could increase the exposure to the PIs, allowing administration of lower doses at reduced dosing frequencies with fewer dietary restrictions. In addition to increasing the potency of an ARV regimen, combinations of PIs might enhance patient adherence, contributing to a more durable suppression of viral replication (Van Heeswijk et al 2001:220). In general, Van Heeswijk et al (2001:220) advised that ART should be individualised and supported by clinical data regarding safety and efficacy, keeping in mind alternative options where treatments fail.

Children with HIV Antibiotic Prophylaxis (CHAP) participated in a randomised placebo-controlled trial of cotrimoxazole prophylaxis in Zambia between 2001 and 2003. Walker, Ford, Mulenga, Thomason, Nunn, Chintu, Gibb and Bangsberg (2008:1) provided evidence

that cotrimoxazole was associated with significant mortality reduction. In a secondary analysis the researchers used the Cox regression models to estimate the association between adherence measured by bottle weights (measurement of the amount of study medication taken between visits, calculated by comparing bottle weights from the previous study visit to the current study visit) and caregivers' reports and subsequent mortality in children surviving more than 28 days (n=496; 153 deaths). Adherence was high and similar in both cotrimoxazole and placebo groups; adherence from bottle weights was 100.0% at 71.0% of visits, while caregivers reported 100.0% adherence at 79.0% of visits. Every 10.0% lower adherence to cotrimoxazole or placebo measured by bottle weights was associated with a 10-11.0% increase in mortality risk. These effects remained after adjustment for baseline predictors of survival and for current and recent changes in primary caregivers. However, the caregivers' reported adherence rates were not associated with survival. Walker (2008:7) noted that adherence to active and placebo medication was strongly associated with survival among HIV-infected children in Zambia.

Outcome differences between orphaned and non-orphaned children receiving ART, (Nyandiko, Ayaya, Nabakwe, Tenge, Sidle, Yiannoutsos, Musick, Wools-Kaloustian & Tierney 2006:418) were investigated in a retrospective review of prospectively recorded electronic data at nine HIV clinics in western Kenya. The population comprised 279 children on ART enrolled between August 2002 and February 2005. The main studied variables were orphan status, CD4 counts, sex- and age-adjusted height (HAZ) and weight (WAZ) z scores, ART adherence, and mortality. Nyandiko et al (2006:424) concluded that it was feasible to provide ART to children in resource-poor settings in SSA. Children treated with ART within the cohort showed significant improvements in CD4 cell counts, especially during the initial 30 weeks of therapy, and substantial weight gains, at least in developmental lags present prior to the initiation of ART. These findings suggested that ART might only be partially capable of reversing significant developmental lags in the HIV-positive paediatric population. Findings of this study also showed that drug adherence was high, responses to therapy were independent of orphan status, and mortality was low, although substantial numbers of patients were lost to follow-up services (Nyandiko et al 2006:424).

2.4 SUMMARY

This chapter reviewed literature relevant to children's adherence to ART and the determinants of paediatric ART adherence.

Determinants of treatment adherence in children with HIV included

- Children being aware of their HIV status
- Children receiving drugs from biological parents or relatives
- Social characteristics such as having children or being a housewife and not planning to have a child in the next year.
- Running out of medicines and the inability to procure more ARVs due to financial constraints.
- Non-availability and inaccessibility and high costs of medicines
- Lack of understanding or disbeliefs in ART
- Lack of choice and feeling emotionally unprepared to take ART
- Difficulties taking ART due to drug side effects, too many pills/medicines, difficulty swallowing pills, taking medicines at school or out of home, and food restrictions
- Disruptions in social routines
- Children cared for in family environment rather than institutional settings.
- Lack of disclosure of HIV status
- Increasing age in years
- Female gender
- Detectable HIV viral load
- Occurrence of recent stressful life events

- Repeating a grade in school
- Self assessment of adherence by the subject
- Diagnosis of depression or anxiety
- Families struggling with poverty, mental health and substance use problems, additional use problems, additional HIV-positive family members and disclosure issues.
- Regimen knowledge deficits and inaccurate identification of prescribed medicines
- Duration of ART
- Higher caregiver income level
- Higher educational status of caregivers
- High child-care giver discrepancies about medication responsibility

Strategies for improving medication adherence and paediatric ART outcomes included:

- Improvement of ARV formulations
- Better counselling for children and their families
- Tailoring of ART according to specific children's needs
- Support in managing treatment difficulties
- Empowerment based treatment education
- Close surveillance of paediatric ART adherence
- Home-based nursing interventions
- Integration of individual differences in paediatric care into home-based care

- Selection of patients' lifestyle tailored regimens
- Pill swallowing training
- Use of practitioners with paediatric ART experience
- Improvement in the quantity and quality of care

The next chapter will present the research methodology adopted to study healthcare workers' perceptions about factors influencing children's ART adherence rates.

CHAPTER 3

RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

This chapter presents the research design and methods utilised in the study. Data were collected using unstructured descriptive FGDs, held in Lagos and Kano, respectively. The study followed a qualitative research paradigm.

3.2 RESEARCH DESIGN

A qualitative paradigm was adopted for this study. Stommel and Wills (2004:442) defined qualitative research as research that focuses on interpretive, non-numerical, narrative interpretations, and does not emphasise quantitative measurements at all.

This study required a rich and in-depth understanding of the perceptions of healthcare workers about factors influencing paediatric ART adherence (of children under five) in health facilities in Nigeria. The qualitative research paradigm was also chosen for this study because of its heuristic value, or its usefulness as a tool for exploration related to knowledge development. It often informs clinical practice by raising questions and providing ideas for improving quality of care and prompting additional research activities.

Stommel and Wills (2004:178) maintained that the main characteristics of qualitative research include that: qualitative research attempts exploration in a “naturalistic” way, under uncontrolled conditions. Its goal is to understand behaviour or actions within their

naturally occurring contexts. It focuses on behavioural or meaningful action variables only. It has a tendency to focus on smaller samples. It has preference for open-ended, non-standardised, reactive data collection procedures. It is oriented toward completeness of description. It is open-ended to inquiry (reactive to preliminary results). It emphasises the uniqueness of individuals or special population groups, preferring narrative summaries or descriptions to measurements.

These characteristics are appropriate for this study because they demonstrate the relevant study strategy for exploring the views of healthcare workers through focus group discussions (to the point of redundancy or saturation). However, Stommel and Wills (2004:291) concluded that although qualitative research is indispensable, it can be criticised for placing too much trust in the credibility and integrity of the individual researcher. Research methods that produce results that cannot be replicated by other researchers under similar circumstances, might not meet the standards of objectivity.

A descriptive research design was used in this study. Polit and Beck (2004:528) defined descriptive research as studies having as their main objective the accurate portrayal of the characteristics of persons, situations, or groups. Thus, descriptive research summarises the status of some phenomena of interest as they exist, without introducing changes. The use of a descriptive research design for this study was justified on the basis of the flexibility of the design in promoting in-depth descriptions of the views of healthcare workers regarding paediatric ART adherence.

Descriptive research designs, when compared to the formal measurement models used for quantitative studies, appear to lack rigour and objectivity. However, it would be erroneous to conclude that clinical research can “do without” the flexible methods provided by qualitative research approaches (Stommel & Wills 2004:291). In the current study the descriptive design provided a platform for the participants to present their views regarding paediatric ART adherence, to the point of saturation, or the point whereby they had nothing else to contribute to the research question.

3.3 RESEARCH METHODS

3.3.1 Population, sample and sampling

3.3.1.1 Population

Stommel and Wills (2004:297,441) defined a population as any universe of subjects, cases, units, or observations. Polit and Beck (2004:534) defined a population as the entire set of individuals (or objects) having some common characteristic(s); sometimes referred to as the universe. The population of this study comprised the healthcare workers in Nigeria involved in providing ART to children under five.

The target population, according to Stommel and Wills (2004:444), refers to the population of all potential study units that meet the study inclusion criteria in which the researcher is interested. Polit and Beck (2004:537) defined a target population as the entire population in which the researcher is interested and to which he or she would like to generalise the results of a study.

A target population relates to the accessible population, which is the study population defined in terms of geographic location, institutional affiliation, or study unit characteristics to which the researcher has access, given the available resources (Stommel & Wills 2004:435). The accessible population as the population of subjects available for a particular study (Polit & Beck 2004:525); often a nonrandom subset of the target population. Stommel and Beck (2004:299), defined an accessible population as the population, often fixed in time and space, from which the actual sample is drawn.

The target population for this study included healthcare workers in Lagos and Kano states of Nigeria, involved in the provision of ART services to children. The accessible population included all healthcare workers involved in the provision of ART services under the US government funded Global HIV/AIDS Initiative Nigeria (GHAIN) project implemented in the Kano and Lagos states of Nigeria.

Stommel and Wills (2004:299) defined the study population as the subset of the target population that is accessible to the researcher, at least in principle, if there are sufficient resources. These accessible study populations are more limited in time and space and are also defined in terms of specific inclusion and exclusion criteria. Thus, the researcher included only adherence counsellors who completed the prescribed training in the care and treatment of children with AIDS and who provided paediatric ART care at the two participating hospitals in Nigeria.

3.3.1.2 Sample and sampling techniques

Stommel and Wills (2004:443) defined a sample frame as the list or data bank that represents all elements/units/participants of an accessible target population; used as a basis for random sampling of participants. Polit and Beck (2004:536) defined a sampling frame as a list of all the elements in the population, from which the sample is drawn.

For the purpose of this study, the researcher obtained the list of all adherence counsellors trained in the care and treatment of AIDS under the US government funded Global HIV/AIDS Initiative Nigeria programme from 2005 till 2008. A convenience sampling technique was used to obtain a sample per location – subset of the accessible study population that was selected to be in the study sample. The study sample refers to the subset of cases, units, or observations from a larger population of cases, units, or observations (Stommel & Wills 2004:443). The sample comprised six participants (ART trained healthcare workers) in each of the designated ART centres in Lagos and Kano, respectively, amounting to a total of 12 participants. Study participants in Lagos were homogenous comprising only nurse/midwives, while in Kano, the study participants were heterogeneous comprising doctors, nurse/midwives, a pharmacy technician and community health technologist.

A non-probability convenience sampling technique was used in this study. Non-probability convenience sampling refers to the selection of the most readily available persons as participants in a study; also known as accidental sampling (Polit & Beck 2004:527).

Convenience sampling is a non-probability approach to selecting participants based on their (easy) accessibility to the researcher (Stommel & Wills 2004:436, 437).

A convenience sampling technique was selected for this study using the most accessible participants for the study. The key reason for this was the practical difficulty of obtaining probability samples from healthcare workers in Nigeria, especially, those trained to provide paediatric ART. Healthcare workers with the capacity to provide paediatric ART in Nigeria are scarce, implying that the available ones are very busy attending to children. Some work shifts while others perform call duties (emergency duties performed after official work hours). Thus, it would have been impossible to gather all trained paediatraic ART workers at the same time for participating in focus group discussions. The researcher requested each health facility's manager to identify volunteers for participation in the focus group discussion. Persons included in the study were adherence counsellors who attended and completed the prescribed training on the care and treatment of CLWA. Such persons were providing ART services to children. Healthcare workers from similar backgrounds who never participated in such training, or who participated but were not providing paediatric ART services, were excluded from the study.

The main problem with convenience sampling is that members of such a sample may have some characteristics, often unrecognised, if not explicitly studied or thought about, that distinguish them from the overall target population. Membership of the study sample could involve an element of self-selection, thus, subjectivity or bias. It might be difficult to gauge the extent to which findings from a particular study could be applicable to broader populations.

3.3.2 Data collection

Qualitative research aims at describing social phenomena and behaviours using rich contextual data that emphasise the subjective experiences of social actors (Malta, Maya, Clair, Freitas & Bastos 2005:1426).

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An unstructured descriptive focus group approach was used in this study. Stommel and Wills (2004:445) defined an unstructured interview as an interview style in which the flow and content of the interview are largely determined by the interactions between interviewer and interviewees. Such exploratory interviews do not contain fixed response formats or predetermined questions, except for directions concerning the general topic areas. Polit and Beck (2004:229) viewed the unstructured interview as "...typically conversational, with no preconceived view of the content or flow of information to be gathered". It is usually conducted in a naturalistic setting. A researcher using a completely unstructured approach may informally ask a broad question relating to the topic under investigation and expect detailed feedback from the interviewee(s). This type of data can be difficult to analyse using qualitative methods. Malta et al (2005:1426) indicated that the value of a qualitative perspective gained favour in social and behavioural health research. In HIV/AIDS research in particular, many of the social phenomena being studied are personal and private.

The unstructured focus group interview is a flexible interview procedure. A researcher initiates talking with the participants because he/she wants to know something specific about the persons concerned. Focus group discussions usually take place in settings that are familiar to the interviewees. The length of FGDs can vary substantially because the participants' personalities might differ, influencing their willingness to communicate their experiences, attitudes perceptions and feelings.

This type of interview process has two potential strengths. One is the hope that participants are more likely to "reveal" themselves in unstructured interviews, providing "unfiltered" personal views of their experiences (Stommel and Wills 2004:445). The second strength is its potential to provide a rich, highly specific perspective of participants' experiences, perceptions and/or attitudes.

Limitations of unstructured interviews include bias, and the establishment of assessment criteria for data quality. A key standard for data quality rests on the ability of another person or researcher to arrive at the same substantial interpretation of a data set as the first researcher. Thus, mechanisms for ensuring the trustworthiness of the research results were implemented to enhance the trustworthiness of the results.

Focus group discussions (FGDs) were used to explore the views of healthcare workers regarding paediatric ART adherence and its determinants. Stommel and Wills (2004:438) define a FGD as a group session for the purpose of conducting a semi-structured, qualitative interview in which a small group of participants (6 to 12 people) discuss among each other a series of pre-determined questions provided by the researcher. Polit and Beck (2004:529) explain a FGD as an interview in which the respondents are a group of 10 to 20 individuals assembled to answer questions on a given topic. The FHI (2005:38) maintains that FGDs are used to gather targeted information from a group of people via open-ended questions.

FGDs were used, rather than in-depth individual interviews, based on the need to identify the experiences, views and perceptions of the participants. The selection of FGD members requires careful decisions to optimise the usefulness of the focus group. For most purposes, groups of 6 to 10 members are optimal (Stommel & Wills 2004:284). The moderator stimulates the exchange of ideas and encourages debates.

The FGD methodology provides in-depth information, but it does not produce quantifiable data and the findings cannot be generalised to a larger population. FGDs capture broad themes that convey participants' experiences and perspectives and uncover why people think and feel as they do. The most important element of the FGD data collection method is the quality of the interaction among FGD participants. The moderator skilfully guided participants through a series of questions intended to trigger free-flowing discussions that included the inert views of participants on the topic under study and debated about suggested ideas. Resistance to an idea, that might have remained hidden during a one-on-one interview, might be uncovered during an FGD.

Procedurally, three separate FGDs of 3-9 persons each were conducted in August and September, 2009, with healthcare workers in the two participating hospitals in Nigeria. The researcher (trained in focus group techniques) introduced the research questions and moderated the focus group to elicit discussions in an unstructured format. The researcher

engaged an assistant who took detailed notes and managed the audio tape recorder. The researcher also wrote brief descriptive summaries that included thoughts and feelings about the FGDs, descriptions of the participants, and sketches of the seating arrangements. This information could be used as part of an audit trail in support of the confirmability of the study findings and for triangulation with the note takers' briefs during the data analysis procedures. Each FGD lasted from 60 to 90 minutes, conducted in English. All adherence counsellors had received training in English and communicate in English in their everyday work situations.

The following questions were asked during the FGDs:

- What are your views regarding ART adherence in children who receive ARVs from your clinic?
- What are your views regarding the pattern of adherence to ART in children receiving free ARVs from your clinic?
- What are your views regarding the factors affecting children's adherence to ART in your clinic?
- What could be done to improve adherence to ART among children (at your clinics specifically and in Nigeria generally)?

Advantages of using focus group discussions

The advantages of FGDs, as noted by Stommel and Wills (2004:284), include:

- Focus groups are an efficient tool for exploring a topic. Thus, participants in this study were encouraged to explore their views to the point of saturation, when no further new information became apparent.
- Although the moderator determined the "focus," the FGDs allowed member-volunteered information and opportunities to express their views about factors influencing paediatric ART adherence rates.

- Group members could enhance their own thinking about paediatric ART adherence in response to other group members' contributions. Thus, some key themes and ideas might have been generated from the interactions among group members.
- Researchers could support their interpretations of the FGD data with ancillary observations such as video/audio-tapes of the group sessions. This would reduce forgetfulness, misrepresentations or selective memories on the part of the researcher.
- Data obtained from FGDs were rich and provided "food for thought" for future research.
- FGDs were flexible and appropriate for addressing a wide variety of factors that might influence paediatric ART adherence rates.

Limitations of using focus group discussions to collect data

Potential and actual limitations of FGDs, as corroborated by Stommel and Wills (2004:284), include:

- Because of the small size of focus groups and the nature of group member selection, the findings typically cannot be generalised to a larger target population.
- Group processes and interactions might produce undesirable effects, such as domination by one member or "shutting down" of group members in response to the behaviour of other participants. The researcher should counteract this potential limitation by managing specific group members' contributions to avoid the domination of any individual member.
- As with all narrative transcripts of unstructured interviews, the data generated in FGDs might be extensive and challenging to interpret, classify, or code into distinct themes, or key issues.
- Some group members might be reluctant to reveal their "true" opinions within a group context, especially if they might be concerned that others in the group would not share their opinions. The researcher shares transcripts with FGD members (member checks), to clarify areas where they experienced difficulties to voice their opinions among other group members.

3.3.3 Ethical considerations

To ensure understanding and full compliance with ethical considerations and standards, the researcher participated in an in-house research ethics training session conducted by FHI in Abuja, Nigeria, on August 1, 2008 (see Annexure A).

3.3.3.1 Protecting the rights of the participants

- *Non-discrimination*

The researcher avoided discrimination against healthcare workers on the basis of sex, race, ethnicity, or other factors that were deemed to jeopardise the trustworthiness of the study results.

- *Beneficence*

The researcher did no harm and refrained from exploiting participants, and promoted both individual and societal benefits that are directly related to participation in this research. This was done by using the study findings to recommend ways in which healthcare workers could improve their services to paediatric patients and ways in which paediatric ART outcomes could be enhanced.

  - *Respect for persons*

The researcher respected the rights of healthcare workers, both for self determination (autonomy) and the right to full disclosure (fully informed consent for research participation). No participant's name would be mentioned in any report (see Annexure E).

  - *Justice*

The researcher respected the rights of the healthcare workers to privacy and the right to fair treatment in the context of research participation. The FGD was conducted in a private room. Every participant in the FGD consented to participation and every participant was requested not to divulge any information from the FGD to any other persons.

3.3.3.2 Protecting the rights of the institutions

- *Legality*

The researcher understood and obeyed relevant laws and institutional and governmental policies regarding research, protection of human subjects, and any other ethical consideration relevant to this study (see Annexures B, C and D).

- *Integrity*

The researcher kept promises and agreements with the research supervisors, institutions providing access to records and any other authority relevant to this study; and acted with sincerity and strove to maintain consistency of actions.

- Openness

The researcher would share data, results, ideas, tools, resources with relevant persons and institutions. An article, based on the research, will be submitted for possible publication to a relevant journal. This will expand the "openness" of this research report to the scrutiny of a wider audience.

- *Respect for Intellectual property*

The researcher honoured copyrights and other forms of intellectual property. He did not use unpublished data, methods, or results without permission. He gave credit where credit was due and gave proper acknowledgement or credit for all contributions to the research.

References to all sources used are supplied throughout the dissertation.

- *Confidentiality*

The researcher protected confidential communications, such as patients' records, institutional information such as personnel records, papers or grants submitted for

publication following acceptance of the dissertation by the University of South Africa.

3.3.3.3 Scientific integrity of the research

- *Honesty*

The researcher maintained honesty in all scientific communications, by honestly reporting data, results, methods and procedures, and publication status after the dissertation's acceptance by the University of South Africa, subject to its specifications. The researcher did not fabricate, falsify, or misrepresent data. He did not deceive colleagues, granting agencies, or the public on any part of the subject matter being studied.

- *Carefulness*

The researcher avoided careless errors and negligence; carefully and critically examined his own work. He kept accurate records of research activities, such as data collected, research design, and correspondence with agencies, supervisors and the institutions participating in this research.

3.3.4 Data analysis

The analysis of this qualitative data began in the field, during data collection, using FGDs. The data being gathered were analysed on the spot to shape the ongoing data collection process. Pope, Ziebland and Mays (2000:114) noted that this sequential analysis or interim analysis has the advantage of allowing the researcher to refine questions on the spot and pursue emerging avenues of inquiry in further depth. Such continuous analysis is almost inevitable in qualitative research. As the researcher is "in the field" collecting the data, it is impossible not to start thinking about what is being heard.

Once the researcher left the field, the textual data (in the form of field notes or transcripts) were subjected to content analysis. Pope et al (2000:114) argued that deductive analysis is less common in qualitative research but is increasingly being used, for example in the "framework approach."

The framework approach was selected for this study because it reflects the original accounts and observations of the people studied (that is, “grounded” and inductive), though, it started deductively from pre-set research purpose and objectives. It was also a preferred choice because the analysis was designed so that it could be viewed and assessed by people other than the primary analyst, required to support the trustworthiness of the study.

3.3.4.1 Stages of data analysis

Pope et al (2000:116) suggested the use of five stages of data analysis in the framework approach, and these were used in this study.

- *Familiarisation*

The researcher was substantially engaged in immersion of the raw data by listening to tapes, reading transcripts, and studying the notes, in order to list key ideas and recurrent themes. The researcher also built upon existing relationships with the participants to strengthen meaningful rapport. Through this process, the transcript was returned to the participants to review, add to, or otherwise revise transcripts of their responses, or to correct the researcher’s interpretation of the meaning of the data. The researcher also shared the transcript with experienced research colleagues in the workplace to review the entire process, proffer suggestions and reach consensus on the best way to improve the data analysis. This was done with dedication, until familiarity had been achieved and the key themes identified.

The researcher shared the transcript for all three FGDs with another experienced qualitative research consultant (who served as note taker in the field) to do an independent analysis. The analysis was then checked for comparability and similarity, and discrepancies were resolved.

- *Identifying a thematic framework*

The researcher engaged in identifying all the key issues, concepts, and themes by which the data were examined and referenced. This included the aims and objectives of the study as well as issues raised by the respondents themselves and views or experiences that recurred in the data. The end product of this stage was a detailed index of the data, which categorised the data into manageable chunks for subsequent retrieval and exploration.

- *Indexing*

The researcher applied the thematic framework or index systematically to all the data in textual form by annotating the transcripts with numerical codes from the index, and supported these with short text descriptors to elaborate the index heading. Single passages of text were combined to comprise a number of different themes, each of which had been recorded in the margin of the transcript.

- *Charting*

The researcher re-arranged the data according to the appropriate part of the thematic framework to which they related, forming charts. The charts contained distilled summaries of views and experiences. Thus, the charting process involved a considerable amount of abstraction and synthesis.

- *Mapping and interpretation*

The researcher used the charts to define concepts, map the range and nature of phenomena, create typologies and find associations between themes with a view to providing explanations for the findings. The process of mapping and interpretation was influenced by the original research objectives as well as by themes that emerged from the data. Each penultimate theme was described in detail in the research results section. The researcher provided “thick” descriptions of defining attributes, descriptions of what the healthcare workers did and did not discuss in the focus groups, and quotes from the

healthcare workers that illustrated specific themes. The researcher used multiple data sources to examine and validate conclusions about meanings. In the discussion section of the research report, the researcher provided commentaries about the specific new knowledge generated by the study, including the healthcare workers' views regarding adherence to paediatric ART, the pattern of paediatric ART adherence and factors affecting children's adherence to ART in the two participating health facilities in Nigeria. The researcher also discussed specific implications of the findings for public health, tying the implications to existing literature, to enhance the credibility of the interpretations of the findings.

3.4 TRUSTWORTHINESS OF THE STUDY

Mdondolo, De Villiers and Ehlers (2003:91) maintained that trustworthiness was the extent to which a study is worth paying attention to, worth taking note of, and the extent to which others are convinced that the findings can be trusted. The basic question addressed by the notion of trustworthiness, according to Lincoln and Guba (1985:290), is simple: "How can an inquirer persuade his or her audiences that the research findings of an inquiry are worth paying attention to?" When judging qualitative work, Stommel and Wills (2004:288) maintained that replicability is a key standard or convention. As a criterion for data quality, replicability means that the readers of a research report should expect to see enough information about the data collection methods and study design so that these methods could be used again (replicated) in a similar study. Thus, to ensure replicability of this study, a descriptive study design and FGD method of data collection were clearly explained. Lincoln and Guba (1985:300) identified criteria employed to judge the trustworthiness of qualitative research. They are: credibility, transferability, dependability and confirmability.

3.4.1 Credibility

Credibility standards involve performing specific activities that increase the trustworthiness of the reported findings (Stommel & Wills 2004:289). It can be enhanced through the triangulation of data. Other techniques for addressing credibility include making segments of the raw data available for others to analyse (peer debriefing), prolonged engagement or

the researcher's substantial immersion in the research process and the use of "member checks," in which respondents are asked to corroborate findings (Lincoln & Guba 1985:313- 316; Stommel & Wills 2004:289).

In this study, the researcher engaged with the research, established valid and meaningful relationships with the participants, and remained open to the deeper meanings that unfolded during the research process. The researcher also interacted with experienced research colleagues in the workplace who could provide guidance for the research design, data collection, and data analysis for review and consensus on how to proceed. Following the FGDs and their transcriptions, the researcher shared the transcripts with the respondents for reviewing the researcher's interpretations of the meaning of the data. Results of the study were also triangulated with data sources reported in the literature to examine and validate conclusions about meanings.

3.4.2 Transferability

Transferability, according to Stommel and Wills (2004:288-289), is conceptually similar to generalisability (external validity) in quantitative studies, which refers to the extent to which findings can be generalised to other situations and target populations. Lincoln and Guba (1985:110-111, 124) admit that generalisability is "an appealing concept," because it allows a semblance of prediction and control over situations. Yet they suggest that the existence of local conditions "makes it impossible to generalize." Stommel and Wills (2004:289) recommend a "thick description," a very detailed description of the nature of the participants, their reported experiences, and the researcher's observations during the study. This is to provide sufficiently detailed information about the study, such as that interested others could gauge the extent to which the findings might apply in another population or setting.

To meet the criteria for transferability, the report of this study provided in-depth discussions of the nature of the participants, their reported experiences/data obtained, the researcher's observations during the study, methods of data analysis and interpretation of the research findings. The researcher also made references to the raw data, kept available for any interested person (researchers) to cross check or verify (providing one aspect of an audit

trail). This detailed information therefore, potentially rendered opportunities to interested others to gauge the extent to which the study findings could be generaliseable or transferable to other situations.

However, the researcher report would emphasise that the findings of this study might not be generalisable to other sites without repeating the study at such sites.

3.4.3 Dependability

Lincoln and Guba (1985:317) proposed one measure which might enhance the dependability of qualitative research. That is the use of an “inquiry audit,” in which reviewers examine both the process and the product of the research for consistency. Stommel and Wills (2004:288) maintained that dependability is conceptually similar to the concept of test-retest and internal consistency (reliability) in quantitative research approaches. Dependability refers to how stable or unstable the data patterns tend to be over time or on different occasions.

To meet the criteria for dependability, the researcher engaged a consultant to do an independent data analysis of each FGD. To enhance objectivity, the researcher shared the transcript with another experienced researcher who independently did an analysis and compared notes. The data and analyses were then checked for comparability and similarity, and discrepancies resolved through ‘member checking’ with the participants. Specific discrepancies that were rectified include the years of experience of two participants in Kano, clarification regarding how long the family centred care model had been piloted at the two study sites, and clarification regarding reasons for better adherence among father headed single parent households in Kano, and not in Lagos. The researcher also did peer debriefings with other research colleagues in the workplace. The researcher disclosed that he has no personal or financial interests that may affect this study.

3.4.4 Confirmability

Confirmability, according to Lincoln and Guba (1985:320-321), refers to the degree to which the researcher can demonstrate the neutrality of the research interpretations, through a “confirmability audit” (Stommel & Wills 2004:288, calls it “audit trails”). This means providing an audit trail consisting of raw data; analysis notes; reconstruction and synthesis products; process notes; personal notes; and preliminary developmental information.

To meet the criteria for confirmability, the researcher used audit trails, in which approaches to data collection, decisions about what data to collect, and decisions about the interpretation of data were carefully documented, so that another knowledgeable researcher could arrive at the same conclusions about the data and for the protection of human subjects, as required by institutional review boards.

3.5 SUMMARY

A qualitative paradigm was used in the study. The researcher used a descriptive research design to conduct the study. The study sample comprised focus groups (comprised of ART trained healthcare workers), in each designated ART centre in Lagos and Kano respectively (comprising a total of 17 participants). These study samples were selected using a non-probability convenience sampling technique. Data were collected using three FGDs. The researcher ensured strict compliance with ethical standards relevant to protecting the rights of the respondents, institutions where data were collected and that of the scientific integrity of the study. The trustworthiness of the study was addressed through ensuring credibility, transferability, dependability and confirmability of the study.

The next chapter will present the analysis and discussion of the data obtained from the three FGDs.

CHAPTER 4

DATA ANALYSIS AND DISCUSSION

4.1 INTRODUCTION

In the previous chapter, the research design and methods were discussed. This chapter focuses on the data analysis strategy and discussion. The analysis of the qualitative data began in the field, during data collection, using the unstructured FGD. The data gathered were analysed on the spot to shape the ongoing data collection process. Once the researcher left the field, textual data exploration continued through content analysis.

4.1.1 The purpose of the study

The purpose of the study was two fold;

- identify and describe the perceptions of health care providers on factors that influenced paediatric ART adherence, at two health care centres where ARVs were supplied free of charge
- make recommendations to health care authorities for addressing the identified factors, thereby enhancing the paediatric ART adherence rates at the two participating health care centres, and possibly also at other sites.

The research questions were:

- What were the health workers' views regarding paediatric ART adherence in children who received free ARVs from the two participating health facilities in Nigeria?
- What were the health workers' views regarding the ART adherence patterns of children receiving free ARVs from the health facilities in Nigeria?

- What were the healthcare workers' views regarding the factors affecting children's ART adherence in the participating health facilities in Nigeria?

- What, according to the healthcare workers, could be done to improve adherence to ART among children (at your clinics specifically and in Nigeria generally)

4.1.2 Sample size

There were 17 participants in the study. At the time of data collection during August and September 2009, some of the expected participants were not on duty. At Kano, two FGDs were conducted – 3 participated in the first FGD and 9 in the second. At Lagos, 5 health care workers participated in the FGD.

4.2 DATA ANALYSIS STRATEGY

The framework approach of data analysis, suggested by Pope et al (2000:116) was used in this study (refer to section 3.3.4). The researcher listened to tapes and studied transcripts and field notes with dedication, until familiarity was achieved. During this stage, the researcher began sifting pieces of data that were considered relevant to the purpose of the study. The researcher coded and categorised these data chunks, while reading and rereading the transcripts, as a means of developing themes. The researcher noted that in some paragraphs, more than one topic emerged and this required different numeric codes. The researcher developed a detailed index of the data, which categorised the data into manageable chunks for subsequent retrieval and exploration. This was followed by systematically annotating the transcripts with numerical codes, supported by short text descriptors to elaborate the index heading. Single passages of text were combined to

comprise a number of different themes, categories and sub-categories, each of which were recorded in the margin of the transcript.

The researcher re-arranged the data according to the appropriate part of the thematic framework to which they related; forming tables. The tables contained distilled summaries of views and experiences. Thus, the tabulation process involved a considerable amount of abstraction and synthesis. The researcher used the tables to provide explanations for the findings. This was influenced by the original research questions as well as by themes that emerged from the data. Each penultimate theme was described in detail, including their associated categories and sub-categories. The researcher provided “thick” descriptions of what was discussed in the focus groups, and quotes from the FGD participants that illustrated specific themes.

In the discussion section of the research report, the researcher provided commentaries about the knowledge generated by the study’s results, including the health care providers’ views regarding adherence to paediatric ART, the pattern of paediatric ART adherence and factors affecting children’s adherence to ART in the two participating health facilities in Nigeria. The researcher also discussed specific implications of the findings for public health, tying the implications to existing literature, to enhance the credibility of the interpretations of the findings.

4.3 DATA ANALYSIS AND DISCUSSION

In section 4.3.1 the demographic data of the FGD participants are presented in quantitative terms in order that the readers can know who these participants were. This might be important for contextualising some qualitative data presented and discussed in sections 4.3.2 – 4.4.

4.3.1 Demographic data of participants

A brief profile of FGD participants was obtained. The demographic information in this section included: gender, professional category of participants, number of years of

experience as paediatric ART adherence counsellors and as general health care practitioners respectively.

A total of three FGDs were conducted and the demographic details are displayed in table 4.1. The result show that the majority of the FGD participants (n=12; 70.6%) were female. The FGD participants were mostly nurse/midwives (n= 11; 64.7%). Most of the FGD participants had one year (n=4; 23.5%), two years (n=4; 23.5%) and three years (n=4; 23.5%) paediatric ART adherence counselling experience, respectively. Participants' general health care experience ranged from mostly from 1-10 years (n=10; 58.8%).

Table 4.1: Demographic data of FGD participants

Category	Frequency				Percentage
	FGD 1 (Lagos)	FGD 2 (Kano)	FGD 3 (Kano)	TOTAL	
Gender					
Male	0	0	5	5	29.4
Female	5	3	4	12	70.6
Total	5	3	9	17	100
Profession					
Doctor	0	0	4	4	23.5
Nurse/Midwife	5	3	3	11	64.7
Community Health Technologist	0	0	1	1	5.9
Pharmacy Technician	0	0	1	1	5.9
Total	5	3	9	17	100
ART adherence counselling experience years					
1 year	1	0	3	4	23.5
2 years	1	1	2	4	23.5
3 years	0	1	3	4	23.5
4 years	2	0	0	2	11.8
>4 years	1	1	1	3	17.7
Total	5	3	9	17	100
General health care experience years					
1 – 10 years	0	2	8	10	58.8
10 – 20 years	1	1	1	3	17.7
20 – 30 years	3	0	0	3	17.7
31 years and above	1	0	0	1	5.9
Total	5	3	9	17	100

4.4 DATA STRUCTURE

In this study, four major themes were identified, namely: health workers' views regarding,

- paediatric ART adherence in children who received free ARVs,
- ART adherence patterns of children receiving free ARVs,
- factors affecting paediatric ART adherence
- strategies for improving paediatric ART adherence

Table 4.2 Themes and the categories

DATA DISPLAY	THEMES AND CATEGORIES	
4.1	**Theme 1**	**Paediatric ART adherence in children who received free ARVs**
4.1.1	Category 1.1	The economic burden of ART on parent was instrumental to paediatric ART non-adherence
4.2	**Theme 2**	**ART adherence patterns of children receiving free ARVs**
4.2.1	Category 2.1	Famiy centred care approach improved children's adherence to ART
4.2.2	Category 2.2	Adherence improved where more than one person in a household was on ART
4.2.3	Category 2.3	Children from mother- headed single parent households (SPHH) adhered to ART better than those from father-headed SPHH
4.2.4	Category 2.4	Children of biological parent presents with higher adherence levels to ART than those from non-biological parent
4.2.5	Category 2.5	Parent's literacy level influenced their children's adherence to ART
4.3	**Theme 3**	**Factors affecting paediatric ART adherence**
4.3.1	Category 3.1	Parents were determinants of adherence in children
4.3.2	Category 3.2	Multiple competing factors challenged children's ability to adhere to ART
4.3.2.1	Sub-category 3.2.1	Poverty
4.3.2.2	Sub-category 3.2.2	Inadequate access to quality paediatric ART services
4.3.2.3	Sub-category 3.2.3	Inadequate treatment knowledge
4.3.2.4	Sub-category 3.2.4	Stigma
4.3.2.5	Sub-category 3.2.5	Side effects of ARVs and other children factors
4.3.2.6	Sub-category 3.2.6	Parent forgot to administer drugs
4.3.2.7	Sub-category 3.2.7	Inadequate health system infrastructure
4.4	**Theme 4**	**Strategies for improving paediatric ART adherence**
4.4.1	Category 4.1	Improved quality of paediatric ART services was fundamental to paediatric ART adherence
4.4.2	Category 4.2	Empowering parents improved adherence to ART in children
4.4.3	Category 4.3	Addressing stigma and discrimination against PLHA improved access to ART

4.4.1 Presentation of themes and categories

The results of this study are discussed along the themes and the categories that were derived from the data. Applicable direct quotes are supplied to substantiate relevant results. Appropriate research reports are also cited to support findings.

4.4.1.1 Theme 1: Paediatric ART adherence in children who received free ARVs

Paediatric ART adherence in children who received free ARVs was one of the major themes that emerged during data analysis. One category appeared to relate to this theme. Data display 4.1 presents an overview of the category in this theme.

DATA DISPLAY 4.1 **PAEDIATRIC ART ADHERENCE IN CHILDREN WHO RECEIVED FREE ARVS (OVERVIEW)**
4.1.1 The economic burden of ART on parent was instrumental to paediatric ART non-adherence

Category 4.1.1: The economic burden of ART on parent was instrumental to paediatric ART non-adherence

The FGD participants explained that adherence was better in children whose parent(s) experienced fewer economic burdens from ART. The resources were required for other expenditures such as transportation, feeding and other medicines since ARVs were provided free of charge in the facilities. The FGD participants linked this to free supplies of ARVs compared to spending out-of-pocket in order to access ARVs. Paying for ARVs was perceived as an obstacle to accessing quality paediatric ARVs. Data display 4.1.1 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.1.1
Paediatric ART adherence in children who received free ARVs

- Most of them will not be able to buy the drugs for the kids…since it is free, the parents come and collect the drugs and give to the kids.
- About 75.0% cannot afford the drugs because they are not well to do and they are always happy to come and receive these drugs free in this hospital.
- They won't take their drugs correctly because they don't have the money to buy the drugs.

Veinot et al (2006:265) viewed costs of medications as barriers to ART. Kloos et al (2007:10) also reported that out of 58 405 patients in Ethiopia, who had started free ART programmes in December 2006, 46 045 (78.8%) were adhering to treatment during that month. Likewise, Ellis and Molyneux (2007:261) shared their experiences of a 12 months' free ART programme for HIV-infected children in Malawi. After one year of treatment monitoring of the cohort of 238 children, 194 (81.5%) were alive and adhering to ART. Of this cohort, 20 (8.4%) had died, 19 (8.0%) were lost to follow-up and 5 (2.1%) had been transferred to other health facilities. From Aminu Kano Teaching Hospital in Nigeria, Mukhtar-Yola et al (2006:141) reported that the most common reasons for non-adherence were running out of medicines and the inability to purchase more medicines due to financial constraints. Other barriers were non-availability of and inaccessibility to medications. Reported evidence from Malawi indicated that free ARVs improved programme quality and reduced the number of ART defaulters (Van Oosterhout 2007:1241).

In Brazil, there was a treatment policy that guaranteed free access to ARVs. Yet, Wachholz and Ferreira (2007:S433) uncovered that the general prevalence of non-adherence was 49.5%. Likewise, Hammami et al (2004:e591) reported that adherent patients showed stronger motivation to stick to the medical regimen. They did so on the basis of personal cost-benefit analyses. This implied that perceived benefits outweighed the costs or difficulties experienced in adhering to the ART regimens.

4.4.1.2 Theme 2: ART adherence patterns of children receiving free ARVs

The second theme that emerged in the data analysis concerned ART adherence patterns of children receiving free ARVs. Data display 4.2 outlines the categories in this theme.

DATA DISPLAY 4.2 **ART ADHERENCE PATTERNS OF CHILDREN RECEIVING FREE ARVS (OVERVIEW)**
4.2.1 Famiy centred care approach improved children's adherence to ART
4.2.2 Adherence improves where more than one person in a household is on ART
4.2.3 Children from mother- headed single parent households (SPHH) adhere to ART better than those from father-headed SPHH
4.2.4 Children of biological parent(s) presents with higher adherence levels to ART than those from non-biological parent(s)
4.2.5 Parent's literacy level influences their children's adherence to ART

Category 4.2.1: Family centred care approach improved children's adherence to ART

The FGD participants explained that children who were accompanied to the clinic by both parent and other siblings adhered better to ART. They described this approach as "fantastic" in supporting children to adhere to their prescribed medications. The FGD participants elucidated that through the family centred care approach, family members came into hospital to access all needed services at one stop – "one stop shop all." This approach reduced repeatability of visits, and unnecessary expenses. It also reduced travelling around town in search of ART care services from different clinics or points of service for each member of the family. Data display 4.2.1 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.2.1 Family centred care approach improved children's adherence to ART
• I think the family centred care approach helps much because if the mother, father and the children are all given appointments on the same day, that will make the adherence better. • It means the same transport, so that they are all going at the same time. • [When] the mother is given another day and the father is given a different day, you know that creates problem. • If all of them go together at the same time, I think it adds value to adherence…even considering the time…instead of may be going one day for the mother, the child going for one day, even the time is together so I think its better economically and everything. • If both family [members] are taking their drugs at the same time, at the same day then may be they choose the same time to take their drugs, it's hard for them to forget it, all of them, it's hardly even if one forgets, the other can remind him. • It helps a lot because the family they come together during their clinic days (the father, wife and kids) they come for their drugs the same time and collect it…this way they all adhere to their drugs as a family. • it adds value to adherence counselling, because the parents ask us if they are not eligible to have drugs from us. We tell them that they can. So, they take referrals from their previous centres so that their clinic day is the same with the child's. • It adds value to their adherence treatment in the sense that it removes stress from the parents and caregivers because there is no going up and down or even spending of money because they can access the treatment at the same spot. • Family centred care approach saves time, saves money at the same time. • It adds value in the sense that both the parents would be coming together for treatment at the same time and would put it in their mind that they have something important to do. • It helps them give [medicine] in a better way because two of them are positive, they both receive treatment at the same time. They don't have to move about. • In fact, it is a very good way of getting people to adhere to treatment because the father is there may be he is more enlightened than the mother of the child, he understands better than the mother. • So if you talk to both of them, if the mother is going to deviate from what you have told them to do, the father is there to correct her. • He will remind her that this is not what you are told, and this is what you are supposed to do. So, that is why I think the family centred approach is fantastic in assisting the adherence.

Byrne et al (2002:151) assert that adherence strategies devised by families depended heavily on family support and the resolution of disclosure issues in the household. Williams et al (2006:e1745) also highlighted the importance of evaluating and supporting the family environment to optimise adherence.

Another study finding was that of Wachholz and Ferreira (2007:S433). They reported that children cared for in a family environment presented a higher risk for ART non-adherence than institutionalised children. However, the researchers did not specify the context of "family environment" to in their study. When the family is treated as a unit of care and guided by the clinicians to ensure adherence for the child, the result is envisaged to be in support of the family centred approach to care. This is irrespective of institutional or home care.

Category 4.2.2: Adherence improves where more than one person in a household is on ART

The FGD participants explained that children from households with existing members on ART adhered better to treatment. The caregivers in these families had more courage to care for the children. They built upon experiences learned from other family members on ART. A family with more than one person on ART was perceived to be less likely to neglect the child on treatment.

FGD participants in Lagos explained that caregivers provided better adherence support if they were themselves adhering to ART. They provided better adherence support if they also had experience and knowledge of the challenges associated with taking ARVs; *"…it's like a child is sick and the mother is not sick, you wouldn't know that level your child is facing until you have the same problems…"*

A FGD participant, in both Kano and Lagos explained that in certain cases, parents felt enough attention should be focused on caring for the healthy children. Such parent(s) thought the children living with HIV were almost hopeless and needed to be left alone. An FGD participant in Lagos commented; *"…they [caregivers/parent] may say, take your drugs, if you like you take it, if you don't like don't take it; so, that may be some form of neglect that would segregate the other children to leave this one part."* Data display 4.2.2 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.2.2 Adherence improves where more than one person in a household is on ART
• The party [another family member on ART] may have more experience [on ART] than the parents, so, when the party is in, then he can be able to convince the parents [on the benefits of adherence]…
• It adds value, in the sense that both the parents would be coming together for treatment at the same time and would put it in their mind that they have something important to do.
• It helps them give [ARVs] in a better way because two of them are [HIV] positive, they receive treatment at the same time…
• It adds value in the sense that both the parents would be coming together for treatment at the same time and would put it in their mind that they have something important to do.
• If an uncle has it [he'll]…say that look O! You know I have this problem and I'm on this drug. A similar thing happened to me but I was encouraged to start taking the drug and did. Today, am relatively okay. If you withdraw these drugs now, you are going back to square one.
• If he is influential and he has a say in the family, he can persuade the person affected that come; this child needs to depend on this drug for survival.
• There is an orphan who has been on ART since the age of 6 months. Her grand mother is dedicated, and the child is now 3 years and very active.
• Because they come together and there is a bond between the parent, family members and child, it gives more courage to the caregiver.

Brackis-Cott et al (2003:252) note that any family with more than one HIV positive member placed excessive burdens on caregivers/parents, thereby, resulting in poor adherence to ART. In addition, Marhefka et al (2006:435) implicated caregivers' psychological distress, arising from excessive burdens on caregivers or parents, as a predictors of children's ART adherence. They suggested that interventions that reduced caregivers' stress levels might help to improve adherence. These include addressing the context within which HIV affected families struggle to meet the demands of their stressful lives.

Category 4.2.3: Children from mother-headed single parent households (SPHH) adhere to ART better than those from father-headed SPHH

FGD participants explained that single mothers were better caregivers to children on ART than single fathers. The single mothers ensured the child adhered to prescribed treatment regimen. The health care workers added that single mothers required a steady income in order to access ARVs and for nutritional supplements for the child. They argued that fathers were always too busy and spent more time outside the home. The FGD participants in Lagos viewed children under the care of fathers as often being neglected. Data display 4.2.3 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.2.3 Children from mother- headed single parent households (SPHH) adhere to ART better than those from father-headed SPHH
• When it is time for the mother to come and take her drugs and her child's drugs and she is financially handicapped, it may hinder her coming to take her drugs, to take her child's drugs. • If the mother is left with the child, it is harder because family pressure and most times her poor financial situation will have adverse effects on the child. • They [fathers] normally abandon the child, so it is rare for the father to care [for the child]. • If it is the mother, the mother will care but if it is the father, he may just leave the child and say I will go and marry another woman and abandon the child. • I remember one [father] that came and said he was a taxi driver and said he doesn't have time; that he has been begging somebody to be bringing the child [to the hospital]. • If it is the father that is alive and the mother is dead, you will see that the father will look for somebody out of his own family that will really give care. • I know a particular family. The man does not believe that there is anything like HIV…so it's the mother that sneaks in occasionally when he is not there and administers the drugs; if the man is around, he will not agree.

Rose and Clark-Alexander's (1998:63) findings highlighted that mother caregivers in the USA provided support to children with HIV/AIDS but these mothers also needed physical and emotional support themselves. The mothers did not report a sense of support from family and friends due to the perceived or real stigma and fear of rejection associated with telling family and friends about their HIV positive status.

Category 4.2.4: Children of biological parent present with higher adherence levels to ART than those from non-biological parent

FGD participants in Kano remained indeterminate in expressing their views regarding paediatric ART adherence in biological and non-biological parent/caregiver homes. FGD participants in Lagos reported that children of biological parents presented with better adherence levels to ART than those from non-biological parent. Highlighting stigmatisation against children of non-biological caregivers, a FGD participant in Lagos recalled her experience of a non-biological parent in the community who said (about a child under her care) *"…they may think that it is all of us that is having this problem O, I beg don't make anybody to look at me with a bad eye..."* Data display 4.2.4 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.2.4 Children of biological parent presented with higher adherence levels to ART than those from non-biological parent
• They will say that I'm not your parent and we don't know where you are coming with this things [AIDS]. They even name this child and all the people in the compound will know the type of illness that the child is going through. • There may be a social neglect of the child because they will try to abandon the child; even feeding and everything. • They [non-biological parents] may even say, I'm tired of taking you to hospital; if I can get anybody that can take you to the hospital. • It creates fear for the non-biological parents, in the sense that they may be scared that the child will infect them. • Any time they feel like coming for the treatment, they might come may be once in a year. Even, they might not even come for years so when the child is now sick, they will now bring the child to the hospital that the child is sick and then it might be too late.

This finding was in line with that of Greeff et al's (2008:96) findings of their South African study. These researchers reported that they were denied opportunities like cooking for the family or being part of community activities. They were also denied access to health services. Greeff et al (2008:102) added that the mere fact that a spouse, child or family member was related and associated with PLWA led to their being stigmatised. Children from other families were hindered from associating with those from the affected family, including playing together.

On the other hand, Giacomet et al (2003:1402) noted that children receiving therapy from foster parents were more adherent than those receiving drugs from biological parents or relatives. Univariate analyses by Marhefka et al (2006:429) showed that an adherent classification (at least an 80.0% refill rate) was associated with having non-biologically related caregivers. Likewise, Williams et al (2008:e1751) report that having an adult other than the biological parent as the primary caregiver was associated with improved adherence. Rose and Clark-Alexander (1998:61) compared the mean scores for total quality of life and the quality of life subscales for non-biological and biologic mother-caregivers. The non-biological (alternative) caregivers scored significantly higher in total ($p < .001$), psychological ($p < .001$), and social ($p < .005$) quality of life than the mothers in this sample.

Category 4.2.5: Parent's literacy level influences their children's adherence to ART

According to the views of the FGDs, paediatric ART adherence rates were reportedly higher among children with better educated parents. Education in this sense referred to passing through a formal school, at least a primary school. Data display 4.2.5 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.2.5 Parent's literacy level influences their children's adherence to ART
• We can relate literacy with awareness…if the person is aware and is determined…it will be better [there will be better adherence]. • Awareness is very important to the caregivers. • If the caregivers are aware or are educated about the medications I think they will be able to cope and the child will be able to adhere with the drugs. • If they are not educated, if they are not aware, I think it is a very big barrier to treatment. • There is a bit of difference in compliance with the educated ones. They are usually more informed and are usually more careful…the ones that are not educated tend to ascribe their situation to divine will. • It is a negative thing because they are not educated. Which ever explanation or counselling you give to them, they will not understand. • If they are educated, they will adhere to the treatment. • Education doesn't mean that one should not follow the normal thing to do; I think proper counselling is better.

Wachholz and Ferreira (2007:S424) reported that a lack of understanding of prescribed ARV regimens, as well as conscious loss of doses contributed to a lack of ART adherence among their study's particpants. Likewise, a multivariate analysis by Wachholz and Ferreira (2007:S425) of the education of caregivers was found to have a borderline association with treatment outcomes. Thus, institutionalised children and those taken care of by people with a higher educational level, appeared to maintain better ART adherence levels. Another finding by Martin et al (2007:61) also supported the fact that greater regimen knowledge among caregivers and fewer child-caregiver discrepancies about medication responsibilities predicted better ART adherence levels. Williams et al (2008:e1753) reported that higher caregiver education levels were associated with improved ART adherence among children.

While this study highlighted that the responsibilities for paediatric ART adherence lay with caregivers/parents, evidence from Hammami et al (2004:e591) suggested that adherent

patients internalised medical information to a greater extent than less adherent patients. Adherent patients also showed stronger motivation to stick to medical regimens on the basis of personal cost-benefit analyses. Furthermore, adherent patients developed greater problem-solving capacities, such as ways of dealing with practical complications of medication intakes. Hammami et al (2004:e591) also revealed that knowledge, motivation, and capacities evolved in a progressive way, related to individual stages of coping with HIV.

4.4.1.3 Theme 3: Factors affecting paediatric ART adherence

The third theme that emerged from the data concerned factors affecting paediatric ART adherence**.** Data display 4.3 outlines the categories in this theme.

DATA DISPLAY 4.3 **THEME 3: FACTORS AFFECTING PAEDIATRIC ART ADHERENCE (OVERVIEW)**
4.3.1 Parents were determinants of adherence in children
4.3.2 Multiple competing factors challenged children's ability to adhere to ART
4.3.2.1 Poverty
4.3.2.2 Inadequate access to quality paediatric ART services
4.3.2.3 Inadequate treatment knowledge
4.3.2.4 Stigma
4.3.2.5 Side effects of ARVs and other children factors
4.3.2.6 Parent forgot to administer drugs
4.3.2.7 Inadequate health system infrastructure

Category 4.3.1: Parents were determinants of adherence in children

FGD participants in both Kano and Lagos explained that parents were the main determinants of paediatric ART adherence. They also argued that parents were targets for adherence counselling training and services, not the child. In Lagos, the FGD participants recognised parents as the main determinants of adherence in children. They also recognised the need for continuous and re-enforced adherence counselling to families. Data display 4.3.1 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.3.1 Parents were determinants of adherence in children
• You see, a child has no say of his own…so it depends on the mother you know to provide the drugs as necessary. • The fault if there is any problem [with adherence] should be with the mother and not the child. • In fact parents are trying, they give them the drugs as it is supposed to be …it is only the adults we use to have problems with, but with the children we don't have much problem. • The parents are more concerned about the children's health so they are more careful with their children than themselves. • You know when a child is sick it is just as if it's the parents that are sick. • They are so worried about their children's illness, so they adhere to the drugs and being that its free they adhere more. • Initially, the caregivers and parents were not complying with the adherence treatment but because of the ongoing adherence [programme] all the time they come to the clinic. • There is no time we don't have adherence counselling with them [the parent], this has really helped. If not because of that, I think they would have forgotten about the treatment totally • If you don't involve the caregiver or parent [in the child's care], you cannot achieve good results because they are the ones monitoring these children at home. • If you inform the parent or caregiver very well, some will adhere very well. • You know, children don't come to the clinic themselves; the caregivers or parents bring them. • It's the parents that give the children these drugs…since the kids don't know how to say give me any drugs.

Martin et al (2007:66) concluded that responsibilities for medication-related tasks should be clarified among family members, such as parents. Regimen knowledge should be emphasized and caregivers should avoid assigning treatment responsibilities to a child prematurely. Likewise, Simoni et al (2007:e1371) in their description of the correlates of adherence also identified family/parent/caregiver, medication and the patient as three important variables influencing ART adherence rates. Furthermore, Pontali (2005:143) recognised the need for tailoring ART regimens to the daily activities of the family. Pontali (2005:143) also recognised the strategic position of the parent in the child's adherence programme. On the other hand, Mellins et al (2004:1035) argued that in logistic regressions controlling for age, caregiver/family factors were the most strongly associated with non-adherence. These include worse parent-child communication, higher caregiver stress, less disclosure to others and quality of life.

Category 4.3.2: Multiple competing factors challenge children's ability to adhere to ART

The results of this study revealed that there were multiple competing factors challenging children's ability to adhere to ART. The FGD participants recognised access, poverty,

stigma and discrimination, inadequate knowledge, and irregular availability of paediatric drug formulations as factors limiting paediatric ART adherence.

Sub-category 4.3.2.1: Poverty

FGD participants perceived that children experienced low ART adherence rates due to the effects of the parents' poverty. These included lack of funds to pay transport costs and medical bills (other than ART costs) in centres providing quality ART services. Data display 4.3.2.1 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.3.2.1 Poverty
• The first barrier you have to break is whatever will make the parents not to be able to come [to hospital for their drug refills], including the economic situation in the family. • Poverty is the major barrier…secondly, distance • We see some of them here, they will tell you madam, the money is not there, I don't have money for transport today that's why. • Some of them are jobless; they don't have jobs to even get money for transportation because they don't want to be seen around their neighbourhood so they don't want to go to that place [anywhere nearer their home]. • A lot of clients default on account of lack of transport fares. • They will be like, *ha*! This *wahala* is too much for me to go the clinic again today. I can't make it. • They are jobless, they don't have anybody. There is no helper, so, because of that, they may not come when it is their due time to come for their drugs.

Rosen et al (2007:524) reported that South Africa is providing ART free of charge in order to increase access for poorer patients and promote adherence. However, non-drug costs of obtaining treatment might limit access. Supporting this, Kip et al (2009:6) argued that economic issues do affect ART adherence rates even if the ARVs are supplied free of charge. To estimate the costs that South African patients incur in obtaining ART, Rosen et al (2007:524-525) reported that patients had to visit a treatment clinic at least six times during the year in which they started ART. The average cost per visit was R120, plus travel and waiting time. Patients and caregivers also spent considerable time and money between visits. Thus, patient costs should be considered in efforts to sustain adherence and expand access.

Ware et al (2009:0039) reported that parents whose children were taking ART routinely overcame economic obstacles through a number of deliberate strategies. These were aimed at prioritising adherence: borrowing and begging transport funds, making impossible choices to allocate resources in favour of treatment, and doing without some necessities. They went without food, and carried out hard manual labour in order to get money to pay back the amount borrowed. Laniece et al (2003:S103) reported that patients who made little or no contribution to the cost of their treatment had better adherence to ARVs than those who fully paid for their ART services.

Sub-category 4.3.2.2: Inadequate access to quality paediatric ART services

The FGD participants perceived that inadequate access to quality paediatric ART services caused drawbacks in paediatric ART adherence in their health facilities. These included far distances from patients' homes to the health facilities providing quality ART services. FGD participants perceived that the patients were given one month's stock of ARVs, while they preferred to receive 2-3 months stock. Data display 4.3.2.2 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.3.2.2 Inadequate access to quality paediatric ART services
• Availability of drugs is a challenge to adherence on the basis that sometimes the parents want the drugs for two to three months duration, but presently that is not obtainable. • Currently, the duration is approximately one month for the longest duration and coming back at such close interval presents a challenge in terms of transportation costs. • Distance, because some are coming from a very far distance like Ogun State.

Accessibility to quality AIDS care and medications was one of the most significant barriers to adherence. This was noted by Mukhtar-Yola et al (2006:144) in their study conducted in Kano, Nigeria. However, even where the medications were available, some caregivers failed to give to these children. For instance, Giacomet et al (2003:1398) reported that of the 94 children on ART in Italy, 16.0% omitted more than 5.0% of the total doses in 4 days. Only 11.0% of caregivers reported that therapy had been administered at the correct times.

The UNICEF (2005:7) reported that fewer than 5.0% of young HIV-positive children in need of paediatric ART, were receiving ARVs. However, in Nigeria fewer than 1.0% of children had access to paediatric ART. This was due to poor health systems and lack of adequate priority setting for health.

Documented evidence indicated that resource poor-settings could have good adherence to ART. In a study report by Ellis and Molyneux (2007:261) children were feasibly and effectively treated with ART in Malawi (resource-poor country), with good adherence reports. Lack of appropriate laboratory facilities, extra staff and paediatric drug formulations, although ideal, did not prevent the commencement of ART for Malawi's children. Likewise, Marston et al (2007:106) reported that the response to ART in a slum population was comparable to that seen in industrialised settings, indicating that resource-poor settings did not necessarily imply poor paediatric ART adherence rates. With government commitment, donor support, and community involvement, it is feasible to implement successful ART programmes even in extremely challenging social and environmental conditions, such as in Nigeria.

Sub-category 4.3.2.3: Inadequate treatment knowledge

Inadequate knowledge of ART also contributed to lack of adherence in children. The FGD participants in both Kano and Lagos explained that even among the educated classes, some were ignorant about the benefits of taking ARVs. Data display 4.3.2.3 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.3.2.3 Inadequate treatment knowledge
• Literacy – how does he understand medication and then how does he accept the medication? • How can I take drugs for life? • Each and every day to be taking drugs? *Kai!* I cannot do that, *Kai!* Let me go to native…once, twice, when I take, it will disappear. • There is a doctor that died in this town…he never believed there was anything like HIV infection. • Some people with their education and every thing they still treat everything with indifference

Marhefka et al (2004:323) reported that significant regimen knowledge deficits were significantly associated with low ART adherence levels. Also in this category was the inaccurate identification of prescribed medications among caregivers. The knowledge gap that contributed to inadequate paediatric ART adherence was not only common to parents and caregivers of children at home. Tindyebwa et al (2005:175-176) identified that in many SSA countries, health practitioners were inadequately prepared to address the needs of HIV-infected children, adolescents and young people. Particularly, they faced knowledge gaps with those who were recently diagnosed. Also, knowledge and experience of services for the mental and psychosocial needs of children living with HIV/AIDS were limited.

Sub-category 4.3.2.4: Stigma

Fear of the unknown might contribute to stigma and discrimination. This made some parents to refuse accessing health services within their immediate communities. Others collected the drugs but failed to administer these to the children as prescribed. They feared that people around them were going to detect the child's HIV status from the labels on the medicine bottle. Data display 4.3.2.4 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.3.2.4 Stigma
• Let's say its time for the mother to administer the drug and there is a third party around and let's say the person is even educated. He can read the label on the bottle. She may not be able to administer the drug at that time because of that fear of stigma. That, that third party may go and broadcast the type of drugs the child is taking. So, she'll not administer the drug. • Some will tell you they don't want people to know the kind of drug the child is on. We tell them they may remove the pack or the label and put something that indicates whether it is Nevirapine or Zidovudine so that they can identify the drug and if anybody asks them they will tell them it is multivitamin for the child. • Some parents can not tell their children their status, that they are HIV positive. • If HIV can be looked upon the way we see diabetes or hypertension, I think everybody will feel better. • If they [children] know that they are [HIV] positive, they will tell other children outside and may be the stigma will come in. • When you see that the father is not HIV positive, but the mother is …you see there is a kind of guilty feeling on the part of the mother.

Bikaalo-Kajura et al (2006) reported that stigma remained a barrier to adherence even for children who had complete disclosure and a supportive relationship with at least one parent.

Kip et al (2009:6) also noted low literacy levels and stigma impacted negatively on ART adherence. Failure to disclose one's HIV positive status to even other family members or relatives was cited as a common problem. This stigma negated regular clinic attendance and ART taking in Botswana (Kip et al 2009:6).

Sub-category 4.3.2.5: Side effects of ARVs and other children-related factors

FGD participants perceived that side effects were major factors that caused paediatric ART non-adherence. In their opinions, children disliked ARVs because they were unpalatable, caused vomiting and other side effects. Data display 4.3.2.5 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.3.2.5 Side effects of ARVs and other children factors
• Even though some adhere to drugs, some people cannot cope with some of the side effects. This is a major cause of default. • When they have knowledge that this thing is a drug, I think most of them are resentful about the whole thing. • Something that is not palatable, they see it as a drug; there seems to be some resentment in taking their medications. • Side effects of drugs…the mother may be discouraged and stop the medication. • There was a mother that was telling me that whenever it is 8 in the evening, the child used to run and hide himself because whenever they give him the drugs, he used to vomit.

Heath, Singer, O'shaughnessy, Montaner & Hogg (2002:211) reported that out of 638 study subjects in British Columbia, Canada, 70 (11.0%) reported intentional non-adherence with between 4.0% and 7.4% reporting this activity over the preceding year. Those subjects reporting at least one severe symptom were more than twice as likely to report intentional nonadherence. Similarly, each additional symptom requiring clinical action was associated with a 25.0% increase in the risk of intentional non-adherence.

Sub-category 4.3.2.6: Parent forgot to administer ARVs to children

Forgetfulness was one of the factors caused a lack of paediatric ART adherence. Some parents/caregivers were perceived to be so busy that they always forgot to administer ARVs to their children. Others forgot to turn up for ARV refills at the hospital, thus, ran out of medicines. Data display 4.3.2.6 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.3.2.5
Parent forgot to administer ARVs to children

- At times, they forget. Some people due to activities, they normally forget social activities. They can forget to come [to hospital].
- Some parents forget the actual time, may be they will be busy doing something till the time to administer the drug will be over.
- The parents may not have time to take care of them. They will leave in the morning to come back late. So, they say that they forgot to take care of the child and give the normal drug at the right time.

Ammassari, Trotta, Murri, Castelli, Narciso, Noto, Vecchiet, Monforte, Wu and Antinori (2002:S126) reported a systematic search of the literature using MEDLINE database for the years 1998 to 2002. They reported that the most common reasons patients reported for skipping ART medications included forgetfulness in taking medications(30.0%-66.0% of participants). Other reasons included the complexity of medication regimens (7.0%–52.0%), difficulties in integrating treatment schedules into their daily activities (36.0%–57.0%), fears of side effects (13.0%–42.0%), worries about HIV disclosures (14.0%–33.0%).

Sub-category 4.3.2.7: Inadequate health systems infrastructure

Health care workers perceived that their health systems infrastructure was overstretched by the increasing number of patients in need of quality paediatric ART services. The rooms earmarked for adherence counselling and the numbers of trained adherence counsellors were no longer adequate for the increasing number of clients. The few trained

members of staff were transferred from the paediatric ART clinic to other units or facilities, resulting in further staff shortages and burnout of the few.

FGD participants in both Kano and Lagos identified the need for health service managers to recognise challenges inherent in their programmes and resolve them early, in order to improve the quality of services. Data display 4.3.2.7 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.3.2.7 Inadequate health systems infrastructure
• Staff shortage and consulting rooms' challenges • The workload is too much • Transfer of trained counsellors to other units or other facilities. • We used to run 2 clinics per week…now, from Mondays to Fridays, we run clinics.

The attainment of patient satisfaction with ART services was challenged by many doctors and nurses, faced with low pay and poor working conditions. They were seeking jobs in industrialised countries (UNICEF, 2005:8). The undermined health system contributed to a total collapse of the quality of paediatric patient care. This lead to inadequate adherence counselling, high losses to follow-up and threats to treatment outcomes. In addition, children affected by HIV/AIDS were increasingly missing out on other measures. These included safe water and sanitation, proper infant feeding practices and nutritional support (UNICEF 2005:8-11). Van Oosterhout et al (2007:1245) report that despite the human resource crisis in the health care system, remarkable improvements in the quantity and quality of care were achieved.

4.4.1.4 Theme 4: Strategies for improving paediatric ART adherence

The fourth theme that emerged from the data analysis concerned strategies for improving paediatric ART adherence**.** Data display 4.4 outlines the categories in this theme.

DATA DISPLAY 4.4 THEME 4: STRATEGIES FOR IMPROVING PAEDIATRIC ART ADHERENCE (OVERVIEW)
4.4.1 Improved quality of paediatric ART services was fundamental to paediatric ART adherence 4.4.2 Empowering parents improved adherence to ART in children 4.4.3 Addressing stigma and discrimination against PLHA improved access to ART

Category 4.4.1 Improved quality of paediatric ART services is fundamental to paediatric ART adherence

FGD participants perceived that improving the quality of ART services is important to patients, staff, and the organisation. They explained that these included staff training and retention, provision of comfortable workspace, such as adherence counselling rooms and disclosure of the type of drug the child was taking. Other quality improvement strategies included reducing staff burnout by evenly spreading workload among staff, providing high quality information and education of clients and caregivers, and reducing the dosing and number of drugs through switching to ARV combination therapies. Data display 4.4.1 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.4.1 Improved quality of paediatric ART services was fundamental to paediatric ART adherence
• There should be more adherence counsellors to counsel clients, because the pressure of dealing with too many clients can compromise quality as a result of fatigue from over work. • Conduct training on how to counsel people on adherence because there is a lot of adherence going on that is not solid. • If you are a trained counsellor…you will be well grounded on how to do it. • I think they should train more on how to counsel. • Awareness creation…if people are better informed, adherence will definitely improve. • Train more staff, re-train and address the issue of staff attrition. • If we reduce the dosing and the number of drugs, may be, by combining them, I think that will aid adherence. • The quality of information we give…counts a lot on how they listen to us and it will have a bearing on the quality of adherence. • Proper education about the side effects of drugs should be given to the parents. • As new information comes concerning the situation, the parent and other parties involved should have such information. • You must disclose to the child the drugs [he is taking]

Shah (2007:55) elucidates that ART is effective in suppressing HIV replication, decreasing morbidity and mortality associated with HIV. It also improves the quality of life in adults as well as children infected with HIV. Kip et al (2009:6) asserted that some patients missed their follow-up clinic appointments because nurses did not always portray positive attitudes

towards them in Botswana. These authors recommended that improved adherence counselling skills and maintenance of supportive attitudes towards ART patients could enable nurses' to help patients to maintain higher levels of ART adherence (Kip et al 2009:7).

FHI (2004:349) suggests that to improve adherence and patient retention, the following intervention strategies should be applied in ART programmes:

- educate and motivate patients
- provide basic drug information
- discuss the importance of adherence
- timing of medication
- provide knowledge about possible drug interactions
- simplify drug regimens
- tailor treatment to the patient's lifestyle
- use an adherence team
- address patient-related issues
- recruit an adherence monitor
- provide adherence promoting devices
- use home-based care staff to promote adherence and
- use the adaptation of directly observed therapy (DOT).

For the purpose of increasing the quality of paediatric ART, Fraaij et al (2004:125) suggested the use of a therapeutic drug monitoring (TDM) tool in the treatment of HIV-1-infected children to assess ART adherence. However, the authors warned that one should be cautious to base assumptions on plasma levels alone because aberrant

plasma levels might also be the result of other factors such as changes in nutritional habits, drug-drug interactions, or changing gastric motility.

Category 4.4.2: Empowering parents improve adherence to ART in children

FGD participants recognised that most parents of children accessing care in both Kano and Lagos were resource-limited. They called for educational and economic empowerment of caregivers/parents to support paediatric ART adherence. These, they suggested should include income generating activities for the parent and caregivers, continuous and re-enforced adherence counselling, provision of job opportunities for caregivers in need, payment of re-imbursements to parent and child for transportation and feeding and re-enforced community care programmes, especially, support group activities as a way of empowering caregivers and those under their care. Data display 4.4.2 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.4.2 Empowering parents improve adherence to ART in children
• Proper education; the parent should be grounded, that if you don't give your child this drug, these are the problems the child will face. • Proper education about the side effects of drugs should be given to the parents. • Empower the parents…the advent of support groups has helped to empower them as they have communal income generating activities like corn blending mills, local spaghetti making machines that give them some income. • For those who don't have jobs, we can invite social workers may be they give them money to start petty trading so that they may have money…for transportation, for feeding and all those things. • Each time they come to the clinic there should be an ongoing adherence counselling to see how they can talk about it. • It's just a matter of empowering them, because most of those people that have problems; if they have something doing they will be able to come for their drugs and adhere to it. • Support groups, when they come, they see others, then, with the things they are given… encouraged them. • [In support group meetings], they discuss, they talk about the drugs they are using. Each one of them will give his or her own opinion about the drugs to others. They ones that are just joining them…will have interest of using that drug because they can see others who have improved. • To employ them [parents] if there is vacancy for their cadre. • Training of the actual client that is having this problem, I mean patient too. • Each time they come to the clinic there should be an ongoing adherence counselling sessions • If we empower them, the parents, they will have courage to come and collect the drugs. • The parents are empowered when they have something doing – they can afford to pay transport fare to come for their drugs, they will adhere very well to treatment.

In univariate analyses, Mellins et al (2004:1035) noted that non-adherence was significantly associated with higher caregiver stress levels. Others include lower caregiver quality of life and worse caregiver cognitive functioning. Also, in logistic regressions controlling for age, caregiver/family factors were associated with non-adherence. These included worse parent-child communications, higher caregiver stress levels, disclosure to fewer persons and a poorer quality of life (Mellins et al 2004:1035).

Brackis-Cott et al (2003:252) concluded that adherence to ART was a long-term, ongoing problem directly tied to the family life of the HIV positive child. It included providers playing an integral part in this struggle. This required that the parent should be empowered with a sustainable capacity to maintain the child throughout life. Mukhtar-Yola et al (2006:141) suggested that the social class of the parent did not significantly affect children's ART adherence levels.

Category 4.4.3: ***Address stigma and discrimination against PLHA in order to improve access to ART***

This referred to the provision of easy and convenient ways of receiving treatment without undue fears of the unknown, stress or pressure to children and families. FGD participants perceived that lack of access was not only due to absolute distance from home to the nearest ART centre. They argued that it also included the distance from home to a location or ART centre that the family felt more comfortable attending. Parents of children living with AIDS were more comfortable with health facilities where they were not known. Parent/caregivers demanded quality care and privacy for their children. They also demanded that ARV refills should be enough to last 2-3 months, to reduce the burden associated with frequent travels. Data display 4.4.3 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.4.3 Addressing stigma and discrimination against PLHA improved access to ART
• Stigma, because people come from far places like Yola and I am sure there are hospitals around their vicinity with ARVs. • They like to go far away because of the fact that nobody who knows them will see them sitting in an ART clinic. • If we can remove the issue of stigma, so that more people will become aware of this, then there will be a lot of improvement. • As long as it [stigma] remains a secret between the patient and the doctor, I think the problem [of lack of adherence] will continue. • The parents want the drugs for two to three months duration, but presently that is not obtainable. • Currently, the duration is approximately one month for the longest duration and coming back at such close interval presents a challenge • Teachers must at least help them, inform them about their treatment

Byrne et al (2002:151) suggested that adherence strategies devised by families depended heavily on family support. Others included the resolution of disclosure issues within households. Williams et al (2006:e1745), on the other hand, highlight the importance of evaluating and supporting the family environment to optimise adherence. Veinot et al (2006:266) noted that children might need support for managing difficulties with treatments. These included side effects, social impacts, and adherence. Developmentally appropriate, empowerment-based treatment education might be helpful for HIV-positive children (Veinot et al 2006:266).

Reddington et al (2000:1148) indicated that adherence proved too difficult for many PLHA. The PLHA are concerned about the loss of their privacy, which might have affected their abilities to adhere to complicated medication regimens. The most helpful interventions would be to make modifications to existing standard operating procedures. Another is to improve the child and parent's convenience to hospital attendance and increase their access to adherence counselling. Zhang et al (2007:598) asserted that there should be improved access to second-line regimens.

Nabukeera-Barungi et al (2007:130) recommend that parents and caregivers should be encouraged to disclose the child's status to at least one other person before starting ART. Other strategies such as home visits, peer counselling and community support groups might need to be incorporated into the care programme (Nabukeera-Barungi et al 2007:130). All these strategies require that the parent or caregiver attend ART services in a facility nearest to their residence. This way, the family could be integrated into the social

network of the community, such as community support groups.

4.5 Summary

This chapter addressed the analysis of data obtained from the three FGDs. The framework approach of data analysis was used in this study. Through this approach, the researcher used a systematic procedure for analysing the qualitative data. The procedure comprised the following steps: familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation. Data were presented in tabular forms, according to themes, categories and sub-categories, which resulted from the data analysis. Four major themes were identified from the data analysis, namely: health workers' views regarding paediatric ART adherence in children who received free ARVs, ART adherence patterns of children receiving free ARVs, factors affecting paediatric ART adherence and strategies for improving paediatric ART adherence. The research findings were elaborated by further explanation of the themes, categories and sub-categories. Quotation of comments by FGD participants were made where appropriate. Description of related literature that aligns or contradicts the views of the FGD participants were also made. The findings, concerning health workers' views about paediatric ART adherence, are summarised in table 4.2.

Table 4.2: Summary of data analysis of health care workers' views regarding paediatric ART adherence

Research question	**Findings from the study**
What were the health workers' views regarding paediatric ART adherence in children who received free ARVs from the two participating health facilities in Nigeria?	**THEME 1: Paediatric ART adherence in children who received free ARVs** • The economic burden of ART on parent is instrumental to paediatric ART non-adherence
What were the health workers' views regarding the ART adherence patterns of children receiving free ARVs from the health facilities in Nigeria?	**THEME 2: ART adherence patterns of children receiving free ARVs** • Family centred care approach improved children's adherence to ART • Adherence improved where more than one person in a household was on ART • Children from mother- headed single parent households (SPHH) adhered to ART better than those from father-headed SPHH • Children of biological parents presented with higher adherence levels to ART than those from non-biological parents • Parents' literacy levels influenced their children's adherence to ART
What were the health care providers' views regarding the factors affecting children's ART adherence in the participating health facilities in Nigeria?	**THEME 3: Factors affecting paediatric ART adherence** • Parents were determinants of adherence in children • Multiple competing factors challenged children's ability to adhere to ART *Poverty *Inadequate access to quality paediatric ART services *Inadequate treatment knowledge *Stigma *Side effects of ARVs and other children factors *Parent forgot to administer drugs *Inadequate health system infrastructure
	THEME 4: Strategies for improving paediatric ART adherence • Improved quality of paediatric ART services were

Research question	Findings from the study
	fundamental to paediatric ART adherence. • Empowering parents is essential for improved adherence to ART in children • Creating jobs and/or income generating projects for the parents would improve their financial situation • Address stigma and discrimination against PLHA in order to improve access to ART

The next chapter (chapter 5) will cover conclusions, limitation and recommendations arising from this study.

CHAPTER 5

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In the previous chapter, data analysis and research findings were discussed. This chapter will focus on drawing conclusions. It will also describe the limitations of the study, and recommendations for improving paediatric ART adherence.

The purpose of the study was to explore and describe the perceptions of health care providers on factors that influence paediatric ART adherence in health facilities in Nigeria. The conclusions, based on the research findings discussed in chapter 4, will be used to answer the research questions which were formulated in section 1.4.2 as follows;

- What were the health workers' views regarding paediatric ART adherence in children who received free ARVs from the two participating health facilities in Nigeria?
- What were the health workers' views regarding the ART adherence patterns of children receiving free ARVs from the health facilities in Nigeria?
- What were the health care providers' views regarding the factors affecting children's ART adherence in the participating health facilities in Nigeria?

5.2 CONCLUSIONS

The research questions were evaluated against the research findings to determine whether they have been answered.

5.2.1 Health workers' views regarding paediatric ART adherence in children who received free ARVs from the two participating health facilities in Nigeria

According to the views of the FGDs, paediatric ART adherence was reportedly higher among children with better economic status. This was the case despite the availability of free ARVs. Parents still needed to incur expenses for travelling to the clinics, for buying medicines other than ARVs and for buying food supplements for their HIV positive children.

The results of this study revealed five patterns of adherence in children. According to the perceptions of the health care workers, paediatric ART adherence was reportedly higher:

- among children whose parent attended the family centred care clinics as a family unit
- in households where more than one person was on ART
- among children from mother- headed SPHH than those from father-headed SPHH
- among children whose caregivers were their biological parent than those from non-biological parent
- among children with better educated parents.

5.2.2 Health care workers' views regarding the factors affecting children's adherence to ART in two health facilities in Nigeria

The results of this study revealed three key determinants namely that paediatric ART adherence was:

- reportedly determined by the parents
- challenged by multiple competing factors, such as poverty, inadequate access to quality paediatric ART services, inadequate treatment knowledge, stigma, side effects of ARVs, and inadequate health systems infrastructure

- *Poverty*

Paediatric ART adherence was reportedly challenged by poverty, including lack of funds to pay transport costs and medical bills (other than ARVs).

- *Inadequate access to quality paediatric ART services*

Long distances impacted negatively on access to adequate ARVs. Parents/caregivers required 2-3months refills, but the health facilities provided only one month's supplies at any one visit.

- *Inadequate treatment knowledge*

Paediatric ART adherence was reportedly challenged by parents/caregivers' inadequate knowledge of ART (dosage, side effects), irrespective of their level of education and exposure.

- *Stigma*

Stigma and discrimination influenced some parents to refuse accessing health services within their immediate communities. Others collected the drugs but failed to administer these to their children at the right times and/or in the correct doses. They feared that other people might detect the child's HIV status from the labels on the medicine bottles.

- *Side- effects and unpalatibility of ARVs*

Side effects of ARVs (especially vomiting) the unpalatability ARVs impacted negatively on paediatric ART adherence levels.

- *Inadequate health systems infrastructure*

Paediatric ART adherence levels were reportedly challenged by health systems' inadequate infrastructures. The increasing number of ART patients made huge demands of the health services. The rooms earmarked for adherence counselling and the number of trained adherence counsellors were inadequate to cope with the ever increasing numbers of ART patients. Transferring trained staff members from the paediatric ART clinic to other units or facilities, resulted in further staff shortages.

5.3 LIMITATIONS OF THE STUDY

The generalisability of the study's findings is limited by the fact that only 17 health care workers participated in the FGDs conducted during this study. Therefore, the findings arising from the study may not be generalised beyond the paediatric ART clinics of the health facilities studied. Only FGDs were used to collect data. Different results might have been obtained if quantitative structured interviews had been conducted with the health care providers, and/or if checklists had been completed about observations during paediatric clinic visits, and/or from paediatric patients' records. Moreover, the results of this study only portray the perceptions of healthcare providers, not those of the caregivers/parents nor of the paediatric ART patients themselves.

5.4 RECOMMENDATIONS

5.4.2 Recommendation for improving paediatric ART adherence

The following recommendations might improve paediatric ART adherence:

- Stable paediatric ART patients should receive three months' supplies of ARVs, in stead of monthly supplies. This could help to reduce the burdens of transportation
- Implement stigma reduction and family integration programmes. This should address stigma and discrimination against families affected by AIDS, and enable parents/caregivers to collect the ARVs from their nearest local clinics rather than from more distant clinics to avoid recognition by their community members.
- Train a critical mass of health care workers and caregivers on treatment adherence, to cope with the increasing demands for paediatric ART adherence counselling.

- Adopt a paradigm shift from a family centred care approach (FCCA) to a comprehensive family centred care approach (CFCCA). This entails looking beyond the family's health problems, to economic, psycho-social, civil, religious, cultural and any other needs that might impact on paediatric ART adherence.
- Strengthen linkages between the health facility and community-based programmes. Community-based programmes should include income-generating activities for parents/caregivers, and care for orphans and vulnerable children. Others include parental empowerment programmes, food and nutrition, education, water and sanitation, basic health care and psychosocial support programmes.
- Mainstream adherence counselling at all points of service delivery so that clients' families will get the same consistent adherence counselling and treatment messages at every point of service.
- Develop and implement targeted treatment education and adherence counselling programmes that are culturally sensitive and adapted to parents'/caregivers' individual differences.
- Encourage the biological parents of CLWHA to personally assume responsibility for ensuring the child adheres to ART.
- Encourage all family members, especially, those on ART, to participate in paediatric ART adherence programmes of the family. They should serve as treatment supporters to the child on ART.

5.4.3 Recommendations for further studies

Future researchers should conduct experimental research studies on the following;

- Investigate the relationship between children's adherence to ART and parents' economic status.
- Studies could be done comparing paediatric ART adherence levels at a site utilising the family centred care approach and another not utilising this approach.
- ART adherence levels should be compared among children from SPHH headed by fathers and those from SPHH headed by mothers.

- Comparative studies of adherence among children whose caregivers are their biological parents and those whose caregivers are non-biological parents.
- Investigate the relationship between parents' literacy levels and ART adherence in their children.
- Investigate the correlation between improved quality of ART services and children's adherence to ART.
- Investigate the relationship between community stigma reduction programmes and ART clinic attendance.

5.5 CONCLUSIONS

This study sought to describe the perceptions of health care providers on factors that influenced adherence to ARVs by children under five in two health facilities in Nigeria. Health care workers were drawn from Kano and Lagos, Nigeria, as FGD participants. The participating health care providers perceived poverty, illiteracy, stigma and discrimination, inappropriate care approaches, and parental factors as major factors influencing children's adherence to ARVs. Mainstreaming adherence counselling in paediatric ART, and adopting comprehensive family centred care approaches were identified as measures for improving paediatric ART adherence. Other measures suggested included quality improvement of paediatric ART services, parental empowerment and stigma and discrimination reduction programmes.

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ANNEXURE A

Certificate of participation in the training on research ethics

ANNEXURE B

Letters requesting permission to conduct the study

ANNEXURE C

Letters granting permission to conduct the study

ANNEXURE D

Ethical clearance certificate from Unisa

ANNEXURE E

Letter of information to FGD participants

ANNEXURE F

Focus Group Discussion Guide