THE ROLE OF PROFESSIONAL NURSES ON ANTI-RETROVIRAL THERAPY ADHERENCE AMONG CHILDREN LIVING WITH HIV/AIDS IN LEJWELEPUTSWA DISTRICT: FREE STATE, SOUTH AFRICA

by

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DECLARATION

I declare that **THE ROLE OF PROFESSIONAL NURSES ON ANTI-RETROVIRAL THERAPY ADHERENCE AMONG CHILDREN LIVING WITH HIV/AIDS IN LEJWELEPUTSWA DISTRICT: FREE STATE, SOUTH AFRICA** 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.

…… **……**

SIGNATURE **DATE**

MOREKU DC

DEDICATION

This work is dedicated to all children, living with HIV/AIDS worldwide, people who are affected by this epidemic and the professional nurses who are forever dedicated and trying thier best to provide services to those in need. **Lastly to my late father Mothibedi Simon Ledibane and brother Leponesa Levy Ledibane who would have been the happiest to see me complete this study.**

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ABSTRACT

Survival of children with HIV/AIDS has increased considerably with the use of effective antiretroviral therapy. However, the benefits of this therapy are limited by the difficulty of adherence to the treatment. This study sought to explore the role of professional nurses on anti-retroviral therapy adherence among children in Lejweleputswa district: Free State, South Africa. An exploratory descriptive qualitative research design was used to identify and describe role of professional nurses toward anti-retroviral therapy adherence among children. Population for this study included seventeen (17) professional nurses working in four purposively sampled Primary Health Care clinics invited to participate in the study. Four focus group discussions were conducted in which each group had 6 participants. The transcribed data was analysed using the framework approach of data analysis. Professional nurses in Lejweleputswa district report poor knowledge of parents/caregivers of children, perceived poverty, stigma and discrimination, inappropriate care approaches, and parental dynamics as factors influencing poor ART adherence. Recommendations for enhancing children ART adherence levels in Lejweleputswa district included: mainstreaming adherence counselling in children ART and adopting a comprehensive family centered care approach were identified as measures for improving children ART adherence. Other measures included integration of ART services into Primary Health Care (PHC) services, parental empowerment, development of a programme to reduce stigma and discrimination in the community.

KEY TERMS: Anti-retroviral therapy (ART), ART adherence, children living with HIV, auto-Immune Deficiency Syndrome (AIDS)

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LIST OF ABBREVATIONS

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

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 : Sexual 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 Education

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CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION AND BACKGROUND

Antiretroviral therapy (ART) is the only lifesaver presently for individuals including children living with Human Immunodeficiency Virus (HIV) as well as Acquired Immune Deficiency Syndrome (AIDS). World Health Organization (WHO) and the joint United Nations programme on HIV/AIDS (UNAIDS) estimated that 34 million people were living with HIV as of 2013 globally, including 3.3 million children of less than 15 years. More than 90% of these children live in sub-Saharan Africa. Approximately 2.5 million people, including 330,000 children, were newly infected with HIV (Scalon & Vreeman, 2013). There is need therefore to identify the caregiver factors associated with adherence as this will help improve adherence among children thus increasing the likelihood of suppressing the virus, postponing the disease progression, decreasing morbidity associated with HIV and improving the quality of life in children infected with HIV. Improving adherence also helps reduce resistance thus reduces exposure to resistant strains of HIV virus and the need for expensive second line treatment

The estimated number of people dying from AIDS-related causes worldwide in 2011 was 1.7 million where 230,000 of them were children. South Africa (SA) is no exception as was an indication from the National Department of Health (2013:22) (NDoH) that South Africa has the highest number of people living with the HIV/AIDS. The introduction of Antiretroviral Therapy (ART) has shown a tremendous reduction in HIV-related mortality and morbidity among people living with HIV / AIDS (Ross, Aung, Campbell, & Ogunbanj, 2011). Adherence to ART is the key to a successful treatment outcome. Maintaining optimal adherence to antiretroviral drugs is essential for HIV infection management. This study aimed at the identification of the roles of professional nurses toward anti-retroviral therapy adherence among children in Lejweleputswa district: Free State, South Africa and to explore the factors influencing adherence amongst ART-prescribed children and caregivers/parents. The study

specifically focused on determining roles of professional nurses/healthcare workers regarding children's adherence to antiretroviral therapy (ART), received free of charge through subsidization in Lejweleputswa district: Free State, South Africa, and factors influencing pediatric patients' adherence to ART.

1.2 VISION ABOUT THE STATUS OF HIV/AIDS EPIDEMIC WORLDWIDE

The emergence of the HIV epidemic is one of the biggest public health challenges the world has ever seen in recent history. In the last three decades HIV has spread rapidly and affected all sectors of society: young people children and adults, men and women, and the rich as well as the poor (FHAPCO 2012:1). However, the vision of UNAIDS (2013:19) was that by 2015 there should not be children born with Human Immunodeficiency Virus (HIV) and that HIV-positive mothers will not die from HIV, therefore giving them a chance to raise their children. HIV remains an important cause of mortality in both women and children worldwide. In the last decade there has been a global scale up of services to prevent HIV transmission from mother-to-child. This has led to a significant impact on decreasing child mortality, improving maternal health and the fight against HIV and Acquired Immune Deficiency Syndrome (AIDS) epidemic: a positive move towards achieving Millennium Development Goals (MDG) 4, 5 and 6. An estimated 33.3 million people young and old are living with HIV globally, 67% of whom reside in sub-Saharan Africa. Furthermore, the region accounted as many as 70% of 1.7 million HIV-related deaths that occurred in 2013 (Mashau, 2015:111); UNAIDS, 2010:19). The impact of HIV in Sub-Saharan varies widely. There is also evidence that scale-up of antiretroviral therapy (ART) can reverse some of the negative social economic impacts of HIV on individuals, families and communities, with positive changes in life expectancy, demographic composition and fertility. Introduction of Antiretroviral Therapy (ART) has shown a tremendous reduction in HIV-related \mortality and morbidity in people living with HIV / AIDS including children. Although this treatment is not curative, continuous, lifelong treatment with antiretroviral therapy has significantly improved life expectancy and turned HIV from a terminal infection into a more chronic disease. However, adherence to ART is the key to a successful treatment outcome. South African study by Mashau (2015:121); Watt, Maman, Golin, Earp, Eng, Bangdiwala and Jacobson (2010:388) report that lifelong treatment of

antiretroviral therapy has significantly improved life expectancy and turned HIV from a terminal infection into a chronic condition. Various campaigns were launched on the basis of making the communities aware about HIV/AIDS and the use of antiretroviral therapy, warned that the level of adherent should be 95% and more to achieve effective suppression of the viral load and to prevent the development of resistant viruses.

Poor adherence, of course may lead to medication failure, viral mutations and development of drug resistance among patients living with HIV. This study assessed the role of professional nurses on anti-retroviral therapy adherence among children who are already on ART. The researcher finds it very important to establish whether professional nurses are facilitating the adherent on ART among children living with HIV/AIDS. There is need therefore to identify the factors associated with adherence as this will help improve adherence in children thus increasing the likelihood of suppressing the virus, postponing the disease progression, decreasing morbidity associated with HIV and improving the quality of life in children infected with HIV.

HIV/AIDS is a global pandemic disease. Globally it is approximated that 34 million people have HIV, of which 17.2 million are men, 16.8 million are women, and 3.4 million are children less than 15 years old (UNAIDS, 2011:10). The disease is widely spread in low and middle income developing countries; such as South Africa, Botswana, and other Sub-Saharan African countries (Jointed United Nations programme on HIV / AIDS (UNAIDS, 2011). However, the rate of HIV infection in South Africa remains high despite the continued efforts to prevent its transmission. Conversely, the rate of AIDS related mortality has been on the decline since the country introduced its comprehensive care and treatment plan.

South Africa's free ARV provision since 2006 increased the access and uptake of ARVs (NACA, 2010:17). 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 14 years and younger received ART (Epidemiological Fact Sheet

on HIV and AIDS 2013:12). This is greatly facilitated by the professional nurses responsible in the clinic and health care centers, PEPFAR and Global Fund Round 5 (GFR5) support ART programmes in South Africa. 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 minute of every day, and a young person aged 15 – 24 contracts HIV every 15 seconds. WHO (2013:14) reports that of the 240 000 HIV positive pregnant women who needed ARVs for PNTCT in South Africa, about 10.0%, or 12 278, received ARVs in 2014. Although it is an increase from less than 1.0% in 2012 and about 5.0% in 2013, increasing numbers of children are still delivered 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 generation population, HIV/AIDS directly affects millions of children, adolescents and young people. In the hardest hit countries, UNICEF (2011:6) 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, 2012:4). Children affected by HIV/AIDS might miss out on ART and the antibiotic contrimoxazole that is effective for decreasing mortalities among HIV – positive children that is effective for decreasing moralities among HIV – positive children (UNICEF 2012:7). While WHO (2013) reports a global picture than 5.0% of young HIV – positive children in need of paediatric ART are receiving it, the case in South Africa is worse – however the children have access to children ART.

In SSA generally, and specifically in South Africa, where ART programme is accessed by millions of the affected patients, designated public hospitals for AIDS treatment are being overwhelmed with caring for AIDS – affected patients. This reduces the ability of health services and the healthcare workers unable to care for children with other life threatening illnesses such as pneumonia, diarrhea and malaria. Health systems are further undermined by the loss of staff. UNAIDS (2013:15) estimates that death rates among patients in most highly affected countries in Africa have increased five or six fold as a result of AIDS – related

illnesses. UNICEF (2012:8) notes that in SSA, many doctors and nurses, faced with low pay and poor working conditions, are seeking jobs in industrialized countries. The undermined health system contributes to a total collapse of the quality of children 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 fed practices and natural support – to help them achieve better treatment outcomes, survive, developed grow (UNICEF 2012:8).

In focusing on the drug adherence situation in Africa, Gill, Hammer, 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, Mashau (2015:1243) assert that more recent research shows that adherence rates in Africa are quite variable and often poor. In direct contrast to the assertion by Mashau (2015:1243), Muller, Bode, Myer, Roux and Von Steinbuchel (2008) report that adherence to children 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, professional nurses' reports seemed to be unreliable in this setting. Similar findings were reported by a study conducted by Senegal, Laniece, Ciss, Desclaux, Diop, Mbodj, Ndiaye, Sylla, Delaporte,and Ndoye (2013:13) that among the 158 patients level of adherence was high. 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 industrialized 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. Greef, et al (2008:102) also add that the mere fact that a spouse, child or family member were 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 Lejweleputswa district, Free State province, 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: borrowing and "begging" transport funds making "impossible choices" to allocate resources in favored of treatment, and "doing without." Patients accomplish prioritization 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 in 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 an determinants of ART adherence in Italian children (Giacomet, Albano, Starace de Franciscis, Giaquinto, Gattinara, Bruzzese, Gabiano, Galli, Vigano, Caselli & Guariono 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, Giacoment 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 2010:323), 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, 2000:171, Tindebwa, 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 addition 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 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 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, Mahenje, 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 industrialized 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 demonstrates 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 suggestions 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 PROBLEM STATEMENT

Children infected with HIV/AIDS like any other patients living with HIV/AIDS, receive free ART in all public health facilities within the country in South Africa. Nevertheless, children ART adherence remains a challenge despite the government's efforts in which ARVs in this country are provided free of charge. Since ARVs in South Africa are supplied for free, factors other than ARVs costs must be influencing children ART adherence rates. Quality provision of the treatment is of importance, however, shortage of professional nurses who should be responsible for the provision of ARV seem to be a major obstacle to successful treatment delivery in many districts of this country. All patients including children are faced with many challenges such as stigma attached to all patients who are seen by people entering into the ARV therapy programmes. These hinder the adherence and many other factors. Due to these factors that affect the provision of the therapy to patients, fear is that the morbidity and mortality rates among children might not decrease unless adherence rates of at least 95.0% are maintained throughout these children s' lives. Access to treatment, care and support for these patients remains grossly inadequate since the best system in helping PLWHA in South Africa to adhere to ARV therapy is still unknown.

1.4 RATIONALE OF THE STUDY

The researcher is a professional nurse in one of the health facilities in district were the study focused. It emanated from the meetings in which ARV adherent challenges for patients living with HIV/AIDS were discussed. The researcher conducted ARV training for professional nurses in few clinics responsible for the provision of ARV in district, and also offered support to clinics that were initiating ARV treatment in the district from 2012 to 2013, and this aroused the researcher 's interest in the ARV adherence. Professional nurses' knowledge on the factors that could influence children's ART adherence rates were addressed in this study.

Identifying such factors, and addressing them, might help to enhance the children's ART therapy adherence rates, to the benefit of the whole South Africa as well as the world's HIV positive children. It is important therefore, to identify the professional nurses' factors associated with adherence as this might improve adherence among children, thus increasing the likelihood of suppressing the virus, postponing the disease progression, decreasing morbidity associated with HIV and improving the quality of life among children living with HIV. Improving adherence would also help reduce resistance, thus reduces exposure to resistant strains of HIV virus and the need for expensive second line treatment. Therefore, the researcher thought of seeking for a solution to this problem by embarking on this research study. Undoubtedly, the results of this study could facilitate the transferring of the knowledge and skills to professional nurses on the comprehensive management of HIV/AIDS. Through this study, the research also developed an interest in working closely with PLWHA, taking ARV treatment as their chronic medication. Therefore, the study is of importance it will steer up and developed a desire to engage in discussions with the health care professionals providing services on the comprehensive management of HIV and AIDS, so as to help and support identify gaps in service delivery of ARV therapy for all patients including children.

1.5 PURPOSE OF THE STUDY

The purpose of this study was to identify the role of professional nurses on factors that influenced children ART adherence in Lejweleputswa district, Free State and to make recommendations to healthcare authorities for addressing the identified factors, to enhance children ART adherence rates.

1.6 RESEARCH QUESTIONS

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

- Do professional nurses have any role in the factors contributing to ART adherence rates among children aged five and younger at the selected healthcare centers in Lejweleputswa district?
- Is the anything that could be done to enable professional nurses to improve adherence to ART among children at your selected clinics?
- According to the professional nurses, is there any factors affecting children's ART adherence in the participating health facilities in Lejweleputswa district?

- How is the ART adherence pattern of children receiving free ARVs from the health facilities in Lejweleputswa district?

1.7 SIGNIFICANCE OF THE STUDY

Taking HAART regimens is not an easy task since it is a lifetime treatment. It is hoped that the findings generated from this study will make several contributions to both knowledge and understanding of what is one of the worst calamities to hit South Africa and the world in many years. It will also contribute to the Sociological /Anthropological understanding of non-adherence and be useful in developing interventions that will take into consideration the problems faced by people taking ARV treatment at the health care facilities and the world at large. The results of this study could add to the existing body of knowledge regarding children ART adherence in SSA in general and South Africa in particular. Policy makers could consider the results of this study to improve paediatric ART adherence in South Africa. Professional nurses/Health workers could utilize the results of this study to improve the overall quality of care rendered to HIV positive children. If children/paediatric ART adherence could be enhance, 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.

1.8 DEFENITION OF KEYTERMS

1.8.1 Adherence

The New Webster's Dictionary (2004:10) defines adherence as the action of adhering or attachment. Family Health International (FHI 2004:348); WHO (2012 define adherence as the term used to describe the patients 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 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 compliance of children with their prescribed ART regimens.

1.8.1.1 Children ART adherence

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

1.8.2 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 clinics visits and maintaining available supplies of ARVs.

1.8.3 Anti – retroviral drugs

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 diseases. 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.

1.8.4 Acquired-immune deficiency syndrome (AIDS)

In children, Tyndyebwa et al (2009-93) assert that AIDS is an immunosuppressive effect of HIV infection characterized by diarrhea, 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 2009-93; WHO 2006:8; FHI 2004:42). All children on ART in this study had AIDS.

1.8.5 CD4 count

Tyndyebwa et al (2009-28) 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.

1.8.6 Children

The Oxford Advanced Learners' Dictionary (2006:245) defines children as young human beings who are not yet adults. Sometime 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.

1.8.7 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 determinates 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 predicators of barriers or facilitators, influencing ART adherence in children.

1.8.8 Professional nurses/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 professional/healthcare workers was used to refer to nurses who participated and trained on adherence counselling and who provided these services within a family – centered model of comprehensive ART services at the two participating centers in health care centers of South Africa,

1.8.9 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.

1.8.10 Human immune – deficiency Virus (HIV)

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

1.8.11 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 Dorkand's Illustrated Medical Dictionary (2007:1983) defines treatment as the management and care of a patient for the for the purpose of combating diseases 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 was used to include HAART.

1.8.12 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 someone 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.

1.8.13 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 biological parent/s, guardian/s or any other person primarily responsible for the child's upkeep and adherence to ART.

1.9 FOUNDATIONS OF THE STUDY

1.9.1 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.

1.9.1.1 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 – centered AIDS care programmes improve adherence to ART among members of the family, including the children.

1.9.1.2 Epistemological assumptions

Epistemological assumptions relate to assumptions about the nature of knowledge and science or the content of truth are 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 five. A decision to use FGDs was driven by the need to experience albeit in an artificial setting, the experience, 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 selected health care centers in Lejweleputswa district, in Free State province, located in the western side of South Africa. These health facilities hosted FHI's project to pilot a family – centered model of AIDS care, and ARVs were provided free of charge. Consequently these sites were suitable for this study attempting to identify factors (excluding ARVs' costs) influencing children/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. However, the costs and time required to reach such population for this study included professional nurses/healthcare workers in Lejweleputswa district, in Free State province, ART services to children. The accessible population included all professional nurses involved in the provision of children/paediatric ART services at the two participating study sites providing family – centered care in terms of the Family Health International (FHI) pilot project. The concept of the research population was 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 was 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 the provincial Department of Health and Managers at the selected healthcare centers and the Research Ethics at the University of Venda. Details of these were outlined in Chapter 3 of this dissertation.

1.9 SCOPE AND LIMITATIONS OF THE STUDY

Selected health facilities that focused on children/ paediatric care and the family – centered approach to ART participated the study. Consequently the results of this study might not be generaliseable beyond these selected sites in which the study focused.

Only the roles of the professional/healthcare workers were studied. Caretakers, parents and/or guardians of children might have different views. However, due to time limitations the views of parents/guardians/caregivers were not obtain since it was not the focus of this study. Permission to conduct interviews with professional nurses granted by the provincial department of Health. The result of this study cannot be generalized 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 ABBREVATIONS

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

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 : Sexual 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 Education

1.11 STRUCTURE OF DISSERTATION

This dissertation is presented in five chapters, organized 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 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 Lejweleputswa district, Free State province?” 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 Lejweleputswa district, Free State province. A qualitative description research design was used, employing FGDs to obtain information from trained healthcare workers.

The next chapter discusses 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 (2013:27); Van Dyke, Lee, Johnson, Wiznia, Mohan, Stanley, Morse, Krogstad, and Nachman (2010:1), 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 2015 regarding:

- The definition of adherence
- Needs of children on ART
- Treatment adherence in children
- Factors influencing 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 none – adherence in Brazil (Wachholz & Ferreira 2012: 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, Kekieiinwa, Byakika – Tusiime & Musoke 2007:123), adherence was defined as taking as least 95.0% of prescribed medication. In a multi – site study in USA (Marheka, Farley, Rodrigue, Sandrik, Sleasman & Tepper 2010: 323), adherence was defined as maintain as least 90.0% pharmacy refill rates, which on this study, was significantly associated with virologic responses.

2.1.2 Pediatric Adherence Rates

A study in Brazil evaluated the effectiveness of treatment at different degrees of adherence in adults and concluded that plasmatic viremia was undetectable in 81% of cases where use level was 95% or more of prescribed dosages, 64% in those individuals that took 90-94% of prescribed dosages, 50% in cases that used 80-90% of the doses prescribed, 25% in cases that used 70-80% of the prescribed doses and 6% in cases the used less than 70% of the doses prescribed (Patterson et al., 2000). The few studies of adherence to antiretroviral regimens in children suggest that only 25% to 50% of HIV-infected children are adherent to all doses of their regime (Falkenberg 2010:12; Reddington et al., 2009:10. Mellins et al., (2011) used a battery of psychological assessments and self-reports adherence data in their study of caregivers and 48 HIV infected children aged 7 years 9 or more. Missed doses in the past month were reported by 40%caregivers and 56% of children. In a study to assess pediatric adherence to ART in Toto, West Africa, only 42% caregivers declared perfect adherence (Julie et al., 2008). The challenges to adherence in HIV-infected children are numerous (Albano et al., 2003; Fish et al., 2001). 2.2.1 Medication Related Challenges Many children are unaware of their disease and are dependent on adults for their care (Mellins et al., 2011). Antiretroviral medications generally require frequent dosing and are supplied in formulations that may be difficult for children to tolerate (large pills, bitter-tasting liquids, and gritty powders). Antiretroviral medications have been associated with significant short- and long-term adverse effects (nausea, rashes, hypersensitivity reactions, lipodystrophy and anemia). Antiretroviral syrups, which often have to be used in young children, can be difficult to store. They may require refrigeration. Some households' don't have any sort of refrigeration, and even those that do; there may not be enough space to store large quantities

of these formulations. 10 Some ARVs need to be taken with food, so care-givers may have to perform the (often difficult) task of providing a meal and administering drugs simultaneously. This is assuming that an adequate supply of food is actually available.

Adherence Strict adherence to antiretroviral therapy is generally required to obtain optimal treatment success. Incomplete adherence may compromise treatment efficacy due to viral rebound and drug resistance8. Future treatment options are limited due to cross-resistance7. Adherence is of the utmost importance for the success of treatment and this makes adherence support central to the care for HIV-infected patients. The risk of transmission of resistant viruses makes adherence to HAART a vital public health concern12, 13. Chapter 1 — 12 — An adherence rate of 95% or more to a regimen containing an unboosted protease inhibitor has been found necessary to achieve and maintain viral suppression14. More recent studies on more potent HAART (boosted PI or NNRTI) suggest that durable viral suppression can be achieved even with lower adherence rates15, 16. However, high levels of adherence, > 95%, remain necessary for optimal viral suppression17. In comparison with other chronic conditions such as diabetes mellitus and hypertension, this is very high. In most studies on adherence to antihypertensive and diabetes medications the, cut-off point to distinguish adherence from non-adherence is 80%18-20. The high adherence rates required make HIV treatment a challenge in comparison with these other chronic therapies21. At the beginning of the HAART era, strict adherence meant that treatment had to be taken at exact times; nowadays more is known about the margins within which pills need to be taken. Non-adherence takes the form of missing, forgetting, deliberately skipping or unduly postponing doses, as well as not respecting food requirements and drug holidays. Based on a study by Lima et al.17 on the relation of adherence and mortality, an information site for people living with HIV (www.aidsmap.com), shows how many doses can be missed per month without endangering effectiveness of the treatment and thus attaining the necessary level of adherence of 95%. In a once-daily regimen no more than one dose can be missed in one month and in twice-daily regimens this is no more than three doses per month.

Research and daily practice show that achieving the necessary adherence is difficult. Because drug interruptions can lead to a rapid viral rebound, adherence to HAART is a lifelong challenge. Since the beginning of the HAART era there has been a growing body of research to measure and explain adherence. Studies about what influences adherence to antiretroviral therapy focus on quantifiable variables and have led to numerous interventions and strategies to improve adherence to HAART being developed. However, the development of these various adherence interventions has meant limited progress in lowering the overall rate of non-adherence. Furthermore, it is unclear which parts of the intervention are effective and for which patients. Adherence support and patients' perspective In order to support patients in attaining long-term high levels of adherence there is a need for adherence-promoting strategies that can be tailored to patients' General introduction — 13 — specific needs. This self-management is the process of patients' individual responses to their illness, encompassing activities to control the illness, planning and managing daily life, constant decision making and it also involves coping with the psychological, physical and social impact of the illness with the aim of making the life of which the illness has become a part a good one. Patients all have their unique illness experience and beliefs, leading to different responses to their illness, its treatment and their adherence. Support and care that anticipate patient's individual needs increases effectiveness.

In order to support patients in enhancing and maintaining adherence, there is a need to understand the individual patterns of taking medication and the dynamics of adherence from the patients' perspective. Knowledge is needed about how individuals adhere to therapy in relation to how they experience their illness and what they do to self-manage their illness effectively. The knowledge from the patients' perspective allows the development of adherence support strategies that include a patient's specific needs. Information is needed about which adherence-promoting strategy is required for which patient and to what extent. This knowledge about and understanding of patients' needs and experiences with taking medication and their reasons for adherence and non-adherence, indicates targets for adherence strategies that will contribute to the development of effective patient-tailored interventions. Individualized interventions have been shown to be more effective than standardized on:

2.1.3 Needs of children on ART

In SSA the provision of paediatric ART is influence by limited resources and capacities to provide effective ART services at the lower levels of healthcare. UNICEF (2015:7) reported a global picture where less than 5.0% of young HIV – positive children in need of ART, was 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 2014; 148)

Luo, Akwara, Ngonogo, Doughty, Gass, Ekpini, Crowley and Hayashi (2011:179) 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, Harris, Luo, Bachman and Graham (2010:687) reported that out of an estimated 4 million children in need of co – trimoxazole prophylaxis worldwide (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 is focused on ART adherence among adults. In order to facilitate adherence and improve paediatric ART adherence and interventions that can improve these adherence rates (Shah 2007:58)

Kloos, Assefa, Mulatu and Mariam (2007:1) shared the Ethiopian Ministry of Health's (MOH's) experiences on the special, temporal and demographic patterns of ART in Ethiopia. A total of 101public hospitals provided ART services and treated 44 446 patients while 91 ART health centers 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 African with an estimated 91 000 HIV – infected children. This programme indicated that even in the resource – poor setting 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 if 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 multicenter 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 none – adherent, because their ART adherence rates were lower than 95.0%. However, only 11.0% of caregivers reported that therapy had been administrated 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 socio-demographic 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, Namibia, 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 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 (2009:141) noted that ART has resulted in declining morbidity rates from HIV – associated diseases in Lejweleputswa district, Free State province, but concerns regarding access and adherence were growing. The paediatric ART adherence levels and the reasons for none – adherence among children, at Lejweleputswa district, Free State province, were studied by Mukhtar – Yola et al (2009: 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 – adherences 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 every day. 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, despite the fact that patients in Lejweleputswa district, Free State province faced huge structural and economic barriers to access regular supplies of ARVs. Mukhtar – Yola et al (2009:144) concluded that expanded access to subsidized ARVs should improve adherence and consequently treatment outcomes for patients in resources – poor settings.

Veinot, Flicker, Skinner, McClelland, Saulnier, Read and Goldberg (2006:261) investigated HIV – positive youths' perceptions and experience 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 of believe in ART's effectiveness (Veinot et al 2006: 263). Some youths 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 treatment.

Wachholz and Ferreira (2007:S424:433) conducted a cross – sectional study to estimate the prevalence of paediatric ART none – adherence in Porto Alegre in Brazil. A total of 194 child caregivers were interviewed, none – 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 none – adherence rate was only 49.5%.

Nabukeera – Barungi, Kalyesubla, Kekitiinwa, Byakika – Tusiime and Mosoke (2011:123) conducted a cross –sectional study if 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) maintained at least 95.0% ART adherence rates compared to only 72% (n=164) by announced pill counts at their homes. When the primary caregiver was only one who knew

the child's serostatus, he/she was three times more likely to be none – adherent (p=0.02, OR 3.34, 95% CI 1.14 – 9.82). Those who had been hospitalized 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 (2011: 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 hospitalized only once or not at all were associated with poorer adherence rates. Nabukeera – Barungi et al (2011:130) 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 counseling 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 2011:130)

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 logistics 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 none – adherent than among the adherent children, and the strength of this association increased with age. Factors associated with increased ART none – 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 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 none –adherence. This will allow interventions to be initiated in good time (William 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 (2013:254) completed questionnaires (five physicians and five registered nurses). They worked with prenatally 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 2013:258). 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 (2013:252) 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 documented caregivers' regimen knowledge; barriers to adherence; and the relationships between adherence, regimen knowledge and barriers in the USA (Marhefka, Farley, Rodrigue, Sandrik, Sleasman & Tepper 2010:323). 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 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 adherence 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 relationships between caregivers' psychosocial characteristics and paediatric ART adherence in the USA. Fifty – four caregivers' of children 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, 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 a time 1 and 79.0% at a time 2. Only 8.0% (n=2) of child – caregiver pairs reported complete agreement regarding who held responsibility for medication – related tasks. Patients' reported responsibility 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 predicated 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 emphasized 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 2016:466). 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 of children 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 (2010: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 and Ferreira (2007:S425) the education of caregivers had borderline associations with treatment outcomes. Reportedly, institutionalized children and this taken care of by people with higher educational levels, reportedly had lower ART none – adherent rates. Albano, Giacoment, De Marco, Bruzzese,Starace and Guarino (2010:765) compared the evaluation of caregivers' reports and physicians' judgments 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 centers. The results indicated that adherence was a major problem but there were discrepancies between caregivers' on specific ART adherence issues should be addressed (Albano et al 2010:766). A similar study could not be traced in the SSA context.

Bryrne, 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 literature. For the purpose of increasing the quality of paediatric ART, Fraaij, Rakhmanina, Burger and De Groot (2014:125) 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 et al 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 (2014:499) concluded that this study demonstrated a lower adherence rate than those reported in clinical records (84.0%). This finding emphasized 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 (2013:211) 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's/nurse questionnaire, and appointment – keeping behavior. 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% 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 behaviors 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 classifying 36.0% of subjects in the 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. The 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 scale, 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 adherence

Specific interventions for improving paediatric ART adherence include improvement of ARV formulations, better counseling for children and their families, and tailoring of ART according to specific children's needs. Generalizing these results should be done cautiously due to the small sample size and to heterogeneity of the cohort (Pontali, Feasi, Toscanini, Bassetti, De Gol, Nuzzolese & Bassetti 2016: 466). Youths might need support for managing treatment difficulties, such as side effects, social impacts, and adherence (Veinot. Flicker, Skinner, McClelland, Saulnier, Read & Golberg 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. Bryrne, Honig, Jurgau, Hefferman 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 adherence to health, demographic, and psychosocial characteristics of children in the USA was studied by Williams et al (2006:e1745). These results highlighted the importance of evaluating and supporting the family environment to optimize ART adherence rates. Wachholz and Ferreira (2007:S424), emphasized the need for close surveillance of paediatric ART adherence in order to evaluate the effectiveness of ART.

Berrien, Salazar, Reynolds and Mckay (2015:355) 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 randomized 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 (2010:355) also inferred adherence from pre – to post – test plasma viral loads and CD4 cell counts. The knowledge score (p = 0.020 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 children and their families to adhere to prescribed medication regimens. A study was concluded 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 naïve to previous ART who received ART in Khayalitsha, 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 loads 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. 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). The 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 patients-healthcare worker collaborations could result in the selection of a lifestyle-tailored regimen characterized 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 of 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 used in HIV patient care. However, D'Oulx, Chiappini, De Martino and Tovo (2007:426) emphasized the need for an expert in paediatric and adolescent HIV infection to take charge of paediatric patient management. This warning corresponds with that by Cunningham 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 patient, aged 4-21. These patients were referred for pill-swallowing training by and experienced paediatric psychologist for swallowing difficulties with prescribed ARV regiments 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 and was one session. Younger children (aged 4-5) 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, Nostilinger, Hoeree, Lefevre, Jonkheer and Kolsteren (2010: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 adherence. Adherent patients were found to internalize 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 analysis, implying that perceived benefits outweighed the perceived cost or difficulties experienced. Adherent patients developed greater problem-solving capacities, such as ways of dealing with practical complications of medications 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 (2010:e591) suggested that coping with HIV and establishing good adherence might be interrelated. Caregivers who accepted the disease might be more likely to internalize 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 (2010:469) 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 failure and the return of detectable plasma virus with 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, centered 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 problem (depending on drug pharmacokinetic and pharmacodynamy 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 regimes. 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 log 10) 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 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 regime.

Psychosocial factors have been identified as contributing factors to the future of children to adhere to ART. Mellins, Brackis-Cott, Dolezal and Abrahams (2011:1035) 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 influencing adherence to ART in perinatally HIV-infected children (Mellins et al 2011:1036). 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 and child reported missed doses (non-adherent was 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 level ($P<0.002$), lower caregiver quality of life ($P<0.003$) and worse caregiver cognitive function ($P = 0.033$). Borderline significance was associated with increased child responsibility for medication ($P<0.07$), HIV disclosure to the child ($P<0.07$) and the child stress levels ($P<0.08$). In logistic regression 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 other ($P<0.05$) and quality of life ($P<0.01$) Mellins et al 2011:35).

Rueda, Park-Wylie, Bayoumi, Tynan, Antoniou, Rourke and Glaier (2010:1) supported the view that patient support and education interventions improved ART adherence. Interventions targeting practical medication management skill, those 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 behavioral 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 marginalized 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 standardization and increased methodological rigour in the conduct of adherence trials (Tueda 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 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 (2009:1148) 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

does 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% 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 to 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 center 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 organizer (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 regiments. 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 2009:1148).

Simoni, Frick, Pantalone and Turner (2013:185) evaluated four randomized controlled trials conducted with adequate methodological rigour. The findings of these studies included some effects of pharmacist-let individualized interventions, cognitive-behavioural educational intervention 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:P191). 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, and

use of peer adherence counselors (especially, in every village), and improved quality of care, especially, record keeping, health education and counseling 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 HV and improving the quality of life in adults as well as in children. However, concerning ART, it needs to be emphasized that "drugs don't work in patients who don't take them". Optimum ART adherence is critical for successful outcome. 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 nevirapine/ efavirenz. Of the children, 51 were ART naïve 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 log 10 copies/mL ($P < 0.0001$) in the previously ART-naïve children. In the ART experienced children, the median CD4 count 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- naïve children and in 16.0% of the ART –experienced children. Weight and CD 4 cell counts improved, and more than half of the previously ART-naïve 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 (Zhat 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 outcome, 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 outcome, censored on 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, Mye, 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 counselors provided adherence and programme support.

Bekker et al (2006:315) reported that during the study period, 1 139 ART-naïve 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 cellos/microl (IQR 490-149), 110 cells/microl (IQR 55-172) and the patients with WHO clinic stages 3 and 4 were 90.0%, 79.0% and 76.0% in each sequential year respectively. The number of counselors increased from 6 to 28 and the median number of clients allocated to each counselor 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 wee 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 1000 in an urban setting without compromising programme performance.

Eley, Nuttall, Davies, Smith, Cowburn, Buys and Hussey (2004:642-6) reported on the early response of children to HAART in South African tertiary referral hospital, where children where 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, bother 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 immune-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 until 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, Stanely, Morse, Krogstad and Nachman (2010:1) found evidence that ART adherence was associated with virological 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 Dyke et al (2010:6) concluded that self-reported adherence, when collected in a standardize manner, could be useful measure of medication-taking behavior predicting the virologic responses to ART.

The use of 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, Meenhorts, 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 pharmacokinetics properties, high does (requiring large numbers of pills) must be ingested, often with food restriction, 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 individualized and supported by clinical data regarding safety and efficacy, keeping in mind alternative options where treatments fail.

Children with HIV Antibiotic Prophylaxi (CHAP) participated in a randomized placebo-controlled trial of contrimoxazole prophylaxis in Zambia between 2001 and 2003 Walker, Ford, Mulenga, Thomason, Nunn, Chintu, Gibb and Bangsberg (2008:1) provided evidence that contimoxazole 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 contromoxazole and placebo group; adherence from bottle weights was 100% at 71% of visits, while caregivers reported 100.0% adherence 79.0% of visits.

Every 10.0% lower adherence to contimoxazole 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, Siddle, Yiannoutsos, Musick, Wools-Kaloustian & Tierney (2006:418) were investigated in a retrospective review of prospective 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 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 cost 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 restriction.
- Disruptions in social routine.
- 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 problem, additional use problems, additional HIV-positive family members and disclosure issue.
- Regimen knowledge deficit 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 counseling for children and their families.

- Tailoring or 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 quality and quality of care.

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

CHAPTER 3

RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

The previous chapter presented the literature review for the study according to the objectives of the study. This chapter presents the research design and methods utilised in the study. Data were collected using unstructured descriptive Focus Group Discussions (FGDs), held in Lejweleputswa district, Free State province in the selected healthcare centers. 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 Lejweleputswa district, Free State province. 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 controlled conditions. Its goal is to understand behaviour or actions within their natural occurring contexts. It focuses on behavioral 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 emphasizes 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 criticized 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 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 approach (Stommel and 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 professional nurses/healthcare workers in Lejweleputswa district, Free State province, those responsible for the provision of 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 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 he would like to generalize 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 (Polity & Beck 2004:525); often a nonrandom subset of the target population. Stommel and Wills (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 professional/healthcare workers in Lejweleputswa district, Free State province those responsible for the provision of ART to children under five. The accessible population included all professional/healthcare workers involved in the provision of ART services at the selected health care facilities in Lejweleputswa district, Free State province.

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 spaces are also defined in terms of specific inclusion and exclusion criteria. Thus, the researcher included only adherence counselors who completed the prescribed training in the case and treatment of children with AIDS and who provided children/paediatric ART care at the selected participating healthcare facilities in Lejweleputswa district, Free State province.

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. Polits 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 professional nurses/healthcare workers trained in the care and treatment of AIDS under at the Department of Health provincially in Lejweleputswa district, Free State province programme from 2009 till 2013. 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 and Wills 2004:443). The sample comprised 24 participants responsible for the provision of ART, these are trained professional/healthcare workers in each of the designated ART health care facility. Study participants in Lejweleputswa district, Free State province nurses and three doctors.

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 2004:537). Convenience sampling is a non-probability approach to selecting participants based on their (easy) accessibility to the researcher (Stommel & Wills 2004:436).

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 Lejweleputswa district, Free State province, especially, those trained to provide paediatric ART. Healthcare workers with the capacity to provide pediatric ART in Lejweleputswa district, Free State province are scarce, implying that the available ones are very busy attending to children. Some work shifts while other performs call duties (emergency duties performed after official work hours). Thus, it would have been impossible to gather all professional/trained pediatric ART workers at the same time for participating in focus group discussions. The researcher requested each health facilities

manager to identity volunteers for participation in the focus group discussion. Persons included in the study were adherence counselors 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 unrecognized, if not explicitly studied or thought about, that distinguishes 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 experience of social actors (Malta, Maya, Clair, Freitas and Bastos 2005:1426).

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 interviews 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 "…typical 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 values of a qualitative perspective gained favor in social and behavioral 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 varyh 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 research 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 optimize the usefulness of the focus group. For most purposes,

group of 6 to 10 members are optimal (Stommel and 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 generalized 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 skillfully 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 Lejweleputswa district, Free State province. 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 tapes 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. The information could be used as part of an audit trail in support of the conformability of the study findings and for triangulation with the note taker's 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 situation.

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 Lejweleputswa district, Free State province 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 generalized 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 share 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, Lejweleputswa district, Free State province, 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 jeopardize the trustworthiness of the study result.

- *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 for 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 person.

3.3.3.3 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, and 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 wide 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 this 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 FGD's. 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 relationship with the participants to strengthen meaningful rapport. Through this process, the transcript was returned to the participants to review, add to, or otherwise revise transcript 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 categorized the data into manageable chunk 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 concept, 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 of what the healthcare workers did and did not discuss in the focus group, and quotes from the healthcare workers that illustrated specific themes. The researcher used multiple data sources to examine and validate conclusion 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 adherence to ART in the two participating health facilities in Lejweleputswa district, Free State province. 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 the 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 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 researchers substantial immersion in the research process and the use of “member checks,” in which respondents are asked to corroborate finding (Lincoln & Guba 1985:313-316).

In this study, the researcher engaged with the research, established valid and meaningful relationship 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 generalized 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 (2004:280) 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, and 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 generaliseable to other sites without repeating the study at such site.

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 Lejweleputswa district, Free State province, clarification regarding how long the family centered care model had been piloted at the two study sites, and clarification regarding reasons for better adherence among father headed single parent households in Lejweleputswa district, Free State province, and not in Lagos. The researcher also did peer debriefings with other research colleagues in the workplace. The researcher disclosed the he has no personal or financial interest 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 center in Lejweleputswa district, Free State province 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 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 twofold:

- Identify and describe the perceptions of health care providers on factors that influenced paediatric ART adherence, at two health care centers 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 centers, and possibly also at other sites.

The research questions were:

- What were the health workers' view regarding paediatric ART adherence in children who received free ARVs from the two participating health facilities in Lejweleputswa district, Free State province?
- What were the health workers' views regarding the ART adherence patterns of children receiving free ARVs from the health facilities in Lejweleputswa district, Free State province?
- What were the health care providers' view regarding the factors affecting children's ART adherence in the participating health facilities in Lejweleputswa district, Free State province?

- What according to the healthcare workers, could be done to improve adherence to ART among children (at our clinics specifically and in Lejweleputswa district, Free State province 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 Lejweleputswa district, Free State province, to 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 categorized 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 categorized 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 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 tabled 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 result, 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 Lejweleputswa district, Free State province. 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 contextualizing 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, and number of years of experience as paediatric ART adherence counselors 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 majority of FGD participants (n=12; 70.6%) were females. 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 counseling experiences, respectively. Participants' general health care experience raged from mostly from 1-10 years (n= 10; 58.8%).

Category	Frequency				Percentage
	FGD 1	FGD 2	FGD 3	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	0	0	1	1	5.9
Technologist	0	0	1	1	5.9
Pharmacy Technician					
Total	5	3	9	17	100
ART Adherence Counselling					
Experience years	1	0	3	4	23.5
1 year	1	1	2	4	23.5
2 year	0	1	3	4	23.5
3 year	2	0	0	2	11.8
4 year	1	1	1	4	17.7
>4 year					
Total	5	3	9	17	100
General health care experience years	0	2	8	10	58.8
1-10 years	1	1	1	3	17.7
10-20 years	3	0	0	3	17.7
20-30 years	1	0	0	1	5.9
31 years and above					
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 receiving 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	Family centered 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 parents presents with higher adherence levels to ART better than those from non-biological parents
4.2.5.	Category 2.5	Parent's literacy level influenced their children children's adherence to ART
4.3.	**Theme 3**	**Factors affecting paediatric ART adherence**
4.3.1.	Category 3.1	Parents were determined 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	Parents 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 the 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 Theme1: Paediatric ART adherence in children who received free ARVs

Paediatric ART adherence in children who received fee 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. 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 ARCs. 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 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 cost 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 month' 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 Lejweleputswa district, Free State province, Mukhtar-Yola et al (2009:141)

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 the 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 analysis. 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 RECEIVED FREE ARVs (OVERVIEW)**
4.2.1. Family centered 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 household (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 centered 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 their prescribed medications. The FGD participants elucidated that through the family centered care approach, family members came into hospital to access all needed services at one stop – "one stop shop all." This approach reduces 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 evidenced hereof.

DATA DISPLAY 4.2.1

Family center care approach improved children's adherence to ART

- I think the family centered 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, child going for one day, even the time is together so I think it's better economically and everything.
- If both family [members] are taking their drugs at the same time, at the same time, at the same day then maybe 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, and 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 counseling, 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 centers 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 centered care approach saves time, saves money at the same time.
- It adds value in the sense that both 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 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 centered 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 optimize 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 that institutionalized 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 centered 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 or 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 and the mother is not sick, you wouldn't know that level your child is facing until you have the same problem.

A FGD participant, in Lejweleputswa district, Free State province explained hat 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 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 given [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 parent 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 or ART since the age of 6 months. Her grandmother is dedicated, and the child is now 3 years and very alive. • 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 (2013:252) 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 suggest 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 drug 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 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 he doesn't have time; that he has 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 occasionally when he is not there and administers the drugs; if the man is around, he will not agree.*

Rose and Clark-Alexander's (1988:63) 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 parents.

FGD participants in Lejweleputswa district, Free State province remained indeterminate in expressing their views regarding paediatric ART adherence in biological and non-biological parents/caregivers homes. FGD participants in Lagos reported that children of biological parents presented with better adherence levels to ART than those from non-biological parents. Highlighting stigmatization against children of non-biological caregivers, a FGD participants 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 level to ART than those from non-biological parents**
• They will say that I'm not your parent and we don't know where you are coming with these things [AIDS]. They even name his 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 am 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.

The 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 their family or being part of community activities. They were also denied access to health services. Greefff et al (2008:102) added that the mere fact that a spouse, child or family member was related and associated with PLWA let to their being stigmatized. 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 that those receiving drugs from biological parents or relatives. Univariate analysis by Marherfa et al (2006:429) showed that an adherent classification, (at least an 80.0% refill rate) was associated with having non-biological related caregivers. Likewise, Williams et al (2008:e175) 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 biological 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 education 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 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 mediations 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 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. Whichever explanation or counseling you give to them, they will not understand.
- If they are educated, they will adhere to the treatment.
- Education doesn't means that one should not follow the normal thing to do; I think proper counseling 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 participants. Likewise, a multivariate analysis by Wachholz and Ferreira (2007:S425) or the education of caregivers was found to have a borderline association with treatment outcomes. Thus, institutionalized 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 internalized 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 effecting paediatric ART adherence

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

DATA DISPLAY 4.3 **THEME 3: FACTORS AFFECTING PAEDIATRIC ART ADHERENCE (OVERVIE)**
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 Parents forgot to administer drugs
4.3.2.7 Inadequate health system infrastructure

Cate***gory 4.3.1: Parents were determinants of adherence***

FGD participants in both Lejweleputswa district, Free State province explained that parents were the main determinants of paediatric ART adherence. They also argued that parents were targets for adherence counseling training and service, not the child. In Lagos, the FGD participants recognized parents as the main determinants of adherence in children. They also recognized the need for continuous and re-enforced adherence counseling 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 children we do not 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 then a child is sick it is just as if it is the parent that are sick. • They are so worried about their children's illness, so they adhere to the drug 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 do not have adherence counseling 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 do not involve the caregiver or parent [in the child's care], you cannot achieve good result 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 do not come to the clinic themselves; the caregivers or parents bring them. • It is the parents that give the children these drugs…. Since the kids don't know how to say give me any drug.

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) recognized the need for tailoring ART regimens to the daily activities of the family. Pontali (2005:143) also cognized the strategic position of the parent in the child's adherence programme. On the other hand, Mellins et al (2011:1035 argued that in logistic regressions controlling for age, caregiver/family factors are 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 result of this study revealed that there were multiple competing factors challenging children's ability to adhere to ART. The FGD participants recognized 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 centers 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, and the money is not there, I do not have money for transport today that is 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 neighborhood 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 drug.

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 ARV's 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 cost 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 prioritizing 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.

Su-category 4.3.2.2; inadequate access to quality paediatric ART services

The FGD participants perceived that inadequate access to quality paediatric AR 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 (2009:144) in their study conducted in Lejweleputswa district, Free State province, Lejweleputswa district, Free State province. 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 a fewer than 5.0% of young HIV-positive children in need of paediatric ART, were receiving ARVs. However, in Lejweleputswa district, Free State province less 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 industrialized 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 Lejweleputswa district, Free State province.

Su b-category 4.3.2.3: Inadequate treatment knowledge

Inadequate knowledge of ART also contributed to lack of adherence in children. The FGD participants in Lejweleputswa district, Free State province 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 are 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 everything 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 the category was 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 (2005:175176) identified that in many SSA countries, health practitioners were inadequately prepared to addressed 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 series 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 with 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 it's 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, the third party may go and broadcast the type of drug 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 cannot 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 that caused paediatric ART non-adherence. In their opinion, 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 drug, some people cannot cope with some of the side effects. This is a major cause of default. • When they have knowledge that this things is 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 (200:211) reported that out of 638 study subject 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 non-adherence. Similarly, each additional symptom requiring clinical action was associated with a 25.0% increasing in the risk of international non-adherence.

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 displays 4.3.2.6 shows direct comments from the FGD participants as evidence hereof.

DATA DISPLAY 4.3.2.6
Parents forgot to administer drugs
• At times, they forget. Some people due to activities, they normally forget social activities. They can forget to come [to hospital] • Some parents forget they 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%), and fear of side effects (13.0%-42.0%).

Sub-category 4.3.2.7: Inadequate health systems infrastructure

Heath 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 counseling and the numbers of trained adherence counselors were no longer adequate for the increasing number of clients. The few trained members of staff were transferred from the paediatric ART clinic to another units or facilities, resulting in further staff shortages and burnout of the few.

FGD participants in Lejweleputswa district, Free State province identified the need for health service managers to recognize 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 evidenced hereof.

DATA DISPLAY 4.3.2.7 Inadequate health system infrastructure
• Staff shortage and consulting rooms' challenges. • The workload is too much • Transfer of trained counselors 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 the industrialized 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 counseling, 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 services is important to patient, staff, and the organization. They explained that these included staff training and retention, provision of comfortable workspace, such as adherence counseling 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 evidenced hereof.

DATA DISPLAY 4.4.1 Improved quality of paediatric ART services was fundamental to paediatric ART adherence
• There should be more adherence counselor 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 counselor … 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 counseling skills and maintenance of supportive attitudes towards ART patients could enable nurses' to help patients to maintain higher level 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 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 recognized that most parents of children accessing care in Lejweleputswa district, Free State province 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 counseling, 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 comments from FGD participants as evidenced hereof.

DATA DISPLAY 4.4.2 Empowering parents improve adherence to ART
• 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 thee should be an ongoing adherence counseling 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 dong 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 drug to others. The 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 counseling 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 (2011:1035) noted that non-adherence was significantly associated with higher caregiver stress levels. Other includes 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 2011:1035).

Brackis-Cott et al (2013:252) 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 lie. Mukhtre-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 center 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 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 patients and the doctor. I think the problem [of lack of adherence] will continue. • The parents want the drug 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 optimize 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 (2009:1148) 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 counseling. Zhang et al (2007:598) asserted that there should be improved access to second-line regimens.

Nabukeera-Barungi et al (2011:130) recommend that parents and caregivers should be encouraged to disclose the child's status to at least one other person before staring ART. Other strategies such as home visits, peer counseling and community support groups might need to be incorporated into the care programme. Nabukeera-Barungi et al (2011:130). 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 intergrated 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 use in this study. Through this approach, the researcher used a systematic procedure for analyzing the qualitative data. The procedure comprised the following steps: familiarization, 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 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. Descriptions 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?	**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 Lejweleputswa district, Free State province?	**THEME 2: ART adherence patterns of children receiving free ARVs** • Family centered 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 better than those from father-headed APHH • Children of biological parents presents with higher adherence levels to ART than those from non-biological parents • Parent's literacy level influenced their children children's adherence to ART
What were the health care providers' views regarding the factors affecting children's ART adherence in the participating health	**THEME 3: Factors affecting paediatric ART adherence**

facilities in Lejweleputswa district, Free State province?	• Parents were determinants of adherence in children • Multiple competing factors challenged children's ability to adhere to ART 5 Poverty 6 Inadequate access to quality paediatric ART services 7 Inadequate treatment knowledge 8 Stigma 9 Side effects of ARVs and other children factors 10 Parents forgot to administer drugs 11 Inadequate health system infrastructure
	THEME 4: Strategies for improving paediatric ART adherence • Improved quality of paediatric ART services were 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 improved access to ART

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

CHAPTER 5

CONCLUSION, 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 Lejweleputswa district, Free State province. The conclusion, 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' view regarding paediatric ART adherence in children who received free ARVs from the two participating health facilities in Lejweleputswa district, Free State province?
- What were the health workers' views regarding the ART adherence patterns of children receiving free ARVs from the health facilities in Lejweleputswa district, Free State province?
- What were the health care providers' view regarding the factors affecting children's ART adherence in the participating health facilities in Lejweleputswa district, Free State province?

5.2 CONCLUSION

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

5.2.1 Professional nurses health workers' views regarding paediatric ART adherence in children who received free ARVs from the two participating health facilities in Lejweleputswa district, Free State province

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 worker, paediatric ART adherence was reportedly higher:

- Among children whose parents attended the family centered 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 parents.
- 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 Lejweleputswa district, Free State province

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*

Paediactric 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 2-3 months 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. Other 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 system 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 counseling and the number of trained adherence counselors 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 finding 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 generalized 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 structure interviews had been conducted with the health care providers, 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

5.4.1 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, instead 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 counseling.
- Adopt a paradigm shift from a family centered care approach (FCCA) to a comprehensive family centered care approach (CFCCA). This entails looking beyond the family's health problems, to economic, psycho-social, civil, religious, and cultural and any other needs that might impact on paediatric ART adherence.
- Strengthen linkages between the health facilities 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 counseling at all points of service delivery so that clients' families will get the same consistent adherence counseling and treatment messages at every point of service.
- Develop and implement targeted treatment education and adherence counseling 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.

5.4.2 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 utilizing the family centered care approach and another not utilizing this approach.
- ART adherence level 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 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 CONCLUDIGN REMARKS

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 Lejweleputswa district, Free State province. Health care workers were drawn from Lejweleputswa district, Free State province, 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 counseling in paediatric ART, and adopting comprehensive family centered 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. Conclusion HCWs play a vital role in the implementation of the country's health policy and the provision of health care services. They have the responsibility of ensuring that the government's health policies are translated into effective and efficient service delivery. However, their rights are often overlooked, and many HCWs are subject to poor working conditions, long hours and inadequate remuneration.

As a result many HCWs have chosen to leave the public health sector. Some have moved to the private sector where conditions are better, and many have emigrated. The single most important factor in achieving a successful ARV rollout programme is the retention and expansion of the present workforce. However, this cannot be addressed in isolation as there are various factors contributing to workforce attrition that need to be simultaneously addressed. Although adequate remuneration for HCWs is important, non-financial incentives such as the improvement of working conditions and the provision of much needed 123 Dagied et al 2007 www.hsrc.ac.za. 124 Dagied et al 2007 www.hsrc.ac.za 21. 125 Dagied et al 2007 www.hsrc.ac.za 21. 126 Orner 2006 AIDS Care 236-240. YA VAWDA AND F VARIAWA PER / PELJ 2012(15)2 508 / 569 support facilities are equally vital. Upgrading the infrastructure within and around health care facilities with the provision of safe water and adequate sanitation facilities, and the availability of the correct quantity and dosage of ARV drugs, will contribute to the creation of conducive working conditions and an effective ARV programme. Ensuring the availability of effective PPE, reducing the number of hours spent on duty per

shift, and ongoing education of the workforce with respect to infection control could dramatically decrease the incidence of adverse events in the workplace. Ongoing in-service training aimed at improving overall skills as well as specific training in dealing with paediatric cases will increase HCWs' confidence and result in more effective service delivery. HCWs treating patients living with HIV/AIDS experience significant psychological and emotional stress. Mechanisms should be in place to ensure that these individuals have timeous access to counselling and support facilities. HCWs are the backbone of the ARV rollout programme. Thus, their complaints and grievances need to be urgently addressed. To this end, efficient monitoring and evaluation of all ARV rollout facilities should be undertaken in order to identify the deficiencies and institute remedial measures. The involvement of HCWs in the decision-making process, as well as setting time limits for the completion of specific interventions, will contribute to a more transparent process and better outcomes. The government has made a commitment to expand the ARV rollout programme. The success of this programme will depend greatly on the HCWs implementing it. Furthermore, a key objective of the proposed National Health Insurance127 is 'to strengthen the under-resourced and strained public sector so as to improve health systems performance.' It is imperative that due cognisance be paid to the rights of HCWs if we are to succeed in achieving these lofty objectives.

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ANNEXURE A

Certificate of research ethics

RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Mrs CD Moreku

Student No:
14015075

PROJECT TITLE: The professional nurse's role in facilitating antiretroviral therapy adherent among HIV infected children in Lejweleputswa district, Free State Province, South Africa.

PROJECT NO: SHS/15/PDC/35/0502

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Prof ML Netshiluweta	University of Venda	Promoter
Mrs AR Tshilila	University of Venda	Co- Promoter
Mrs CD Moreku	University of Venda	Investigator - Student

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: February 2016
Decision by Ethical Clearance Committee Granted
Signature of Chairperson of the Committee: .....
Name of the Chairperson of the Committee: Prof. G.E. Ekosse

University of Venda
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ANNEXURE B

Letters requesting permission to conduct the study

ANNEXURES AND BUDGET

ANNEXURE (A)

PERMISSION LETTER

The Head of Department

Provincial Department of Health

P/Bag x

BLOEMFONTEIN

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Dear Sir / Madam

REQUESTING PERMISSION TO CONDUCT RESEARCH

This letter serves as an application to conduct research on " professional nurses facilitation of adherence to antiretroviral treatment within the LejweleputswaL District, in Free State Province"

I am presently studying for a Master Curationis degree at the University of Venda. The study will be conducted at the Lejweleputswa District. The study is conducted under the supervision of Professor L. Netshikweta and Mrs A.R. Tshililo, of the said university.

The purpose of this study is to explore and describe the professional nurses in facilitating adherence to antiretroviral treatment in children within the Lejweleputswa District of Free State Province.

ANNEXURE C

Letters granting permission to conduct the study

health
Department of Health
FREE STATE PROVINCE

23 January 2017

Mrs. CD Moreku
12 Jason's Way
Riebeeckstad
Welkom

Dear Mrs. CD Moreku

Subject: Professional nurse's role in facilitating antiretroviral therapy adherence among HIV infected children in Lejweleputswa, Free State province, South Africa.

- Permission is hereby granted for the above - mentioned research on the following conditions:
- Participation in the study must be voluntary.
- A written consent by each participants must be obtained.
- Serious adverse events to be reported and/or termination of the study.
- Ascertain that your data collection exercise neither interferes with the day to day running of the facilities nor the performance of duties by the respondents or health care workers.
- Confidentiality of information will be ensured and no names will be used.
- Research results and a complete report should be made available to the Free State Department of Health on completion of the study (a hard copy plus a soft copy).
- Progress report must be presented not later than one year after approval of the project to the Ethics Committee of the University of Venda and to Free State Department of Health.
- Any amendments, extension or other modifications to the protocol or investigators must be submitted to the Ethics Committee of the University of Venda and to Free State Department of Health.
- **Conditions stated in your Ethical Approval letter should be adhered to and a final copy of the Ethics Clearance Certificate should be submitted to** [illegible] **before you commence with the study**
- No financial liability will be placed on the Free State Department of Health
- Please discuss your study with the institution managers/CEOs on commencement for logistical arrangements
- Department of Health to be fully indemnified from any harm that participants and staff experiences in the study
- Researchers will be required to enter in to a formal agreement with the Free State department of health regulating and formalizing the research relationship (document will follow)
- You are encouraged to present your study findings/results at the Free State Provincial health research day
- Future research will only be granted permission if correct procedures are followed see [illegible]

Trust you find the above in order.

Kind Regards

Dr D Motau
HEAD: HEALTH
Date: 23/01/2017

Head : Health
PO Box 227, Bloemfontein, 9300
4th Floor, Executive Suite, Bophelo House, cnr Maitland and Harvey Road, Bloemfontein
Tel (051) 408 1646 Fax (051) 408 1556 e-mail [illegible] chikobvup@fshealth.gov.za
www.fs.gov.za

ANNEXURE D

Letter from editor

STEVENS EDITING AND PROOFREADING
~ EDITING ~ PROOFREADING ~ WRITING ~

BA: English; Industrial psychology (Unisa)
Sole Proprietor
***Membership*:**
PEG (SA)
SfEP (UK-Intermediate)
IPEd (WA)

20 May 2017

THIS IS TO CERTIFY THAT:

I have language edited a thesis titled *the role of professional nurses on anti-retroviral therapy adherence among children living with HIV/AIDS in Lejweleputswa district: free state, south Africa*

for Ms Dikeledi Caroline Moreku, E-mail: caroline.moreku23@gmail.com, a Masters student Philosophy student in Health studies at the University of Venda, South Africa.

The scope of my editing comprised:

- Spelling
- Vocabulary
- Word usage
- Checking of referencing style
- Tense
- Punctuation
- Language and sentence structure

It has been a gratifying experience working with this student who has clearly displayed integrity in a well-prepared paper and prompt communication with the editor when necessary.
The student has advised me that payment will be effected on Friday 19 May 2017 and her communication in this matter is appreciated. My best wishes for good success and a great career accompany Ms Tshililo.

Yours faithfully,
Charlotte Stevens (Ms)
Stevens Editing and Proofreading
e: ajc.stevens@gmail.com
[Note: Signature withheld for security purposes.]