The Psycho-social Experiences of Children Living with Vertically Transmitted HIV/AIDS at Messina Hospital, South Africa

By

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ABSTRACT

The aim of the study was to explore the psycho-social experiences of children living with vertically transmitted HIV/AIDS in Messina Hospital, South Africa. The study utilised the qualitative approach, in particular the exploratory research design. The population of the study comprised both male and female children between the ages of 12-17 years, who are receiving care and support at Fountain of Hope Clinic in Messina Hospital. Non-probability sampling, in particular its sub-type, purposive sampling, was used to select the children who participated in the study. Eleven participants (11) were interviewed, and the sample size of the study was guided by data saturation during data collection. Semi-structured, open-ended face to face interviews were used to collect data. In order to analyse data, the researcher adopted thematic content analysis, following Tech's eight steps of qualitative data analysis. Three main themes emerged from the raw data, namely living with HIV/AIDS infection; challenges of living with HIV/AIDS infection; and coping with HIV/AIDS. Sub-themes emerged from the main themes. Ethical considerations were observed and trustworthiness was ensured in the study. The study results were analysed and recommendations based on the results were formulated to enhance the experiences of children living with vertically transmitted HIV/AIDS.

Keywords: *children, experiences, HIVAIDS and psycho-social.*

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DECLARATION

I, Ramarumo Takalani, (11533486), hereby declare that the dissertation for the Master of Arts (Psychology) degree at the University of Venda, hereby submitted by me, has not been submitted previously for a degree at this or any other university, that this is my own work in design and in execution, and that all reference material has been duly acknowledged.

Signature : ________________________________

Date : ________________________________

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ABBREVIATIONS

AIDS Acquired Immune Deficiency Syndrome

ALHIV Adolescent Living with HIV

APA American Psychology Association

ASSA Actuarial Society of South Africa

ART Anti-Retroviral Treatment

DOH Department of Health

HIV Human Immunodeficiency Virus

MTCT Mother to child transmission

OARAC Office of AIDS Research Advisory Council

PLHIV People Living with HIV

SSA Statistic South Africa

UNAIDS Joint United Nations Programme on HIV and AIDS

UNICEF United Nations Children’s Emergency Fund

WHO World Health Organisation

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CHAPTER 1: INTRODUCTION AND BACKGROUND OF THE STUDY

1.1 Introduction

According to Chearskul, Chokephaibulkit, Chearskul, Phongsamart, Plipat, Lapphra and Vanprapar (2005), the Human immunodeficiency Virus (HIV) infection was first identified in the United States of America, in 1981, among homosexual men who had developed symptoms of the late stages of a disease called Acquired Immunodeficiency Syndrome (AIDS). It was concluded that the disease was transmitted sexually and that it affected heterosexual men, as well as their sexual partners. It was, however, puzzling to the research community when even children, who do not engage in sexual activities, were also showing symptoms of the disease. This caught the attention of researchers because many children were dying (Armstrong, Pungula, Sobantu, Cheserem & Moshal, 2013; Dreyfuss & Fawzi, 2002). Years later, it was found that the transmission was being transmitted from mother to child (MTCT). Transmission was through the placenta in the uterus during pregnancy, especially during labour and delivery, as well as post-natal through breast feeding (Morobadi & Webber, 2014; UNAIDS, 2015).

At the end of 2015, an estimated 1.8 million children less than 15 years of age were living with HIV infection worldwide, 90% in sub-Saharan Africa. More than 90% of those children acquired their infection through mother to child transmission (UNAIDS, 2016b). The 2013 UNICEF statistics indicated that 15-35% of MTCT was due to lack of treatment among pregnant mothers. The discovery of Antiretroviral drugs (ARV) to suppress the progression of HIV infection to AIDS came with a lot of relief as survival and quality of life of the infected individuals improved. This brought relief to parents of infected children. The drugs improved the survival and quality of life of the infected children and, if given to a pregnant woman at an appropriate time in her gestation, they reduced vertical transmission by about 30-90% (UNICEF, 2013).

According to WHO (2013), the 2013 mid-year population count estimated that the overall HIV prevalence globally is approximately 10%, with the total number of people living with HIV/AIDS estimated at approximately 5.3 million. The 2013 statistics also reveal that an

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estimated 15% of the South African population is HIV positive. In addition to these geographical statistics, there is an estimated 3.4 million children living with HIV in sub-Saharan Africa. WHO (2012) stated that an estimated 2 million children aged between 10-19 years old are living with the HIV infection worldwide, and most of them are not aware of their HIV status. Sub-Saharan Africa (SSA) remains the region in the world which is heavily affected by HIV/AIDS, with Southern Africa remaining at the centre of the epidemic. South Africa has the world's largest HIV epidemic and over 3 million people are on treatment, which represents roughly half of the people living with HIV in the country (UNAIDS, 2014).

Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu, Labadarios & Onoya (2014) found that in 2012, 12% of the population (6.4 million persons) were HIV positive in South Africa, which is 1.2 million more people than in 2008. The top four high HIV prevalence provinces being KwaZulu-Natal, Mpumalanga, Free State, and the North West with the lowest being Western Cape. Northern Cape and Limpopo have lower HIV prevalence than the other provinces. SSA (2010) pointed that Limpopo Province is one of South Africa's most rural and underserved provinces. The province serves as South Africa's gateway to the rest of Africa, as it shares borders with Botswana, Zimbabwe and Mozambique. Clearly, Limpopo Province is not isolated from the broader negative impact that HIV/AIDS has within South Africa.

According to Johnson, Dorrington & Moolla (2017b), by the middle of 2015, high levels of HIV diagnosis were achieved in South Africa, with an estimated 85% of HIV positive adults diagnosed. Rates of HIV diagnosis were similar across provinces, ranging from 82% in Gauteng to 88% in KwaZulu-Natal. Overall, 3.39 million South Africans were on ART by mid-2015, a more than 30-fold increase on the total in 2005. Approximately, 287 000 ART patients in 2015 (8%) were receiving treatment from the private sector. Over the period from mid-2010 to mid-2013, the annual number of new ART patients was relatively stable at around 560 000 per annum, but in the more recent years enrolment declined, reaching 413 000 over the period from mid-2014 to mid-2015. The decline in annual new enrolment was particularly pronounced in children, from 39 500 (Johnson, Dorrington & Moolla, 2017a).

According to Busza, Besana, Mapunda, and Oliveras (2013), progress has been made in treating children born with HIV infection efficiently. If they have continuous access to antiretroviral (ARV) treatment, these children can now lead a long productive life. The complete success in reducing MTCT means that paediatric HIV has now become an adolescent epidemic, especially with those already infected surviving into adulthood (UNAIDS, 2016a).

Despite outstanding clinical progress in improving survival rates and life expectancy, the lives of HIV infected children continue to be characterised by bio-psychosocial uncertainties (Bernays, Seeley, Rhodes & Mupambireyi, 2015). Chronic medical conditions in the paediatric population create a range of potential bio-psychosocial challenges not only for the child, but also for family members and health care providers (Avert, 2015).

Hysing, Elgen, Gillberg, Lie and Lundervold (2007) asserted that children who have been living with HIV infection since birth share stressors experienced by children with other chronic illnesses such as ongoing medical treatment, hospitalisation, exposure to pain and sheltered life experiences. However, children who are living with HIV infection also face unique stressors that relate to the bio-psychosocial impact of HIV/AIDS, for example, stigma and infectious illnesses that may make transition through adolescence very difficult (Wu & Li, 2013). People who have been living with HIV infection for a long time are at risk of developing mental health problems due to genetic, bio-medical, familial and environmental factors (Mellins & Malee, 2013).

Santamaria, Dolezal, Marhefka, Hoffman, Ahmed, Elkington and Mellins (2013) indicated that psycho-social issues are important as children develop through adolescence towards adulthood, where they try to develop a sense of self while striving for autonomy. As children's relationships with their parents and peers change, children may experience stressful challenges because they have immature coping skills and inadequate resources available to them (Wollett, 2013). Children who enter adolescence under difficult conditions may be poorly prepared to effectively cope with changes, thus, making the period of adolescence very challenging. However, as children develop they are plagued by challenges

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of coping with stigma associated with HIV infection, sexually transmittable chronic illnesses, management of medical treatment and adjustment of family loss due to HIV/AIDS (Mellins & Malee, 2013).

1.2 Background of the study

Eley, Kibel, Lake, Pendelburg and Smith (2010) asserted that, in South Africa, HIV/AIDS continues to be a social and health problem that affects every individual community member. HIV/AIDS poses a huge public health threat among young people, particularly children and adolescents who are supposed to bring a brighter future for society. The HIV/AIDS pandemic emerged as a biological, psychological and social problem that affects children's health and other spheres of life. HIV has no cure and, given the number of AIDS orphans, HIV results in social, cultural and spiritual crises that lead to problems in families and communities (Eley et al. 2010).

According to UNAIDS (2011), the phenomenon of HIV and AIDS has increased research interest in children who constitute about 21% of people living in sub-Saharan Africa. However, very little attention has been given to children living with vertically transmitted HIV/AIDS in the region. Even when issues regarding children are addressed, researchers rarely differentiate those who are vertically infected from those who have acquired HIV/AIDS sexually (UNAIDS, 2012; UNAIDS, 2016b).

Amzel, Toska, Lovich, Widyono, Patel, Foti, Dziubah, Phelps, Sugandhi, Mark and Altschuler (2013) stated that psycho-social wellbeing is complex and that it has effects on the mental health and social adaptation of children infected with HIV/AIDS. Psycho-social wellbeing includes the ability to cope with illness or death of a caregiver and resilience to live positively despite the challenges associated with HIV/AIDS, as well as cognitive capacity to participate as full members of society now and in the future.

Vranda and Mothi (2013) indicated that the developmental stages of children infected by HIV/AIDS, who survive to adolescence, such as puberty, sexuality and the desire to "fit" or be "normal", are seriously complicated by the HIV disease. The effects of HIV/AIDS on growth and pubescent maturity create challenges for the infected young people in their

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adolescence years. When HIV infected children move through adolescence and become sexually active, they need support to manage issues of integrating healthy sexual development with their HIV infection (Armstrong et al. 2013).

Mothi, Swamy, Lala, Karpagam and Gangakhedkar (2012) found that HIV infected children often face physical challenges such as delayed growth, development and late puberty. There are also challenges related to disclosure of one's HIV positive status, treatment adherence, as well as psychological and social challenges that impact their ability to deal with the illness. Wilson, Wright, Safrit and Rudy (2010) also argued that HIV/AIDS affects the children's emotional health and, coping with HIV infection can be hard for children because of various factors such as social stigma, side effects from treatment, parent or parents' death due to HIV/AIDS, fear of death and of disability, feelings of anger and anxiety. Therefore, these challenges must be addressed at all levels to encourage and support these vulnerable children.

Orne-Gliemann, Becquet, Ekouevi, Leroy, Perez and Dabis (2008) argued that the psychological impact of HIV/AIDS on children has been greatly underestimated and yet the world of a child living with HIV/AIDS in a family infected by HIV/AIDS goes through many changes. These children witness the physical deterioration and pain suffered by their infected parents as well as the death of their parents due to HIV/AIDS.

Islam, Scott and Minichiello (2014), in their study, found that children born into HIV infected families have numerous physical and psychological problems such as fear, isolation, depression, anxiety, grief, a low self-esteem, and trauma. These children also face multiple social difficulties including the disruption or loss of parental care and support, increased poverty, loss of income, malnutrition, withdrawal from school enrolment and attendance, decreased access to health care, increased participation in household activities, as well as increased risks of abuse and exploitation. Orne-Gliemann et al. (2008) also stated that these children are anxious about their source of income and their ability to retain the family home after their parents' deaths; separation from siblings is the commonest source of trauma among children. The loss of adult figures is likely to create a sense of insecurity and abandonment among children infected with HIV/AIDS.

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A recent study done by Sherr, Cluver, Betancourt, Kellerman, Richter and Desmond (2014) revealed that children who were born into a family infected by HIV experience problems related to health, cognitive development, education and exposure to sexually risky behaviour. Vranda and Mothi (2013) noted that the main factor that differentiates HIV/AIDS from other chronic or terminal illnesses is stigma. Too often, many HIV infected children and their families live in a conspiracy of silence and shame associated with HIV/AIDS. The HIV/AIDS illness is often kept as a secret and one of the results of a "conspiracy of silence'' is that the families may be withdrawn, become socially isolated and emotionally cut off from support systems.

UNICEF (2011) indicated that millions of children are affected as HIV/AIDS wears down families and communities in which they live. More than 15 million children have lost one or both parents due to the disease and these children suffer the effects of increased poverty, family disruption, interrupted or prematurely terminated education and taking up additional work including becoming caregivers. As HIV/AIDS continues to affect families, an increasing number of youth headed households have emerged with young people assuming the roles of breadwinner for their younger siblings. Richter, Beyrer, Kippax and Heldari (2010) asserted that children have to cope with the psycho-social challenges caused by the presence of serious illnesses affecting family members, discrimination and social separation that often accompanies HIV/AIDS. Midtbo, Shirima, Skovdal and Daniel (2012) indicated that HIV positive children experience high rates of psycho-social challenges compared to the average population. These challenges include disclosure, anxiety about medical prognosis, physical appearance and body image (wasting and dermatologic conditions), as well as disturbances in neuro-cognitive development.

According to Vranda and Mothi (2013), a family with HIV/AIDS infected children is generally a family dealing with a crisis because of illness, lack of resources, social isolation and need for medical, psychological and social services. It is important to assist these children and their families through multi-disciplinary interventions aimed at improving their quality of life. These approaches may also provide appropriate support for the infected children and their siblings, as well as connect families to services and community resources such as medical, mental health and social welfare services.

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Gupta, Shringi, Mahajan, Venkatesh and Srivastava (2015) concluded that appropriate counselling services, education and ways to decrease the bio-psychosocial impact of HIV/AIDS will benefit children. Education and support are the most effective tools that can help children and adolescents infected with HIV to survive into a psychologically and socially healthy adulthood. According to Wu and Li (2013), education can also help to reduce the stigma within the communities. Through support of family, friends and health care professionals, these infected children will grow into tomorrow's happy and healthy adults.

1.3 Problem statement

Statistics from the Messina Hospital Operational Manager's office indicate that, in January 2016, there were 119 male and female children below 18 years enrolled for the HIV/AIDS care and support programme at Fountain of Hope Clinic in Messina Hospital. More than 90% of the children are vertically infected with HIV/AIDS in sub-Saharan Africa and little is known about the psycho-social factors that impact their wellbeing, or how they cope with these challenges. Therefore there is a need to look at these children and gain insight into their psychosocial experiences of living with HIV/AIDS.

Across the globe, children born with perinatal HIV infection are reaching adolescence and young adulthood in large numbers. The majority of research has focused on bio-medical outcomes yet there is increasing awareness that long-term survivors with HIV infection are at high risk for mental health problems, given genetic, bio-medical, familial and environmental risk. Research and interventions studies on counselling, emotional and social support for children infected HIV/AIDS are scare and mostly focused on specific difficulties and trauma.

HIV/AIDS is one of much researched topic in the world and much focus on the attempt to address the needs of children living with HIV/AIDS but focuses on the material needs like poverty alleviation and education, however little information has been sought to the personal experiences of children who survived this epidemic. Children have physical, psychological and emotional and social needs but material needs are given preferences over psychological and social needs such as stigma and overall acceptance. Reproductive and sexual health needs of children with perinatal HIV/AIDS remain largely unaddressed by existing HIV

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programmes in this regard and this is why the bio-psychosocial model will be used to look at different challenges this group is facing.

The increase in the uptake of antiretroviral therapy (ART) has led to a significant increase in the survival of vertically transmitted HIV/AIDS infected children, many of whom are currently living into adolescence and early adulthood. The increase in life expectancy in this population has led to a rise in interest in understanding the psycho-social experiences of HIV/AIDS infection in this age group, such as mental health, cognitive development, sexuality, reproductive health, day to day challenges, life skills and barriers to their care. Despite the increased interest in understanding these challenges and experiences of children living with vertically transmitted HIV/AIDS remain largely understudied especially in sub-Saharan Africa.

The researcher, who is a Registered Counsellor, works in the study area daily and has observed that some of the children who were vertically infected with HIV/AIDS are not coping well. They struggle with the social stigma in the community and in schools; some have behavioural problems, engage in substance and drug use, while others attempt to commit suicide and have poor adherence with ARV treatment. Some of the infected children also have medical health problems and are deteriorating due to stress, poor relationships and depression, as well as being victims of sexual assault.

Despite all these observed challenges, most research studies have focused on the children from an adult, caregiver or service provider perspective. These children's experiences and voices tend to be underrepresented in the literature of children living with vertically transmitted HIV/AIDS in sub-Saharan Africa in general and South Africa in particular. It is, therefore, important that the psycho-social issues impacting children due to HIV/AIDS are addressed before a critical point is reached. Another aspect of concern is that the transition phase is a neglected area in research and more qualitative study data are required from rural areas.

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1.4 Aim and Objectives of the study

1.4.1 Aim

The aim of this study is to explore the psycho-social experiences of children living with vertically transmitted HIV/AIDS at Messina Hospital, South Africa.

1.4.2 Objectives

The objectives of this study were as follows:

- To determine the psycho-social experiences of children living with vertically transmitted HIV/AIDS;
- To determine the challenges faced by children who are living with vertically transmitted HIV/AIDS infection; and
- To identify and describe the coping strategies of children who are vertically infected with HIV/AIDS.

1.5 Research Questions

The study attempted to answer the following questions**:**

- What are the psycho-social experiences of children living with vertically transmitted HIV/AIDS?
- What challenges do children who are living with vertically transmitted HIV/AIDS infection face?
- What are the coping strategies of children who are vertically infected with HIV/AIDS?

1.6 Significance of the study

An understanding of these experiences could significantly help in planning programmes to assist other children and parents in different areas who are in the same HIV/AIDS programme. The study findings might contribute to new knowledge pertaining to psycho-social needs of HIV/AIDS vertically infected children in a developing country like South

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Africa. The findings could also contribute to the scientific body of knowledge in the field of psychology and social work.

This study explored the children's subjective psycho-social experiences of living with vertically transmitted HIV/AIDS with a view to building a holistic picture of their experiences as perceived by the children themselves. Therefore, findings from this study could inform and improve educational and psychological interventions for infected children in South Africa.

The study findings might also help stakeholders, such as programme designers, professionals and policy makers, to develop policies and provincial HIV/AIDS programmes specifically focussing on the psycho-social care of children living with HIV/AIDS.

The study could assist the training institutions in developing the content of psychology and social work programmes and assist in the practical training during their practicum to run support groups for children living with HIV/AIDS.

1.7 Theoretical framework

The researcher utilised the bio-psychosocial model as a theoretical framework for the study. This theory was originally developed in 1980 by American Psychiatrist, George L. Engel (1913-1999) who viewed people as united bio-psychosocial persons rather than bio-medical persons. The bio-psychosocial model perceives health and illness in terms of biological, psychological and social factors rather than purely in biological terms (Sperry, 2012). The word bio-psychosocial is derived from the words biological (physical, biochemical, genetic and physiological) psychological (mind, brain and personality) and social (external relationship and environment). This model stems from a general theory, which assumes that systems exist within systems and that nothing exists in isolation. This theory postulates that an individual's behaviour can only be understood in relation to the context within which it occurred (Vorster, 2003).

Therefore, psycho-social experiences of children living with vertically transmitted HIV/AIDS are viewed in the context of family where the infection took place. The bio-psychosocial

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model recognises that biological, psychological and social forces work together to determine an individual‘s health (Straub, 2012). This model holds that health status is the result of genetic inheritance, learned behaviour, cultural influences, quality of physical environment, socioeconomic status, amount of stress experienced, coping strategies, diet, sense of empowerment, social support and access to medical care services especially at primary level (Cowles, 2012). In this research study, the assumption is that the bio-psychosocial experiences faced by children living with vertically transmitted HIV/AIDS could be explained using their physical and psychological beings, as well as their day to day interaction within their families, school, church and peers.

In the bio-psychosocial model, health and wellness are explained in a multiple context (Straub, 2012). Sperry (2012) indicated that illness can be caused by a combination of biological factors such as a virus, psychological factors such as behaviour and beliefs, and social factors such as employment. The biological component of the model seeks to understand how the cause of illness stems from the functioning of the human body, while the psychological component looks at the belief that health and illness are subject to psychological influences (Straub, 2012).

Sperry (2012) in this model, disease is considered as the symbolic network linking body, self and society. The bio-psychosocial model is based on the general systems paradigm and it proposes that disease and illness can only be truly understood by evaluating all potential factors including the social and psychological context. From this perspective, illness behaviour and disease are viewed as subject to genetic, biological, psychological, socio-cultural and ecological factors. The model proposes that all three factors affects and are affected by an individual’s health. In view of the above discussion, it could be argued that man is a social being rather than a biological specimen; illness cannot be separated from the psychological, social or cultural context. Therefore, there is need to view an individual holistically to understand his or her illness. Focus should be on the role of individual health behaviours, and lifestyles, as well as on social, cultural and institutional environments as they, together, affect individual and community health (Habib & Ranman, 2010).

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HIV infection is not only a medical issue, but a psycho-social one as well. Infection and progression of this disease exposed the patient with a broad range of personal experiences to negotiate (NACC, 2010). Psychological effects of HIV/AIDS refer to the factors that can affect the emotional state of people living with HIV/AIDS (PLWHA) and make them psychologically unstable (Sitienei, 2016; NACC, 2010). The psychological component of the model will include emotional turmoil, stress management, negative thinking and poor coping skills (Cowles, 2012; Straub, 2012).

Ross and Deverell (2010) pointed out that children living HIV/AIDS live in fear, of being found to have the disease. HIV/AIDS carries a double stigma of being a terminal and sexual transmitted diseases. As a result, there are psychological effects on the patient. Sitienei (2016) living with HIV/AIDS is associated with psychological stress such as fear, anxiety, depression and guilt. In this regard the aspects of disclosure, adherence and stigma and discrimination were explored with the participants.

According to Agrawal, Jain, Agrawal, Singh & Yadav (2015), it is important to treat HIV/AIDS with bio-psychosocial perspective in mind with special emphasis on recognising and managing psychological problems during routine assessment and management of medical problems. Focused counselling, cognitive behaviour therapy and group therapy among others, along with medical treatment can lead to better outcome (Jehangir, 2013). Through therapy, psychosocial issues such as, patient’s journey, life challenges, along with grief, anger, guilt and relationship difficulties are addressed (Agrawal et al. 2015; Mellins & Marlee (2013).

The biological component of the model seeks to understand the anatomical structure, effects of patient’s biological function and how the cause of illness stems from the function human body. HIV virus exists in the human body and has effects on the biological function of human body (Dogar, 2007). The fight against child mortality due to perinatal HIV/AIDS infection was won with the introduction of ART treatment. HIV/AIDS is now manageable, however it has adverse effects on the body of a children born with the virus. As children grow up living with HIV virus, they are more likely to develop the infectious diseases (Mellins & Marlee, 2013). Midtbo (2012) indicated that children living with HIV virus have health challenges such as constant sickness that require medical assistance. In a study conducted by Gray (2009) adolescents were mostly hospitalised due to immune suppression, tuberculosis and

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pneumonia among other illnesses. Lipshuitz, Miller, Wilkinson, Scott, Somarriba, Cochran and Fisher (2013) revealed that HIV infection is primary the cause of acquired heart disease and pulmonary artery hypertension.

The social component of the model includes culture, religious and environmental and familial experience on the expression of illness (Dogar, 2007). Social factors include social systems like churches, schools, and society as a whole, placing emphasis on how these social systems relate with the individual. These social factors are more dependent on lack of social support and high levels of responsibility of home, school and community at large (Cowles, 2012; Straub, 2012). It is regarded that HIV is a stigmatised illness and children living with HIV/AIDS will experience disclosure difficulties, stigma and discrimination. Zanoni (2013) indicated that stigma is one social aspect that affects everyone infected and affected by HIV/AIDS. Stigma has effects on the disease progression as it can affect or lead to non-adherence and non-disclosure. Wollett (2013) argued that stigma has danger of having lasting effects on children's social and psychological function which include denial of the disease and in turn affects the adherence.

Pienaar and Visser (2012) discovered that adolescents had increased need for independence and acceptance within their peer group. They found out that adolescents living with HIV/AIDS were struggling with issues of disclosure, lack of support from social environment. Baryamutuma and Baingana (2011) revealed that HIV/AIDS management is constrained by lack of communication and support from health care providers among children living with HIV/AIDS. Pienaar and Visser (2012) children had extended support from teachers which were not enough, they needed support from friends and community as whole. Due to non-disclosure, the social support system is limited to parents and caregivers. It was usually in form of physical support, hence emotional support which is an important aspects in treatment adherence was lacking.

The social aspects were explored on issues like children's social support system available. This involves asking about participant's interaction and support received from friends, family, school, community and health systems as a whole. This enabled the researcher to explore the children's challenges form biological, social, and psychological aspects to obtain a full account of the challenges they face.

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There is a need to look at health illness from a bio-psychosocial perspective and political perspective to help in evaluating the various contributing factors of health illness in different contexts. With this view, health illness and behaviour are viewed as matter of various factors that are not limited to genetic, psychological, social and ecological perspective (Habib & Rahman, 2010). While the biomedical model views HIV/AIDS as a chronic infectious disease that affects the immune system of an individual, the social perspective views HIV/AIDS as a social and a biological disorder, thefore social and political contexts are required to understand and treat the disease (Watkins-Hayes, 2014).

The bio-psychosocial model assisted the researcher to develop a better understanding of the psycho-social experiences faced by children living with vertically transmitted HIV/AIDS. The researcher believes that, besides having the virus to deal with, being HIV positive comes with many biological, psychological and social challenges. The challenges include disturbed physical and cognitive development, discrimination, stigma, issues of disclosure, and failing to adhere to ART treatment and support services. Therefore, the researcher considered this model appropriate for this study.

1.8 Operational Definitions of Concepts and Key Terms

- **Psycho-social:** Psycho-social refers to behavioural, psychological, social and emotional experiences that limit normal functioning or cause unhappiness for an individual or the people around him/herself (Foster & Wiliamson, 2000). In this study, psycho-social also means challenges such as HIV/AIDS disclosure, treatment adherence, stigma and discrimination, death and bereavement, as well as relationship challenges.

- **Experience:** According to Kolb (2013), experience is the unity of sight and action, perception, conception, knowledge, theory and practice. It has to do with seeing into a situation or acting within it and involves both knowledge and evaluation of objects, events and situations. In this study, experience is the accumulation of knowledge or skill that results from direct participation in events or activities, and it includes cognitive, behavioural, neurological, social, medical, economical and psychological aspects of living with HIV/AIDS.

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- **Children:** According to the Constitution of the Republic of South Africa Children's Act No. 38 of 2005, a child is a person under the age of 18 years (Children's Act 38 of 2005). In this study, children refer to individuals between 12 and 17 years of age living with vertically transmitted HIV/AIDS infection and who are receiving care and support at an ARV Clinic at Messina Hospital. The study focused on children aged from 12 years because, according to the Children's Bill of Rights in the constitution, they can legally give consent to obtain health services (Proudlock & Jamieson 2008). According to Engler (2014), children between 12 and 18 years old are referred to as adolescents; adolescence is a period of transition from childhood to adulthood.

- **HIV:** This is an acronym for Human Immunodeficiency Virus that attacks white blood cells (T lympcetes) in human blood thereby weakening the functioning of the immune system (American Psychological Association, 2002). HIV destroys the body's ability to fight off infection and disease, and this ultimately leads to AIDS (UNAIDS, 2011).

- **AIDS:** This is an acronym for Acquired Immunodeficiency Syndrome, which is caused by a virus that changes the immune system and weakens the body's ability to fight infection (American Psychological Association, 2002). AIDS is an epidemiological disease based on clinical signs and symptoms caused by HIV (UNAIDS, 2011).

- **Living with HIV/AIDS:** According to UNAIDS (2012), this refers to a condition where antibodies against HIV have been detected in the blood test or gingival exudates test; the synonym is seropositive. In this study, living with HIV/AIDS means when one, in particular a child, has HIV, which was transmitted from one's mother, in one's blood system.
- **Vertical transmission of HIV/AIDS:** According to WHO (2010), vertical transmission is the passage of a disease- causing agent (pathogen) from mother to baby during the period immediately before or after birth. It is also called perinatal transmission. In this study, vertical transmission is when children get infected with HIV/AIDS via their mothers (MTCT) through the placenta in the uterus during pregnancy, during labour, delivery or post-natal through breast feeding.

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1.9 Structure of the Study

This dissertation is made up of five chapters, each with a specific subject matter.

Chapter 1: Introduction and Background of the Study

This chapter comprises the introduction and background of the study, problem statement, aim and objectives of the study, research questions, and significance of the study. It concludes with the theoretical framework which guided the study, as well as operational definitions of concepts and key terms.

Chapter 2: Literature Review

This chapter reviews literature pertaining to the study.

Chapter 3: Research design and Methodology

This chapter discusses the methodology used to carry out the study. on the chapter discusses the research approach, research design, population and setting, sampling, research instrument, data collection, data analysis and ethical considerations that were adhered to when conducting the study.

Chapter 4: Data analysis, themes and literature control

This chapter presents and analyses data gathered from the participants.

Chapter 5: Conclusion and Recommendations

This chapter concludes the study. It concentrates on conclusions, limitations and recommendations based on the results of the study.

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CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter discusses literature pertaining to children living with vertically transmitted HIV/AIDS globally and sub-Saharan Africa in general and South Africa in particular. In this section, previous research studies conducted on the topic were reviewed to bring forth a clear understanding of the phenomenon under study. The experiences of children living with vertically transmitted HIV/AIDS will be discussed using bio-psychosocial model framework. This model acknowledges that HIV/AIDS pandemic is not only about physical health aspects of individual but also the social and psychological aspects. This model will guide the researcher to examine how HIV/AIDS affects these children on their daily lives with interaction with family, society and community. The literature review covers aspects of psycho-social experiences of children living with vertically transmitted HIV/AIDS such as the psychological effects of living with vertically transmitted HIV/AIDS; psycho-social challenges of living with HIV/AIDS; and coping strategies that children employ to deal with HIVAIDS.

2.2 Psychological effects of living with vertically transmitted HIV/AIDS

According to The National AIDS Control Council (NACC) (2010), psychological effects are factors which can influence the emotional state of an individual either positively or negatively and they can affect the emotional state of PLWHA and make them psychologically unstable (Sitienei, 2016). Mellins and Marlee (2013) argue that children are living with HIV infection experience emotional and behavioural problems including psychiatric problems at a higher rate than those in the general population. They are at greater risk of psychiatric problems, such as depression, anxiety, and feelings of isolation. The psychological conditions and poverty under which many children with HIV/AIDS live increase difficulties in their illnesses and treatment. The commonest disorders found are anxiety disorders followed by attention deficit hyperactivity disorders, conduct disorders, and mood disorders (Vranda & Mothi, 2013).

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Brown, Lourie and Pao (2000) explored the psychological effects and manifestation of psychiatric problems which accompany paediatric HIV/AIDS infection. Their investigation of 84 HIV positive children found an association between poor emotional functioning, social support and school performance. The psychological status of these children was confirmed by an evaluation of their anxiety and depression levels, as well as self-reported physical problems such as pain or sleeplessness (Zanoni, 2013). According to Mwoma and Pillay (2015), psycho-social effects stress the close connection between aspects of our subjective experiences involving personal thoughts, emotions, behaviour and social experiences which involve relationships, tradition and culture.

Vreeman, Gramelspacher, Gisore, Scanlon and Nyandiko (2013) found out that learning about one’s HIV positive status was clearly an emotional and critical point in children’s lives. Children describe reacting with sadness and grief, anxiety and worry about what their diagnosis means for the future. Children shared their caregiver’s worries about negative consequences that may result if their status is revealed to others). Mutwa, Van Nuil, Asiimwe-Kateera, Kestelyn, Vyankandondera, Pool, Ruhirimbura, Kanazuke, Reiss, Geelen, van de Wijgert and Boer (2013) noted that, when children find out their status, they experience feelings of confusion and anger towards their parents. Some children might attempt to punish their parents due to confusion about why they had HIV infection and not the others.

However, when children were narrating their experiences at the time of disclosure of their HIV positive status, they described feelings of shock, anger and betrayal towards family members. Their feelings of anger were related to the way they were infected with HIV and to not being told about their HIV positive status earlier. The emotions were often linked to a sense of blame by these children (Willis, Frewin, Miller, Mavhu & Cowan, 2014). Although some children, upon disclosure, experience sadness or anger and blame, these feelings were gradually replaced by calm, relief and comfort because of understanding the condition, reasons for treatment and taking and participating in their own care (Amzel et al., 2013).

Gupta et al. (2015) found that children living with HIV/AIDS experienced anger, isolation, fearfulness, loss of confidence, frequent sickness and that they had suicidal tendencies. HIV infected children reported that they had problems of being physically different from their

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peers. These children were physically small, had skin disfigurations and were concerned about their delayed puberty (Willis et al. 2014).

In bio-psychosocial model, the psychological component looks at the belief that health illness are subject to psychological influences. The potential psychological causes and effects of health problems such as HIV/AIDS will include emotional turmoil, stress management, negative thinking and poor coping skill (Straub, 2012). People living with HIV/AIDS suffer from a wide range of psychological issues such as depression, anger, stress, suicidal ideation, low self-esteem and adjustment issues. This is because knowing that one has tested HIV positive can have a damaging effect on one's mental health. Societal labelling, negative attitudes and misconceptions about the person's status increase the stress level (Wu & Li, 2013; Sitienei, 2016) the psychological effects, such as fear and anxiety, anger, depression and guilt are discussed next.

2.2.1 Fears and anxiety

Fear is a negative emotional feeling that one can have when one is in danger or when something bad has happened, or when a particular thing frightens the individual. Anxiety is the feeling of worry, nervousness or unease about something with an uncertain outcome and a strong desire or concern to do something or for something to happen (Sperry, 2012). According to Taylor (2010), fear is an intense anxiety that makes an individual to remain coiled in a particular position. HIV/AIDS is usually associated with a lot of fear that makes PLWHA afraid of taking steps in life or of socialising with other people in society. Fear can worsen symptoms of depression and lead to feelings of hopelessness, frustration and being overwhelmed (UNAIDS, 2010).

Fear and anxiety may also be caused by not knowing how others will treat them if they find out they have HIV. Children living with HIV/AIDS may also be afraid of telling other people, such as friends and family members, that they are HIV positive (Jehangir, 2013). Mupambireyi, Bernays, Bwakura-Dangerembizi and Cowan (2014) found out that fear of stigma and discrimination made it difficult for children to openly talk about their HIV positive status in other care environments such as the home and school. According to Zanoni

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(2013), children living with HIV/AIDS have also fear and anxiety over the possibility of a disruption in the supply of treatment, as well as fear of finding future marriage partners who are willing to accept their HIV positive status.

Sitienei (2016) stated that HIV positive children have fears and about uncertainty of the future. They are afraid of dying, particularly dying alone and in pain. Their fear may be caused by not knowing enough about being HIV positive and how the problem can be handled. They often experience anxiety because of the prognosis of the illness, the risk of infection with disease, and the risk of infecting loved ones with HIV. Fabianova (2011) argued that individuals living with HIV/AIDS are usually afraid of losing their lives, their ambitions, physical performance and sexual relations. Mellins and Malee (2013) indicated that adolescents living with HIV infection may be at increased risk of anxiety and depression compared to other adolescents because of a complex mix of psycho-social issues and bio-medical factors that are associated with chronic illness.

2.2.2 Anger

According to Sitienei (2016), anger is a strong negative emotion which involves violence towards oneself and other people. Anger can be expressed verbally and through physical abuse of others, and it usually occurs when one is prevented from doing what one wants to do. Falvo (2014) pointed out that people with HIV infection may be angry that their condition was caused by negligence or it could have been avoided. Anger may be directed towards other people or circumstances when they perceive themselves as victims. If they believe that their own actions were to blame for their health condition, then anger may be directed to themselves. Anger may also be a result of frustration (Eller et al., 2014). Individuals may show their frustration and anger by displacing hostility towards others even when those other individuals have not contributed to the development of their health condition or influenced its effects. Anger may also be an expression of the realisation of the seriousness of the situation or it may be associated with feelings of helplessness (Zanoni, 2013; Mellins & Malee, 2013).

Sitienei (2016) indicated that people with HIV infection are often very angry with themselves and others and that the anger is sometimes directed to those people closest to them. They are angry because there is no cure for HIV/AIDS and because of the uncertainty of their future.

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Singh, Naidu, Davies and Bohlius (2017) they may also be angry because their antiretroviral treatment is too expensive or that the roll out of the ARV programme in the public sector is very slow. They are often angry with those who infected them and with society's reaction of hostility and indifference. Falvo (2014) stated that, at times, anger may not be openly expressed by an individual with a health condition, but rather it will be hidden in quarrelling, arguing, complaining or by being excessively demanding in an attempt to gain some sense of control of the situation.

2.2.3 Depression

Depression is an emotional state characterised by feelings of sadness, low self-esteem and guilt or reduced ability to enjoy life (Sperry, 2015; Mellins & Malee, 2013). Major depression or clinical depression, is an illness characterised by changes in mood, thinking, concentration, sleep, appetite, energy; it may curtail a person's normal capacity to gain pleasure and motivation to live positively (APA, 2013). Diagnosis of this condition depends on a number of these symptoms being present consistently for at least 2 weeks. It may cause impairment in day to day activities and/or noticeable problems in relationships with others (APA, 2013). It is not considered a mental disorder unless it significantly disrupts the individual's daily functioning (Sperry, 2015; Fabianova, 2011).

Mutwa et al. (2013) indicated that non-acceptance of the HIV/AIDS diagnosis by children leads to feelings of depression and isolation and these feelings were often related to anger and confusion. Infected children questioned why they were infected with HIV/AIDS while their siblings were not infected (Eller et al., 2014). When these children felt depressed and isolated, they were less motivated to take ART treatment. However, when they accepted their status, they developed a will to live and adhere to ART (Jehangir, 2013).

Breuer, Myer, Strother and Joke (2011) indicated that the average prevalence of depression in sub-Saharan Africa is roughly 5%, but it is higher in people living with HIV/AIDS. Some of depression symptoms found in people living with HIV/AIDS can be attributed to factors such as challenges of coping with the diagnosis, disease symptoms, bereavement, relationship crises, social rejection, co-existing poverty and the side effects of certain ARVs. Depression is a predictor of worse HIV/AIDS treatment outcomes, it is associated with treatment failure

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and the emergence of drug-resistant HIV strains, as it leads to poor adherence to ART treatment (Gonzalez, Batchelder, Psaros & Safran, 2011; Nakimuli-Mpungu, Bass & Alexandre, 2011). Two studies conducted in Ethiopia found a significant association between depression and non-adherence to ART (Amberbir, Woldemicheal, Getachew, Girm & Deribe, 2008). Depression may affect adherence due to repetitive negative thinking, increased forgetting or lack of concentration and poor problem solving skills. In the later stages of AIDS, depression is a common reaction to living with deteriorating physical illness (Nakimuli-Mpungu et al. 2011).

According to Falvo (2014), some individuals living with HIV infection may experience feelings of depression after realising the implication of their condition. They may express feelings of helplessness, hopelessness, rejection and discouragement. Signs of depression include sleep disturbances, changes in appetite, thinking about death, feeling sad, anxious and irritable, difficulty in concentrating, as well as withdrawal from previously enjoyed activities and sadness. Prolonged or unresolved depression can result in self destructive behaviours such as suicide attempts or drug use. However, Fabianova (2011) noted that symptoms of depression in children are associated with extremely sad moods, slowing down of psychomotor speed, sleep disturbances and suicidal thoughts. A typical symptom is presented by increased irritability, and behavioural problems showing an element of aggression.

Lawan, Amole, Jahun and Abute (2015) found that more than half of the children in the study, 54%, reported being depressed most of the time and were afraid of death because HIV/AIDS infection has no cure**.** The results of a study done in Rwanda by Betancourt, Ng, Kirk, Munyanah, Mushashi and Ingabire (2014) indicated that HIV infected children demonstrated higher levels of depression, anxiety, conduct problems and functional impairment compared to unaffected children. However, a study by Barua, Sharma and Basalio (2013) explored the various aspects of depression in HIV/AIDS participants, such as apathy, sleep disturbance, pessimism, fatigue, irritability and social withdrawal, which were associated with depression. This study asserted that, every participant in the study who was living with HIV infection were suffering from symptoms of depression. Females showed high levels of depression compared to their male counterparts and this, on many occasions, prevented these individuals from seeking treatment.

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In the study on prevalence of psychopathology, 36% of the patients tested positive for major depression and 27% for dysthymia (Bing et al. 2001). HIV/AIDS increases the risk of developing major depression, chronic stress, worsening social isolation and intense demoralisation (Nakimuli-Mpungu et al. 2011).

Willis, Mavhu, Wogrin, Mutsinze and Kagee (2018) found that participants recognised their experiences of depression to their relationships and interactions with their family members and peers. A sense of being different from others was common among the participants, both due to their HIV status and the impact HIV has had on their life circumstances. Participants described a longing to be important or to matter to the people in their lives. A sense of isolation and rejection was common, as well as grief and loss, including ambiguous and anticipated loss Nakimuli-Mpungu et al. (2011) found increase in depression in HIV infected individuals.

2.2.4 Loss

According to Sitienei (2016), loss is a state of being not in possession of something or somebody. Sadness is one of the outcomes for people who have experienced losses repeatedly. People living with HIV/AIDS may have to grieve the loss of family and friends while at the same time mourn the loss of their own future. Fabianova (2011) argues that individuals living with HIV/AIDS lose their sense of privacy and control over their lives. As the disease progresses, they experience helplessness which forces them to need other people to take care of them most of the time. The loss of independence may affect their future and ability to make decisions about their lives.

UNAIDS (2010) and Jehangir (2013) stated that most often HIV positive children lose everything that is important and beautiful to them. They experience loss of control and independence, loss of their ambitions, their healthy physical attractive appearance and sexual relationships. They also lose their ability to care for themselves and their families, as well as mourn the loss of life itself. The loss of loved ones may lead some children to engage in negative coping practices and risky behaviours that could endanger their health (Zanoni,

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2013). However, those who have lost loved ones from HIV/AIDS are sometimes able to find meaning in their loss; some experience changes in their spiritual and faith system because of bereavement (Hereen et al. 2012; Vaz et al. 2010).

Mavhu, Berwick, Chirawa, Makamba, Copas, Dirawo, Willis, Araya, Abas, Cobett, Mungofa, Laver, and Cowan (2013), in a study in Zimbabwe, revealed that orphan hood was common. Seventy six percent (76%) of the participants stated that their parents had died due to HIV/AIDS infection. Short and Goldberg (2015) indicated that while not all parental deaths result from HIV/AIDS, in 2013 over 15 million children in sub-Saharan Africa were estimated to have lost one or both parents to HIV/AIDS. In Swaziland and Lesotho, an estimated 70% of orphans lost their parents due to HIV/AIDS. Habib and Rahman (2010) vertically infected children with HIV/AIDS who experienced parental death have been found to be at increased risk of poor health and schooling outcomes compared to HIV negative children. Willis et al. (2018) found that the majority of participants had been orphaned and demonstrated signs of profound, unresolved grief and described the death of parent/parents as contributing factor to their depression.

Mavhu et al. (2013) most of the children lived in households which were not headed by their parents, 19% of the children reported that they could not afford to eat at least two meals a day and 40% had not attended school because there was no money to pay their school fees. A study done in South Africa found that, over half of the children were orphans, and that the loss of biological parents was emotionally painful. For about 80% of the orphaned children, factors such as worrying about who was going to care for them, loss of someone who loved them and families fighting over them seemed to have a great influence on how these children experienced loss (Petersen, Bhana, Myeza, Alicea, John, Holst, McKay & Mellins, 2010).

Vranda and Mothi (2013) stated that, as the disease progresses, children confront the physical and mental decline associated with AIDS. Children and adolescents must cope with the mortality of their loved ones who are infected with HIV/AIDS, as well as their own mortality. Facing and understanding their own possible death are major challenges faced by children and youth with HIV/AIDS. In a study done by Willis et al. (2014) children described multiple losses such as the death of their parents, siblings and loss of childhood when growing up

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without these people in their lives. Children's experiences of family death and recurrent messages that say HIV/AIDS kills left them worried and fearful for their future.

2.2.5 Guilt

According to Falvo (2014), guilt is self-criticism or self-blame. Individuals may feel guilty if they believe they contributed or in some way caused the health condition they have. In some situations, they may experience guilt because they believe their health condition places a burden on the family or that they are unable to fulfil the roles they used to fulfil. Others may feel guilty that they have survived a situation that others have not. Guilt can be expressed by individuals with a health condition such as HIV/AIDS and it can occur in different dimensions (Heath et al. 2014). Children tend to internalise the stigma and discrimination, that leads to negative self-image, self-blame with question and suffer from guilt (Eller, Rivero-Mendez, Voss, Chen, Chaiphibalsarisdi, Iipinge & Brion, 2014).

Guilt can be an obstacle to successful adjustment to a health condition or to its implications. Demmer (2014) stated that when HIV infected individuals who are lucky enough to access ARV treatment and who have experienced improved health look realise that many in their community have died due to HIV/AIDS, they may feel guilty. Some individuals may experience survivor's guilt because many people died before they could benefit from the new treatment. Individuals may question why they survived when other people did not. Fabianova (2011) argues that people infected with HIV/AIDS can also feel helpless and hopeless; they might be unable to deal with and adjust to the situation which will reduce the quality of their lives.

In conclusion, a review of literature on the psychological effects of living with vertically transmitted HIV/AIDS offers mixed findings. Some studies found greater levels of psycho-social problems among children living with vertically transmitted HIV/AIDS, while others find no significant differences between children living with vertically transmitted HIV/AIDS and their peers who are HIV negative. The reason for these mixed findings could be because some of these studies are based on health care professionals or caregivers' perspectives which ignore the perspective of infected children (Zanoni, 2013; Wollett, 2013; Mavhu et al., 2010; Peterson et al., 2010).

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2.3 Psycho-social challenges of children living vertical transmitted HIV/AIDS

Foster and Wiliamson (2000) define psycho-social challenges as behavioural, psychological, social and emotional experiences or challenges that limit normal functioning or cause unhappiness for individuals or the people around them. According to Petersen et al. (2010), more than 90% of the children in sub-Saharan Africa are vertically infected with HIV/AIDS and yet little is known about the psycho-social factors that impact their wellbeing, or how they cope with these challenges. Adolescents living with HIV (ALHIV) experienced similar psycho-social challenges and concerns (Li, Jaspan, O'Brien, Rabie, Cotton, & Nattrass, 2010; Petersen et al., 2010). Findings by Mellins and Malee (2013) indicate that children experience a lot of challenges such as ongoing medical treatment, hospitalisation, and exposure to pain and life experiences. Challenges include lack of disclosure of HIV status, erratic drug taking, stigma, difficulty in identifying with HIV negative peers, anxiety about sexual relationships and a low self-esteem (Kamau, Kuria, Mathai, Atwoli & Kangethe, 2012; Li et al., 2010; Petersen et al., 2010).

Adolescents also reported emotional problems such as feeling angry and fearful of HIV, depression, emotional pain due to stressful life events like severe illness and death of parents, siblings or close relatives, worrying about who will take care of them, poverty, social withdrawal, loneliness, anger, crime, violence and stigma (Kamau, Kuria, Mathai, Atwoli & Kangethe, 2012; Li et al., 2010; Petersen et al., 2010). The combination of HIV/AIDS related issues of life expectancy, bereavement, change of caregivers, family silence, disclosure, transmission of the virus to others and the rapid changes of adolescents create exceptional and complex challenges for children living with vertically transmitted HIV/AIDS (Kamau et al. 2012; Ferrand, Lowe, Whande, Munaiwa, Langhaug, Cowan, Mugurungi, Gibb, Munyati, Williams & Corbett, 2010; Petersen et al., 2010). Children infected with HIV/AIDS often share common problems and concerns, but they also experience unique challenges (Mitchell, Richter & Rochat, 2015).

2.3.1 Diagnosis and disclosure

Vreeman, Gramelspache, Gisore, Scanlon and Nyandiko (2013) defined disclosure as gaining knowledge about one's own health status, such as being HIV/AIDS infected, and revealing it

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to others. According to Siu, Bakeera-Kitura, Kennedy, Dhabangi and kambugu (2012), HIV disclosure, with regards to children, is associated with four different circumstances. The first one is when parents and guardians disclose their own HIV positive status to their children; the second one is when parents or guardians or caregivers, such as healthcare providers, inform children living with HIV that they are HIV positive; the third one is when children disclose their status to a third party; and lastly is when the children's HIV positive status is disclosed to a third party by a parent, guardian or health care provider (Thoth, Tucker, Leahy & Stewart, 2013).

Rochat, Mkwanazi, and Bland (2013) stated that each of these forms of disclosure can be beneficial to children if it is planned and timed well. Disclosure of the HIV status to children has positive outcomes in their lives compared to keeping it a secret (Heeren et al., 2012; Vaz, Maman, Eng, Barbarin, Tshikandu & Behets, 2011). Children who have been told about their own HIV positive status may be in a better position to access antiretroviral therapy from health facilities, and have psycho-social support from peers and support groups (Midtbo et al. 2012). At the same time, explaining to children that they have HIV infection fulfils their right to know about their own health; this may also improve their adherence to ARTs and improve their survival (Fielden, Chapman & Cadell, 2011).

When disclosing the HIV positive status to children, the process should be gradual and children should be given age appropriate information regarding their illness. The process should lead to full disclosure when the child has the cognitive and emotional maturity to process the information (Thoth et al. 2013). The disclosure of the HIV status to children should occur between the ages of 10 and 16 years as they are old enough to process the information with regard to HIV/AIDS (Heeren et al. 2012; Madiba, 2012).

Children indicated negative effects of delayed disclosure and positive effects of disclosure. They have reported a desire to know their HIV status, and wished for honest and open talk about their illness (Heeren et al. 2012; Hodgson et al. 2012). Children who had been informed of their HIV positive diagnosis at age of 12 years expressed that they thought it would be better if their caregivers had informed them around the age of five (Heeren et al. 2012).

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Mburu, Hodgson, Kalibala, Haamusjompa, Cataldo, Lowenthal, and Ross (2014b) found that the disclosure had various effects on children. After being told that they were HIV positive, the children said that they felt anxious, depressed, and blamed themselves. On the other hand, Abubakar et al. (2016) found that children accepted their status when they learnt of their HIV positive status. However, there were a few who reported experiencing distress such as crying and having suicidal ideas. Children indicated that support from parents and sharing with counsellors helped them to get over the distress fairly quickly.

Mburu, Ram, Oxenham, Haamujompa, Lorpenda and Ferguson (2014a) noted that children living with HIV infection in Zambia reported that, after learning about their HIV positive status, they went through changes in which they endured the challenges associated with being HIV/AIDS infected. These children survived after being diagnosed with a lifelong condition. However, some of the children described feeling hopeless when they learnt about their HIV positive diagnosis, which was disclosed after a prolonged period of illness. To these children, disclosure was both terrifying and disempowering. Mistrust, fears of stigma and discrimination and secrecy contributed to prolonged disclosure of their HIV positive status by caregivers (Willis et al. 2014).

According to Petersen et al. (2010), 22 children indicated that when they received news of their HIV positive status, they experienced emotional difficulties. Only three children did not experience emotional difficulties; one was too young to understand what being HIV positive really meant while the other two indicated that it was because their parents were HIV positive. However, these children were well-informed about the HIV disease and they did not see it as a terminal disease. Those children who experienced emotional difficulties reported feeling alone in the world and they perceived that their futures had been shortened. This was due to lack of information about ARV treatment and believing that they would be unable to lead a normal life (Heath, 2015; Zanoni, 2013).

Furthermore, the children’s family circumstances did not allow them to express their sorrow because of the HIV/AIDS related stigma within the family. Eighteen (72%) of the children stated that health care providers assisted by disclosing their HIV positive status to them (Petersen et al., 2010). Wolf, Halpen-Felsher, Bukusi Agot, Cohen and Auserswald (2014) found out that most of the children living with HIV infection experienced HIV related stigma from their family members. Family members believed that an HIV positive diagnosis was a death sentence, and this contributed to limited educational and psycho-social support for the infected child. Wollett (2013) indicated that in the process of trying to enforce non-disclosure to children to avoid stigma, the family is actually stigmatising themselves.

Mburu, Hodgson, Kalibala, Haamusjompa, Cataldo, Lowenthal and Ross (2014b) argue that disclosure created opportunities for children to access adherence support and other forms of psycho-social support from family members and peers. Disclosure was reported to have strained the children's sexual relationships, though it did not always lead to rejection. Midtbo et al. (2012) found that disclosure of the HIV diagnosis helped HIV infected children to cope with stigma. Although disclosure has its challenges, it has enabled these HIV positive children to seek support from family, friends, teachers and health care workers (Hodgson et al. 2012; Li et al. 2010). Disclosure has shown to improve children's ART adherence and the strong family support has enabled them to cope much better with the HIV/AIDS diagnosis. Furthermore, adolescents, in South Africa, have been reported to use the knowledge about HIV/AIDS to manage their own lives and cope with stigma.

Gupta et al. (2015) found that 65% of the children who participated in their study knew about their HIV positive status and said disclosure was mostly done by doctors and caregivers who helped them to realise the importance of adherence to ART. Knowledge about the nature of disease was not known by most of the children in this study. However, all the children who participated in Mutwa et al.'s (2013) study, were vertically infected with HIV and they had challenges regarding disclosure. The children's HIV positive status was kept hidden even after they had begun taking ARTs; the children did not know what the treatment was for.

Vreeman et al. (2013) found out that the disclosure process was a one-time event, while others described it as a gradual process done by caregivers. The common barrier to disclosure was the caregivers' fears; they were afraid that the children would disclose their HIV positive status to others and that they might be stigmatised. Caregivers were concerned about the children's emotional or physical health when they learnt about their HIV positive status. Findings from the study suggested that adherence to antiretroviral therapy (ART) had

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improved post disclosure, but that the emotional and psychological effects of disclosure were not consistent (Vreeman et al. 2013; Zanoni, 2013).

In a study by Mburu et al. (2014a), children reported having disclosed their HIV positive status to their boyfriends and girlfriends, some children had not done so because they feared abandonment or other negative consequences. Wolf et al. (2014), however, found that children were afraid of family members discovering their HIV positive status and this negatively affected their follow up treatment at clinics and ART adherence.

2.3.2 Treatment adherence

According to Agwu and Fairlie (2013), adherence is the term that is used to describe taking treatment properly according to prescription. In sub-Saharan Africa, many children living with HIV infection, who are on treatment, were diagnosed in the first few years of their lives and started ART at ages between 3-4 years old. This is a period of physical and psycho-social development. Martinazzo, Sousa, Harrad, de Brito Almeida, Moraes, da Silveira Rossi and Hallal (2013) indicated that antiretroviral therapy (ART) is effective in suppressing HIV replication, preventing opportunistic diseases, reducing mortality and improving the wellbeing of HIV/AIDS infected children and adults. High adherence levels delay the disease's progression in the long-term and, without adequate adherence, antiretroviral (ARV) drugs are not sufficient to suppress HIV replication in the infected cells. Poor adherence to ARV treatment leads to the development of drug resistance (Ferrand et al., 2010).

Chronic diseases like HIV/AIDS require continuous treatment to sustain the health of a patient (Sperry, 2012). However, special conditions apply to children who must take treatment for a generally stigmatised disease such as HIV/AIDS. Wollett, 2013 and Zanoni (2013) identified the main barriers to children's adherence to antiretroviral therapy and they are: interruption of daily routine; side effects; taste and size of treatment pill; stigma; and issues of disclosure and deception. Office of AIDS Research Advisory Council (OARAC) (2015) states that adherence to ARV treatment is a complex health behaviour that is influenced by many factors such as regimen, patient, family factors and characteristics of health providers. Children usually depend on others, especially parents or caregivers, for

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administration of ARV treatment. Adherence is influenced by caregivers and the environment, ability and willingness of the children to take drugs.

Studies in Southern Africa have shown that adolescents are less likely to adhere to ARVs than adults due to challenges accompanying treatment adherence (Bygrave, Mtangirwa, Ncube, Ford, Kranzer & Munyaradzi, 2012; Nglazi, Kranzer, Holele, Kaplan, Mark, Jaspan, Lawn, Wood & Bekker, 2012). They also have lower survival rates compared to younger children (Bakanda, Birungi, Mwesigwa, Nachega, Chan, Palmer, Ford & Mills, 2011). Studies done by Chandwani, Koenig, Sill, Ambramowitz, Conner and D'angelo (2012) and Shroufi Gunguwo, Dixon, Nyathi, Ndebele, Taziwa, Fereyra, Vinoles and Ferrand (2013) show that adolescents are not adhering to ARV treatment and that poor adherence is a major concern as it increases the risk of drug resistance.

Findings of the study done by Mavhu et al. (2013), in Zimbabwe, indicated that some children missed their dose of ART, and the major reasons for missing the dose were forgetfulness, travelling, lack of monitoring by adults, concealing from others and lack of bus fare to collect treatment. Non-adherence was reported sometimes as a conscious act triggered by depression among children with HIV infection. However, Lawan, Amole, Gambojahun and Eneitbute (2015), in their study, found out that about 90% of the children adhered well to the prescribed ART treatment while 9% did not adhere to ART due to loss of confidence in the drugs because of the belief that ARV do not cure HIV infection.

According to Zanoni (2013), psycho-social factors associated with poor adherence and non-adherence among children living with HIV/AIDS, include, delayed disclosure, alcohol use, difficulty in identifying with HIV negative peers, anxiety about sexual relationships and future planning, low self-esteem and feelings of hopelessness. These factors were sometimes complicated by the adolescent having to head a family and take care of ill relatives and siblings (Chandwani et al. 2012; Nglazi et al. 2012; Bakanda et al. 2011). However, other studies found that structural factors outside the children's control which include ARV stock outs, lack of access to the clinic, transportation difficulties and poverty were barriers to ART adherence (Nachega, Leisegang & Bishau, 2010; Atuyambe, Neema, Otolok-Tanga, Wamuyu-Maina, Kasasa & Wabwire-Mangen, 2008). Children's perceptions of the direct benefits of the treatment they are taking and the side effects have led to treatment

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interruption. Bad feelings towards treatment, regimen fatigue or pill burden have also been identified as barriers to treatment adherence among children infected with HIV (Martinazzo et al. 2013).

Bernays et al.'s (2015) study indicated that maintaining adherence and managing the side effects of treatment made worse by household food insecurity. These children also had protected themselves against disclosure by avoiding ART treatment. They also reported feeling tired or being overwhelmed by the relentless daily doses, or that they had forgotten. Children expressed their frustration and lack of sympathy as they struggled to take treatment every day. They also described how they felt when adults dismissed the psycho-social reasons that contributed to non-adherence to treatment.

A study done by Mburu et al. (2014a) found that family members were a regular source of adherence support for children. Family members verbally reminded children to take treatment and they encouraged them when they were experiencing side effects from ARV treatment. Some children stated that family members frequently accompanied them to clinics to refill their ART and they also helped them with new routines of taking ARV treatment. Petersen et al. (2010) also found out that children showed good adherence with ARV treatment, and care givers were identified by children as playing a supportive role in reminding them to take their treatment. Family, peer and community support emerged as key factors in assisting these children to cope with HIV infection. However, five children who indicated that they receive little social support displayed either emotional numbing or reported behavioural or emotional problems, including suicidal thoughts and aggressive behaviour.

According to Petersen et al. (2010), counselling services provided by hospitals provided children with opportunities to talk to counsellors about issues such as sex that they could not talk about with their caregivers. Attending support groups and being with other HIV positive children was reported to be helpful as children could see that other HIV positive children are living healthily; this made them feel that they are not all alone. Data from this study suggest that South Africa's HIV positive children have similar stressful experiences and emotional challenges. Positive thinking and having life goals helped the children to cope well with HIV/AIDS infection (Lawan et al., 2015).

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Agwu and Fairlie (2013) asserted that decreased parental supervision of children taking treatment often decreased non-adherence with ART. This may, in the long run, increase mortality among the children living with HIV/AIDS. Zanoni (2013) indicated that other factors that caregivers face, such as forgetting doses, changes in routine, being too busy and children's refusal to take treatment may contribute to non-adherence to ARV treatment for children. Some caregivers may place too much responsibility of managing treatment on older children before they are developmentally able to undertake such tasks, whereas some face challenges due to substance use and other medical conditions (Mutwa et al., 2013).

2.3.3 HIV/AIDS related stigma and discrimination

Maunthner, Birch, Miller and Jessop (2012) defined stigma as an ideology that claims that people with specific diseases are different from those in normal society. Stigma is a complex phenomenon caused by a variety of factors which could be defined as mistaken beliefs or attitudes due to lack of knowledge of HIV/AIDS, fear of HIV/AIDS and mode of health care delivery to people living with HIV/AIDS (Koka, Ahorlu & Agyeman, 2013). According to Kheswa (2014), stigma is the burden of a special, discrediting and unwanted mark on a person or specific category of persons in such a way that in their interactions with others, they are viewed by others and themselves as shamefully different.

Stigma in the context of HIV/AIDS is the negative response of individuals to the awareness of one's infection with HIV/AIDS. The response may include discriminatory behaviours such as avoidance of that person or gossip, as well as activities designed to chase the individual from their home or community (Mutwa et al., 2013). In the eyes of the 'normal', the stigmatised person is seen as having disgraceful attributes and, therefore, has to be treated with less respect (Judgeo & Moalusi, 2014).

Schweitzer, Mizwa, and Ross (2006) defined discrimination as an action or treatment based on stigma directed toward the stigmatised and as an action which allows harassment and violence because of one's infection or association with HIV/AIDS. According to UNAIDS (2013), HIV/AIDS related stigma and discrimination remain major barriers to effective treatment, care and support in many countries across the globe, including South Africa.

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Stigma arises when some people do not believe they are at risk of HIV infection because of their race, sex, creed, religion, sexual preferences or national origin (Mutwa et al., 2013).

The results of a study done by Judgeo and Moalusi (2014) revealed how HIV/AIDS stigma was experienced by children. A spoiled identity, poor social relations and the need to manage information emerged as strong themes in their study. The self-stigmatising HIV positive individual faces the consequences of rejection by family, friends and society. This may convince a person not to disclose one's HIV status, to isolate oneself and not seek support groups, HIVAIDS treatment, as well as possibly engaging in unprotected sex. Mburu et al.'s (2014a) study found out that there were instances in which children had internalised HIV stigma; they were shy and ashamed of being infected with HIV. This stigma led to self-pity and a low self-esteem. Although some children reported that internalised stigma had affected their ability to engage socially, many of the children said that they were able to accept their situation and to regain their self-esteem. Children had hope for the future and they interacted with their families and peers. This, in turn, strengthened their self-efficacy and resilience.

Findings from a study done by Mavhu et al. (2013) indicated that children perceived themselves as being stigmatised by their community; they felt that other children from their community avoided them. Some felt that people avoided them at school, while others were supported by teachers. Mburu et al. (2014a) discrimination at school greatly affected the children's experiences was a frequent cause of absenteeism. In some instances, teachers would hint at the presence of students living with HIV infection in a manner that was interpreted as warning others not to associate with the infected children. However, other children perceived that they were treated differently from other children in their household. For example, they said they were expected to work more at home than other children their age or younger siblings and, sometimes, they were given less food than others of the same age or younger (Mavhu et al., 2013).

Amzel et al. (2013) indicated that experiences with stigma and discrimination can also lead to poor mental health, social isolation, postponement of education, exclusion from religious organisations and reduced health-seeking behaviour. Experiences of stigma and discrimination take various forms such as reduced social support, family neglect and verbal and physical abuse. Mburu et al. (2014a) found that children identified stigma and

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discrimination that they encountered in communities as a significant factor affecting the quality of their life. Children described actual experiences of discrimination based on their HIV positive status and how their fear of potential discrimination affected their decision whether to disclose their HIV status.

However, a study done by Lawan, Amole, Jahun, Abute and Gamboja (2015) indicated children reported being discriminated against at home in the form of deprivation from sharing utensils with their HIV negative siblings. Some children made offensive comments towards them due to their HIV positive status (Armstrong et al. 2013). Children reported being avoided by friends and colleagues in intimate relationships and during social interaction such as football, parties or other gatherings in the community while others dropped out of school due to discrimination (Lawan et al. 2015).

Richter et al. (2010) indicated that children who lost their parents due to HIV/AIDS are often stigmatised by their communities. HIV/AIDS related stigma may remain long after the infected individual has passed away. This is seen when survivors often try to conceal the true cause of the loved one's death. Mutwa et al. (2013) and Zanoni, (2013) stated that living with HIV/AIDS is difficult for young people and the social stigma of HIV/AIDS remains. The difficulties of not being able to talk openly to friends and family about HIV, means that many of these young people feel isolated and lonely.

Petersen et al. (2010) found out that some children had difficulties after finding out their HIV positive status; 36% reported that they withdrew from friends and social activities as they felt different. The internalised stigma was evident in over 50% of the children who felt uncomfortable when people were talking negatively about HIV positive people. These children had worries about heterosexual relationships, and only 6 children indicated that they had girlfriends (3) or boyfriends (3). Two of these children chose partners who were also HIV positive. Children had concerns about how to negotiate future heterosexual relationships while living with HIV infection (Armstrong et al. 2013; Petersen et al., (2010).

According to Martinez, Harper, Carleton, Hosek, Bojan, Glum, and Ellen (2012), HIV infected individuals who have high levels of stigma are three times likely not to adhere to their treatment compared to those with low HIV stigma concerns. In this study, HIV infected

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children revealed that HIV/AIDS related stigma was responsible for poor treatment adherence. About 50% of the children feared that, if they took antiretroviral treatment, their friends and family might discover their HIV status and reject them. Mutwa et al. (2013) noted that stigma played an important role in children's adherence to ART even within their own homes. Children wanted to adhere to ART treatment, but due to lack of privacy, they skipped their doses and failed to obtain refills from clinic to avoid being seen. People living with HIV/AIDS tend to internalise the stigma and discrimination, thus leading to a negative self-image; they will blame and question themselves and they usually suffer from guilt. They have a low self-esteem and low self-efficacy due to rejection, loss of social identity, and the physical consequences of HIV disease (Eller et al. 2014).

2.3.4 Death, grief and bereavement

Taylor (2010) defined grief as the intense emotion which floods the life of a person when the inner security systems are shattered by an acute loss which is associated with the thought of one's death or the death of a significant person. Bereavement is the long-term adjustment or accommodation to the loss of a loved one (Demmer, 2014). Doka (2013) argued that emotions and feelings are a prominent part of most grief reactions once someone experiences pain, sadness and anger. If children were to experience the death of a significant person, one would expect them to first react to that experience in the form of grief. How children share their reactions to loss depends on their personalities, their ability to communicate what they are experiencing, what their immediate environment (circumstance, family and culture) does and does not approve (Doka, 2013).

According to Dorrell et al. (2008), even with improved treatment, young people still live with fear of death as there is still no cure for HIV/AIDS. Many children live with a medical crisis and some need to come to terms with the idea of dying prematurely. Close and Rigamonti (2006) stated that when children face their own death, many experience anticipatory grief, which is the grief expressed when the loss is perceived as inevitable. Children may exhibit signs of anticipatory grief when they feel death approaching. These children may also experience multiple losses in their families because of HIV/AIDS; some may have lost their mothers, fathers or both parents and others may have lost siblings or members of their

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extended family (Zanoni, 2013). Bereavement may result due to severity of HIV/AIDS, loss of health, a decrease in functioning, the deterioration of body integrity and anticipatory loss of life. The bereaved person usually suffers the symptoms of sadness, insomnia, poor appetite, and weight loss (Agrawal, Jain, Agrawal, Singh & Yadav, 2015).

Vranda and Mothi (2013) state that, as HIV progresses, children face up to the physical and mental decline associated with HIV/AIDS. Family members are overwhelmed at this stage and have difficulty communicating with the child about the issues related to the prognosis and death. In addition to coping with their own mortality, children must cope with the mortality of their loved ones who suffer from HIVAIDS. Facing and understanding their own possible death are major challenges faced by children living with HIV/AIDS. The cognitive and emotional maturity of children often determines their level of awareness about their own mortality, as well as their coping skills and defences to deal with this realisation (Vranda & Mothi, 2013).

Cambell, Griffiths, Beer, Legamah and Saine (2014) stated that little is known about the psychological and emotional impact of parental death from HIV/AIDS related diseases on children. Parental death from HIV/AIDS may have negative effects on children. In a study of bereaved children and young people in South Africa, it was reported that the death of a parent from HIV/AIDS was a major factor in the development of emotional and behavioural problems of those children as compared to children whose parents died of other causes. Doka, (2013) found poor psychological adjustment among children who were bereaved through HIV/AIDS than through other causes.

The death of parents introduces a major change in the life of a child, and this change may involve moving from middle or upper class urban home to a poor rural relative’s home, separation from siblings, being forced to live alone or the creation of child-headed families (Demmer, 2014). All these changes easily affect physical and psychological wellbeing of a child. Factors such as socio-economic status, abuse, social support, family disruption and stigma pose psychological difficulties for HIV/AIDS orphans (Cluver & Orkin, 2009).

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Dorrell et al. (2008) pointed out that grief can be overwhelming and hard to understand for children who have lost parents or family members. Yet grieving experiences are unique to each individual. Grief can also cause different responses, for example, physical, emotional, behavioural, cognitive, spiritual and social effects. It is important for grieving children to acknowledge their loss and to be given an opportunity to release their grief (Demmer, 2014). These children may experience psychological problems into adulthood if they are not given an opportunity to release their grief, and they may never recover from their loss. It is important to understand how children view death and how grief is shaped by their developmental age. For children of all ages, support is a key factor in the grieving process and this support can come from families, friends and communities (Dorrell et al. 2008). Grief is often exacerbated where participants were living in unsupportive households or where a loving, caregiver relationship was lacking (Willis et al. 2018). Heath, Donald, Theron and Lyon (2014) indicated socio-emotional support to be key in addressing children's grief in addition to the stigma and challenges associated to living with HIV/AIDS.

2.4 Coping strategies for children living with vertically transmitted HIV/AIDS

Kotze, Visser, Makin, Sikkema and Forstyth, (2012) defined coping as constantly changing cognitive and behavioural efforts to manage specific external demands that are considered as demanding the resources of the person. According to Ying-xia, Golin, Jin, Emrick, Nan and Ming-Qiang (2014), being diagnosed with a serious health condition like HIV/AIDS, represents an important stressor that includes the process of coping. When an individual realises that the illness represents a challenge rather than a threat, she or he initiates coping strategies to regulate the stressful situations.

According to Park and Nachman, (2010), living with the HIV infection is a stressful experience. However, many HIV positive individuals can maintain their emotional well-being. This raises questions about what strategies these individuals employ to allow them to do so, what feelings they have and how they deal with illness. Infected individuals had to create lifelong coping strategies. One way for dealing with their challenges and possibly seeking help is through religion and spirituality. Some adopt several strategies to deal with

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the HIV status, for example, accepting their own fate, disclosing their own status to friends and joining ongoing support groups (Doka, 2013).

Falvo (2014) indicated that coping skills are learned by individuals with health conditions and that these are developed over time to manage, tolerate or reduce stress associated with life events and restore psychological balance. Individuals develop different coping skills through life experiences and cope with health conditions in different ways. Some cope by actively confronting their condition, learning new skills and becoming proactive in the management of their health condition. According to Habib and Rahman (2010), others defend themselves from stress and realities of the condition by denying the seriousness of the condition, by ignoring advice on how to manage the condition or refusing to learn new skills to enhance their functional ability.

According to Falvo (2014), coping strategies are subconscious mechanisms used to cope with stress. Although they are useful for reducing anxiety and maintaining balance and productivity, overusing them can be damaging to an individual. Examples of coping mechanisms or strategies include denial, accommodation and acceptance and psycho-social support. These are described below.

2.4.1 Denial

According to Sitienei (2016), denial is characterised by efforts to block, blunt and not accept a stressful situation and its consequences. It creates distance between the stressor and the individual, which provides temporary relief from negative thoughts and emotions. To this end, failing to disclose one's HIV positive status and living as if one is HIV negative is an attempt to distance oneself from the reality of being HIV positive. However, denial prevents the individual from confronting the stressor directly. Denial is frequently reported in studies on coping with health-related stress and is commonly believed to be used in the initial stages shortly after diagnosis. The study findings reveal that one participant in was facing denial in the family as the topic of HIV/AIDS is never raised (Visser & Pienaar, 2012).

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Falvo (2014) stated that learning about a health condition, such as HIV/AIDS, can provoke anxiety and, as way of dealing with it, people may subconsciously use denial to work against the reality of the situation. Denial may be beneficial in the early adjustment period because it enables individuals to adjust to the reality of the situation at their own pace, by preventing excessive anxiety. If denial continues, it can interfere with the management of the condition and the individual's denial can negatively impact on others by placing them at risk as well. Other individuals who are in denial of the condition may avoid use of proper precautions to prevent the spread of disease to others (Donna, 2014).

Denial is another factor associated with HIV/AIDS wherein, the people infected deny the presence of the disease. It leads people to avoid the treatments and further follow up sessions, hence denying the chance to manage the disease progression (Eller et al., 2014). Bernays et al. (2015) stated that HIV threatens a person's life, goals, expectations and significant relationships. It is not surprising that people are reluctant to admit their diagnosis or their risk of infection. To win the HIV battle successfully, people living with HIV infection must have some level of acceptance of the disease, so that they can seek counselling, social support and medical care.

2.4.2 Accommodation and acceptance

Adler and Carlson (2009) stated that accommodation is a strategy whereby a patient acknowledges and deals with the problem produced by the illness, for example, a pain or managing drug regimen. This entails the acceptance of the diagnosis and of the deteriorating physical health. At this stage, people may be too weak to be depressed or angry and they may alternatively become more at peace with their situation. The everyday work of handling the disease becomes part of normal living (Vosvick, Martin, Smith & Jenkins, 2010). No attempt is made to build a special status for the illness. Instead, the individual tries to deal with other people in terms of his or her other characteristics, for example being a football fan, or a member of a church and so on. They try not to make their illnesses a central part of their lives (Habib & Rahman, 2010).

According to Sitienei (2016), acceptance implies an acknowledgement of reality and an attempt to deal with the stressful situation. Acceptance of one's HIV positive status is seen as

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the preparedness to recognise the impact that HIV will have on one's life. People living with HIV infection may not necessarily achieve acceptance of their HIV positive status immediately after diagnosis, but may steadily develop a sense of acceptance as time progresses. Most of the participants achieved acceptance once they had overcome the initial distress of the discovery of their HIV positive status (Vervoort, Grypdonck, de Grauwe, Hoepelman & Borleffs, 2009).

Mburu et al. (2014b) found out that children living with HIV infection were motivated, accepted their status and had a sense of purpose even after being diagnosed with HIV infection. These children thought positively about marriage and childbearing, with 48% children out of the interviewed planning to have children in future. Some children described performing a range of duties at home, for example, caring for their own siblings who were not living with HIV infection. Children valued their own personal relationships and strived to sustain them. Van Nuil, Mutwa, Asiimwe-Kateera, Kestelyn Vyankandondera, Ruhirimbura, Kanakuze et al. (2014), in their study done in Rwanda, also found out that children had anxieties on how to disclose their HIV positive status to their potential sex/marriage partners and whether to have children. However, they felt that they had a right to love, be loved and they were aware of prevention of mother to child transmission (PMTCT) options available to them. These children spoke about their future role in a positive manner. Although children struggled with aspects of sex, love, marriage and having children, most of them agreed that they would find love, marry and have children in the future.

The desire to have children and a family by children living with vertically transmitted HIV/AIDS has also been widely documented in sub-Saharan Africa (Hodgson et al. 2012; Li et al. 2010). In a Ugandan study of adolescents living with vertically transmitted HIV, only one third of the participants had never engaged in sex, and of these, 86% intended to have sex in future (Birungu, Obare, Mugisha, Evelia & Nyombi, 2009). In a Kenyan study, three quarters of the participants who had accepted their HIV status wanted to have children in future, although most wanted to delay this to later in life (Obare et al. 2010). Despite this, low rates of contraceptive use, 66% were reported; 68% of the sexually active female respondents had already been pregnant and three quarters of those were unintended pregnancies (Obare et al. 2010). Similarly, in a study done in the United Kingdom (UK) among female adolescents living with vertically transmitted HIV/AIDS, one fifth had been pregnant and 75% of these had been unplanned pregnancies (William, 2010). Other studies in Eastern Africa reported the same findings, as well as noting unsafe sexual behaviour (Beyeza-Kashesya, Kaharuza, Ekstrom, Neema, Kulane & Mirembe, 2011).

Education and support are the most effective tools that can help children who are infected with HIV/AIDS to accept their status survive into psychologically and socially healthy adulthood. Education can also help to reduce the stigma within the communities. Through these changes and support of family, friends and health care professionals, these infected children will grow up into tomorrow's happy and healthy adults who have accepted their HIV positive status (Gupta, 2015).

2.4.3 Psycho-social support

Mitchell, Richter and Rochat (2015) stated that psycho-social support includes rebuilding and strengthening relationships which are vital to human development. Psycho-social support involves the care and support provided to influence both the child and his or her social environment with a view to enhancing the child's psychological and social well-being (Mwona & Pillay, 2015; UNICEF, 2009). It is a process of providing for the emotional, social, mental and spiritual needs of patients and it is an essential element for promoting human development through a variety of approaches such as one on one counselling, support groups, and play therapy (Zanoni, 2013). Support services include available social facilities which are meant to assist the children to live a good life. These services must be age-appropriate and identify the child's emotional, spiritual, cognitive, social and physical needs, through interaction with their surroundings and the people who care for them. (Mitchell, Richter & Rochat, 2015; UNAIDS, 2011). Cowles (2012) stated that psycho-social support and care are key issues in ensuring that children are protected and receive any needed support to enhance their emotional and psychological functioning. The aim of psycho-social support and care is to help children living with HIV/AIDS to live a fulfilling and independent life (Bilson & Westhood, 2012).

UNICEF (2009) identifies three domains of psycho-social aspects considered to be most helpful in assessing children's lives and experiences. The domain includes skills and knowledge such as life skills, appropriate coping mechanisms, emotional wellbeing, such as

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feeling safe, trust in others and self-worth, social wellbeing, such as relationships with peers, sense of belonging, and access to socially appropriate roles. McCleary-Sills, Kanesathasan, Brakarsh, Vujovic, Dlamini, Namisango, Rose, Fritz, Wong, Mark and Bowsky (2013) indicated that psycho-social support is an important element in the ongoing care of all people living with HIV/AIDS, especially children. It creates a foundation from which they can establish their identity and place in society, manage their care, cope with challenges and plan their future. Psycho-social support also helps to build resilience in children and supports families and caregivers to meet the multiple needs of the infected children.

Abubakar et al. (2016) explored the psycho-social experiences of this unique, emerging population of children living with vertically transmitted HIV/AIDS in Kenya and stressed that the growing population is poorly served by care and support services largely because of an underestimation of the extent of the number of children living with vertically transmitted HIV/AIDS in sub-Saharan Africa (Hodgson, Ross, Haamujompa & Gitau-Mburu, 2012; Cataldo, Malunga, Rusakaniko, Umar, Teles & Musandu, 2012; Birungu et al. 2009).

HIV/AIDS subjects children to stigma outside the family and this becomes a barrier to receiving psycho-social support. Grandparents and extended family members in many communities who provide social support are usually overburdened with caring for children whose parents have died through HIV/AIDS. This hinders the provision of intended psycho-social support for these children due stigma (Health, Donald, Theron & Lyon, 2014).

Mburu et al.’s (2014b) study revealed that care and support services provided through non-governmental and church centres influenced the experiences of children living with HIV infection. Such services included nutritional, psycho-social, and adherence support delivered through home visits, youth friendly services, youth clubs and centres. Evidence shows that youth corners in HIV clinics provided an environment where children could speak privately with peers and health care providers. This helped the children to develop a better understanding of their own needs and challenges (Habib & Rahman, 2010). According to WHO (2011), psycho-social support addresses the ongoing concerns and social problems of HIV/AIDS infected individuals, their partners and caregivers. It affects all dimensions of the infected individual’s life, such as physical, psychological and social well-being. Psycho-

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social interventions at healthcare facilities, such as counselling and social support, can help infected individuals to cope more effectively with each stage of the HIV/AIDS infection and enhances their quality of life (Agrawal, 2015).

Mavhu et al. (2013) reported that 90% of the children who attended the support group at least once a month found that being a member of a support group was helpful because it gave them a sense of belonging, a safe social place where they felt normal and able to play and mix with other children. However, they stressed that life outside the support group was more challenging. For example, there was a lack of understanding of these children’s illnesses at home seen in their ignorance about ARVs, their concern about safety of dating and worry about future aspirations (Mavhu et al., 2013). Support groups helped children to understand the importance of taking ARV treatment exactly as recommended by the clinic and the effects of non-adherence more clearly than getting the information at home and at the clinics. Children reported that support groups restored the children’s confidence and helped them realise that they were not the only children living with HIV/AIDS (Mupambireyi et al. 2014). Children living with HIV infection, who attended support groups along with family members, stated that these helped them to build friendships, share coping strategies, feel valued and gain a sense of identity (McCleary-Sillset al., 2013).

In Wolf et al.’s (2014) study, children reported positive support from family such as financial and emotional support helpful and these support appeared to play an important role in improving the children’s mental health and well-being. However, a few children pointed out that lack of family emotional support contributed to poor adherence to ART and their failure to seek care. Mburu et al. (2014b) found out that family was the most important social structure that made children feel accepted and valued. However, there were instances where children, especially older ones, felt that, since the HIV positive diagnosis, their family members had become over-protective of them. Mutwa et al. (2013) found out that children who were living with their own families felt that family members, including parents and siblings, provided a supportive environment by reminding them to collect and to take their treatment. Children argued that their families supported them when they reminded them of clinic appointments, treatment and when they discussed their infection difficulties with them Wolf et al. (2014). However, 19 out of 42 orphans who lived in orphanages or foster families

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and boarding schools reported that they did not have the same level of support from their own foster parents.

McCleary-Sills et al. (2011) stated that some children may have acute emotional and mental health needs that require care and basic and ongoing support from those within the child's life, for example, family, friends and teachers. Psycho-social support plays an essential role in ensuring emotional development as the children mature and it can improve adherence to ART. Amzel et al. (2013) indicated that psycho-social programmes can take the form of one on one counselling sessions, care giver support and training, support groups for children and care givers, peer mentorship from youth living with HIV/AIDS, as well as recreational therapy developed to deal with HIV/AIDS related grief and bereavement.

Results from a study done by Mwona and Pillay (2015) indicated that children needed counselling services due to challenges they face daily, for example, behavioural problems, low self-esteem, and lack of communication with teachers or other learners. Behavioural challenges among children, such as bullying, aggression and low self-esteem, were reported to be a challenge, not only for the learners but also for educators. Therefore, provision of counselling services by trained professionals, such as counsellors, psychologists and social workers, to these HIV/AIDS infected children, would be the best way of helping children with such behaviours. This would enhance their self-esteem (Habib & Rahman, 2010).

In bio-psychosocial model social factors include system like churches, school, and society as a whole and placing emphasis on how these social systems relate with individual. These social factors are more reliant on lack of social support and high level of responsibility at home, school or community at large (Straus, 2012). People who have higher levels of social support from family and friends are more likely to have better health outcomes.

2.5 Conclusion

This chapter reviewed literature on the experiences of children living with vertically transmitted HIV/AIDS in sub-Saharan Africa. The literature revealed that children who grow up with HIV/AIDS, face various psycho-social challenges in their lives. These challenges

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include diagnosis and disclosure, treatment adherence, as well as stigma and discrimination. The coping strategies that these children use to come to terms with various stressors associated with living with HIV/AIDS were also discussed.

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CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

According to Punch (2013), research methodology refers to ways of obtaining, organising and analysing data. The choice of methodology depends on the nature of the research question. Burns and Grove (2010) stated that methodology includes the design, setting, sample, methodological limitations, and the data collection and analysis techniques.

This chapter focuses on the research methodology employed to explore the psycho-social experiences of children living with vertically transmitted HIV/AIDS. It describes the research approach, research design, population and setting, sample and sampling procedure, research instrument, pretesting, data collection procedure, methods of data analysis and measures of ensuring trustworthiness, as well as ethical considerations that the researcher took into account in the implementation of the research process.

3.2 Research Approach

According to Maxwell (2012), research approach is research that is intended to help the researcher to better understand the meaning and perspectives of the people under study. It aims to see the world from their point of view and understand how their perspectives are shaped by and shape their physical and social context. For the purpose of this study, a qualitative research approach was adopted.

According to Creswell (2013), qualitative research is an approach for exploring and understanding the meaning individuals or groups assign to a social or human problem. During the interaction between the researcher and the participants, their world is discovered and interpreted by means of the qualitative method. The process of research involves emerging questions and procedures, data collected in participants' setting, data analysis built from particular to general themes and the researcher interpreting the meaning of data. Common data collection methods in qualitative research include focus group discussions, in-depth interviews and ethnographic participation.

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Esterberg (2002) stated that qualitative methods allow for the telling of detailed stories about a small number of cases. This makes it possible to gain insight into the participants' lived experiences by understanding what the experiences mean to the individuals, exploring how people interact with each other and looking at how they interpret and interact with the world around them.

The qualitative approach was deemed appropriate because the main focus of this study was to explore the psycho-social experiences of children living with vertically transmitted HIV/AIDS. The qualitative approach was adopted because it allowed the subjects being studied to give richer answers to questions put to them by the researcher. This approach might also give valuable insights that may have been missed if any other methods had been used. The qualitative approach has its roots in the social sciences and it is more concerned with understanding why people behave as they do. The approach helps the researcher to assess their knowledge, attitudes, beliefs and behaviour. This is in line with the first objective of this study (Cohen, Manion, & Morrison, 2013; De Vos, Strydom, Fouche & Delport, 2011).

3.3 Research design

The research design is a type of inquiry within qualitative, quantitative and mixed method approaches that provides direction for actions in the research process (Creswell, 2013). The design of a study refers to the plan or steps followed to collect, analyse and interpret data. It guides planning and implementation of the study, to achieve the objectives of the study (Creswell, 2007 & Willig, 2013). For the purpose of this study, the exploratory research design was adopted.

The researcher used the exploratory study design to explore the full nature of the little understood phenomenon of children living with vertically transmitted HIV/AIDS. The exploratory design was used to help the researcher understand the experiences of children living with HIV/AIDS, the challenges they encounter, the support they receive and the various strategies these children adopt to cope with the disease (Creswell, 2013; Ritchie, Lewis, Nicholls & Ormston, 2014). One of the main purposes of this type of study, according to Babbie (2010), is to gratify the researcher's curiosity and aim for a better understanding.

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3.4 Population and setting

3.4.1 Study Population

Bless, Higson-Smith and Kagee (2006) defined population as the entire set of objects of the research study and about which the researcher wants to determine some characteristics. According to De Vos et al. (2011), population refers to individuals in the universe who possess specific characteristics or set of entities that represent all measurement of interest to the researcher. Neuman (2011) stated that, when defining the population, the researcher must specify the unit being sampled, the geographical location and temporal boundaries of the situation. The population of this study comprised all male and female children aged between 12-17 years, who are living with vertically transmitted HIV/AIDS and who are receiving treatment, care and support services at Fountain of Hope Wellness Clinic at Messina hospital in Limpopo Province. These children are either on Antiretroviral (ARV) treatment or they are not and they all are aware of their HIV/AIDS status.

3.4.2 The study setting

The study setting is Messina Hospital in Limpopo Province, South Africa. Limpopo is one of the nine provinces in South Africa and it is situated in the far northern part of the country. The hospital is situated in Musina Municipality. Musina is a small town situated in Vhembe District and it is located just before the Beitbridge border post between South Africa and Zimbabwe. Because this is a border town, there are people from different countries living in the area.

Musina Municipality comprises of people who speak different languages including Tshivenda, Xitsonga, Sesotho, Shona, and English (Musina Local Municipality, 2014/15). The hospital has an ARV Clinic that provides voluntary counselling and testing, medical treatment and support services to children and adults. Statistics from the Operational Manager’s office indicate that there were 119 children below 18 years enrolled for HIV/AIDS care at Fountain of Hope Clinic in Messina Hospital in January 2016.

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The Limpopo Province is 125 754 square kilometres large and it is the third largest province in South Africa, constituting 10.3% of South Africa's total land area (SSA, 2010). According to SSA (2011), 5 554 657 people were living in Limpopo in 2011, constituting 11% of South Africa's overall population. According to the Department of Health, Limpopo (2008), Limpopo Province has approximately 400 000 people living with HIV/AIDS. It has 34 district hospitals and several primary health care facilities (22 health centres, 396 fixed clinics and 3977 mobile clinics).

3.5 Sample and sampling procedure

A sample is a subset of a population selected to participate in the study (Burns & Grove, 2010). According to Punch (2013), the sample is studied to assist in explaining some facts of the population, as it is not feasible to study the whole population. De Vos et al. (2011) indicated that the sample is composed of elements that contain the most characteristics or attributes that are representative of the population of the study. The sample, in this study, was made up of five male and six female children aged between 12-17 years, who are living with vertically transmitted HIV/AIDS and who are receiving care and support services at Fountain of Hope Wellness Clinic in Messina Hospital in the Limpopo Province. These children are either on antiretroviral (ARV) treatment or they are not and they are aware of their HIV/AIDS status.

Sampling refers to the process of selecting a portion of the population that conforms to a designated set of specifications to be studied (Burns & Grove, 2010). The researcher used a non-probability sampling method, a procedure in which all the persons, events or objects have an unknown and usually different probability of being included in the sample (Grinell, 2010). According to Rubin and Barbie (2008), purposive sampling is a type of non-probability sampling method in which the researcher uses his or her judgement in selecting the sample and it is sometimes called judgemental sampling. Purposive sampling, a non-probability sampling approach, which involves selecting participants composed of elements that contain the most characteristics or attributes of the population that serves the purpose of the study best was used to recruit participants for this study (Creswell, 2013).

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3.5.1 Inclusion criteria

- All the participants for this study were children residing in Musina Municipality who are living with vertically transmitted HIV/AIDS and who are receiving care and support at Fountain Hope Wellness Clinic at Messina Hospital.
- Participants were both male and female children between the ages of 12-17 years.
- Participants were children who knew their HIV status, and were either on ARV treatment or not.

3.5.2 The recruitment process of participants

The recruitment of the study participants commenced when the ethics approval of the study was obtained from the University of Venda's Higher Degrees Committee. Permission to conduct the study at Fountain of Hope Wellness clinic was obtained from the Department of Health, Limpopo Province, the CEO of Messina Hospital and the Operational Manager at the clinic.

The invitation to participate in the study was offered to all 25 children who met the inclusion criteria of the study and who were present during the briefing of the study. They were informed that they should approach their support group social worker if they were interested in participating in the study. Only 18 children approached the social worker and indicated their willingness to participate in the study. The social worker then contacted their guardians and caregivers and invited them to Fountain of Hope Wellness clinic for a briefing of the research study with the researcher. The social worker introduced the researcher to the guardians and caregivers for her to explain the purpose and nature of the research study, the methods and possible outcomes. All the 18 guardians and caregivers agreed for children in their care to participate in the study and gave their written consent for their children to participate.

The social worker was helpful in facilitating a meeting between the researcher and children living with vertically transmitted HIV/AIDS and who belonged to a support group of children aged between 12 and 17 years. The researcher explained the aim and objectives of the study to the children, the nature of the research study and the possible outcomes. Participants were

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made aware that the interviews would be tape recorded with their permission. The researcher explained to the participants that participating in the study was voluntary, and that they had a right to withdraw from the study at any time without negative consequences. The children signed written consent forms before the interviews commenced to show that they agreed to be part of the study.

3.6 Research Instrument

According to Punch (2013), any device that is used to aid in data collection can be called an "instrument". Research instruments range from questionnaires, surveys, tests to interviews (Gray, 2013). For the purpose of this study, semi-structured interviews were adopted. According to Bless et al. (2010), a semi-structured interview is a technique used during an exploratory research process and it helps to clarify concepts and problems, as well as create possible answers or solutions to the problem.

In this study, the researcher used semi-structured interviews as a tool to collect data because it provided the participants with an opportunity to fully describe their experiences. Semi-structured interviews allowed the participants to share their own stories in their own words, rather than be forced by pre-established lines of thinking developed by the researcher (Barbour, 2013). The researcher conducted in-depth interviews with 11 participants in Messina Hospital. The English language was used due to language diversity in Musina Municipality during the interviews. Face to face, one on one interviews were conducted with children living with vertical transmitted HIV/AIDS infection and these interviews lasted one hour per session per child. The interview process continued until data saturation was reached (Seidman, 2013).

3.7 Pre-testing

Sapsford and Jupp (2006) stated that a pre-test is a small-scale trial before the main investigation, and it is intended to assess the adequacy of the research design and of the instrument to be used for data collection. Pre-testing the data collection instrument, an interview schedule or questionnaire, is essential. According to De Vos et al. (2011), the pre-test forms part of the research process and it can be viewed as a dress rehearsal for the main

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investigation. The idea is to ascertain trends, test data gathering instrument, as well as to address the objectives of the study, resources, research population, procedures of data collection and possible errors.

In this study, the researcher tested the interview schedule to determine the effectiveness of the instrument and whether it was relevant. Two male and three female of 18 children who agreed to participate in the study, who had the same characteristics as those in the criteria of inclusion for the research participants, were interviewed using the questions in the interview schedule. The pre-testing also allowed the researcher to gain insight into the research study and to help identify and fix possible errors before embarking on the main study.

3.8 Data collection procedure

Data collection is the precise and systematic gathering of information relevant to the research purpose or the specific objectives, questions, and hypothesis of the study (Burns & Grove, 2010). In this study, the researcher used semi-structured interviews as a data collection method because they allowed the researcher access to the knowledge and life experiences of others. According to Barbour (2013), a major characteristic of interviews in qualitative research is the use of open-ended questions which allow the respondents to focus on the issue of greatest importance to them rather than allowing the agenda to be determined entirely by the researcher's interest. Rubin and Herbert (2011) pointed out that the researcher will be looking for rich and detailed information when conducting interviews.

The interviews were face to face and they commenced with a general inquiry into the biographical information of the participants; this served as an introduction. Thereafter, participants' experiences of living with HIV/AIDS and learning about their HIV status, as well as their knowledge of HIVAIDS were explored. After establishing how, where, who and when the participants learnt their status, the participants were asked to describe how they received their HIV diagnosis. Participants were also asked about the challenges that they have encountered daily since they discovered their status. For example, challenges of self-disclosure and their experiences with disease management and treatment at home, school and at the clinic, were also discussed. Participants' coping strategies and the support they have

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received since they discovered their HIV positive status and if support is helpful. The interviews were concluded by exploring the participants' sexual relationships and future plans.

3.9 Method of data analysis

Since the study was qualitative in nature, qualitative data analysis techniques were used, in particular thematic content analysis. According to Stommel and Wills (2004), thematic content analysis aims to identify themes within data. It is more inductive because the categories into which themes will be sorted are not decided prior to the coding of data and they are induced from the data. In this study, qualitative thematic analysis was conducted and categories were developed according to Tesch's eight steps of data analysis (Creswell, 2013).

Step 1: The researcher carefully read through all the transcriptions, making notes of ideas that come to mind.
Step 2: The researcher selected one interview and read it to try and get meaning from the data. Thoughts coming to mind were written down.
Step 3: After going through the transcripts, the researcher arranged similar topics in groups by forming columns which were labelled major topics, unique topics and leftovers.
Step 4: The researcher abbreviated the topics as codes and wrote the codes next to the appropriate segment of the text. The researcher then studied the organisation of data to check if new categories or codes had emerged.
Step 5: The researcher found the most descriptive wording for the topics and converted them into categories. The aim was to reduce the total list of categories by grouping together topics that related to each other. Lines were drawn between the categories to indicate interrelationships between categories.
Step 6: A final decision was then made in the abbreviation of each category and the codes were arranged alphabetically.
Step 7: Data material belonging to each category were put together in one place and preliminary analysis was performed.
Step 8: Recoding of the data was done.

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3.10 Ensuring Trustworthiness

In quantitative studies, validity and reliability are not easy to ensure. Instead, trustworthiness is used to ensure data quality (Lincoln & Guba, 2012). For that purpose, credibility, transferability, dependability and confirmability were ensured.

3.10.1 Credibility

According to De Vos et al. (2011), credibility is the alternative to internal validity and its goal is to demonstrate that the research was conducted in a manner that ensured that the subject was accurately identified and described. The qualitative researcher may use various strategies to increase the credibility of qualitative research, for example, prolonged engagement and persistent observation in the field, triangulation of different methods, peer debriefing, member checks, and formalised qualitative methods such as grounded theory and analytic induction. In this study, the researcher gained an in-depth understanding of the topic and aspects of participants' experiences. To ensure credibility of the study, the researcher prolonged the engagement with participants until data saturation was achieved. Findings were revealed to the participants to allow them to verify them and to ensure that their opinions were accurately represented. The researcher tape recorded the interviews and took field notes to ensure credibility.

3.10.2 Transferability

Transferability refers to the probability that the study would have a similar meaning to others in similar situations. It is also called fittingness, for it determines whether the findings fit in or are transferable to similar situations (De Vos et al. 2011). Polit and Beck (2008) indicated that the reader notes the details of research situations and methods and then compares them to similar situations that they are more familiar with. If they are comparable, then the original research would be deemed more credible. In this study, the researcher ensured transferability of the study findings by giving the transcript to a colleague who is experienced in research to randomly read the selected transcript and to identify major categories, so that readers could have a clear picture of the research findings.

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3.10.3 Dependability

According to Polit and Beck (2008), dependability is achieved by securing credibility of the findings. It is related to consistency of findings. This means that, if the study is repeated in a similar context with the same participants, the findings would be consistent. It is an alternative to reliability, and cannot be present without credibility. In this study, dependability was achieved by describing and interpreting the research findings, as well as making recommendations to demonstrate that the investigation is supported by data and is internally coherent. A tape recorder was used for all interviews to increase reliability.

3.10.4 Confirmability

Confirmability means that the researcher determines the accuracy or credibility of findings through specific strategies and it is concerned with testing and confirming the findings (Obiakor, Bakken & Rotatori, 2010). Confirmability captures the traditional concept of objectivity as it stresses the need to ask whether the findings of the study could be confirmed by another researcher (De Vos et al. 2011). In this study, the researcher ensured confirmability by carefully planning each phase of the research process, such as the research design, sampling design and data collection process, and making sure that the conclusions of the study findings are supported by the analysed data and literature (Stommel & Wills, 2004).

3.11 Ethical Considerations

In this study, ethical considerations were the main principles applied. The researcher obtained permission to conduct the study from the University Research and Ethics Committee, the Department of Health, Limpopo Province and the Chief Executive Officer and Operational Manager of Fountain of Hope Wellness Clinic, to conduct the study in Messina Hospital.
According to Punch (2013), ethics refer to what are good, right or honourable courses of action and these can be approached from different points of view. Ethical considerations apply to the treatment of participants in both qualitative and quantitative research (Willig, 2013). Mauthner et al. (2012) stated that ethics, in relation to social research, refer to the moral deliberation, choice and accountability on the part of the researcher throughout the research process. Ethical decisions arise throughout the entire process, from conceptualisation

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and design, through to data gathering and analysis, literature review and report writing. Since this research involved human participants, the following ethical principles were adhered to:

3.11.1 Informed consent

According to Hesse-Biber and Leavy (2010), informed consent is a question of basic human rights intended to safeguard the participants from any mental and physical harm that might happen because of their participating in the study. It is a crucial component in ethical research that uses human participants. Informed consent is the permission by participants to participate in the study if they are given full information. Consent involves the procedure by which an individual may choose whether to participate in a study. In this study, the researcher's task was to ensure that participants had a complete understanding of the purpose and methods to be used in the study, objectives, duration, the potential risks involved, and the demands that would be placed upon them as participants (Burns & Grove, 2010).

The researcher, in this study obtained written informed consent from the guardians and caregivers of children under the age of 18 years. The researcher ensured that participants were fully informed of the information needed from them to make a decision. They were informed that their participation was voluntary based on the understanding of what the study was about, how the results were to be used, how the study would directly or indirectly affect them and also that their identities would be protected (Sarantakos, 2012; Burns & Grove, 2010). The researcher and participants signed a consent document to indicate their willingness to participate in the study after obtaining the written informed consent from the guardians and caregivers. Participants were made aware of any potential risks that could come with participation in the study and the procedures that were put in place to deal with any negative outcomes that might occur (Sarantakos, 2012).

3.11.2 Privacy, Confidentiality and Anonymity

According to Punch (2013), privacy refers to the individual's right to control what they consider personal or non-public information about themselves. It is seen as the people's right to be free from any research intervention that may be unwelcome and intrusive and allows them to withhold any information that they consider personal and sensitive. Leedy and

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Ormrod (2013) argue that every individual has a right to privacy, confidentiality and anonymity. De Vos at el. (2011) point out that every participant has a right to decide when, where, to whom and to what extent their personal information can be revealed. In this study, the researcher to cognisance of the fact that invasion of privacy is possible at all the stages of research, starting from choice of topic, to publication and beyond, for example, in storage, archives, and follow ups.

Confidentiality arises from respect of the right to privacy and it functions as a precautionary principle (Burns & Grove, 2010). Confidentiality is related to the researcher's management of private information shared by the participants. In this study, the researcher protected the participants' right to privacy by ensuring that any data collected would not be traced back to the participants. The researcher ensured that confidentiality was maintained throughout the study and that information on identity of the study participants would not be made public. The researcher refrained from sharing the information given by participants without their authorisation and no one except researcher and supervisor had access to the study data (Burns & Groove, 2010).

According to Burns and Grove (2010), anonymity occurs when even the researcher cannot link a participant with the data of that person. In this study, the researcher ensured that the identifiable information about participants would not be made public and that their identities remained protected through various processes designed to protect them (Sarantakos, 2012). When reporting the results of the study, researcher made use of pseudonyms to disguise the identities of participants (De Vos et al. 2011). The researcher also ensured that the records of the interview sessions were handled anonymously and that they would not be traced back to the participants.

3.11.3 Debriefing of the participants

Debriefing is the process where participants get to work through their experiences after the interviews (De Vos et al. 2011). In this study, participants were given an opportunity to reflect on the experiences of being part of the study. This was an opportunity to resolve possible misconceptions, or emotional reactions, which could have resulted from the interview. The debriefing by social worker gave the researcher an opportunity to answer

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questions that may have arisen from the participants during the interviews. In cases where participants appear emotionally affected, appropriate referrals would be made. However, in this study, this was not necessary.

3.12 Conclusion

This chapter outlined the research methodology used in this study. The research used the qualitative approach and an exploratory study design. The population of this study comprised all male and female children aged between 12-17 years. The non-probability sampling approach was used to recruit children who met the inclusion criteria of the study. Semi-structured open-ended interviews were conducted with eleven children living with vertically transmitted HIV/AIDS and who were receiving HIV treatment, care and support services at Fountain of Hope Wellness clinic. Qualitative data analysis, in particular thematic content analysis was used to analyse data and Tesch's eight steps of data analysis were used for this purpose. Measures of ensuring trustworthiness and ethical considerations were applied in this study.

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CHAPTER 4: PRESENTATION AND DISCUSSION OF RESEACH FINDINGS

4.1 Introduction

In this chapter, the results of the study are presented and discussed. First to be presented is the demographic profile of the participants, followed by the themes and sub-themes. The responses were presented verbatim to authenticate analysed data. Pseudonyms, age and gender are used to indicate the respondent, for example: Irene, 15 years, female.

4.2 Demographic Information

Table: 4.2.1 DEMOGRAPHIC INFORMATION

Participants	Age	Gender	Level grade	Number of years on ART	Status knowledge
Ace*	15	Male	Grade 8	10 years	Yes
Brenda*	16	Female	Grade 10	Since birth	Yes
Candy*	17	Female	Grade 10	09 years	Yes
Dorah*	17	Female	Grade 11	Since birth	Yes
Emma*	14	Female	Grade 8	04 years	Yes
Fred*	12	Male	Grade 6	Since birth	Yes
Gully*	16	Female	Grade 9	05 years	Yes
Happy*	17	Male	Grade 9	Since birth	Yes
Irene*	15	Female	Grade 10	Since birth	Yes
Joe*	13	Male	Grade 7	02 years	Yes
Kevin*	14	Male	Grade 4	Since birth	Yes

* Represent Pseudonym

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Table 4.2.2 SOCIO-DEMOGRAPHIC INFORMATION

Participants	Parents	Occupation for parent/caregiver	Number of children	Home language/ethnicity
Ace*	Both parents are alive. Staying with both parents in shack	Mother- unemployed Father- Piece jobs	2nd born of 4 children	Tsonga
Brenda*	Both parents are alive. Staying with both parents and siblings in RDP house	Mother- Clerk Father- General worker	2nd born of 3 children	Tshivenda
Candy*	Both parents died. Stays with Grandmother, uncle and his wife, cousins in RDP house	Uncle-General worker.	1st born of 2 children	Tshivenda
Dorah*	Both parents died. Stays with her Aunt and 3 cousins in a shack.	Aunt sells vegetables and fruits	4th born of 4 children	Tshivenda
Emma*	Both parents alive. Stays with mother and step-father in shack	Mother-Peer educator Step-father- Farm worker	2nd born of 2 children	Shona
Fred*	Both parents died. Stays with aunt in a shack	Aunt- unemployed Depend on social grant	2nd born of 6 children	Tsonga

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Gelly*	Both parents are alive. Stays with mother and sister in a shack	Mother -General worker Father -Chef	2nd born of 2 children	Shona
Happy*	Both parents alive and divorced. Stays with mother, aunt and brother in RDP house.	Mother- Cleaner	1st born of 2 children	N. Sotho
Irene*	Mother died. Father is alive. Stays with grandmother and aunt in shack.	Father- Piece jobs	5th born of 6 children	Tshivenda
Joe*	Both parents are alive. Stays with mother and step father in RDP house.	Mother unemployed. Stepfather-Driver	3rd born of 6 children	N. Sotho
Kevin*	Both parents alive Stays with mother, father and sister in RDP house.	Mother- General worker Father- Chef	3rd born of 3 children,	Tshivenda

Table 4.2.1 and 4.2.2 above illustrates the demographic profile of the participants that were interviewed. The participants' ages ranged from 12 to 17 years and both males and females were interviewed in this study.

4.3 Themes and sub-themes

This section provides the themes and sub-themes that emerged from the collected data. Table 4.2 provides the summary of the themes and sub-themes. The aim of the study was to explore

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the psycho-social experiences of children living with vertically transmitted HIV/AIDS at Messina Hospital, South Africa. The research questions were:

- What are the psycho-social experiences of children living with vertically transmitted HIV/AIDS?
- What challenges do children who are living with vertically transmitted HIV/AIDS infection face?
- What are the coping strategies of children who are vertically infected with HIV/AIDS?

Themes and subthemes which merged during the thematic analysis are outlined in the table below.

Table: 4.3 THEMES AND SUB-THEMES

Main theme	**Sub-themes**
1. Living with HIV/AIDS infection	1.1 Knowledge about HIV/AIDS 1.2 Being sick 1.3 Fear and anxiety 1.4 Acceptance of HIV positive status
2. Challenges for living with HIV/AIDS	2.1 Knowing my HIV status 2.2 Disclosure difficulties 2.3 Treatment adherence 2.4 Stigma and discrimination
3. Coping with HIV/AIDS	3.1 Regular attendance of wellness clinic 3.2 Taking ART treatment 3.3 Religion 3.4 Involvement with school activities 3.5 Family support

Theme 1: Living with HIV/AIDS infection

Participants in the study indicated that living with HIV infection is not easy and that this had affected them negatively in their daily lives. During the interview, they indicated that they

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knew about their own HIV status. They also spoke about being sick, their fears and anxiety and whether they had accepted their HIV positive status.

Sub-Theme 1: Knowledge about HIV/AIDS

All the participants had some knowledge of HIV/AIDS prior to knowing their HIV positive status, although for some, the first time they heard about HIV was at home, at the time their disease was disclosed. They knew how HIV is transmitted, its symptoms and that it cannot be cured. Some also had knowledge about vertical transmission of HIV/AIDS. These are their explanations:

> *"I know that you can get HIV virus by touching blood of somebody who is HIV positive"* (Irene, 15 years, female).
>
> *"One can get HIV virus if you have unprotected sex, like when you don't use condoms and if your parents were HIV positive when you were born"* (Ace, 15 years, male).
>
> *"What I know about HIV is that, HIV is a sickness that cannot be cured, you get it through blood and unprotected sex. It's very hard to live with, it is like a big thing that's heavy on your shoulders if you didn't accept it"* (Gelly, 16 years, female).
>
> *"I know you can get some sores if you don't take your medication and you can die when you are HIV positive"* (Joe, 13 years, male).

Four children (36%) had an idea what vertically transmitted or perinatal HIV/AIDS is. Seven (63%) were aware that they were infected through their mothers, but they do not seem to understand how this happened. This is what they had to say:

> *"I was born with HIV"* (Irene, 15 years, female).
>
> *"I got HIV from my mother and she told me that she got it from my father"* (Emma, 14 years, female).

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> *"My mom said that I got it from her and she got it from my father. She said my father was open about his status when they met and she accepted him knowing his HIV status"* (Gelly, 16 years, female).

> *"I was born with it and I don't understand why my younger brother doesn't have HIV"* (Fred, 12 years, male).

In their study of six positive adolescents, Kalafong, Visser and Pienaar (2012) found that only one of the adolescents was not aware of what HIV/AIDS is. This shows that children have a little knowledge of HIV/AIDS. Although they are generally aware of HIV/AIDS, it is evident that they do not know much about the perinatal HIV as seen in the responses of the participants.

Sub-Theme 2 Being sick

Participants believed that living with HIV/AIDS is being sick. They have experienced recurring or serious illnesses and recall multiple hospital admissions. Their childhood was disturbed by ill health and clinic or hospital visits. The following responses attest to that:

> *"I was very sick in 2015 and I used to be in and out of hospital. Then, I got tested and I started with my medication"* (Emma, 14 years, female).

> *"I have been very sick since I was born and I thought it was normal to be sick like that. I used to have diarrhoea, TB and flu, and then my mom took me to hospital and I tested HIV positive but now it is better. Medication is fighting the virus and these days I feel much better"* (Gelly, 16 years, female).

> *"I was always very sick since I was young. My mom took me to hospital where I was tested for all diseases and they found out that I am HIV positive"* (Joe, 13 years, male).

According to Bernays et al. (2015), children's experiences of living with HIV/AIDS infection were constructed in relation to the language of sickness. Although all the infected children

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were on ART and most of them were healthy, they associated HIV with illness and weakness. These children described people living with HIV/AIDS as being visibly ill and thin, small and physically short, with scars, and wounds all over their bodies and thinning hair. Despite these characteristics, many children did not consider themselves to be sick, instead, they described themselves as being strong and healthy (Bernays et al. 2015; Midtbo, 2012).

Four participants (36%), in the study, have experienced long term ill health since childhood and two participants (18%) reported at least one hospital admission after starting with ART treatment.

> *"I remember being very sick in 2014. I was admitted in the hospital for a week. I was afraid that I will die and my mom said to me, don't be afraid, you know your disease*" (Ace, 15 years, male).

> *"In 2013, I was very sick. I had a headache, diarrhoea and TB and stayed in the hospital for weeks"* (Dorah, 17 years, female).

> *"I was admitted once, but not for a long time. My temperature was very high. I was kept in the hospital until it was normal. It was for three days"* (Gelly, 16 years, female).

In this study, four of the participants (36%) indicated that they experienced recurring or serious illnesses. They recalled several hospital admissions and much of their childhood were disrupted by ill health and visits to clinics or hospitals:

> *"I always came to the hospital and at times I stayed there for weeks because of flu and coughing"* (Brenda, 16 years, female).

> *"I used to get sick so often. I remember when I was 8 years old, I thought it was a normal stage of growing up; that I had to be sick. When I saw other kids playing, I thought they were not normal or healthy because that's what I knew, to be sick all the time. I didn't know what was going on with me"* (Gelly, 16 years, female).

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Being sick, mostly affected five of the children (45%) in the study and they had to repeat a grade at school. They failed their grades because they were sick most of the time and they could not attend school well and studying was difficult as they were sick:

> *"I was always sick and I missed school a lot. I failed grade 6 and I had to repeat"* (Happy, 17 years, male).

> *"I failed grade 2 and grade 3 because I was always sick and didn't go to school"* (Kevin, 14 years, male).

The above responses show that having HIV/AIDS has a negative impact on the academic performance of the children because most of the time they are ill and they also miss school. When children do not attend school frequently, their academic performances drop down. This could be an obstacle for a successful and healthy future.

Sub-Theme 3 Fear and anxiety

Living with fear is a norm for most children living with HIV infection. Ross and Deverell (2010) asserted that children are afraid of being known to have HIV and fear of rejection is always greater than fear of dying. Zanoni (2013) added that perinatal HIV is coupled with mental health issues, frequent disruption of social and academic activities because of clinic visits or hospitalisation that often lead to feeling of anxiety and depression.

Some of the participants indicated that when they are living with HIV/AIDS, they also experience fear and anxiety. Participants had difficulty accepting HIV in their lives and associated living with HIV infection with dying. Two children (18%) expressed fears and anxiety over an uncertain future. They were afraid of not finding a future marriage partner who is willing to accept their HIV positive status and also of falling ill or being attacked by opportunistic infections. All the children in the study feared death or the possibility of having a very low life expectancy. The following extracts support this observation:

> *"I always use condoms when we have sex. I'm scared of dying because if I don't use a condom I may get sick and die"* (Happy, 17 years, male).

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> "*I was afraid that I would die and my mom said to me, don't be afraid, you know your disease*" (Ace, 15 years, male).

> *"HIV is always in my head. Most of the time I think about dying and I even dream of myself being very sick or dying''* (Emma, 14 years, female).

> *"For me, HIV means I am going to die and I'm scared. Sometimes I am afraid to sleep you know! I ask myself am I gonna wake up? Am I going to die?"* (Gelly, 16 years, female).

> *"My mother is sick; she has TB and HIV. I am scared that she can die"* (Kevin, 14 years, male).

These findings are similar to those of previous studies (Hodgson et al. 2012; Li et al. 2010; Petersen et al. 2010) in which participants had difficulties integrating HIV into their lives and they associated living with HIV with dying. Fabinova (2011) found that people infected with HIV/AIDS can also feel helpless and hopeless, and their ability to deal with and adjust to the situation is reduced. This, consequently, reduces the quality of their lives. In a South African multi-clinic study of 343 children, 27% had symptoms of anxiety, depression or post-traumatic syndrome (Woollett, Cluver, Bandeira & Brahmbhatt, 2017). In contrast, the study conducted in Botswana and Tanzania reported that adolescents living with perinatal HIV live healthy and normal lives and view themselves with positive identities in spite of living with chronic illness (Midtbo, 2012).

Sub-Theme 4 Acceptance of HIV positive status

There were insights into the participant's own attitudes and beliefs about their HIV positive status and health seeking behaviour. It shed some light on participant's own involvement in their treatment and takes into account the participant's own feelings and how they use these to process their situation and in turn their treatment. Participants used a normalising method to deal with their own fears and beliefs. Dorah (17 years, female) said that "*there are many diseases that they cannot be curable so why can't I cope with this HIV disease*". In this way

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she is "normalising" living with HIV/AIDS in terms of it being just like other illnesses that are not curable and therefore should not be more important than any other disease.

When asked what is it like to live with HIV, Dorah (17 years, female) responded by saying that she "*always told herself that everybody is sick in this world*". She stated that she must accept herself before somebody else can accept her and by stating that, she acknowledges her own role in acceptance. Furthermore, by telling herself that many people in the world are sick, she normalises the disease by realising that it is not just her who is living with HIV/AIDS and therefore does not need to view herself as being different.

Studies conducted in Zambia (Mburu Mburu, Hodgson, Teltschik, Ram, & Haamujompa, 2013) and Uganda (Obare & Birungi, 2010) also found that HIV positive adolescents accepted their status and expected a future that includes the same educational and career opportunities as their non-HIV infected peers, as well as marriage and having children. However, Mavhu et al (2013) study in Zimbabwe found that children had difficulties in accepting their HIV positive status and the feelings of despair, hopelessness and sense of imminent death were common among these infected children. Participants mentioned that being diagnosed with HIV infection was not easy to accept, but eventually they had to accept it. Six children (66%) reported that their feelings changed as time progressed. They have become more positive in their attitudes since gaining awareness of their HIV positive status.

> *"I am the second born in a family of four children and I am the only one who is HIV positive. I didn't understand why others didn't have it. It was hard for me, but now I have accepted it. My parents are also taking the medication"* (Ace, 15 years, male).
>
> *"Now I have accepted it and I know it's nobody's fault that I am HIV positive. I was born with this disease"* (Dorah, 17 years, female).
>
> *"It was not easy for me to accept it and I didn't understand but later I accepted that I have HIV"* (Happy, 17 years, male).

Hill (2012) found that adolescents were confused because society expects them to live two lives. On one hand, they are expected to be completely honest and accept their status and on the other hand they cannot disclose their status to society. This has lasting effects on patients

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and might lead to self-stigma. These findings relate to those of the study done by Vervoort et al. (2009) which revealed that most of the participants achieved acceptance once they had overcome the initial distress of the discovery of their HIV positive status. Participants in this study indicated how their own attitudes towards their HIV status impacted on their motivation to continue going for checkups, accepting their HIV status and taking their treatment so that they could continue to live a healthy life. A study from Zimbabwe found that the availability of ART contributed to acceptance and normalisation of HIV, showing that it is possible to live a close to normal life in spite of being HIV positive (Campbell, Skovdal, Madanhire, Mugurungi, Gregson & Nyamukapa et al. 2011).

Theme 2: Challenges of living with HIV/AIDS

The common challenges for people living with HIV/AIDS are fear of death, coping with uncertainty, stigma and discrimination attached with the disease. Participants in this study revealed several challenges they face daily. They pointed out that living with perinatal HIV is not easy. Challenges identified included disclosure difficulties, treatment adherence, stigma and discrimination.

Sub-Theme 1 Disclosure difficulties

There are different viewpoints when it comes to disclosure outside family structure because HIV/AIDS is still treated with secrecy. The study findings also revealed that non-disclosure to significant others were influenced by family members and children themselves. Visser and Pienaar (2012) indicated that discussing HIV/AIDS issues openly is limited in family and family has influence on disclosure outside the family structure. The bio-psychosocial model states that social systems like family, school and community contribute to health and illness. Family set up has impact on how children view and treat their HIV diagnosis (Sperry, 2012).

The participants had difficulties disclosing their HIV positive status and they expressed fears of rejection, isolation, stigma and discrimination by friends, family or the community. All the

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children reported that they considered their HIV diagnosis as a private matter and that they cannot trust anyone, including friends, with it. The following responses attest to this:

> *"I haven't told anyone; I have a friend but I don't trust her with my personal matters"* (Gelly, 16 years, female).
> *"I just don't want to talk about it. It's my secret"* (Gelly, 16 years, female).

> *"I have never told anyone; I cannot trust anyone with my secret"* Ace, 15 years, male and Joe, 13 years, male said the same thing.

> *"Yes, I have had a boyfriend for a year now* (she laughs)*, but no, I haven't told him. I will never tell him my status... As long as we are always using protection it's good. I can't afford to tell every boyfriend my status, 'coz I'm still young and I would probably date a few people before I get married. I can only tell my husband if we are married 'coz he deserves to know"* (Dorah, 17 years, female).

Two children (18%) reported going to great lengths to cover their HIV positive status among their peers to avoid stigma and discrimination. They hid their treatment regimen as follows:

> *"I hide them in the container so that my roommates cannot see them and I always make sure I am alone when I drink my medication"* (Emma, 14 years, female).

> *"I have been to school trips before and I'm so clever. I took my medication wrapped in tissue and a bottle of water and went away from people to drink it without anyone noticing it"* (Gelly, 16 years, female).

The extracts above show that disclosing their HIV positive status to people within their immediate environment is a major challenge for these children and they guarded their secret carefully. These children preferred partial and selective disclosure to disclose their HIV status to people around them. Partial disclosure (where only a few people who must know are informed about the HIV status) was a preferred strategy for most of the children in this study. Four participants (36%) explained that the following:

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> *"It's only me and my family who know about it and I don't want other people to know my status because they will treat me differently and they won't play with me anymore"* (Ace, 15 years, male).

> *"Yes, I only told my best friend, only one friend. I told her last year and she was surprised because I looked well and she was very supportive. I cannot tell my teachers at school 'coz there are those who talk too much and they might teach about me in class"* (Candy, 17 years, female).

> *"You know, it's very difficult for me to tell my classmates about my status. Maybe I should tell my teachers the reason being that, you know how we teenagers behave. If I tell someone that I am HIV positive and she goes around telling other people bad things about me and I would not want that"* (Dorah, 17 years, female).

Four participants (36%) believed that if they revealed their status to peers and teachers, they risked rejection, isolation and stigmatisation. Other participants perceived non-disclosure of their HIV status to others as the best way to avoid negative social consequences:

> *"No, I don't think I can tell my teachers because I would be like saying to them feel sorry for me or pay attention to me. I want to be treated equally the same as others and normal. Sometimes I get scared that they might talk and everybody would know, but I'm not that worried about that"* (Gelly, 16 years, female).

> *"I am scared that people will talk badly about me or treat me differently"* (Brenda, 16 years, female).

> *"There is this girl who is HIV positive in my class ok. Some of my classmates make cruel jokes and laugh at her and most of the time she is sad and crying alone. The other day I got so angry at them for laughing at her I threatened to tell the teachers, but it didn't help. You see, that is why I can't risk telling anyone"* (Candy, 17 years, female).

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The above findings confirms the findings by Tshabalala (2014) and Woollett (2013) who found that HIV related stigma and discrimination was an obstacle factor to the disclosure of one's HIV positive status. Four participants (36%) didn't disclose their status to extended family members and their peers to avoid stigma and it contribute to complicated social relationships:

> *"I didn't tell anyone and I don't like talking about it. I am scared because people out there don't treat people with HIV the same as those who don't have it"* (Happy, 17 years, male).
>
> *"It's because they might treat me badly or other kids might not want to play with me anymore and they might tell people or use it against me with my enemies"* (Joe, 13 years, male).
>
> *"I cannot tell anyone because people are scared of HIV and I don't want to lose my friends and be alone"* (Irene, 15 years, female).

These findings resonate with those of Hogwood, Campbell and Butler (2012) who found that children living with HIV/AIDS may be willing to disclose their HIV positive status but may face many difficulties, such as the uncertainty of other's reactions, rejection, stigma, and loss of control of their personal information.

The disclosure of the HIV positive status to partners was a delicate issue among the children in the study. The desire to tell and share these important aspects of their lives was hampered by fear of rejection and fear of being exposed to others. Three participants (27%) who indicated that they were in romantic relationships expressed their worry and reluctance to disclose their status to their partners. The children stated that they were not willing to disclose their HIV positive status to their partners because they were scared. They were thus not ready to tell.

> *"I have had a girlfriend since December last year, but I will not tell her my HIV status. Things could get messy. I'm scared that she might leave me or tell people about my status, but we are using condoms every time we have sex''* (Happy, 17 years, male).

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> *"I have a boyfriend and we have been dating for 1 year, 2 months now. I haven't told him my status. I need time and I am scared that he might not accept it and leave me. I am also scared that he will tell other people about my status. We use condoms and sometimes we don't"* (Brenda, 16 years, female).

> *"I have a boyfriend and we have been dating for 6 months now. He told me that he is HIV positive and he gets his medication from a private doctor because his mother has medical aid. But still I couldn't tell him my status and I think I'm not ready to do that"* (Gelly, 16 years, female).

This finding concur with earlier studies' (Fair & Albright, 2012) evidence that disclosing HIV status to a sexual partner often results in negative outcomes such as rejection and stigma.

Studies conducted in sub-Saharan Africa reveal that disclosing HIV status to partners is very challenging to adolescents as they fear rejection and loss of respect if their status is known (Siu et al. 2012; Birungi et al. 2009). The study findings are contrary to those of Hogwood et al. (2012), who found that youths were more likely to reveal their HIV diagnosis in specific circumstances, such as in a romantic relationship, when getting married or when having a child or getting a job. A similar study, conducted in Zambia on barriers, attitudes and outcomes of HIV disclosure by PLHIV confirmed that the majority of adolescents do not disclose their status to their sexual partners because of a fear of rejection (Cataldo, Haamujompa, Hodgson, Kalibala, Lowenthal, Mburu & Ross, 2014).

Two participants (18%) who were in a relationship did not disclose their HIV positive status to their partners. Although, they have been encouraged by the clinic staff to disclose their HIV status to their partners, some of these children have not done so because they see no urgency of telling their partners. This is because they were not yet engaged in sexual activities; others saw no need to tell their partners because they were using protection. This is how they said it:

> *"He doesn't know I have HIV, I haven't told him yet. You know! there is no need to tell him 'coz we are not sleeping together but maybe in future, maybe I will tell him*

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> *because you know, he deserves to know and he told me his status"* (Gelly, 16 years, female).
>
> *"At the clinic, they encourage us to disclose our status to our partners, so that we don't infect them. I feel that I don't have to, 'coz as long as we are always using protection that's good. I can't afford to tell every boyfriend my status, 'coz I'm still young and I would probably date a few people before I get married"* (Dorah, 17 years, female).

Two participants (18%) had disclosed their status to someone outside their immediate family, such as friends and teachers. One participant disclosed his status to school teachers because he did not want them to make a fuss when it was time for him to go to the clinic.

> *"I told my school principal and teachers at school so they don't get surprised when I come to school late, when I go to collect my medicine"* (Joe, 13 years, male).

Consistent with current study results, studies found low levels of HIV status disclosure among adolescents living with HIV/AIDS (Hodgson et al. 2012; Midtbo et al. 2012; Siu et al. 2012; Petersen et al., 2010). Over half of the adolescents have never disclosed their HIV status beyond their immediate family members due to the fear of stigma and discrimination, fear of rejection, abandonment, abuse and isolation. The social stigma associated with having HIV/AIDS remains a reality and the difficulties of not being able to talk openly to friends and family about one's HIV positive status means that many of these children feel isolated and lonely (Hogwood, Campbell & Butler, 2012). Participants were discouraged by their caregivers from disclosing their status to other people, sometimes including extended family members, friends, school teachers and community members for fear of stigma and discrimination: *"My grandmother wants us to keep it a secret, because she doesn't know how people will react"* (Dorah, 17 years, female). These findings mirror those of other studies on HIV disclosure to children living with vertically transmitted HIV/AIDS in South Africa, where caregivers reported that they told children living with HIV not to disclose their status due to fear of being stigmatised (Heeren et al. 2012; Madiba, 2012).

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Sub-Theme 2 Treatment adherence

The participants seem to regard treatment adherence as important and they all showed a sense of responsibility in maintaining good ART treatment adherence even though they face many challenges along the way. The children identified some barriers to treatment adherence. However, they understood the importance of ART in their lives and never stopped taking them. In contrast, with study findings (Kim, Mazenga, Yu, Ahmed, Paul, Kazembe & Abrams, 2017) adherence amongst children in Malawi found that self-reported adherence was poor with nearly half (45%) of all children, children reported missing ART in the past and the most commonly reported barriers to adherence were forgetting (90%), travel from home (14%), and busy doing other things (11%). Three participants (27%) complained that being on ART treatment disturbed their personal lives. Their interaction with friends at home and at school was affected by ART treatment and it, sometimes, made their lives difficult. This is how they explained their dilemma:

> *"It's like when I'm playing with friends, sometimes you must tell them that you are going home when it is still early so that you can take your medication on time"* (Ace, 15 years, male).

> *"I am staying at a school hostel and it's a struggle sometimes to hide my medication from my roommates. Sometimes we come back late from the studies and I panic when my time to take medication passes by"* (Emma, 14 years, female).

This finding concurs with those of Michaud et al. (2010) who found that adherence to ART treatment often deteriorates for a variety of reasons, including forgetting, stigma, problems with body image, and a desire to be normal (Hazra et al. 2010). However, two participants (18%) experienced fatigue and indifference with adherence to the treatment regimen. While they understood the importance of ART in their lives, they acknowledged that, sometimes, ART treatment interfered with their lives. However, they have never stopped taking them:

> *"I know, I have to take my medication every day, but sometimes I get tired. However, I have never stopped taking them 'coz I'm scared of losing my life. I sometimes wish that I could have 1 pill per month, or if my everyday meal can become my medicine, if*

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> *eating food was part of treatment that would be much better" (she laughs)* (Gelly, 16 years, female).

> *"Yes, I do get tired sometimes, but I don't stop taking them because I know I have to take them for me to live healthy"* (Happy, 17 years, male).

Often, what made study participants feel different was not necessarily having HIV, but rather having to follow a daily treatment regimen. Three children (27%) had this to say:

> *"Sometimes, I feel it to be a burden to take my medication every day and sometimes I just take the medication without stress"* (Candy, 17 years, female).

> *"I get so tired sometimes and wish I could be normal and not take the pills like other people"* (Fred, 12 years, male).

The above responses show that being HIV positive has effects on the daily lives of these children. They have to alter their lifestyles to suit their status and to keep up with their ART treatment. This finding concurs with that of Mellins (2010) who found that perinatal HIV makes adolescents feel like social misfits since the treatment regime disturbs their lives. Furthermore, Willis et al. (2014) found that adherence was a major challenge for children living with HIV/AIDS. Although children had access to ARV treatment, they had many fears concerning the taking of ART for the rest of their lives.

As was mentioned above, the bio-psychosocial model of understanding health illness incorporates psychological and the social factors into the already established bio-medical model of health (Sperry, 2012). The cognitive, emotional and behavioural aspects that make up the psycho part of the model played a role here. The way in which these participants normalised their challenges shows a cognitive understanding of their position and results in intellectualising their status. They rationally understand that living with HIV/AIDS is similar to living with any other incurable disease and therefore realise that in order to live they need to adhere to their treatment. In this way it can be seen how all these aspects of the bio-psychosocial model work together in order to promote treatment adherence.

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Sub-Theme 3 Stigma and discrimination

In this study, Stigma and discrimination were described as major challenges that confronted children living with HIV/AIDS. Dorrell, Earl, and Reveley (2008) argue that stigma affects everyone who is infected and affected by HIV/AIDS and victims find themselves stigmatised, feel lonely and isolated and have no escape. It has effects on the progression of the disease as it affects or leads to non-adherence to treatment (Martinez et al. 2012).

The presence of stigma also affects a person’s psychological and emotional well-being, as it is associated with less social support from family and friends (Mburu et al. 2014a). Two participants (18%) reported having experienced stigma and discrimination at some point in their lives within the family and in the community:

> *“...the problem is with my aunt she sometimes calls me names, she doesn’t treat me well and she insults me with my HIV status”* (Brenda, 16 years, female).

Another participant narrated how a neighbour made fun of her taking pills daily after she had seen her at the hospital clinic. She said:

> *“I know that I am HIV positive and I didn’t choose to be positive; I was born like this. I had a problem with another woman who stays next to my home. She saw me at an ARV clinic and I think she was scared that I would tell people. So, two days later, she sent her sister to borrow money from me and I told her I didn’t have money. Eish!, that lady was so angry with me, she was screaming at me standing on the street and she said, “you think you are better than everyone else, you are taking ARVs and you are dying ’coz you are HIV positive”. Ya! I know how it feels hey, and I said to her, as you know that I am HIV positive, to you it can be hard, but I know myself, I won’t kill myself because I have HIV and it’s not like I was sleeping around with boys when I got infected with HIV”* (Dorah, 17 years, female).

In relation to this study, it may be suggested that stigma experienced by children living with HIV/AIDS could be a social element that could affect or influence all other elements in their

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lives. Stigma plays an important role in treatment adherence of people living with HIV/AIDS, with higher levels of stigma leading to lower levels of treatment adherence and therefore it has a negative effect on the person's health.

The results of this study are in line with a study conducted by Mavhu et al. (2010) who asserted that, although stigma and discrimination against HIV positive people was decreasing, it was still common in Harare. It was also reported that stigma is most prevalent in the school environment from peers if one's HIV positive status gets known to one's peers. Two participants (18%) shared their school experiences of stigma and discrimination when they said:

> *"My school mates used to tease me and would not want to play with me because they said I was sick and I'm gonna die"* (Candy, 17 years, female).

Dorah experienced stigma at school and reported that her teacher was supportive towards her. She said:

> *"I still remember the other day when I was in grade 7 after I discovered my status and I told my teacher about my status. There was another girl who heard me saying the word 'positive' and she assumed I was saying I'm HIV positive. Then she started to tell people about my status; I was hurt because I would prefer to tell people on my own if I have to. The teacher was supportive and she talked to that girl and she was disciplined"* (Dorah, 17 years, female).

These findings confirm that, even though HIV/AIDS is well known these days, people living with HIV/AIDS and their families are still facing stigma and discrimination in society. Campbell, Skovdal, Mupambeyi and Greyson (2010) also found that children and adolescents living with HIV/AIDS are more likely to be stigmatised by peers, family and community members. In South Africa, participants reported being chased out of the family house, being asked to use different utensils and being restricted in their own individual rooms (Cloete, Strebel, Simbayi, van Wyk, Henda and Nqeketo, 2010) therefore, stigma and discrimination represents a significant challenge to an individual lifestyle, makes it impossible for PLHIV to live well and to continue with the normal activities of life.

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Theme 3: Coping with HIV/AIDS

Coping with HIV/AIDS infection is challenging. It emerged in the study that participants attempted to manage the challenges of living with HIV/AIDS such as stigma, discrimination and adherence to ART treatment. In order to cope, participants indicated that they regularly attended the wellness clinic, adhered to treatment, joined a religion, got involved in school activities and sought family support while living with HIV infection.

Sub-Theme 1 Regular attendance of wellness clinic

Since members of support groups are all in similar circumstances or life situations, they help meet the emotional, social and psychological needs of each other. Research shows that being part of support group of PLHIV is one of the key ways or strategies used by people living with HIV to cope. In these studies, support groups give members a sense of identity, belonging and acceptance and help with overcoming negative outlooks such as being angry and sad (Liamputtong, Haritavorn & Kiatying-Angsulee, 2012; Campbell, Skovdal, & Gibbs, 2011; Russell & Seeley, 2010). Participants in this study identified regular visits to the wellness clinic as helpful in coping with the challenges of living with HIV/AIDS in their daily lives. All participants mentioned that being part of a group in which they are not expected to explain their status and hide their HIV status was helpful. This is what they had to say:

> *"Since I was very young, I always came to the clinic. So coming here is part of my life and I don't feel alone here because I am with other children who are just like me"* (Kevin, 14 years, male).
>
> *"I feel much better knowing that I am not the only one with HIV"* (Ace, 15 years, male).
>
> *"When I come here I meet others like me, who are HIV positive and I don't have to pretend or hide"* (Candy, 17 years, female).

> *"When am at home, I feel like am the only one taking ARVs, but when I come here I see children like me who also take the treatment, I don't feel alone here"* (Irene, 15 years, female).

Midtbo et al. (2012) and Petersen et al. (2010), in their studies, also found that social engagement with others who have similar illnesses and life experiences prevents feelings of depression and loneliness in one's situation and enhance feelings of belonging. Participants, in this study, reported that attending the wellness clinic affords them an opportunity to learn from others how to cope and deal with issues of mutual concern such as stigma, the challenges they face, and how they overcome such challenges. Participants explained it as follows:

> *"From the support group, I have learnt about CD4 counts and how important it is to protect others from getting HIV"* (Happy, 17 years, male).
>
> "*I come to the hospital every time for the support group; I find it very helpful and nurses are so supportive and they treat us the same"* (Candy, 17 years, female).

Participants also indicated that they get emotional and moral support from support groups. These are some of their views regarding support groups:

> *"Meeting with other young HIV positive people gives me hope because if others are surviving with HIV, then I can also do it"* (Emma, 14 years, female).
> *"I feel like I am the same with them when I'm at the support group, but when I'm not in the clinic, I feel different like I don't belong anywhere"* (Ace, 15 years, male).

This finding concurs with findings by Mavhu et al. (2013) who found that most children attended the support group at least once a month. Adolescents reported that they received much support from their social network after being informed about their status (Hodgson et al. 2012). Nearly all participants in the study stated that being a member of a support group was helpful and it gave them a sense of belonging. The study results indicated that support groups empower children to deal with numerous difficulties that they face while living with HIV/AIDS. Support groups also provide a strong source of social support that helps children living with HIV/AIDS to cope with numerous stressors.

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> *"It made feel better that I am not alone and it was not my fault that I got the HIV"* (Candy, 17 years, female).

> *"I felt relieved when I realised that I was not alone. I used to think I was the only one who had HIV. So, I saw at the clinic that there are others as well. It makes me happy"* (Emma, 14 years, female).

> *"We can talk about anything at the support group. It is nice to be with people who are going through the same stuff as you are, you know"* (Irene, 15 years, female).

> *"At support group we talk about HIV, how important it is to take our medication. We are all HIV positive and you get to talk about stuff that is bothering us"* (Dorah, 17 years, female).

Support group services provide treatment education, adherence support, opportunities to boost one's self-esteem, support to deal with HIV/AIDS related stigma and mentoring. All these are important for adolescents living with vertically transmitted HIV/AIDS (Midtbo et al. 2012; Petersen et al., 2010). Support groups help the infected children to improve their confidence and to use health care services (Hodgson et al. 2012).

Sub-Theme 2 Adherence to treatment

In this study, adherence to ART treatment was described by children as a protective factor. Five participants (45%) stated that availability of life prolonging ART was a positive means of coping with the psycho-social challenges described above:

> *"I have never stopped taking my medication and I never thought of stopping, because I know once I stop taking them I will have a lot of problems, I can get sick and die"* (Ace, 15 years, male).

> *"The fact that I am healthy and I don't suffer from side effects makes it easy for me to take them sometimes. The other day a nurse told me that I'm lucky because the ARVs*

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> *are treating me well, the viral load is very low and I should keep taking them"* (Gelly, 16 years, female).

> *"No, I haven't stopped them, they are good to me and because they keep HIV asleep"* (Kevin, 14 years, male).

Adherence and non-adherence are determined by individual's experiences. Participants in the study revealed that fear of death was the biggest reason for adherence to treatment and was influenced by their parents, caregivers and health care providers. Four participants (36%) have embraced the importance of taking ART treatment in their lives and this motivates them to live. They hope that as long as they are taking their ART treatment they will be well and live longer.

> *"After she told me about my HIV positive status and gave me the medication, I was told that if I stop taking them I'm gonna die"* (Emma, 14 years, female).

> *"I have not thought of stopping my medication and they keep me healthy. 'Coz if I stopped them, I would die"* (Brenda, 16 years, female).

This finding is consistent with those of other studies (Li et al. 2010; Midtbo et al. 2012) who found that children and adolescents trusted the ARVs to keep them healthy and they were adhering to their ART treatment. Contrary to study by Agwu and Fairlie, (2013) most participants had one time forgotten, skipped or decided not to adhere to their treatment due to various reasons and achieving total adherence was reported in only 20% of the cases.

The psychological aspects of health and illness are described in terms of cognitions (e.g. expectations of health, support from peers), emotions (e.g. fear of treatment, fear and anxiety about death), and behaviours (e.g. attending school, taking treatment) (Sperry, 2012; Ogden, 2004). In this context, the patient's emotions are more important and it is when there are positive emotions associated with treatment that it is encouraged. In this study, it was seen how the participant's positive emotions towards treatment adherence, their health care providers and their peers are directly linked to positive feelings towards their health care settings, their peers and their treatment plans.

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Sub-Theme 3 Religion

The availability of ARV treatment for people living with HIV/AIDS has moved the focus of HIV/AIDS from an incurable illness to a more chronic disease. Infected individuals and their families have therefore had to create lifelong coping strategies. One way for dealing with their challenges and possibly seeking help is through religion and spirituality. Along with the social aspect of religion, the belief systems that people incorporate into their daily lives may influence how they approach their medical care (Park & Nachman, 2010).

Religion appeared for the participants as being an important aspect in the way in which they dealt with their HIV positive status and used as a way of self-strengthening by children in coping with the weaknesses that the disease can expose. Children reported that at first they did feel a level of fear and anxiety in terms of their future and what was going to happen to them. There was a sense that by turning to religion and praying to God will enable them to live with a sense of purpose. Participants used faith as a source of strength, comfort and hope to fight the disease to try to understand their situation. It was also observed that children who reported "no religion," but who believed in God, sought in Him a source of strength, comfort and hope in coping with HIV/AIDS challenges.

All the participants indicated that it is not easy for them to live with their HIV infection, and that they used religion as a way of dealing with their HIV positive status. The following statements support this observation:

> "*I pray to God everyday to give me strength and it really helps me to live in peace*" (Happy, 17 years, male).
> *"I am a Christian and a believer; I know that God exists but those medicines also were inspired by God. God is the one who gave inspiration to doctors to make medicine for us"* (Gelly, 16 years, female).
>
> "*...I was born like that and it is the plan of God*" (Joe, 13 years, male).

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Both participants explain how even though at first there was a level of fear, it did not stop them from visiting the hospital. They turned to God to help them survive through their fear and continued to go to the hospital to get their treatment. Participants trust God to make it possible for an HIV cure to be found. Two participants (18%) explained the role that religion plays in their lives when coping with the challenges of living with HIV/AIDS:

> *"I am a Christian. I love God and I am dedicated and committed, so, I have a spiritual Father, he is my mentor. When I am going through emotional challenges, he guides me, and if he is not around and I don't have a phone. I pray, read my bible and would feel much better*" (Dorah, 17 years, female).

> *"I am a Christian and I pray a lot that God heals me. I have faith in God that He is powerful and that nothing is impossible with Him. I do believe that the HIV positive status can change. There is a prophet in Zimbabwe who prays for people living with HIV and he advises people not to stop taking medication"* (Gelly, 16 years, female).

These findings also support previous research that has been conducted on the relationship between spirituality and coping mechanisms for people living with HIV/AIDS. It has been found that people with HIV/AIDS who have more positive religious coping strategies, such as a secure relationship with God, a belief in life's larger meaning, and a sense of spiritual connectedness with others show higher levels of wellbeing over time (Trevino et al, 2010). Ross and Deverell (2010) also pointed out that religion and beliefs determine health behaviours of HIV infected individuals. It was observed that religious beliefs influence the perceptions of infected individuals and whether they adhere to treatment. People living with HIV/AIDS cope with psycho-social challenges through religion and spiritual beliefs. These belief systems help infected people to cope with the illness, influence good adherence to ART treatment and contribute to health care visits to get wellness support and disease management (Hereen et al. 2012; Vaz et al. 2010).

The patient's relationship with their religion and God could also function as a supportive relationship, as it allows the patient to feel less fearful, cope well with challenges and be more in control of their lives while living with the virus. The person's spiritual beliefs have an influence on the manner in which they deal with their health issues (Trevino et al. 2010).

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However, the role of spirituality and religion among HIV infected adolescents has not been fully explored. Religion may have negative effects on the wellbeing of HIV infected individual, as religious beliefs have also been associated with HIV stigma. Additionally, religious beliefs and/or religious leaders may also interfere with patient's adherence to ART (Kagee & Delport, 2010).

This study illustrates that discussion on HIV/AIDS should acknowledge the effects of social factors such as religious and cultural beliefs because they have significant effects on the treatment intake by infected individuals. Ross and Deverell (2010) also confirmed that various aspects that determine health behaviours include religion, race and ethnicity as well as western and traditional healing methods. The bio-psychosocial model in this regard helped to understand the extent in which religion has influence on HIV/AIDS coping strategies, perception and treatment adherence challenges.

Sub-Theme 4 Involvement in school activities

Participants, in this study, said being at school helps them to cope because at school they experience normal socialisation with other children and enjoyed their childhood experiences regardless of their challenges. They perceived being at school as an opportunity to participate in sporting activities and to plan for their future. The following responses bear testimony to this:

> *"I am studying very hard, so that I finish my school and then I will go to the university and study to be a doctor"* (Emma, 14 years, female).
>
> *"I feel very happy when I am at school; I love school and when I'm there I forget a lot of things. I get to play netball with other kids"* (Candy, 17 years, female).
>
> *"I feel good when I am at school; my class teacher is very nice. She encourages us to study hard and she would say to me I'm very bright and have a great future ahead of me. She cares about all of us and it's good"* (Gelly, 16 years, female).

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School is helpful as a source of information to the participants. They get knowledge on HIV/AIDS during the life orientation classes. Children often have many questions about HIVAIDS and they get answers from friends and at school. Participants felt that the information they received on HIV/AIDS from their families and health care professionals was not enough. The school gave them more information to help them to understand their HIV status. The following quotations attest to that:

> *"I am learning a lot of things about HIV/AIDS from school. I ask the teachers more questions about it, 'coz I cannot ask my mother who doesn't know"* (Ace, 15 years, male).

> *"I first heard about HIV/AIDS in school before I even found out about my status"* (Candy, 17 years, female).

> *"I learned about HIV/AIDS for the first time in school when I was in grade 6"* (Gelly, 16 years, female).

> *"You know, some kids don't know that there are children of my age that were born with HIV, they think you get HIV by having sex only. I think teachers need to teach about these things, so that other kids understand this type of HIV"* (Dorah, 17 years, female).

A positive life view has also been reported in previous studies on adolescents living with vertically transmitted HIV/AIDS (Mburu et al. 2013; Baryamutuma & Baingana, 2011; Obare et al. 2010; Birungi et al. 2009). Participants recognised the importance of schooling in achieving a better life and most of the respondents reported that school motivated them to continue with their education and to get involved in school activities. Children between the ages of 6-18 years spend most of their days in school and consequently positively influencing the quality of time in school could greatly increase their wellbeing. Furthermore, schools help to shape cognitive, social, emotional, and behavioural functioning of these children. For children living with HIV infection, school conditions may facilitate or hinder adherence to ART and other interventions (Wollett et al. 2017).

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Sub-Theme 5 Family support

The participants indicated that their immediate family members were their source of support. Family support was highly effective as a coping strategy for the participants.

> *"My grandmother always keeps a reminder of the hospital review dates and she makes sure that I do not miss any appointments"* (Candy, 17 years, female).

> *"I manage to drink my medication everyday because my sister and mother encourage me to take them every day"* (Kevin, 14 years, male).

> *"...she knows that she gave birth to a child who is HIV positive and who is very alone. She is there for me, very supportive and she loves me"* (Gelly, 16 years, female).

> *"They help me with everything at home. My family gives me love and the support I need"* (Fred, 12 years, male).

It also emerged that children who seek or who receive unconditional social support from family members could deal with issues such as stigma and discrimination and other various fears. One participant said:

> *"...my classmates used to make bad comments about my status, laugh at me, tell me I have AIDS... I told my mom what happened, she was very supportive and she told me not to focus on them and they will soon forget about it"* (Brenda, 16 years, female).

Children indicated that the support they received from their families was necessary for them to lead happy lives. They valued the support they received from family. The support that children received ranged from meeting basic needs to financial support. The family paid their school fees and taxi fares to go to the hospital. Four participants (36%) had this to say:

> *"...I have family who love me and they care about me a lot. Sometimes money is a problem at home, but they try to give me what I need"* (Candy, 17 years, female).

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> *"My grandmother is taking care of me. She makes sure I have clothes, food and money and my uncle and his wife also give me money to buy girl's stuff. She is even saving my foster money so that I can go to university" (*Dorah, 17 years, female).

> *"My family gives me money for transport to the clinic when they have it, but sometimes I walk to the clinic if they don't have money"* (Irene, 15 years, female).

Mburu et al. (2014a) also found that family members were a regular source of support especially regarding adherence to treatment. They verbally reminded the children to take treatment and also encouraged them when they were experiencing side effects from the ARV treatment. Participants, in the study, stated that family members frequently accompanied them to clinics to refill their ART and to help them with new routines of taking ARV treatment. They found this support helpful to them. In addition, participants indicated that family support was not limited to the domain of HIV/AIDS; the family supported them on safety-related issues, and gave them emotional support and guidance. They stated the following regarding family support:

> *"My family helps me with everything. They guide and protect me and I always feel safe because I know they are there for me"* (Irene, 15 years, female).

> *"I talk to my sister about everything, and she gives me advice and support in everything"* (Emma, 14 years, female).

Participants recognised the central role their families played in helping them cope with both their illnesses and life in general. Children received love and support from their caregivers, siblings, aunts, uncles and other family members who were staying with them. Four participants (36%) had this to say:

> *"My mom, my sister and my stepfather give me all the support I need and they care and love me and it makes life easier knowing that they care"* (Emma, 14 years, female).

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> *"At home, they treat me the same as others; everyone treats me well and they love me"* (Ace, 15 years, male).

"I feel grateful for the social grant that I get every month and my aunt is a domestic worker. She can't afford everything that we need at home; she tries her best to give us a better life and the social grant really helps us" (Dorah, 17 years, female).

Three participants (27%) stated that their families assisted them to take their ARV treatment and stay healthy. Ace, whose caregiver is also living with HIV infection, describes how he and his mother both remind each other to take their pills and how this has facilitated his adherence to ARV treatment:

> *"We take our pills at the same time so we always remind each other. When she takes hers, she calls me to take mine"* (Ace, 15 years, male).
>
> *"My sister and grandmother always encourage and remind me to drink my medication. They always tell how important it is for me to be healthy and to live longer. I really feel loved and cared for"* (Dorah, 17 years, female).

It also emerged in the study that care and reassurance from caregivers boosts the confidence of these children. Four participants (36%) explained how their families cared for them:

> *"If it wasn't for my parents, I would have died a long time ago. They have taught me to live with my condition and I am happy just like any other child. I will continue following my doctor's advice, and I know I will make it"* (Brenda, 16 years, female).
>
> *"My mother makes sure that I eat meals in good time so that I can drink my medication on time. She cares a lot and she wants me to be happy and healthy"* (Kevin, 14 years, male).
>
> *"...she also makes sure that I do take my medication every day and she reminds me because it is good for my health"* (Fred, 12 years, male).

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This finding concurs with Michaud et al.'s (2010) who found that family members and caregivers are often the ones who remind children to take their ART treatment. For participants in this study, family means having people who loves them unconditionally despite their HIV status, people who understand their illness and support them in everything, from taking treatment to finances and life in general; Family is where they never should hide their illness. Studies by Mellisa and Fullem (2012), in Botswana and South Africa, revealed that the family, in the delivery of HIV/AIDS care, was effective in helping HIV positive children cope and adhere with treatment. The importance of family support was identified by Midtbo et al. (2012) who stated that strong family support improves treatment adherence and coping mechanisms in children living with HIV/AIDS.

In this study participants mentioned the above coping strategies while living with HIV/AIDS. As any incurable medical condition, one needs to develop coping strategies to deal with psychological aspects that came with being HIV positive. However, contrary to the findings in this study, Zanoni (2013) indicated that due to frustration, anger and failure to cope with HIV infection children turn to negative coping strategies and resort to behavioural problem of drug abuse, sexual misconduct, depression and social phobia among others.

4.4 Conclusion

This chapter analysed data collected from selected children living with HIV/AIDS. The themes were explained using direct quotes from the participants. Three main themes were discussed, namely living with HIV/AIDS; challenges of living with HIV/AIDS and coping with HIV/AIDS. The bio-psychosocial model played a major role in understanding how biological, psychological and social factors affect attitudes, reactions and perceptions of children living with vertically transmitted HIV/AIDS. The next chapter draws conclusions, discusses the limitations and makes recommendations of the study.

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CHAPTER 5: CONCLUSION AND RECOMENDATIONS

5.1 Introduction

This chapter presents the summary of the study findings, conclusions, recommendations and limitations of the study. Some limitations have been identified in this study. The psycho-social experiences of children living with vertically transmitted HIV/AIDS have been explored.

5.2 Summary of the study findings

The purpose of the study was to explore the psycho-social experiences of children living with vertically transmitted HIV/AIDS at Messina Hospital, South Africa. Themes that emerged from the study findings were as follows: living with HIV/AIDS infection; challenges of living with HIV/AIDS; and copying with HIV/AIDS.
The findings are summarised below.

5.2.1 Living with HIV/AIDS infection

Participants understood a few facts about HIV/AIDS, for example, how HIV spreads and that HIV is a lifelong disease which is managed through ART treatment. Most children did not understand what was meant by vertically transmitted or perinatal HIV/AIDS, although they were living with the virus. Most participants experienced long-term illness and underwent numerous hospitalisations before the diagnosis was made and also after starting their ART treatment. Being sick affected some of the children in their schooling because they were forced to repeat grades. They failed because they were sick most of the time; they could not attend school regularly and studying was difficult as they were sick.

Participants had difficulty accepting HIV in their lives and they associated living with HIV infection with dying. Even though they recognised that taking ART treatment would prolong their lives, they were still very much aware that they could still die and they were worried and scared of dying. Some children expressed their fear and anxiety about an uncertain future and about finding a future marriage partner who would be willing to accept their HIV positive

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status. Most children indicated that they acknowledged and accepted their HIV positive status despite the challenges that they encounter every day. Although, it was not easy to accept their HIV positive status after disclosure, the children had to accept and learn to live with it.

5.2.2 Challenges of living with HIV/AIDS

Total disclosure remained a challenge to infected children as they found it difficult to disclose their HIV positive status to people outside their families. Their families also encouraged them to be discreet about their status. For most children, their HIV positive status was a secret that was to be guarded and kept to themselves and the family. These children did not struggle with issues around treatment adherence, as no participant had stopped taking their ART treatment. A few of them felt burdened by the daily intake of ART treatment for the rest of their lives. Children complained that being on ART treatment disturbed their personal lives; their interaction with friends at home and at school was affected by ART treatment and it made their lives difficult sometimes.

The study findings indicated that stigma and discrimination against people living with HIV/AIDS are still a challenge in society and, as a result, children living with vertically transmitted HIV/AIDS live in fear of being stigmatised and discriminated against if their status is known by other people outside their families. However, only a few children had experienced acts of stigma and discrimination at school and at home.

5.2.3 Copying with HIV/AIDS

The study found that participants had positive experiences of visiting the wellness clinic regularly and that they enjoyed good relationships with the health professionals. This made the routine clinic visits enjoyable. Participants were provided with safe and supportive health care services which were friendly and confidential. The visits allowed them to receive comprehensive treatment from different professionals such as doctors, nurses, social workers, dieticians and pharmacists.

Participants stated that being a member of a support group was helpful because it enabled them to cope with their challenges and learn more about HIV/AIDS. It gave them a sense of

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belonging, a home where they could be themselves without fear and meet friends from whom they could obtain mutual support and share their experiences. The children enjoyed the activities that they do during their monthly meetings, and indicated that they even forget about their status for a while.

Participants regarded their ARVs positively, recognising that their treatments were an important and beneficial part of their daily lives. This motivated them to live. They hope that, as long as they are taking their ART treatment, they will be well and live longer. Participants explained the role that religion plays in their lives especially in coping with the psycho-social challenges of living with HIV/AIDS. They deal with their challenges and possibly seek help through religion. Participants who felt confident or relaxed about the future spoke about the support they received from family and God. This support helped them to maintain the faith that they would achieve their dreams, thus allowing them to approach the unknown with optimism. The children were hopeful about their future despite the challenges they were experiencing. They had dreams of leading normal lives after finishing school, having meaningful careers and building families of their own. They recognised the importance of schooling towards achieving that better life.

These children have, though limited, a remarkable social support system available to them. Their family members and the support groups that they attend are the only support available to them. Participants described their immediate families as the main source of support, which helped them to cope with the infection and the challenges that they encounter daily. They acknowledged the role that their families played in helping them cope with their illnesses and other aspects of life such as safety, emotional support and guiding them. Family members helped them adhere to their ARV treatment; they cared and supported them, thus boosting their self-esteem and giving them hope to live happy lives.

5.3 Limitations of the study

Firstly, the study was conducted at one regional hospital in Vhembe District, Limpopo Province where children living with vertically transmitted HIV/AIDS are cared for and supported. The study findings cannot be generalised to all hospitals within the province since the contexts are different. The sample size was relatively small; only eleven children

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participated in the study. The researcher used the qualitative approach, thus, the findings cannot be generalised to the larger population.

The age range of 12-17 years was too broad because it included pre-teen and teen-age children whose experiences with HIV/AIDS might differ significantly. However, in depth interview conducted gave an opportunity to probe into the experiences faced by children living with HIV infection.

Lastly, due to ethical challenges associated with speaking to children who have not fully been disclosed to their HIV status, researcher only recruited children who were fully aware of their status and were attending the wellness clinic support group. This may bias the results and may not make them generalised to those who are either not fully disclosed or those who are not attending specialised HIVAIDS clinics regularly.

5.4 Conclusions of the study

Given the purpose of the study, which was to explore the psycho-social experiences of children living with vertically transmitted HIV/AIDS, the study managed to address all the objectives.

- The study discovered that living with HIV/AIDS was not easy for these children and it affected them negatively. HIV/AIDS brought many fears and anxiety associated with death and dying, serious illnesses and hospitalisation. Their school attendance was also affected. Being diagnosed with HIV infection was not easy to accept. However, eventually, these children had to accept and live with it.
- All the children in the study knew their HIV positive status. They encountered various challenges when they found out that they were HIV positive. The children had difficulties disclosing their HIV positive status to people around them. They also had to deal with treatment adherence issues. Stigma and discrimination were major challenges to them.
- Coping with HIV infection was challenging for these children. They employed various coping mechanisms to deal with the challenges. Regular attendance to wellness clinics, adherence to treatment, religion and involvement in school activities

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were some of the mechanisms that helped these children to cope with the HIVAIDS infection and challenges accompanying it. Attending regular support groups helped them to have a sense of belonging. In these groups, they could be themselves without fear and they could share their experiences. The children mentioned family as the most important source of support in the study. It helped them to deal with challenges and enabled them to lead happy lives.

The theoretical framework of this study, the bio-psychosocial model, played a great role in understanding the study. When exploring the experiences of children living with vertically transmitted HIV/AIDS, the researcher looked at the biological, psychological and social factors that had a bearing in the experiences of the participants. The researcher found out that the children had a minimal understanding of the biological functioning of their bodies and that this was one of the reasons why the children still could not fully comprehend what vertically transmitted HIV/AIDS is. They did not fully understand how exactly they were infected and how ART treatment worked in their bodies. The model also helped the researcher to understand that psychological effects of living with HIV/AIDS contributed to fear and anxiety, stigma, non-disclosure and poor adherence. The social context of this model described how social relationships with family, peers and the community affected the children and their attitudes towards the disease. Recommendations are discussed below.

5.5 Recommendations

Based on the findings, the following recommendations are suggested for children living with vertically transmitted HIV/AIDS:

- ❖ It is important that children growing up with HIV/AIDS and who are on ART treatment are fully made aware of the condition they are living with. This can be done by health care providers and teachers at schools by providing them with comprehensive information on HIV/AIDS in order to improve their wellbeing.
- ❖ Families and school teachers should be given knowledge on perinatal HIV/AIDS so that they can understand how to structure their HIV/AIDS education curriculum, be supportive and sensitive to children who are on ART treatment.

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- There is also need to support parents and caregivers by providing them with accurate information on the disclosure process to help children living with HIV infection.
- Children need intensive care and support services that would enhance their positive self, facilitate total self-disclosure and treatment adherence to ART.
- The Department of Education should collaborate with school officials to formulate school policies that would outline measures aimed at discouraging the stigmatisation and discrimination of children living with HIV/AIDS.
- There is also need to educate teachers to deal with stigma and discrimination cases in school.
- The Department of Health should, through awareness campaigns, address stigma and discrimination against children living with vertically transmitted HIV/AIDS in the communities.
- The children, their families and caregivers should be educated on the availability of bio-psychosocial support from different sources, such as school, peers, the community and health care systems.
- There is need for intensive psychological, social, material and spiritual support to help children develop a positive sense of self that is not based on their HIV status.
- For children living with vertically transmitted HIV/AIDS to thrive and achieve their full potential there is a need to develop and implement a multi-sectorial evidence-based intervention program aimed at addressing the full spectrum of their challenges.

5.6 Suggestions for future research

It is recommended that a larger randomly selected sample, covering a larger geographical area, be studied to generalise the findings to a larger population. In addition, these research projects should also consider the inclusion of caregivers, health care providers and teachers to provide a holistic view of the psycho-social experiences of children living with vertically transmitted HIV/AIDS.

As the study focused mainly on children between 12-17 years, future research studies could incorporate older adolescents because their experiences are important especially considering that high risk behaviours are increasingly common in late adolescence. Finally, more research

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studies should focus on specific psycho-social experiences such as stigma and discrimination of children living with HIV/AIDS in rural areas.

5.7 Summary

In this chapter, the findings of the study were summarised in relation to the purpose and objectives of the study. The limitations of the study were discussed and recommendations and suggestions for further research were also made.

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References

Abubakar, A., Van de Vijver, F.J., Fisher, R., Hassan, A.S., Gona, J., Dzombo, J.T., ... & Newton, C.R. (2016). "Everyone has a secret they keep close to their hearts": challenges faced by adolescents living with HIV infection at Kenyan coast. *BMC Public Health, 16(*197). Retrieved from http://doi.org/10.1186/s12889-016-2854-y (accessed on 26 June 2015).

Actuarial Society of South Africa. (2008). *ASSA 2003 and Demographic Model: Summary of provincial HIV and AIDS statistics for South Africa.* Retrieved from www.aids.actuarialsociety.org.za/aids (accessed on 25 May 2015).

Actuarial Society of South Africa. (2011). *ASSA AIDS model 2008.* Retrieved from www.actuarialsociety.org.za/aids (accessed on 24 May 2015).

Adler, A., & Carlson, H.G. (2009). The *Psychology of Stress and Coping*. Oxford: MacMillan Publisher Limited.

Agwu, A.L., & Fairlie, L. (2013). Antiretroviral treatment, management challenges and outcomes in perinatally HIV-infected adolescent. *Journal of International AIDS* Society, *16*(1), 1-13. Retrieved from http://dx.doi.org/10.7448/IAS.16.185789 (accessed on 26 May 2016).

Agrawal, A., Jain, M., Agrawal, S., Singh, S., & Yadav, M. (2015). Psychological Dimension of HIV/AIDS and Recent Advances in Its Management. *The International Journal of Indian Psychology*, 3(3). Retrieved from http://www.ijip.in (accessed on 27 February 2017).

AIDSTAR. (2012). *Transitioning Care and Other Services for Adolescents living with HIV in sub-Sahara Africa*. Arlivington: USAID.

Amberi, A., Woldemicheal, K., Getachew, S., Girm, B., & Deribe, K. (2008). Predictors of adherence to antiretroviral therapy among HIV-infected persons: A prospective study in Southwest Ethiopia. *BMC Public Health, 8*, 265-278.

American Psychological Association. (2002). *Ethical Code of Conduct Document.* Washington DC: APA.

American Psychological Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

© University of Venda

Armstrong, A. Pungula, B., Sobantu, Z., Cheserem, E., & Moshal, K. (2013). The Sexual and Reproductive Health Needs of Adolescents Living with HIV. *HIV Nursing Matters,* 4(1), 26-29.

Amzel, A., Toska, E., Lovich, R., Widyono, M., Patel, T., Foti, C., ... & Altschuler, J. The Child Survival Working Group of the Interagency Task Team on the Prevention and Treatment of HIV-infection in Pregnant women, Mothers and Children. (2013). Promoting a Combination Approach to Paediatric HIV Psychosocial Support. *AIDS Care, 27*(02), S147–S157. Retrieved from http://doi.org/10.1097/QAD.0000000000000098 (accessed on 26 May 2016).

Anthony, D. (2011). *The state of the world's children 2011 adolescence: An age of opportunity.* United Nations Children's Fund (UNICEF).

Atuyambe, L., Neema, S., Otolok-Tanga, E., Wamuyu-Maina, G., Kasasa, S., & Wabwire-Mangen, F. (2008). The effects of enhanced access to antiretroviral therapy: A qualitative study of community perceptions in Kampala city, Uganda. *African Health Sciences, 8,*13-19.

Avert. (2015). *Prevention of Mother-to-Child Transmission (PMTC) of HIV.* Retrieved from www.avert.org/aidssouthafrica (accessed on 25 May 2015).

Aveyard, H. (2014). *Doing a Literature Review in Health and Social Care: A Practical Guide.* United Kingdom: McGraw-Hill Education.

A working group of the Office of AIDS Research Advisory Council (OARAC). (2015). *Guidelines for use of Antiretroviral in Paediatric HIV infection developed by the HHS panel on Antiretroviral Therapy and Medical management of HIV-infected children.* Retieved from http://aidsinfo.nin.gov/guidelines (accessed on 25 May 2016).

Babbie, E. (2010). *The Practice of Social Research* (12th ed.). Belmont: Thomson Wadsworth.

Bakanda, C., Birungi, J., Mwesigwa, R., Nachega, J.B., Chan, K., Palmer, A., ... & Mills, E.J. (2011). Survival of HIV-infected adolescents on antiretroviral therapy in Uganda: Findings from a nationally representative cohort in Uganda. *PLoS ONE, 6*(4), 19261-6.

Barbour, R. (2013). *Introducing Qualitative Research*: *A Student's Guide* (2nd ed.). London: Sage.

Barua, A., Sharma, Y., & Basalio, M.A. (2013). Burning issue of HIV/AIDS: A Psychosocial Study. *International Journal of Collaborative Research on Internal Medicine & Public Health (IJCRIMPH), 5*(7), 545-551.

© University of Venda

Baryamutuma, R., & Baingana, F. (2011). Sexual Reproductive Health Needs of Young People with Perinatally Acquired HIV in Uganda. *African Health Sciences, 11*(2), 211-218. http://www.ncbi.nim.nin.gov./pmc/articles/PMC3158520 (accessed on 24 May 2016).

Bernays, S., Seeley, J., Rhodes, T., & Mupambireyi, Z. (2015). What am I “living’’ with? Growing up with HIV in Uganda and Zimbabwe. *Sociology of Health & Illness*, *37*(2), 270-283.

Betancourt, T.S., Ng, L.C., Kirk, C.M., Munyanah, M., Mushashi, C., Ingabire, C., ... & Sezibera, V. (2014). Family-based prevention of mental health problems in children affected by HIV/AIDS: an open trial. *AIDS Care, 28*(3), 359-368.

Beyeza-Kashesya, J., Kaharuza, F., Eskstrom, A.M., Neema, S., Kulane, A., & Mirembe, F. (2011). To use or not to use a condom: A prospective cohort study comparing contraceptive practices among HIV-infected and HIV-negative youth in Uganda. *BMC Infectious Diseases, 11*(1), 144-159.

Bilson, A., & Westwood, J.L. (2012). *Making Social Work Work: Improving Social Work for Vulnerable Families and Children Without Parental Care Around the World:* A Literature Review. London: Routledge. Retrieved from http://www.everychild.orguk/docs/makingsocialworkwork.pdf (accessed on 13 June 2015).

Bing, E.G., Burnam, M., & Longshore, D. (2001). Psychiatric disorders and drug use among Human Immunodeficiency Virus-infected Adults in the United States. *Achieves of General Psychiatry*, *58*, 721-728.

Birungi, H., Obare, F., Mugisha, J.F., Evelia, H., & Nyombi, J. (2009). Preventive Service Needs of Young People Perinatally Infected with HIV in Uganda. *AIDS Care, 21*(6), 725-731.

Bless, C., Higston-Smith, C., & Kagee, A. (2006). *Fundamentals of Social Research Methods*: *An African Perspective* (4th ed.). Cape Town: Juta and Company Ltd.

Braun, V. & Clarke, V. (2013). Teaching Thematic Analysis. Overcoming challenges and developing strategies for effective learning. *The Psychologist, 26*(2), 120-123.

Breuer, E., Myer, L., Struthers, H., & Joska, A. (2011). HIV/AIDS and Mental Health Research in sub-Saharan Africa: A systematic review. *African Journal of AIDS Research, 10*(1), 101-122.

© University of Venda

Brown, L.K., Lourie, K.L., & Pao, M.J. (2000). Children and Adolescent living with HIV and AIDS: a review. *Journal of Child Psychology and Psychiatry*, and Allied Disciplines, *41*(1), 87-96.

Brown, J.B., Oladokun, R.E., Osinusi, K., Ochigbo, S., Adewole, I.F., & Kanki, P. (2011). Disclosure of HIV status to infected children in a Nigerian HIV care programme. *AIDS Care, 23*(9), 1053-1058.

Bryman, A. (2012). *Social Research Methods* (2nd ed.). Chicago: Policy Press.

Burns, N., & Grove, S.K. (2010). *Understanding Nursing Research: Building Evidence-Based Practice* (6th ed.). ST Louis, Missouri: Elsevier Health Sciences.

Busza, J., Besana, G.V., Mapunda, P., & Oliveras, E. (2013). "I have grown up controlling myself a lot." Fear and misconceptions about sex among adolescents vertically-infected with HIV in Tanzania. *Reproductive Health Matters*, *21*(41), 87-96.

Bygrave, H., Mtangirwa, J., Ncube, K., Ford, N., Kranzer, K., & Munyaradzi, D. (2012). Antiretroviral therapy outcomes among adolescents and youth in rural Zimbabwe. *PLoS ONE, 7*(12), e52856. Retrieved from http://dx.doi.org/10.1371/journal.pone.0052856 (accessed on 15 June 2015).

Campbell, C., Skovdal, M., Madanhire, C., Mugurungi, O., Gregson, S., & Nyamukapa, C. (2011) 'We, the AIDS people…': How antiretroviral therapy enables Zimbabweans living with HIV/AIDS to cope with stigma. *American Journal of Public Health, 101*(6), 1004-1010.

Campbell, C., Skovdal, M., and Gibbs, A. (2011). "Creating social spaces to tackle AIDS-related stigma: Reviewing the role of church groups in Sub-Saharan Africa". *AIDS & Behaviour*, *15*(6), 1204-1219.

Campbell, T., Griffiths, J., Beer, H., Legemah, P., & Saine, M. (2014). HIV+ children and their families in the UK: Results from a family-clinic based 'look-back' exercise in London. *Perspectives in Public Health*, *134*(1), 31-37.

Carducci, B. (2009). *The Psychology of Personality: Viewpoints, Research and Applications* (2nd ed.). Maldan MA: John Wiley & Sons.

Cataldo, F., Malunga, A., Rusakaniko, S., Umar, E., Teles, N., & Musandu, H. (2012). Experiences and challenges in sexual and reproductive health for adolescents living with HIV in Malawi, Mozambique, Zambia and Zimbabwe. *XIX International AIDS Conference. Dignitas International AIDS*, Washington DC, July 2012.

© University of Venda

Cataldo, F., Haamujompa, C., Hodgson, I., Kalibala, S., Lowenthal, E.D., Mburu, G., & Ross, D. (2014). Adolescent HIV disclosure in Zambia: barriers, facilitators, outcomes. *International HIV Society, 17*(91), 101.

Chandwani, S., Koenig, L.J., Sill, A.M., Abramowitz, S., Conner, L.C., & D'angelo, L. (2012). Predictors of antiretroviral medication adherence among a diverse cohort of adolescents with HIV. *The Journal of Adolescent Health, 51*, 242-251.

Coetzee, M., & Spangenberg, J. (2003). Coping styles and quality of life in people with HIV/AIDS: A review. *Acta Academica, 35*(3), 205-222.

Cowles, L.A.F. (2012). *Social Work in the Health Field: A Care Perspective.* (2nd ed.). New York: The Haworth Press.

Children's Act No. 38, (2005). Vol 492, No. 28944. Cape Town: Republic of South Africa. Retrieved from http://www.gov.za/sites/www.gov.za/filesa3805.3.pdf (accessed on 26 May 2016).

Chearskul, P., Chokephaibulkit, K., Chearskul, S., Phongsamart, W., Plipat, N., Lapphra, K., & Vanprapar, N. (2005). "Effect of antiretroviral therapy in human immunodeficiency virus-infected children." *Journal of Medicine Association Thai, 88*(8), 221-231.

Close, K.L., & Rigamonti, A.X. (2006). *Psychosocial aspects of HIV/AIDS: Children and adolescents.* HIV Curriculum for Health Professionals. Baylor International, Paediatric AIDS Initiative.

Cluver, L.D., & Orkin, M. (2009). Stigma, Bulling, Poverty, and Aids Orphanhood: Interactions meditating psychological problems for children in South Africa. *Social Sciences Medicine. 69*(8), 1186-1193.

Cohen, L., Manion, L., & Morrison, K. (2013). *Research Methods in Education* (5th ed.). London: Routledge Falmer.

Creswell, J.W. (2014). *A Concise Introduction to Mixed Methods Research*. London: Sage.

Creswell, J.W. (2013). *Research Design*: Qualitative, Quantitative, and Mixed Methods Approaches (4th ed.). Thousand Oaks CA: Sage.

Creswell, J.W. (2007). *Qualitative Inquiry and Research design: Choosing Among Five Traditions* (4th ed.). Thousand Oaks CA: Sage.

Das, S., & Leibowitz, G.S. (2010). Mental health needs of people living with HIV/AIDS in India: A literature review. *AIDS care*, *5*(1), 1-9.

© University of Venda

De Vaus, D. (2001). *Research Design in Social Research*. London: Sage.

De Vos, A.S., Strydom, H., Fouche', C.B., & Delport, C.S.L. (2011). *Research at Grass Roots: For the Social Science and Human Service Professions* (2nd ed.). Pretoria: Van Schaik.

Demmer, C. (2014). AIDS and Bereavement in South Africa. *Social Work/ Maatskaplike Werk. 40*(3), 294-315.

Denzin, N.K., & Lincoln, Y.S. (1994). *Handbook of Qualitative Research* (4th ed.). Thousand Oaks CA: Sage.

Doga, A.I. (2007). *Bio-psychosocial Model*. Faisalabad: Funjab Medical Collection.

Doka, K.J. (Ed). (2013). *Living with Grief: Children, Adolescents and Loss*. United States of America: Routlege.

Dollfus, C., Le Chenadec, J., Faye, A., Blanche, S., Briand, N., Rouzioux, C., & Warszawski, J. (2010). Long-term outcomes in adolescents perinatally infected with HIV-1 and follow up since birth in the French perinatal cohort. *Clinical Infectious Diseases, 51*(2), 214-224.

dos Santos, M.M., Kruger, P., Mellors, S.E., Wolvaardt, G., & van der Ryst, E. (2014). An exploratory survey measuring stigma and discrimination experienced by people living with HIV/AIDS in South Africa: People living with HIV stigma index. *BMC Public Health, 14*(1), 1-8.

Dorrell, J., Earle, S., Katz, J., & Reveley, S. (2008). Growing up with HIV: The experiences of young people living with HIV since birth in the UK. *Death and Dying: A Reader*, 237-244.

Dreyfuss, M.L., & Fawzi, W.W. (2002). Micronutrients and vertical transmission of HIV-1. *The American Journal of Clinical Nutrients*, *75*(6), 959-970.

Eley, B., Kibel, M., Lake, L., Pendlebury, S., & Smith, C. (2010). *HIV, TB and Child Health in South African Child Gauge 2009/2010*. Cape Town: Children's Institute, University of Cape Town.

Eller, L.S., Rivero-Mendez, M., Voss, J., Chen, W.T., Chaiphibalsarisdi, P., Lipinge, S., & Brion, J.M. (2014). Depressive symptoms, Self-esteem, HIV symptom management self-efficacy and Self-compassion in people living with HIV. *AIDS Care*, *26*(7), 795–803.

Eiser, C., & Jenny, M. (1994). Social support in chronically sick children and their families, Social networks & social supports in childhood & adolescence. *AIDS Care, 4*(1), 347-359.

Elise, A., France, A.M., Bata, D., Branncois, R., & Rogers, S. (2005). Assessments of adherence to highly active antiretroviral therapy in a cohort of African HIV infected

© University of Venda

children in Abidjan,Cote d' Ivoire. *Journal of Acquired Immune Deficiency Syndrome, 40*(4), 498-500.

Engler, B. (2014). *Personality Theories* (9th ed.). United States of America: John David Hague, Nelson Education.

Esterberg, K.G. (2002). *Qualitative Methods in Social Research.* Boston: McGraw Hill.

Fabianova, L. (2011). Psychosocial aspects of people living with HIV/AIDS. In G. Letamo (Ed.), *Social and Psychological Aspects of HIV/AIDS and their Ramifications*. InTech. Retrieved from http://www.intechopen.com/books/social-and-psychological-aspects-of-hiv-aids-and-their-ramifications/psychosocial-aspects-of-people-living-with-hiv-aids (accessed on 9 February 2017).

Fair, C., Albright, J. (2012). "Don't tell him you have HIV unless he's 'the one'": romantic relationships among adolescents and young adults with perinatal HIV infection. *AIDS Patient Care STDs, 26*(12), 746-754.

Falvo, D. (2014). *Medical and Psychological Aspects of Chronic Illness and Disability* (5th ed.). Burlington: Jones and Barlett.

Ferrand, R.A., Lowe, S., Whande, B., Munaiwa, L., Langhaug, L., Cowan, F., ... & Corbett, E.L. (2010). Survey of children accessing HIV services in a high prevalence setting: Time for adolescents to count? *Bulletin for the World Health Organization, 88*(6), 428-434.

Ferrand, R.A., Corbett, E.L., Wood, R., Hargrove, J., Cowan, F., Gouws, E., ... & Ndhlovu, C.E. (2009). AIDS among older children and adolescents in Southern Africa: Projecting the time course and magnitude of the epidemic. *AIDS Care, 23*, 2039-2046.

Fielden, S.J., Chapman, G.E., & Cadell, S. (2011). Managing stigma in adolescent HIV, silence, secrets and sanctioned spaces. *Culture Health Sexuality*, *13*(3), 267-281.

Fitzpatrick. J.J., & Kazer, M. (2011). *Encyclopaedia of Nursing Research*. United States of America: Springer.

Flick, U. (2014). *The Sage Handbook of Qualitative Data Analysis*. London: Sage.

Foster, G., & Williamson, J. (2000). A review of current literature of the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS, 14*(3), 275-284.

Gast, L.D., & Ledford R.J. (2014). *Single Case Research Methodology: Application in Special Education and Behavioural Sciences* (2nd ed.). New York, NY: Routledge.

Gray, D. (2014). *Doing Research in the Real World* (3rd ed.). London: Sage.

© University of Venda

Gray, G. E. (2009). Adolescent HIV- Cause for Concern In South Africa. *Plos Medicine*, 7 (2). Retrieved from http://www.plosmedicine.org/article/info%/3Adoi%2f10.137%fJournal.Pmed.1000227 (accessed on 24 May 2016).

Gonzalez, J.S., Batchelder, A.W., Psaros, C., & Safren, S.A. (2011). Depression and HIV/AIDS Treatment Non-adherence: a Review and Meta-analysis. *Journal of Acquired Immune Deficiency Syndromes, 58,* 181-187.

Gupta, R., Shringi, S., Mahajan, V., Venkatesh, G., & Srivastava, K. (2015). A study of psychological impact of diagnosis of HIV in Children and Adolescents in Indian population*:* HIV/AIDS Research and Treatment. *Open Journal, 1*(1), 16-20.

Habib, T.Z., & Ranman, M.S. (2010). Psycho-social aspects of Aids as chronic illness: Social Worker role perspective. *Anthrocom fisica, 6*(1), 79-89.

Harma, M., Ross, M.W., Orrs, M., & D'Agostino, A. (2006). Relationship between expressed HIV/AIDS related stigma and HIV believed knowledge and behaviours in families of HIV infected in Kenya. *Tropical Medicine and International Health, 11*(4), 513-527.

Hazra, R., Siberry, G.K., & Mofenson, L.M. (2010). Growing up with HIV: Children, adolescents, and young adults with perinatally acquired HIV infection. *Annual Review of Medicine, 61*, 168-185.

Heath, M.A., Donald, D.R., Theron, L.C., & Lyon, L.C. (2014). Aids in South Africa: Therapeutic Intervention to strengthen resilience among Orphans and Vulnerable Children. *School Psychology International, 35*(3), 309-337.

Heeren, G.A., Jemmott III, J.B., Sidloyi, L., Ngwane, Z., & Tyler, J.C. (2012). Disclosure of HIV-infected Children in South Africa: Focus groups for intervention development. *Vulnerable Children and Youth Studies*, *7*(1), 47-54.

Hesse-Biber, S.N.H., & Leavy, P. (2011). *The Practice of Qualitative Research* (2nd ed.). London: Sage.

Herbert, J., & Rubin, I.S. (2012). *Qualitative Interviewing: The Art of Hearing Data* (3rd ed.). London: Sage.

Heymann, J., Sherr, L., & Kidman, R. (2012). *Protecting Childhood in AIDS Pandemic: Finding Solutions that Work.* New York, NY: Oxford University Press.

© University of Venda

Hill, A. (2012). *Teenagers born with HIV tell of life under society's rador: HIV positive youngsters who were infected before or at birth reveal their secret lives*. Sunday 11 March 2012. Retrieved from http://www.guadian.co.uk (accessed on 23 May 2016).

Hodgson, I., Ross, J., Haamujompa, C., & Gitau-Mburu, G. (2012). Living as an adolescent with HIV in Zambia lived experiences, Sexual Health and Reproductive Needs. *AIDS Care, 24*(10), 1204-1210.

Hogwood, J., Campbell, T., & Butler, S. (2012). I wish I could tell you but I can't: Adolescents with perinatally acquired HIV and their dilemmas around self-disclosure. *Clinical Child Psychology and Psychiatry, 1*(12), 1-17.

Holloway, I., & Wheeler, S. (2013). *Qualitative Research in Nursing and Healthcare* (3rd ed.). Malaysia: John Wiley & Sons.

Hysing, M., Elgen, I., Gillberg, C., Lie, S.A., & Lundervold, A.J. (2007). Chronic Physical illness and mental health in children. Results from a large-scale population study. *Journal of Children Psychology Psychiatry*, *48*(8), 785-792.

Ikiugu, M.N., & Ciaravino, E.A. (2007). *Psychosocial Conceptual Practice in Occupational Therapy: Building Adaptive Capacity*. St Louis Missouri: Mosby Elsevier.

Islam, M.S., Scott, J., & Minichiello, V. (2014). Children Living in HIV Families: A review. *Journal of Child and Adolescent Behaviour*, *2*(170), 2375-4494.

Jehangir, S. (2013). *The AIDS epidemic and sociological enquiry*. Srinagar, Jay Kay books.

Johnson, L.F., Dorrington, R.E., Moolla, H. (2017a). Progress towards the 2020 targets for HIV diagnosis and antiretroviral treatment in South Africa. *South Africa Journal of HIV Medicine*. 18(1), 694. Retrieved from https://doi.org/10.4102/sajhivmed.v18i1.694 (accessed on 27 June 2018).

Johnson, L.F., Dorrington, R.E., Moolla, H. (2017b). HIV Epidemic Drivers in South Africa: A model-based evaluation of factors accounting for inter-provincial differences in HIV prevalence and incidence trends. *South African Journal of HIV Medicine*. 18(1), 695. Retrieved from https://doi.org/10.4102/sajhivmed.v18i1.695 (accessed on 27 June 2018).

John-Stewart, G.C., Wariua, G., Beima-Sofie, M., Richardson, C.F., Farquhar, C., Maleche-Obimbo, A., ... & Wamalwa, D. (2012). Prevalence, perceptions and correlates of paediatric HIV disclosure in an HIV treatment program in Kenya. *AIDS Care, 25*(9), 1067-1076.

© University of Venda

Joint United Nations Programme on HIV/AIDS (UNAIDS) (2014). 90-90-90. An ambitious treatment target to help end the AIDS epidemic. Retrieved from http://www.unaids.org/sites/default/files/media_asset/90-90-90en0.pdf (accessed on 5 April 2015).

Joint United Nations Program on AIDS (UNAIDS) 2016. Children and HIV. Facts HIV. Retrieved from http://www.unaids.org/sites/default/files/media_asset/FactSheetChildrenen.pdf (accessed on 27 June 2018).

Judgeo, N., & Moalusi, K.P. (2014). My secret: The social meaning of HIV/AIDS stigma. *SAHARA- J, 11*(1), 76-83.

Kagee, A., & Delport, T. (2010). Barriers to Adherence to Antiretroviral Treatment: The Perspectives of Patient Advocates. *Journal of Health Psychology, 15*(7), 1001-1011.

Kamau, J.W., Kuria, W., Mathai, M., Atwoli, L., & Kangethe, R. (2012). Psychiatric morbidity among HIV-infected children and adolescents in a resource-poor Kenyan urban community. *AIDS Care, 24*(7), 836-842.

Kheswa, G. (2014). Exploring HIV and AIDS Stigmatisation: Children's Perspectives. *Mediterranean Journal of Social Sciences, 5*(15), 529-545.

Kidia, K.K., Mupambireyi, Z., Cluver, L., Ndhlovu, C.E., Borok, M., & Ferrand, R.A. (2014). HIV status disclosure to perinanatally-infected adolescents in Zimbabwe: A qualitative study of adolescent and health worker perspective. *PLos one*, *9*(1), 0087322. Retrieved from https://doi.org/10.1371/journal.pone.0087322 (accessed on 25 May 2017).

Kim, M. H., Mazenga, A. C., Yu, X., Ahmed, S., Paul, M. E., Kazembe, P. N., & Abrams, E. J. (2017). High self-reported non-adherence to antiretroviral therapy amongst adolescents living with HIV in Malawi: barriers and associated factors. *Journal of the International AIDS Society*, *20*(1), 21437. Retrieved from http://doi.org/10.7448/IAS.20.1.21437 (accessed on 27 June 2018).

Koka, E., Ahorlu, C.K., & Agyeman, D.K. (2013). Social Death through HIV and AIDS Stigmatization and Discrimination in Ghana: A Case Study of the Central Regional Hospital, Cape Coast, Ghana. *Advances in Applied Sociology, 3*(6), 231-256.

Kolb, D.A. (2014). *Experiential Learning: Experience as the Source of Learning and Development* (2nd ed.). Australia: Pearson Education Inc.

© University of Venda

Kotze, M., Visser, M., Makin, J., Sikkena, K., & Forstyn, B. (2012). Psychosocial variables associated with coping of HIV- positive women diagnosed during pregnancy. *AIDS and Behaviour*, *17*(2), 498-507.

Lane, R.E. (2000). Diminishing returns to income, companionship and happiness. *Journal of Happiness Studies*, *1*(1), 103-109.

Lawan, U.M., Amole, G.T., Jahun, M.G.G., & Abute, J.E. (2015). Psychosocial challenges and adhere to antiretroviral therapy among HIV-positive adolescent attending an ART centre in Kano, north western Nigeria. *International Journal of Medicine Science and Public Health, 4*(10), 1439-1444.

Lazarus, R.S., & Folkman, S. (1984). *Stress, Appraisal and Coping.* New York, NY: Springer.

Levine, L.E., & Munsch, J. (2010). *Child Development: An Active Learning Approach.* London: Sage.

Li, R.J., Jaspan, H.B., O'Brien, V., Rabie, H., Cotton, M.F., & Nattrass, N. (2010). Positive futures: A qualitative study on the needs of adolescents on antiretroviral therapy in South Africa. *AIDS Care, 22*(6), 751-758.

Liamputtong, P., Haritavorn, N., & Kiatying-Angsulee, N. (2012). "Living Positively: The experiences of Thai women living with HIV/AIDS in central Thailand". *Qualitative Health Research*, *22*(4), 441-451.

Lincoln, Y.S., & Guba E.G. (2012). *Naturalistic Inquiry*. Beverly Hills CA: Sage.

Lipshultz, S.E., Miller, T.L., Wilkinson, J.D., Scott, G.B., Somarriba, G., Cochran, T.R., & Fisher, S.D. (2013). Cardiac Effects in Perinatally HIV infected and HIV exposed but uninfected children and adolescents: A view from the United States of America. *Journal for International Aids Society, 16*(1), 1-19.

Maddi, S.R. (1989). *Personality Theories: A Comparative Analysis.* Thousand Oaks CA: Dorsey Press.

Madiba, S. (2012). Disclosing HIV to Infected Children in South Africa in the Era of HAART: A Grounded Theory Study on the Process, Reasons and Outcomes of Disclosure. *World Journal of AIDS, 2*, 319-329.

Mapupye, E.M., Suleman, F., & Govender, T. (2015). Investigating extemporaneous compounding practices in Polokwane tertiary hospital pharmacies in South Africa-a pilot study. *African Journal of Pharmacology, 9*(48), 1099-1105.

© University of Venda

Martinez, J., Harper, G., Carleton, R.A., Hosek, S., Bojan, K., Glum, G., Ellen, J., & the Adolescent Medicine Trials Network. (2012). The impact of stigma on medication adherence among HIV positive adolescent and young adult females and the moderating effects of coping and satisfaction with health care. *AIDS Patient Care and STDs, 26*(2), 108-115.

Martinazzo, A.G., Sousa, T.T.R., Harrad, D.I., de Brito Almeida, A. Moraes, J.A., da Silveira Rossi, A., ... & Hallal, R. (2013). Recommendations for Integral Care for Adolescents and Young Adults Living with HIV/AIDS, Ministry of Health in Brazil.

Mauthner, T., Birch, T., Miller, M., & Jessop, J. (2012). Conclusion: navigating ethical dilemmas and new digital horizons. *Ethics in Qualitative Research*. Thousand Oaks CA: Sage.

Mavhu, W., Berwick, J., Chirawa, P., Makamba, M., Copas, A., Dirawo, J., ... & Cowan, F.M. (2013). Enhancing Psychosocial Support for HIV positive adolescent in Harare, Zimbabwe. *PLoS One*, *8*(7), 702554-70270.

Maxwell, J.A. (2012). *Qualitative Research Design: An Interactive Approach* (3rd ed.). Washington DC: Sage.

Mellins, C.A., & Malee, K.M. (2013). Understanding the mental health of youth living with perinatal HIV infection: Lessons learned and current challenges. *Journal of International AIDS Society, 16*(1), 1-3.

Mburu, G., Ram, M., Oxenham, D., Haamujompa, C., Lorpenda, K. & Ferguson, L. (2014a). Responding to adolescent living with HIV in Zambia: a social ecological approach. *Children and Youth Services Review*, *45*, 9-17.

Mburu, G., Hodgson, I., Kalibala, S., Haamujompa, C., Cataldo, F., Lowenthal, E. D. & Ross, D. (2014b). Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes. *Journal of the International AIDS Society*, *17*(1), 18866-18710.

Mburu, G., Hodgson, I., Teltschik, A., Ram, M., & Haamujompa, C. (2013). Rights-based services for adolescents living with HIV: adolescent self-efficacy and implications for health systems in Zambia. *Reproductive Health Matters, 21*(41), 176-185.

McCleary-Sills, J., Kanesathasan, A., Brakarsh, J., Vujovic, M., Dlamini, K., Namisango, E., ... & Bowsky, S.R.N. (2013). Foundation for the future: meeting the psychosocial needs of children living with HIV in South Africa and Uganda. *Journal of HIV/AIDS & Social Services, 12*(1), 49-62.

Melissa, S., & Fullem, A. (2012). *Transitioning of care and other services for adolescents living with HIV in Sub-Saharan Africa*. Arlington, VA: USAID's AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1.

Midtbo, V., Shirima, V., Skovdal, M., & Daniel, M. (2012). How disclosure and antiretroviral therapy help HIV- infected adolescent in sub-Saharan Africa cope with stigma. *African Journal of AIDS Research*, *11*(3), 261-271.

Mitchell, C., Richter, L., & Rochat, T. (2015). *The psychological, social and development needs of babies and young children and their caregivers living with HIV and AIDS.* (Commissioned by the National Department of Health (Maternal, Child and Women's Health and Nutrition Cluster) and supported by UNICEF). Retrieved from http://hdl.handle.net/123456789/5081 (accessed on 10 February 2016).

Michaud, P., Suris, J., Thomas, R., Gnehm, H., Cheseaux, J., & MoCHIV. (2010). Coping with an HIV Infection. *Swiss Medicine Weekly, 140*(17-18), 247-253.

Miller, T., Birch, T., Mauthner, M. & Jessop, J. (2012). *Ethics in Qualitative Research* (2nd ed.). London: Sage.

Morobadi, M.D. & Webber, L.M. (2014). Growing up with HIV in Southern Africa HIV-Infected children and adolescents. *Journal of Human Virology Retrovirology (JHVRV), 1*(1), 1-6.

Mothi, S.N., Swamy, V.H.T., Lala, M.M., Karpagam, S. & Gangakhedkar, R.R. (2012). Adolescents living with HIV in India- the clock is ticking. *The Indian Journal of Paediatrics*, *79*(12), 1642-1647.

Mupambireyi, Z., Bernays, S., Bwakura-Dangerembizi, M., & Cowan, F. M. (2014). "I don't feel shy because I will be along others who are just like me....": The role of support groups for children perinatally infected with HIV in Zimbabwe. *Children and Youth Services Review*, *45*, 106-113.

Musina Local Municipality. (2014/2015). *Review Integrated Development Plan.* Compiled by Municipal Manager Office.

Mutumba, M., Bauermeister, J.A., Harper, G.W., Musiime, V., Lepkowski, J., Resnicow, K., & Snow, R.C. (2017). Psychological distress among Ugandan adolescents living with HIV: Examining stressors and the buffering role of general and religious coping strategies. *Global Public Health*, 12(12), 1479-1491.

Mutwa, P.R., Van Nuil, J.I., Asiimwe-Kateera, B., Kestelyn, E., Vyankandondera, J., Pool, R., ... & Boer, K.R. (2013). Living situation affects adherence to combination

© University of Venda

antiretroviral therapy in HIV-infected adolescents in Rwanda: a qualitative study. *PLoS One, 8*(4), e60073. Retrieved from https://doi.org/10.1371/journal.pone.0060073 (accessed on 23 June 2016).

Mwoma, T. & Pillay, J. (2015). Psychosocial supports for orphans and vulnerable children in public primary school: Challenges and intervention strategies. *South African Journal of Education*, *35*(3), 1-9.

National Department of Health. (2010). *National antenatal sentinel HIV and Syphilis Prevalence Survey*, South Africa.

Nachega, J., Leisegang, R., & Bishau, D. (2010). Association of antiretroviral therapy adherence and health care costs. *Annals of Internal Medicines, 152*(4), 18-25.

Nakimuli-Mpungu, E., Musisi, S., Katabira, E., Nachega, J., & Bass, J. (2011). Prevalence and factors associated with depressive disorders in an HIV+ rural patient population in southern Uganda. *Journal of Affect Disorder, 135*(13), 160-167.

Nakimuli-Mpungu, E., Bass, J., & Alexandre, P. (2011). Depression, alcohol use and adherence to antiretroviral therapy in Sub-Saharan Africa: a systematic review. *AIDS and Behaviour, 16*(1), 2101-2118.

Nakimuli-Mpungu, E., Musisi, S., Katabira, E., Nachega, J., Bass, J. (2011). Prevalence and factors associated with depressive disorders in an HIV+ rural patient population in Southern Uganda. Journal of Affect Disorder, *135*(13), 160-167.

Neuman, W.L. (2011). *Social Research Methods: Qualitative and Quantitative Approaches* (7th ed.). Boston: Pearson.

New, M.J., Lee, S.S., & Elliott, B.M. (2007). Psychological adjustment in children and families living with HIV. *Journal of Paediatric Psychology, 32*(2), 123-133.

Nglazi, M.D., Kranzer, K., Holele, P., Kaplan, R., Mark, D., Jaspan, H., ... & Bekker, L. (2012). Treatment outcomes of HIV-infected adolescents attending a community-based antiretroviral clinic in South Africa. *BMC Infectious Disease, 12*(21). Retrieved from http://doi.org/10.1186/1471-2334-12-21 (accessed on 13 December 2016).

Obare, F., Van der Kwaak, A., Adieri, B., & Owuor, D. (2010). *HIV-positive adolescents in Kenya: Access to sexual and reproductive health services*. Amsterdam: KIT Publishers.

Obare F, Birungi H. (2010). The limited effect of knowing they are HIV-positive on the sexual and reproductive experiences and intentions of infected adolescents in Uganda. *Population Studies, 64*(1), 97-104.

© University of Venda

Obiakor, F.E., Bakken, J.P., & Rotatori, A.F. (Eds.). (2010). *Current Issues and Trends in Special Education: Research, Technology, and Teacher Preparation: Research, Advances in Special Education* (Vol. 20). Bingley UK: Emerald Group.

Ogden, J. (2000). *Health Psychology: A Textbook* (2nd ed.). Philadelphia: Open University Press.

Orne-Gliemann, J., Becquet, R., Ekouvei, D.K., Leroy, V., Perez, F., & Dabis, F. (2008). Children and HIV/AIDS: from research to policy and action in resource-limited settings. *AIDS Care, 22*(7), 797-805.

Park, J. & Nachman, S. (2010). The Link Between Religion and HAART Adherence in Paediatric HIV Patients. *AIDS Care, 22*, 556-561.

Patton, M.Q. (2015). *Qualitative Research and Evaluation Methods: Integrating Theory and Practice* (4th ed.). Thousand Oaks CA: Sage.

Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., ... & Mellins, C. (2010). Psychosocial challenges and protective influence for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation. *AIDS Care*, *22*(8), 970-978.

Pienaar, L., & Visser, M.J. (2011). An exploration of the experiences of adolescents living with HIV. *Vulnerable Children and Youth Studies, 7*(1), 66-74.

Pinho, C.M., Damaso, B.F.R., Gomes, E.T., Trajano, M.F.C., Andrade, M.S., & Valena, M.P. (2017). Religious and spiritual coping in people living with HIV/AIDS. *Rev Bras Enferm,* 70(2), 392-399. Retrieved from http://dx.doi.org/10.1590/0034-7167-2015-0170 (accessed on 03 July 2018).

Polit, D.F., & Beck, C.T. (2008). *Nursing Research: Generating and Assessing Evidence of Nursing Practice* (8th ed.). China: Lipponcott Williams and Wilkins.

Proudlock, P., & Jamieson, L. (2008). The Children's Act: Providing a strong legislative foundation for a developmental approach to child care and protection. *South African Child Gauge*, 35-40.

Punch, K.F. (2013). *Introduction to Social Research: Quantitative and Qualitative Approaches* (3rd ed.). London: Sage.

Ramaiya, M.K., Sullivan, K.A., O' Donnell, K., Cunningham, C.K., Shayo, A.M., & Mmbaga, B.T. (2016). A Qualitative Exploration of the Mental Health and Psychosocial Contexts of HIV-Positive Adolescents in Tanzania. *PLoS ONE*, *11*(11): e0165936. Retrieved from https://doi.org/10.1371/journal.pone.0165936 (accessed on 26 June 2015).

© University of Venda

Richter, L., Beyrer, C., Kippax, S., & Heidari, S. (2010). Visioning services for children affected by HIV and AIDS through a family lens. *Journal of the International AIDS Society*, *13*(2), 1-12.

Ritchie, J., Lewis, J., Nicholls, C.M.C., & Ormston, R. (2014). *Qualitative Research Practice: A Guide for Social Science Students & Researchers*. Los Angeles: Sage.

Roberts, K.J. (2005). Barriers to antiretroviral medication adherence in youth HIV infected children. *Youth & Society, 37*(2), 230-245.

Rochat, T.J., Mkwanazi, N., & Bland, R. (2013). Maternal HIV disclosure to HIV-uninfected children in rural South Africa: a pilot study of family-based intervention. *BMC Public Health*. *13*(1), 1-18.

Ross, E., & Deverell, A. (2010). Health, Illness and Disability: Psychosocial Approaches (2nd ed.). Pretoria: Van Schaik.

Rubin, A., & Barbie, E. (2011). *Research Methods for Social Work* (7th ed.). Belmont: Cengage Learning.

Rubin, H., J., & Herbert, I.S. (2011). *Qualitative Interviewing: The Art of Hearing Data* (7th ed.). Belmont: Sage.

Russell, S., and Seeley, J. (2010). “The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy”. *Social Science & Medicine*, 70(3), 375-382.

Santamaria, E.K., Dolezal, C., Marhefka, S.L., Hoffman, S., Ahmed, Y., Elkington, K., & Mellins, C.A. (2011). Psychosocial implications of HIV serostatus disclosure to youth with perinatally acquired HIV. *AIDS Patient Care and STDs*, *25*(4), 257-264.

Sapsford, R., & Jupp, V. (Eds). (2006). *Data Collection and Analysis* (2nd ed.). London: Sage.

Sarantakos, S. (2012). *Social Research* (4th ed.). New York: Palgrave Macmillan.

Seidman, I. (2013). *Interviewing as Qualitative Research: A Guide for Researchers in Education and Social Sciences* (4th ed.). New York: Teachers College Press.

Schweitzer, A.M., Mizwa, M.B. & Ross, M.W. (2010). Psychosocial Aspects of HIV/AIDS Adults. *Baylor International Paediatric AIDS Initiative*, 334-349.

Sherr, L., Cluver, L.D., Betancourt, T.S., Kellerman, S.E. & Richter, L.M., Desmond, C. (2014). Evidence of impact: health, psychological and social effects of adult HIV on children. *AIDS*, *28*(3), 251-259.

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Shisana, O., Rehle, T., Simbayi, L.C., Zuma, K., Jooste, S., Zungu, N., ... & Onoya, D. (2014). *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012*. Cape Town: HSRC Press.

Short, S.E., & Goldberg, R.E. (2015) Children Living with HIV-Infected Adults: Estimates for 23 Countries in sub-Saharan Africa. *PLoS ONE*. 10(11) e0142580. Retrieved from https://doi.org/10.1371/journal.pone.0142580 (accessed on 27 June 2018).

Shroufi, A., Gunguwo, H., Dixon, M., Nyathi, M., Ndebele, W., Taziwa, F., ... & Ferrand, R.A. (2013). HIV-infected adolescents in southern Africa can achieve good treatment outcomes: results from a retrospective cohort study. *AIDS, 27*(12), 1771-1778.

Simbayi, L.C. (2006). *Psycho-social issues affecting orphaned and vulnerable children in two South African Communities*. Cape Town: HRSC Press.

Sitienei, E.C. (2016). Psychological Effects Of HIV/AIDS And The Role of Psychological Counselling In Dealing With HIV/AIDS Among Person Living With HIV/AIDS (PLWHA) In KENYA .*International Journal of Current Research in Life Sciences, 5*(3), 545-548. Retrieved from *www.ijcrls.com* (accessed on 20 May 2016).

Siu, G.E., Bakeera-Kitaka, S., Kennedy, C.E., Dhabangi, A., & Kambugu, A. (2012). HIV serostatus disclosure and lived experiences of adolescents at Transition Clinic of infectious Diseases Clinic in Kampala, Uganda: A qualitative study. *AIDS Care*, *24*(5), 606-611.

Singh, E., Naidu, G., Davies, M. A., & Bohlius, J. (2017). HIV Associated Malignancies in Children. *Current Opinion in HIV and AIDS*, *12*(1), 77–83.

Skinner, E.A., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological Bulletin, 129*(2), 216-269.

South Africa (Republic). Department of Health. (2010). *Guidelines for the management of HIV infection in children*. Pretoria.

Sperry, L. (2015). *Mental Health and Mental disorders, An Encyclopaedia of Conditions, Treatment and Wellbeing*. Routledge: Florida.

Statistics South Africa. (2010). *Stats in Brief 2010*. Retrieved from http://www.statssa.gov/zapublications/statsinbrief/2010 (accessed on 27 May 2015).

Statistics South Africa. (2011). *Statistical Release: P0302. Mid-year population estimates*. Retrieved from http://www.statssa.gov/zapublications/p0302/p03022011 (accessed on 27 May 2015).

© University of Venda

Statistics South Africa. (2012). Census 2011: Highlights of Key Results. Retrieved from http://www.statssa.gov.za/census2011 (accessed 27 May 2015).

Straub, R.O. (2012). *Health Psychology: A Bio-Psycho Social Approach* (3rd ed.). New York: Worth.

Stommel, M. & Willies, C. (2004). *Clinical Research: Concept and Principles for Advanced Practice Nurses*. Philadelphia: Lipponcott Williams and Wilkins.

Srinivasan, S. (2014). Psychosocial problems faced by HIV/AIDS Patients. *Journal of Research Extension and Development, 2*(8), 1899-2319.

Taylor, S.E. (2010). *Health Psychology* (7th ed.). Boston, MA: McGraw-Hill.

Tshabalala, N.D. (2014). Issues of Disclosure in Relation to HIV/AIDS: Evidence from the KwaZulu-Natal Province. *Mediterranean Journal of Social Sciences,* 5(20), 2067-2074.

UNAIDS, (2010). *The Report on the Global HIV/AIDS Epidemic*. Geneva : UNAIDS.

UNAIDS. (2012). *UNAIDS Report on the Global AIDS Epidemic*. Geneva: UNAIDS.

UNAIDS. (2013). Joint United Nations Programme on HIV/AIDS) *2013 Regional report: Getting to zero: HIV in Eastern and southern Africa.* Geneva: UNAIDS.

UNAIDS. (2014). The gap report. Geneva: UNAIDS.

UNAIDS. (2015). '15 by 15'– A global target achieved. Retrieved from http://www.unaids.org/en/resources/documents/2015/15by15aglobaltargetachieved (accessed on 1 May 2016).

UNAIDS. (2016b). *Report on the global AIDS epidemic update*. Geneva: UNAIDS.

UNAIDS. (2016a). *Children on the brink*: A Joint report of new orphan estimates and a framework for action. New York: USAID. UNICEF. (2009). Children and AIDS: *Fourth Stocktaking Report*, 2009.

UNICEF. (2009). *Guide to the evaluation of psychosocial programming in the emergences.* Retrieved from http://www.resourcecentre.savethechildren.se./sites/default/files/documents/6454.pdf (accessed on 24 May 2016).

UNICEF. (2011). *Opportunity in Crisis. Preventing HIV from early adolescence to young adulthood.* Retrieved from www.unicef.org/aids/index58689.html (accessed on 10 December 2016).

UNICEF. (2013). Towards an AIDS-free generation: *children and AIDS*: sixth stocktaking report, 2013.

Van Nuil, J.I., Mutwa, P., Asiimwe-Kateera, B., Kestelyn, E., Ruhirimbura, J., Kanakuze, C., ... & van de Wijgert, J. H. (2014) ''Let's Talk about Sex'': A Qualitative Study of Rwandan Adolescent's Views on Sex and HIV. *PLoS One*, *9*(8), e102933. Retrieved from https://doi.org/10.1371/journal.pone.0102933 (accessed on 27 June 2016).

Vaz, L.M., Eng, E., Maman, S., Tshikandu, T., & Behets, F. (2010). Telling children they have HIV: Lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS Patient Care and STDs*, *24*(4), 247-256.

Vaz, L.M., Maman, S., Eng, E., Barbarin, O.A., Tshikandu, T., & Behets, F. (2011). Patterns of disclosure of HIV status in a sub-Saharan setting. *Journal of Developmental and Behavioural Paediatrics, 32*(4), 307-315.

Venning, A.J., Elliot, J., Whitford, H., & Honnor, T (2007). The impact of a child's chronic illness on hopeful thinking in children and parents. *Journal of Social & Clinical Psychology*, *26*(6), 708-727.

Vervoort, S.C.J.M., Grypdonck, M.H.F., de Grauwe, A., Hoepelman, A.I.M., & Borleffs, J.C.C. (2009). Adherence to HAART: Processes explaining adherence behaviour in acceptors and non-acceptors. AI*DS Care, 21*(4), 431-438.

Vosvick, M., Martin, L.A., Smith, N.G., & Jenkins, S.R. (2010). Gender differences in HIV-related coping and depression. *AIDS and Behaviour, 14*(2), 390-400.

Visser, M.J., Kershaw, T., Makin, J.D., & Forsyth, B.W.C. (2008). Development of parallel scales to measure HIV-related stigma. *AIDS and Behaviour, 12*, 759-771.

Vijayan, T., Benin, A.L., Wagner, K., Romano, S., & Andiman, W.A. (2009). We never thought this would happen: Transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. *AIDS Care, 21*(10), 121-145.

Vorster, C. (2003). *General Systems Theory and Psychotherapy: Beyond Post Modernism.* Centurion: Satori.

Vranda, V.M. & Mothi, S.N. (2013). Psychosocial Issues of Children Infected with HIV/AIDS. *Indian Journal of Psychological Medicine*, *35*(1), 19-22.

Vreeman, R.C., Gramelspacher, A.M., Gisore, P.O., Scanlon, M.L. & Nyandiko, W.M. (2013). Disclosure of HIV status to children in resource-limited settings: a systematic review. *Journal of the International AIDS Society*, *16*(1), 18466. Retrieved from https://doi.org/10.7448/IAS.16.1.18466 (accessed on 26 May 2016).

© University of Venda

Watkins-Hayes, C. (2014). Intersectionality and the Sociology of HIV/AIDS: Past, Present, and Future Research Directions. *Annual Review of Sociology*, *40*(1), 431-457.

Wiener, L., Mellins, C.A., Marhefka, S., & Battles, H.B. (2007). Disclosure of an HIV diagnosis to Children: History, Current Research, and Future Directions. *Journal of Developmental and Behavioural Paediatrics: JDBP*, *28*(2), 155-166.

Williams, B. (2010). Pregnancy outcomes in women growing up with HIV acquired perinatally or in early childhood. *HIV Medicine, 11*(1), 144-149.

Willig, C. (2013). *Introducing Quantitative Research in Psychology* (3rd ed.). New York, NY: Open University Press, McGraw-Hill Education.

Willis, N., Mavhu, W., Wogrin, C., Mutsinze, A., & Kagee, A. (2018). Understanding the experience and manifestation of depression in adolescents living with HIV in Harare, Zimbabwe. *PLoS ONE*, *13*(1), 0190423. Retrieved from http://doi.org/10.1371/journal.pone.0190423 (accessed on 27 June 2018).

Willis, N., Frewin, L., Miller, A., Mavhu, W., & Cowan, F. (2014). "My story"- HIV positive adolescents tell their story through film. *Children and Youth Services Review*, *45*, 129-136.

Wilson, C.M., Wright, P.F., Safrit, J.T., & Rudy, B. (2010). Epidemiology of HIV infection and risk in adolescents and youth. *Journal of Acquired Immune Deficiency Syndromes, 54*(1), 5-22.

Wolf, H.T., Halpen-Felsher, B.L., Bukusi, E.A., Agot, K.E., Cohen, C.R., & Auerswald, C.L. (2014). "It is all about the fear of being discriminated [against]…the person suffering from HIV will not be accepted": a qualitative study exploring the reasons for loss to follow-up among HIV-positive youth in Kisumu, Kenya. *BMC Public Health*, *14*, 1154.

Woolett, N. (2013). The Psychosocial challenge of HIV Positive Youth: The silent Epemdemic. *HIV Nursing matters*, *4*(1), 22-25.

Woollett, N., Cluver, L., Bandeira, M., & Brahmbhatt, H. (2017). Identifying risks for mental health problems in HIV positive adolescents accessing HIV treatment in Johannesburg. *Journal of Child and Adolescent Mental Health*, *29*(1), 11-26.

World Health Organisation. (2011). *Standards and operational guidance for ethics review of health-related research with human participants*. Geneva: World Health Organisation.

World Health Organisation. (2012). *Global report: UNAIDS report on global AIDS epidemic 2010.* Geneva: Switzerland World Health Organisation.

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World Health Organization. (2012). *Global HIV/AIDS response:* Epidemic update and health sector progress towards universal access: Progress report 2011. Geneva: WHO; 2011. 233.

World Health Organisation. (2013). *Global report: UNAIDS Report on Global AIDS Epidemic 2010.* Geneva: Switzerland World Health Organisation.

Wu, L., & Li, X. (2013). Community-based HIV/AIDS interventions to promote psychosocial well-being among people living with HIV/AIDS: a literature review. *Health Psychology and Behavioural Medicine*, *1*(1), 31-46.

Ying-xia, Z., Golin, E.C., Jin, B., Emrick, C.B., Nan, Z., & Ming-Qiang, L. (2014). Coping strategies for HIV related stigma in Liuzhou, China. *AIDS and Behaviour*, *18*, 212-220.

Yahaya, L.A., & Jimoh, A.A.G. (2011). Psychosocial Needs and Support Services Accessed by HIV/AIDS Patients of the University of Ilorin Teaching Hospital, Nigeria. *Social* and *Psychological Aspects of HIV/AIDS and their Ramifications, 127.*

Zanoni, B.C. (2013). Behavioural, Psychiatric and Cognitive Problems in Adolescence with Perinatal HIV Infection: Unrecognised Consequences. *HIV Nursing Matters, 4*(1), 14-18

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APPENDIX A: INFORMATION LETTER

I am Ramarumo Takalani, and my student number is 11533486. I am doing a Master of Arts in Psychology in the School of Health Sciences at the University of Venda. I am conducting a study on**: "The Psycho-social Experiences of Children Living With Vertically Transmitted HIV/AIDS at Messina Hospital, South Africa."** The purpose of the study is to explore the experiences of children living with vertically transmitted HIV/AIDS. The objectives of the study are: to determine the psycho-social experiences of living with vertically transmitted HIV/AIDS infection; to determine the challenges faced by these children; and to identify their coping strategies.

The study will be conducted at Fountain of Hope Clinic in Messina Hospital in Musina Municipality, Limpopo Province. Participation in this study is voluntary. Participants for this study will comprise male and female children between the ages 12-17 years, who are receiving care and support at the Clinic. The researcher will use face to face interviews as a data collection tool to obtain information from the participants and the interviews will be tape recorded with consent of the participants. Interviews will be held within the hospital premises and they are expected to last for one hour for each participant.

In this study, the researcher will request approval and permission to conduct the study from the Higher Degrees Committee (HDC) of the School of Health Sciences at the University of Venda. When the approval by HDC has been granted, the proposal will be forwarded to the University Research and Ethics Committee for approval. The proposal will also be submitted to the Department of Health, the Chief Executive Officer (CEO), and the Operational Manager at Fountain of Hope Wellness Clinic in the hospital to seek permission to conduct the study.

I look forward to a positive response.

Regards

………………………..

Ramarumo Takalani

© University of Venda

APPENDIX B: REQUEST FOR PERMISSION TO CONDUCT RESEARCH

University of Venda
Department of Psychology
Private Bag X 5050
Thohoyandou
0950

The Chief Executive Officer
Department of Health, Messina Hospital
Private Bag X60
Musina
0900

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am a Master of Arts in Psychology student in the School of Health Sciences at the University of Venda. I am conducting a study on**: "The Psycho-social Experiences of Children Living With Vertically Transmitted HIV/AIDS at Messina Hospital, South Africa."** The purpose of the study is to explore the experiences of children living with vertically transmitted HIV/AIDS.

I, therefore, request permission to conduct my study at Fountain of Hope Wellness Clinic in the Hospital. My participants for this study will comprise male and female children between the ages of 12 and 17 years, who are receiving care and support at the Clinic.

I look forward to your positive response.

Yours faithfully

………………………………
Ms. Takalani Ramarumo
Registered Counsellor / Master of Arts in Psychology Student.

© University of Venda

APPENDIX C: CONSENT FORM (Parents and Children)

I am Takalani Ramarumo, a postgraduate student in the Department of Psychology at the University of Venda. I am researching on **"The Psycho-social Experiences of Children Living With Vertically Transmitted HIV/AIDS at Messina Hospital, South Africa."** The purpose of the study is to explore the experiences of children living with vertically transmitted HIV/AIDS.

I would like to invite you to participate in the study. Please be informed that your participation in the study is of utmost importance. Participation is voluntary and should you wish to withdraw, you are free to do so. To ensure your privacy, I will take into consideration issues of confidentiality and anonymity. The study will adhere to privacy by refraining from using participants' names. Participants will not be expected to give their names.

Should you require further information, please do not hesitate to contact me.

I thank you in advance for your interest in participating in the study.

Yours truly

Researcher's name..................... Date.............................

I agree to participate in this research project. I have read the content and voluntarily consent to participate in the study.

Respondent's name…………………… Date………………

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Informed consent (Participant)

I ....hereby consent to participate in the study entitled "The Psycho-social Experiences of Children Living With Vertically Transmitted HIV/AIDS at Messina Hospital, South Africa."

I understand that I can stop this interview at any time should I want to discontinue. My anonymity is guaranteed by the researcher and data will, under no circumstances, be reported in such a way that they would reveal my identity.

I agree to participate in this study. I have read and understood the content and voluntarily consent to participate in the study.

Name of the Participant..................................Signature.........................
Date.........................

Researcher's signature............................ Date....................

© University of Venda

Informed consent (parent/guardian)

I .... parent/guardian of ....hereby give consent that my child can participate in the study entitled “The Psycho-social Experiences of Children Living With Vertically Transmitted HIV/AIDS at Messina Hospital, South Africa.”

I understand that my child can stop this interview at any time should he/she want to discontinue. His/her anonymity is guaranteed by the researcher and data will under no circumstances be reported in such a way that they would reveal his/her identity.

I agree that my child should participate in this study. I have read and understood the content and voluntarily consent to my child participating in the study.

Name of Participant’s parent/guardian..............................Signature...................
Date........................

Researcher’s signature............................ Date...................

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APPENDIX D: INTERVIEW GUIDE

1. Tell me what it is like to live with HIV infection?
2. How did you feel when you learned about your HIV positive status? How do feel now that you know? What does being HIV positive mean to you?
3. What have your experiences been like at home and at school since you learnt of your status?
4. What are the difficulties you have experienced when dealing with your HIV positive status?
5. Can you please explain how you cope or deal with problems that you come across on a daily basis?
6. What kind of support do you have?
7. Where do you receive this support from?
8. How helpful is this support?

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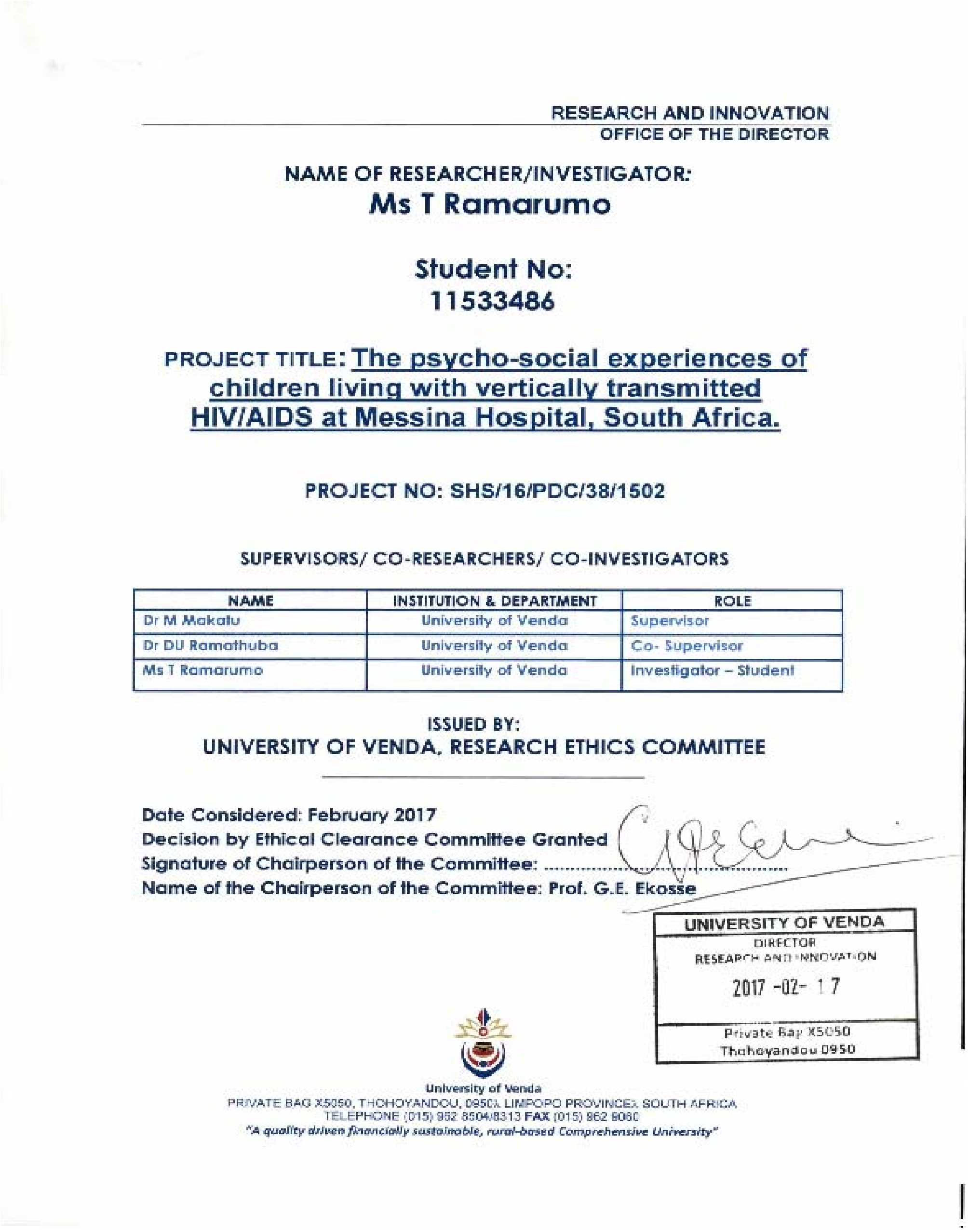
APPENDIX E: ETHICAL CLEARANCE LETTER



RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Ms T Ramarumo

Student No:
11533486

PROJECT TITLE: **The psycho-social experiences of children living with vertically transmitted HIV/AIDS at Messina Hospital, South Africa.**

PROJECT NO: SHS/16/PDC/38/1502

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Dr M Makatu	University of Venda	Supervisor
Dr DU Ramathuba	University of Venda	Co- Supervisor
Ms T Ramarumo	University of Venda	Investigator – Student

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: February 2017
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
DIRECTOR
RESEARCH AND INNOVATION
2017 -02- 17
Private Bag X5050
Thohoyandou 0950

University of Venda
PRIVATE BAG X5050, THOHOYANDOU, 0950, LIMPOPO PROVINCE, SOUTH AFRICA
TELEPHONE (015) 962 8504/8313 FAX (015) 962 9060
"A quality driven financially sustainable, rural-based Comprehensive University"

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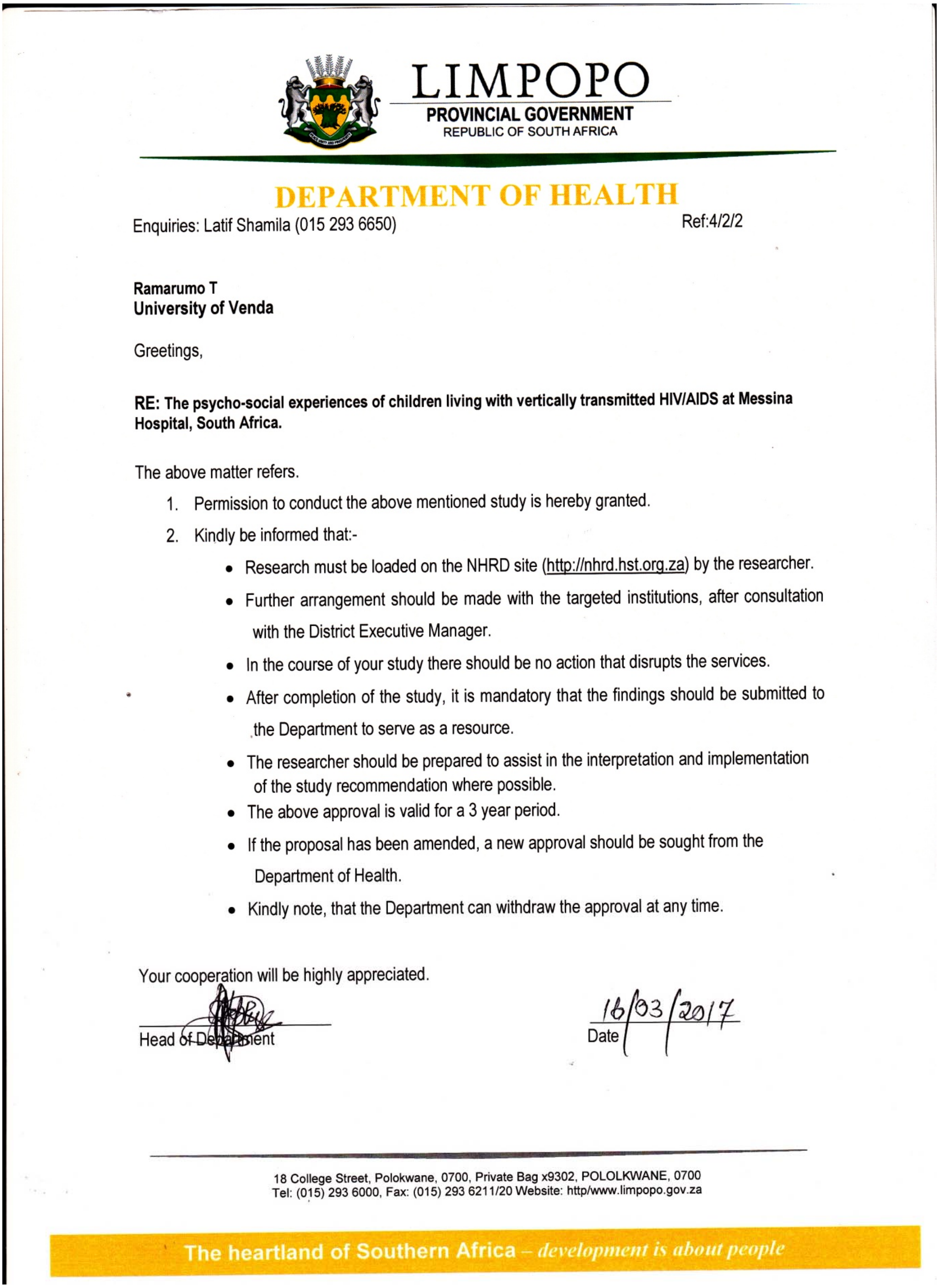
APPENDIX F: PERMISSION LETTER TO CONDUCT STUDY



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila (015 293 6650) Ref:4/2/2

Ramarumo T
University of Venda

Greetings,

RE: The psycho-social experiences of children living with vertically transmitted HIV/AIDS at Messina Hospital, South Africa.

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
   - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
   - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
   - In the course of your study there should be no action that disrupts the services.
   - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - The above approval is valid for a 3 year period.
   - If the proposal has been amended, a new approval should be sought from the Department of Health.
   - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

Head of Department

16/03/2017
Date

18 College Street, Polokwane, 0700, Private Bag x9302, POLOLKWANE, 0700
Tel: (015) 293 6000, Fax: (015) 293 6211/20 Website: http/www.limpopo.gov.za

The heartland of Southern Africa – *development is about people*

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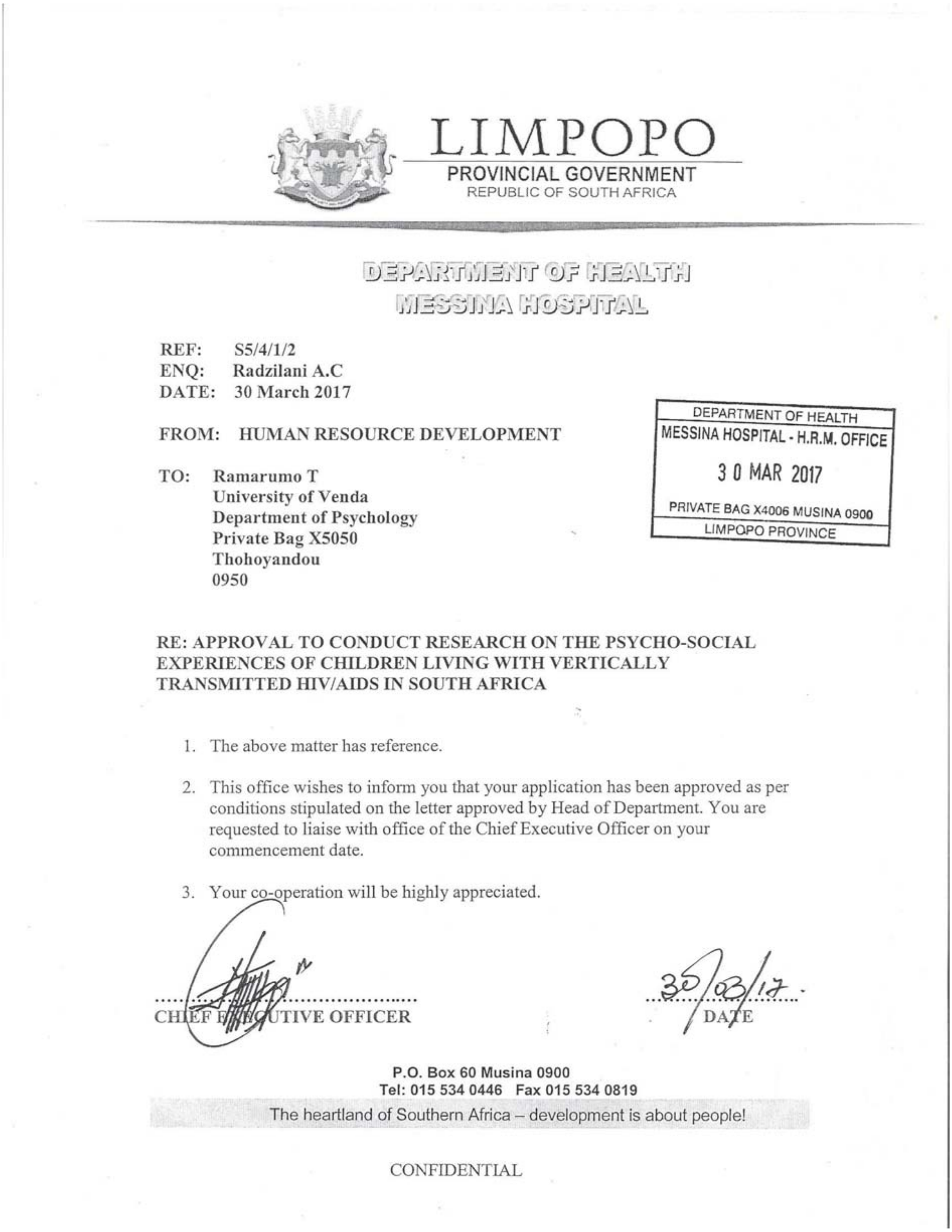
APPENDIX F: PERMISSION LETTER TO CONDUCT STUDY (Messina Hospital)



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
MESSINA HOSPITAL

REF: S5/4/1/2
ENQ: Radzilani A.C
DATE: 30 March 2017

DEPARTMENT OF HEALTH
MESSINA HOSPITAL - H.R.M. OFFICE
30 MAR 2017
PRIVATE BAG X4006 MUSINA 0900
LIMPOPO PROVINCE

FROM: HUMAN RESOURCE DEVELOPMENT

TO: Ramarumo T
University of Venda
Department of Psychology
Private Bag X5050
Thohoyandou
0950

RE: APPROVAL TO CONDUCT RESEARCH ON THE PSYCHO-SOCIAL EXPERIENCES OF CHILDREN LIVING WITH VERTICALLY TRANSMITTED HIV/AIDS IN SOUTH AFRICA

1. The above matter has reference.
2. This office wishes to inform you that your application has been approved as per conditions stipulated on the letter approved by Head of Department. You are requested to liaise with office of the Chief Executive Officer on your commencement date.
3. Your co-operation will be highly appreciated.

………………………………………
CHIEF EXECUTIVE OFFICER

30/03/17
……………………
DATE

P.O. Box 60 Musina 0900
Tel: 015 534 0446 Fax 015 534 0819
The heartland of Southern Africa – development is about people!

CONFIDENTIAL

APPENDIX G: CONFIRMATION BY LANGUGE EDITOR

EDITOR DECLARATION

I, Dr Bevelyn Dube, of the Communication and Applied Language Studies Department at the University of Venda declare that I edited and proofread the Master of Psychology dissertation entitled *“The Psycho-social Experiences of Children Living With Vertically Transmitted HIV/AIDS at Messina Hospital, South Africa*” by Ramarumo, T. (student number 11533486)

BDube

Dr BEVELYN DUBE: BA, Grad CE, BA Hons (English), MA (English) University of Zimbabwe, DPhil (SU)
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