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DEPARTMENT OF NURSING

CHALLENGES FACED BY HIV-INFECTED ADOLESCENTS IN RURAL AREAS OF BOTSWANA

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PROPOSAL IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR MASTERS' PROGRAM IN COMMUNITY HEALTH NURSING

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ACKNOWLEDGEMENTS

Firstly, I will like to thank the Almighty God for giving me the opportunity to complete this proposal. I will secondly like to thank my amazing supervisor, Dr T.R. Monau, for guiding me through this process and through all the challenges I met in my studies. Your guidance and advices have been most fruitful. Regardless of how much you had in your plate, you always had time for me. You were such a great inspiration. Thank you.

I will also like to thank my dear husband for the continuous support and encouragement. My sincere gratitude's also goes to my children for their understanding and continuous support. You sacrificed your time to support each other when I was not there to support you. You were beyond my understanding.

Dr. Dithole and Mrs B. Ratshaa, thank you for your tremendous contribution. You dedicated your time and your resources in making sure that I complete this proposal. Your continuous support and encouragement meant a lot to me. To you all that I have not mentioned, but having contributed to the completion of this proposal and my study, may the grace of God be with you for all the days of your lives.

OPERATIONAL DEFINITION

This section here, presents the definition of the key terms in the study. These terms are defined within the context of this research proposal.

Adolescents

- Individuals in the 10-19 year age group (UNAIDS, 2013; UNICEF, 2013). Even though adolescents are the main focus of this study, the terms youth, children and paediatric are used as some of the literature used includes them. When referring to caregivers and their children, the term your child refer to your adolescent as it is more natural to refer to someone's child rather than someone's adolescent

HIV

- Human Immuno-deficiency Virus which causes Acquired Immune-Deficiency Syndrome (AIDS)

HIV-infected adolescents

- Individuals in the 10-19 year age group infected with HIV. This includes those behaviourally and perinatally infected (Littler & Oberg, 2005; UNAIDS, 2013).

Peri-natally HIV-infected adolescents

- Adolescents who acquired HIV from their mothers as embryos, foetuses or babies during pregnancy or child birth. Perinatal HIV transmission and vertical HIV transmission are used interchangeably to mean the same thing in this research (Hazra, Siberry & Mofenson, 2010; UNAIDS, 2013).

Behaviourally HIV-infected adolescents

- Adolescents who acquired HIV infection due to their behaviours like through sex or injection drug use. In this study, horizontal transmission and behavioural transmission of HIV are used interchangeably. These two concepts have the same meaning (Hazra, Siberry & Mofenson, 2010).

Rural area

- The less developed side of the country compared to town or cities. Sparsely populated lands lying outside urban areas (Plessis, Beshiri, Bollman & Clemenson, 2002).

Challenges

- Negatively stimulating or stressing situations (George, 1995).

ABSTRACT

Background: Sub-Saharan Africa has the world's highest HIV incidence, with about 71.4% of HIV infection worldwide in 2013. Botswana has the second highest infection rate in the world and the epidemic has left a large number of children and adolescents orphaned. Adolescents living with HIV are an emerging group in the HIV and AIDS pandemic. A number of HIV-infected adolescents continue to increase, and this is largely a reflection of successful treatment of peri-natally infected children, infections during early adolescence and the expansion of access to Anti Retroviral Therapy (ART) worldwide. Experience from the developed world suggests that providing care and treatment for adolescents is challenging and requires looking into not only biomedical aspects, but also psychosocial needs and challenges. Although numerous studies have investigated HIV infected adolescents in developed and developing countries, majority of work in this area is focused on the biomedical aspects and adherence and data on challenges faced by HIV-infected adolescents is limited. Few studies have examined challenges for HIV-infected adolescents in Botswana, but to my knowledge, no study has focused on those in rural areas of Botswana.

Objectives: The objectives of this study will be 1) to identify challenges faced by HIV-infected adolescents in rural areas, 2) to describe the challenges faced by HIV-infected adolescents, 3) to find out how HIV-infected adolescents cope or deal with these challenges.

Methods: The study will utilize a qualitative design guided by Grounded Theory approach to investigate the challenges faced by HIV-infected adolescents in rural areas of Botswana. Grounded theory will assist in inductive construction of a theory about the challenges faced by HIV-infected adolescents in rural areas of Botswana. The goal of the qualitative research is to document and interpret as fully as possible, what is being studied from the people's point of view. The aim of grounded theory is to generate or discover a theory from data that is systematically obtained. Grounded theory will provide a way to know

the challenges faced by HIV-infected adolescents in rural areas of Botswana to knowing the causes of these challenges and how they cope with these challenges.

For this study, the target population will be all HIV-infected adolescents aged 10-19 years in Salajwe, Kaudwane, Sorilatholo and Khudumelapye villages. Permission to do the study will be sought from the University of Botswana, Ministry of Health and said facilities. Informed consent will be obtained from the caregivers of participants below 18 years of age and from all participants 18 years and above. The convenience sampling will be used. The data collection will have two sections which will be a demographic survey and focus group discussion. All discussions will be recorded, transcribed and translated into English. For this study, data will be analysed using constant comparative analysis. In this analysis, data will be used for the development of a general theory of challenges faced by HIV-infected adolescents in rural areas of Botswana.

Key concepts

Adolescents, HIV, Challenges. Rural areas.

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti-Retro Viral
ART	Anti-Retroviral Therapy
BAIS	Botswana AIDS Impact Survey
BIPAI	Baylor International Pediatric AIDS Initiative
CSO	Central Statistics Office
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human Immunodeficiency Virus
SIV	Simian Immunodeficiency Virus
UNAIDS	the Joint United Nations Programme on HIV and AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization

CHAPTER ONE: INTRODUCTION AND PROBLEM STATEMENT

1.1 Introduction

This chapter will cover the background of Human Immuno-deficiency Virus (HIV) and Acquired Immuno Deficiency Syndrome (AIDS) pandemic and some of the challenges met by HIV-infected adolescents. The chapter will also include the problem statement, justification, aims and objectives, research questions and conceptual definitions.

1.2 General background

Globally, 35 million people were living with HIV in 2013. Sub-Saharan Africa was the most affected region globally with 24.7 million of HIV infected individuals in 2013 which is nearly 71% of the global population. The region accounted for 1.5 million new infections among adults and children while the new infections globally were 2.1 million. There were 1.5 million deaths due to Acquired Immuno Deficiency Syndrome (AIDS) worldwide and Sub-Saharan Africa accounted for 74% in 2013. The introduction of highly active antiretro-viral treatment (HAART) has had a major impact in the quality of life and dramatic decline in mortality in HIV-infected persons (UNAIDS, 2014).

HAART has been seen to be able to inhibit viral replication and delay disease progression. Success of HAART in prevention and treatment of HIV and AIDS in developed countries has brought a significant change in lives, growth and wellbeing of children worldwide. Before the introduction of HAART, most perinatally infected children did not survive beyond two years of life. With HAART, HIV positive children now live longer. In developed countries, HAART has been widely available since 1996 and survival of perinatally infected children into adolescent is now a norm. With the improvement in HIV and AIDS care over the past decades, HIV-infected adolescents and their caregivers are now facing management of a chronic illness and addressing the psychosocial barriers to optimum health (Hazra, Siberry & Mofenson, 2010; Li et al., 2010; Midtbø, 2012).

Adolescent health care is distinct from both paediatric and adult health care due to the physiological, intellectual and psychosocial transitions that occur during this period. Adolescence is a phase of physical growth and development accompanied by sexual development towards maturity, often leading to intimate relationships. HIV interferes with these normal developmental processes. On the other hand, the transition from childhood to adulthood also presents significant challenges to HIV-infected youth. Youth need to address a number of adaptations, ranging from demands for self-management of health care, the impact of their illness on their emerging sexuality, stigma, disclosure, lack of knowledge on HIV and AIDS, loss of parents and/or siblings and often difficult transition from familiar paediatric care settings to unfamiliar adult providers and many more (Childs & Maxwell, 2009; Li et al., 2010; Midtbø, 2012; Petersen et al., 2010; Wrang, 2012).

Programs of HIV and AIDS in developing countries have historically focused on adults and child populations. However, there is growing appreciation, that other age groups pose a particular challenge to the provision of HIV and AIDS services. For instance, the number of HIV-infected adolescents continues to rise which is largely due to successful treatment of perinatally infected children, infection during early adolescents and the expansion of access to HAART worldwide. As these children enter adolescence, it's important that appropriate services are available to monitor their physical being and counsel them on psychosocial and sexual safety, adherence to HAART and reproductive choices in order to prevent further transmission and other complications (Bakanda et al., 2011; Ross et al., 2010).

In Botswana, where HAART became publicly available in 2002, perinatally infected infants are now entering adolescence and the horizontal (behavioural) transmission is also on the rise. Experience from the developed world suggests that providing care and treatment for adolescents is challenging and requires looking into not only biomedical aspects, but also

psychosocial needs and challenges. Although numerous studies have investigated HIV-infected adolescents in developed (Childs & Maxwell, 2009; Hazra, Siberry & Mofenson, 2012 & Ross et al., 2010) and developing countries (Hilburn , Potterton & Stewart, 2010, Midtbø, 2012, Thupayagale-Tshweneagae, 2010 & Wrang, 2012), majority of work in this area is focused on the biomedical aspects and adherence and data on challenges faced by HIV-infected adolescents is limited (Childs & Maxwell, 2009; Hilburn, Potterton & Stewart, 2010; Ross et al., 2010).

Few studies (Bakanda et al., 2011; Childs & Maxwell, 2009; Midtbo, 2012; Ross et al., 2010; Thupayagale-Tshweneagae, 2010; Wrang, 2012) have examined challenges for HIV-infected adolescents, but to my knowledge, in Botswana, no study has focused on those in rural areas. It can be helpful to focus on other parts of the country to examine the challenges faced by HIV-infected adolescents in rural areas. Findings reveal that the rural population is less privileged than their urban counterparts which lead to differences in quality of care benefited by both. In urban areas, there are tertiary institutions with multidisciplinary staff and programs to render quality care which is different in rural population (Li et al., 2010; Petersen et al., 2010).

1.3 Statement of the problem

Paediatric HIV infection is a worldwide public health challenge, but the prevalence rate differs greatly between developing and developed nations. AIDS was said to be the number one killer in Africa and number two killer of adolescents worldwide in 2013. Globally, AIDS-related deaths fell by almost 40% between 2005 and 2013 for all the people except adolescents. Estimates reveal that AIDS-related deaths are increasing in this age group. Between 2005 and 2012, adolescents' AIDS-related deaths increased by 50%. This demonstrated the gaps in HIV testing and counselling, the need for linkages to care, treatment and quality support for adolescents aged 10-19 years (UNAIDS, 2014; UNICEF, 2013).

Adolescents are a rich human resource and an important part of the development process. Good health of adolescents will help in raising the health status of the community. About 18.6% of the total population of Botswana falls between the ages of 10 and 19 and 41.3% are below 19 years. In Botswana, statistics show a decrease in the HIV prevalence among adolescents from 2004 to 2008 and an increase in 2012. The table below shows the HIV prevalence from 2004 to 2012 (Central Statistics Office, 2013).

Table 1

HIV Prevalence among adolescents in Botswana (Central Statistics Office (CSO), 2013)

Age in Years	2004 Percentage	2008 Percentage	2012 Percentage
10-14	3.9	3.5	5
15-19	6.5	3.7	5

Table 1 shows that in 2004 and 2008, the 15-19 years age group's prevalence was more than the 10-14 age groups. This may be due to high risk behaviours which become increasingly common in late adolescence. This is an age group where the adolescents are sexually active and experimenting sexually. The HIV prevalence of adolescents was showing a declining trend from 2004 to 2008. But in 2012, the prevalence increased, and it was the same for both age groups (10-14 and 15-19 years). This may be due to the high horizontal transmission and the increasing population of the perinatally infected as HIV and AIDS care improves (CSO, 2013; UNAIDS, 2014).

Many HIV-infected adolescents experience challenges adhering to HIV treatment regimens, medication related side-effects, denial and fear of their HIV infection. Literature also revealed that other challenges faced by HIV-infected adolescents include;

misinformation, distrust of the medical establishment, fear and lack of belief in the effectiveness of medications, low self-esteem, unstructured lifestyle and refusal to take medication due to rebellious behaviour, lack of social and familial support and unavailable or inconsistent access to care or health services (Childs & Maxwell, 2009; Hilburn, Potterton & Stewart, 2010; Midtbø, 2012; Wrang, 2012).

In order to provide quality care for HIV-infected adolescents, addressing the distinct challenges for adolescents is a requirement. There is need for research which will look into challenges faced by adolescents living with HIV and AIDS in rural areas in Botswana. Wrang (2012) did a study on challenges faced by HIV-infected adolescents, but focused on those in urban areas and specifically "examining how the empowering strategies of the Botswana Baylor Adolescent Programme are addressing problems HIV-positive adolescents are facing" (p.2). Thupayagale-Tshweneagae (2010) also has done a study on HIV-infected adolescents in Botswana but focused on behaviours used by HIV-infected adolescents to prevent stigmatization in Botswana in urban Gaborone. Midtbø (2012) also did a study in urban areas of Botswana on HIV-infected adolescents to gain knowledge on the resources they have to make some of them thrive inspite of challenging situations. Unlike rural areas, urban areas have strong health resources and have multi-disciplinary clinics at tertiary hospitals. The clients from urban areas are relatively privileged and this lead to differences in quality of care rendered between them and their rural counterparts. In urban areas like Gaborone and semi-urban areas like Ramotswa, there are adolescents' clinics, teen's clubs, dieticians, paediatricians, social-workers and pharmacists, but in HIV clinics in rural areas like Salajwe, there are just nurses and a medical doctor who sees patients once or twice a month.

In Gaborone, which is the capital city of Botswana, there is the Botswana-Baylor Children's Clinical Centre of Excellence which is private-public funded. The centre was established in 2003 and its one of the first in the country to fight HIV and AIDS through

comprehensive care and treatment, capacity building and clinical research addressing the psychological issues of being HIV positive. One of the programmes run by this Centre of Excellence (COE) is Botswana Baylor Adolescents Program (BBAP), which deals with clinical and psychological management and support of adolescents. BBAP has different branches including; Teen Club, Teen Mother Support Group, Adolescent Forum and Teen Leaders which deals with clinical and different aspects of adolescence empowerment (Botswana-Baylor Children's Clinical Centre of Excellence, (2011); BIPAI, 2011).

Results of studies have shown that these programs make adolescents better at coping with the disease in their daily lives, with their families and friends, giving them the incentives to study, practising life skills and increase their hopes for the future (BIPAI, 2011; Midtbø 2012; Wrang, 2012). Peer support groups have been an effective approach in other parts of the world, creating a venue for HIV-specific health promotion and opening dialogue about living with the virus. People living with HIV and AIDS spoke positively about these peer groups. Studies have shown that empowerment and/or support groups foster power in people, for use in their own lives, their communities and their society, by being able to act on issues that they define important. Adolescents in rural areas need to be empowered too like their urban counterparts in order to use this power in their lives, their communities and society, by being able to identify and act on the challenges they face (Li et al., 2010; Midtbø, 2012; Pettitt, 2010; Thupayagale-Tshweneagae, 2010; Wrang, 2012).

1.4 Justification or significance of the study

Due to the current demographic trend, Botswana is in a time of transition, in which the peri-natally infected Batswana children are navigating their way through adolescence. In addition to peri-natally infected adolescents, youth are among those at greatest risk of acquiring HIV and mostly affected by the pandemic. HIV-infected adolescents perceive that most people of their age are having sex and that there is indeed pressure to have sex, both by a certain age and at a certain point in a relationship like their uninfected peers. In addition to these, adolescents living with HIV confront many challenges including; concerns about medication regimen, doctors' appointments, disclosure, stigma, HIV transmission, loss of parents or parent and/or siblings, lack of social support and pregnancy (Li et al., 2010; Midtbø, 2012; Naswa & Marfatia, 2010; Petersen et al., 2010; Ross et al., 2010).

Fewer HIV and AIDS cases have been reported in rural than in urban areas and this may hinder the community to recognize that HIV is a problem that needs to be addressed. In 2013, Botswana rural areas' HIV prevalence was 17.4%, and was low compared to urban areas which were at 19.2% (Central Statistics Office, 2013). There is a need to provide adolescents with increased HIV services in rural areas, given the fact that rural adolescents may perceive less susceptibility to and severity of HIV infection. In order to provide quality care for HIV-infected adolescents and to combat the HIV transmission, distinct challenges of adolescents need to be addressed. This will in turn assist health care professionals to plan effective, efficient and acceptable ways of managing challenges faced by HIV-infected adolescents. With the knowledge of challenges faced by HIV-infected adolescents, policy makers and health care providers will be able to develop a policy which will focus on reducing or eliminating these challenges so as to enable adolescents to live quality life and live positively with their HIV status (Central Statistics Office, 2013; UNICEF, 2013).

Adolescence is a window of opportunity for changing the course of the pandemic as many adolescents are not yet sexually active and new policies targeting adolescents can possibly change the course of HIV and AIDS. The findings of this study will also challenge health care workers and policy makers to continue to work to reduce the challenges faced by HIV-infected adolescents to provide innovative initiatives to target vulnerable groups like adolescents.

1.5 Aim and objectives of the study

1.5.1 Aim

The aim of this study is to explore the challenges faced by HIV-infected adolescents in rural areas of Botswana.

1.5.2 Objectives

The objectives of this study will be:

- To identify challenges faced by HIV-infected adolescents in rural areas of Botswana
- To describe the challenges faced by HIV-infected adolescents in rural areas of Botswana
- To find out how HIV-infected adolescents in rural areas of Botswana cope or deal with the challenges

1.5.3 Research Questions

1. What are the challenges faced by HIV-infected adolescents in the rural areas?
2. Describe the challenges faced by HIV-infected adolescents
3. How do HIV-infected adolescents cope with these challenges?

1.6 Conceptual Definitions

Numerous definitions were reviewed to determine their appropriateness in defining the concepts and their relationships towards challenges faced by HIV-infected adolescents. These key concepts includes: challenges faced by HIV-infected adolescents, coping strategies used by HIV-infected adolescents to overcome the challenges they face. Below are the defined concepts;

Challenges: challenges are negatively stimulating or stressing situation or stressors. According to Neuman (1995), stressors are stimuli that produce tension and have the potential for causing system instability. The experience of stress is individual, subjective and uniquely personnal. It is important to identify the type and nature of a stressor experienced by a person. This will help to develop prevention strategies to alleviate stress. King's Open system's theory (1990) sees stressors as events that evoke energy response from a client. Both Neuman and King view a stressor as event or stimuli that produce tension or cause instability. The two also view client as an open system to the environment with stressors but maintains stability through protection and defences. Neuman and King are for the view that challenges are stressors. This study is in agreement with Neuman and King's views that it is important to identify challenges faced by HIV-infected adolescents in rural areas because this will assist in developing prevention strategies to alleviate and/or control these stressors (as in George, 1995).

Coping: coping is a capacity to respond and recover from something stressful. It is an ever changing process involving cognitive and behavioural actions in order to manage situations that are perceived to be difficult to the individual's current resources. Roy's adaptation model used the term coping mechanisms to describe the control processes of the person as an adaptive system. These coping mechanisms are considered to be subsystems of the person as an adaptive system. The experiences for coping are individual perception and

life experiences which lead to the ability to praise and manage situations and the availability of adequate resources and support systems. The components of coping include anxiety, adaptability, stress, conflict resolution. The positive consequences of coping may include ability to identify stressors. Roy's Adaptation theory includes individual perception as an antecedent of coping and stress as a subconcept or a component of coping. By knowing the antecedents and attributes of coping one can be in a state of preventing a situation before it happens. One can also use or encourage the resources used by the individual to overcome a stressful situation to assist others in the same situation (George, 1995; WHO, 1999).

1.7 Summary

Studies had shown that adolescents infected with HIV have many challenges. Information specific to challenges faced by HIV-infected adolescents in Botswana was identified as inadequate in the literature. The aim of this study is to explore the challenges faced by HIV-infected adolescents in rural areas of Botswana. In order to provide quality care for HIV-infected adolescents and to combat the HIV transmission, distinct challenges of adolescents need to be addressed. This will in turn assist health care professionals to plan effective, efficient and acceptable ways of managing challenges faced by HIV-infected adolescents. With the knowledge of challenges faced by HIV-infected adolescents, policy makers and health care providers will be able to develop a policy which will focus on reducing or eliminating these challenges so as to enable adolescents to live quality life and live positively with their HIV status. The research questions for this study are: 1) what are the challenges faced by HIV-infected adolescents in the rural areas? 2) describe the challenges faced by HIV-infected adolescents and 3) how do HIV-infected adolescents cope with these challenges?

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter will look at literature related to the origin of Human Immuno-Deficiency Virus (HIV) and Acquired Immune-Deficiency Syndrome (AIDS). The chapter will continue to look at updates on HIV and AIDS and then adolescents and HIV and AIDS. The chapter will then focus on identifying the challenges faced by HIV-infected adolescents and discussion of identified challenges. At the end of the chapter, will be a summary of discussed literature on transition to methodology section.

This literature review is a report or a summary of the work or research that has already been conducted on this research problem. It demonstrates the amount of knowledge that exists in this area of study. It will serve as an overview of that which is already known. Literature review here will be used as a guide in grouping and discussing data in themes or topics. Literature review in this study will serve as a theoretical foundation to compare findings from the actual data gathered during the study. In this study literature review will also supplement interviews and stimulate thinking about concepts that will be emerging from the data (Polit & Beck, 2013; Strauss & Corbin, 1998).

2.2 History of HIV and AIDS

AIDS came to wide public attention in the mid 1980's, after clusters of deaths from Pneumocystic Carinii Pneumonia (PCP) and Kaposi's sarcoma (KS) were reported in young, previously healthy gays in New York City, Los Angeles and San Francisco. Reports of similar findings followed immediately from France, the Caribbean and Central America. This disease was first called gay cancer and then labelled gay-related immune deficiency. It is widely believed that HIV is the result of an animal to human (zoonotic) transfer of a simian immuno-deficiency virus (SIV). The circumstances under which SIV was transmitted to

humans and became an epidemically spreading pathogen are said to be unknown (Sharp, Shaw & Hahn, 2005).

Simian immunodeficiency viruses are primate lenti-viruses that affect more than 36 different primate species. Two of these viruses, SIVcpz from chimpanzees and SIVsmm from sooty mangabeys, have crossed species barriers on many occasions and produced HIV type 1 and 2. HIV-1, which is responsible for the AIDS pandemic and found in Sub-Saharan Africa, is closely related to a SIVcpz, which infects the chimpanzees. HIV-2, which is prevalent in West Africa and has spread to Europe and India, is almost indistinguishable from SIVsmm that infects sooty mangabey monkeys. The precise geographic origin of HIV is still unknown. Primates infected with SIV do not develop AIDS compared to HIV-infected people who almost always have a gradual destruction of immune system and develop AIDS (Hirsch, Olmsted., Murphey-Corb, Purcell, & Johnson, 1989; Sharp, Shaw & Hahn , 2005).

2.3 Update on HIV and AIDS

Since the start of the HIV and AIDS pandemic in 1980 up to 2007, 24 million people have died globally, most of them in Sub-Saharan Africa. Based on estimates, reports show that by 2030, the total of HIV/AIDS deaths is projected to reach 75 million worldwide. According to recent studies, number of HIV/AIDS deaths globally is showing a significant decline from 3.4 million in 2001 down to 1.5 million in 2013 (UNAIDS, 2014; UNICEF, 2012).

In 2013, 35 million people worldwide were living with HIV. Globally, in 2013, there were 2.1 million new infections compared to 3.4 million new infections in 2001. The overwhelming majority of people living with HIV globally live in the developing world. Sub-Saharan Africa bears the burden of HIV and AIDS epidemic carrying 71% of the global total HIV-infected people. Because of AIDS, companies doing business in Africa were suffering

as their workers sickened and died. The pandemic drive elders to withdraw their children from school to care for the sick, for some, missing school was usual due to ill health and death before second birth day was common (Global HIV Prevention Working Group, 2008; UNAIDS, 2013; UNAIDS, 2014).

In the 1980s to 2004, about half of all people who acquired HIV became infected before the age of 25, and died of AIDS before their 35th birthday. This age factor made AIDS uniquely threatening to children because this is a child-bearing age. By the end of 1999, the epidemic had left behind a cumulative total of 11.2 million AIDS orphans; who had lost their mother before reaching the age of 15. In 2000, an estimated 600 000 children aged 14 or younger became infected with HIV. Over 90% HIV positive babies were born to HIV-infected women and this was due to mother-to-child transmission; during pregnancy, birth or breastfeeding. Of these, almost 90% were in Sub-Saharan Africa (UNAIDS, 2009).

Globally, countries began to embark on health education to prevent the spread of HIV infection. As this pandemic continued to threaten mankind and dropped the economy of countries worldwide, Anti-retro Viral (ARV) therapy was discovered (Littler & Oberg, 2005). ARV drugs are classified according to the steps they inhibit in the viral life-cycle. ARV therapy was found to be able to reduce the ability of the virus to replicate and hence increase the ability of the body to fight diseases. In 1986 the first ARV drug Zidovudine (AZT) was approved. AZT was used as monotherapy for prevention of HIV replication by inhibiting the activity of the enzyme reverse transcriptase which is essential in the process of HIV replication. AZT is part of a group of ARV drug class called nucleoside reverse transcriptase inhibitors (NRTI) (Littler & Oberg, 2005; Palmisano & Vella, 2011).

After 1991, several other NRTI drugs were discovered together with other classes of ARV drugs named Non-nucleoside reverse transcriptase inhibitors (NNRTI) and protease

inhibitors (PIs). NNRTI work the same as NRTI but differs in that NNRTIs are more quickly activated once they enter the blood stream. PIs do not inhibit reverse transcriptase enzyme activity but inhibit enzyme protease which is also important for HIV replication. Despite the discovery of a number of classes of ARV, monotherapy remained the standard ARV therapy until 1995 (Littler & Oberg, 2005; Palmisano & Vella, 2011).

Between 1986 and 1995, there were many advances in understanding the function of HIV in the host's body. Mutation and drug resistance studies were also done which implicated the monotherapy against HIV. This led to the shift from monotherapy to combination therapy in which different classes of ARV drugs were used simultaneously which had a dramatic effect in mutated forms of HIV. Combination therapy for HIV is commonly known as Highly Active Anti-Retroviral Therapy (HAART). Up to 2010, more than 20 antiretroviral agents were licensed and up to seven classes were discovered (Littler & Oberg, 2005; Palmisano & Vella, 2011).

In developed countries, ARV therapy has been widely available since 1996, while in developing countries, ARV therapy became publicly available in 2002. After the introduction of ARV therapy for individuals and for prevention of mother-to-child transmission of HIV, the mother-to-child transmission, AIDS morbidity and mortality rates decreased. Since the introduction of ARVs, a number of people dying from AIDS globally each year have dropped from 2.3 million in 2005 to 1.5 million in 2013. New HIV infections have also fallen by 38% since 2001 upto 2013 (Palmisano & Vella, 2011; UNAIDS, 2014).

2.4 Adolescents and HIV

Globally, in 2013, 31.9% of all new reported HIV infections occurred in adolescents and young people aged 10-24 years. There were 5 million adolescents and young people globally living with HIV age 10-24 years in 2013. Of this 5 million, 2.1 million were adolescents and more than 80% of them were living in Sub-Saharan Africa. UNAIDS (2010) estimated that every year, around four million people younger than 20 years are diagnosed with sexually transmitted infections including HIV (Naswa & Marfatia, 2010; UNAIDS, 2014).

Numbers of adolescents' AIDS-related deaths continue to rise. There are concerns that a lack of access to testing and treatment could explain why AIDS-related deaths among adolescents are not decreasing like other age groups. A number of HIV-infected adolescents continue to increase. Evidence shows that, this is largely a reflection of successful treatment of peri-natally infected children, infections during early adolescence and the expansion of access to ART worldwide (UNAIDS, 2014; UNICEF, 2012).

18.6% of Botswana population is adolescents. HIV prevalence among adolescents in Botswana for those between 10 – 14 years of age was 3.9 in 2004 and 3.5 in 2008 and 5 in 2012. For those between the ages of 15 – 19 years, the prevalence was 6.5 in 2004 and 3.7 in 2008 and 5 in 2013. This shows a decrease in prevalence comparing 2004 and 2008 but an increase comparing 2008 and 2012. This may be due to the high horizontal transmission and the increasing population of the perinatally infected as the HIV and AIDS care improves (Central Statistics Office, 2013; UNICEF, 2012).

2.5 Challenges faced by HIV-infected adolescents

HIV-infected adolescents are an emerging group in the HIV and AIDS epidemic. Studies have revealed a number of challenges that are faced by this group globally. Below are challenges faced by HIV-infected adolescents from the studies done around the world;

2.5.1 Medication non-adherence

More common to challenges faced by HIV-infected adolescents, there were issues of poor medication adherence. HAART is seen to be able to reduce the morbidity and mortality caused by HIV and AIDS. Adherence to HAART has been shown to be the single most important factor in achieving undetectable viral load in people living with HIV. Poor HAART adherence has also been implicated in the emergence of drug resistant strains of HIV which has an impact on broader public health (Ferrand et al., 2009; Hardon et al., 2006; Maokisa, 2011; Naswa & Marfatia, 2010; Petersen et al., 2010; Rao et al., 2007; Ross et al., 2010; Wrang, 2012).

Adolescents living with HIV experience many contributors to poor adherence including; mental health issues, substance abuse, HIV stigma and disclosure, side effects, misinformation, lack of social support and immature concrete reasoning (Naswa & Marfatia, 2010; Petersen et al., 2010; Rao et al., 2007; Ross et al., 2010). In resource limited regions in Sub-Saharan Africa, even if HAART is free, related costs like transport expenditures, lost wages due to frequent clinic visits and long waiting times were reported to be added obstacles to optimal adherence. Adolescents' poor adherence may also be due to the fact that adolescents may view providers as adults with power and authority, and may fear discussing poor adherence when they believe they will be criticized. Adolescents also stated that the act of taking medication was a negative reminder of their disease state (Ferrand et al., 2009;

Hardon et al., 2006; Maokisa, 2011; Naswa & Marfatia, 2010; Petersen et al., 2010; Rao et al., 2007; Ross et al., 2010; Wrang, 2012).

2.5.2 Stigma and discrimination

Despite global efforts to reduce and eliminate HIV and AIDS related stigma and discrimination, stigma continues to be extremely common around the world. HIV and AIDS related stigma and discrimination interfere with prevention efforts and discourage people from safe sex practices, care-seeking behaviour and finding a diagnosis. Stigma also compromises the quality of care provided to people living with HIV and their partners and the communities. Stigma and discrimination were also reported to hinder adherence. In one study, half of the adolescents acknowledged that they skipped doses when they feared that friends or family might discover their status. They also described feeling discriminated against by their family members and peers (Abadia-Barrero & Castro, 2006; Cloete et al., 2010; Rao et al. 2007).

Even though stigma and discrimination related to HIV status exist, access to HAART assured survival and improves quality of life. HAART changes the social course of AIDS and the experience of stigma when children reach adolescence. HIV-infected adolescents progress from being perceived as sick and innocently infected to being feared as potential victimizers as adolescent sexual subjects, which was perceived by the community as new ‘problem’. Thupayagale-Tshweneagae’s (2010) study revealed that adolescents adhere to treatment as a means of avoiding stigma and discrimination associated with HIV/AIDS. Adolescents were found to seek treatment for common illnesses earlier to get treated immediately and keep silent about their HIV status to protect themselves from stigma and discrimination (Abadia-Barrero & Castro, 2006; Thupayagale-Tshweneagae, 2010).

2.5.3 Side effects

Nausea and vomiting are the most common side effects of Highly Active Anti-retro Viral Therapy (HAART) which in turn lead to non-adherence. Morphological alterations (MOA) were also reported to be side effects of HAART. HAART, especially protease inhibitors and nucleoside reverse transcriptase inhibitors act on fat distribution and lipid metabolism. This is characterized by abnormal alterations in body shape: loss of fat from the face, limbs and buttocks, increased deposition of fat on the abdomen which increases abdominal girth, breast enlargement, 'buffalo hump' and development of lipomas. Fat redistribution normally appears at puberty. However, the development of MOA which patients link to HAART and resultant loss of body image can put the patient at risk of poor adherence which may in turn lead to virological failure. These morphological alterations are also increasingly associated with dyslipidemia and impaired glucose intolerance in HIV infected children which are risk factors for cardiovascular diseases and diabetes (Hazra, Siberry & Mofenson, 2010; Guaraldi et al., 2003).

Use of HAART was said to contribute to bone loss by increasing bone turnover especially Tenofovir disoproxil fumarate (TDF). TDF is said to decrease bone mass density. Lifetime peak bone mass is normally attained at adolescence stage. Impaired bone mineralization during adolescence leads to higher rates of osteoporosis and fractures later in adult. Renal complications of ARV therapy were said to be increasing. Death due to renal failure have increased from <1% to 5% and become a cause of mortality in perinatally infected youth (Hazra, Siberry & Mofenson, 2010).

2.5.4 Bodily developments

Bodily developments were identified as challenges among HIV-infected adolescents. The notable feature from the clinical history and examination of HIV-infected adolescents

was a high prevalence of stunting. This is related to long standing growth failure related to high burden of chronic HIV related complications that were due to delay between the first manifestations of immune-suppression and diagnosis of HIV infection and treatment. The delayed diagnosis contributes to the high burden of morbidity in this age group. Most delays were between the first clinical manifestation of HIV infection and the first HIV test. This suggests that there were barriers of demand and supply to diagnostic testing which exist for this age group. These challenges (delayed bodily developments) were particularly among those who had not yet developed secondary sexual characteristics and were shorter and weigh less than their peers because of HIV and AIDS complications. Perinatally infected adolescents were mostly stunted, and went through puberty later than their peers (Dago-Akribi & Adjoua, 2004; Ferrand et al., 2007; Naswa & Marfatia, 2010).

2.5.5 Culture

Adolescents are often occupied with their bodies and with the development of their secondary sex characteristics. Delayed puberty due to longstanding growth failure which is related to chronic HIV and AIDS complications is a cultural challenge as well. In certain cultures like in Ivory Coast, adolescents who had not achieved puberty were unable to participate in traditional rituals and worried whether they could ever marry or have children. This was seen as a challenge as these rituals were regarded as passage to womanhood and manhood (Dago-Akribi & Adjoua, 2004; Naswa & Marfatia, 2010).

2.5.6 Disclosure

Disclosure of HIV status was also identified as one of the largest challenges facing people living with HIV (PLWHIV) including adolescents. Many adolescents do not access health care services for fear of disclosure to parents or guardians. Further, disclosure beyond the immediate care-giving family is a concern for HIV-infected adolescents and their care-

givers due to fear of stigma and discrimination. Disclosure to schools resulted in greater academic support for HIV-infected adolescents. However, disclosure through rumours and gossip had the potential to result in stigma and discrimination. Decisions about disclosure are dependent on perceived AIDS-related stigma (Cloete et al., 2010; Petersen et al., 2010).

Most adolescents seek acceptance from their peers in nearly every facet of life, including sexual behaviours. Being able to confide in a best friend can be a way for adolescents to 'normalize' their sexual experimentation. HIV-infected adolescents' sexual experimentation is complicated by the decision to disclose their HIV status, or not, to a friend and a potential or current sexual partner. The outcome of disclosing can be devastating and may result in rejection, harassment or violence (Childs & Maxwell, 2009; Petersen et al., 2010; Wrang, 2012).

The disclosure issue for HIV-infected adolescents has another twist. Adolescents worry that if they do not have sex with their boyfriends, they would assume that something was wrong with them. In this adolescents' world, sex is a norm and not to engage would highlight a problem (Childs & Maxwell, 2009; Petersen et al., 2010; Wrang, 2012).

2.5.7 Sexual behaviours or intimacy

Adolescence is the time when individuals initiate several behaviours including sexual intercourse which affect their health status. Adolescence can be a confusing time for youth, especially those living with a chronic and often stigmatized disease. HIV-infected adolescents were reported to be engaging in risky sexual behaviours due to depression, peer pressure, and other pressures of living with the virus (Naswa & Marfatia, 2010).

As adolescence is said to be a time of renegotiating and experimentation with autonomy, they turn to 'act out' with their parents. During this process, they fight with their

parents on issues of sexuality. For the perinatally infected, parents fail to set limits and spoil them due to the sense of guilt by the parents. On the other hand, adolescents turn to see this as a way of 'clinging' on them. As the adolescents' way of challenging the status core, they engage in risky sexual behaviours like multiple sexual partners to prove that they are adults (Childs & Maxwell, 2009; Naswa & Marfatia, 2010).

Parents were also reported to be too controlling over their HIV-infected adolescents sexual behaviours. Parents were sometimes reported to be conveying harmful restrictive messages to their adolescents trying to prevent transmission and re-infection. These harmful messages were said to erode the adolescents' sense of sexual being. In response, adolescents engage in multiple sexual partners trying to defy their parents and to find a sense of support and understanding that does not exist in their families (Childs & Maxwell, 2009; Naswa & Marfatia, 2010).

Research revealed that sexual intercourse is not only the act of pleasure and procreation, but for some it can be viewed as means of becoming totally cared for as many are struggling with issues of loss and bereavement of parents and siblings. Adolescents may use sex as a means of working through feelings that are difficult to express like grief (Childs & Maxwell, 2009).

2.5.8 Condom use

Consistent condom use with regular partner is very low among young people. CSO (2013), revealed that 65.2% of population aged 15 – 24 said they always use condoms with non-married or non-regular partner. The percentage dropped to 57.2% among population aged 15 – 24 who were HIV positive. Conditions such as poverty and unemployment are associated with sexual abuse, sexual intercourse in exchange for money and support for basic needs. Social and cultural reasons also place adolescents in a situation whereby young girls

may be less able to refuse sex or less able to insist on condom use. Often adolescents are confronted with challenges of seeking, receiving and using condoms due to lack of transport, discomfort with facilities (none youth friendly, unfriendly staff, long waiting time), lack of knowledge on condom use, and felt far and uncomfortable to buy and ask and lack of confidentiality on the facility staff (Ngomi, 2008; Sales & DiClemente, 2010).

2.5.9 Pregnancy

HIV-infected adolescents face some similar sexual health challenges as their non-HIV infected peers, including pregnancy. Unexpected pregnancies in HIV-infected adolescents who have not told their partners of their status create a crisis that requires the decision whether to disclose not only the pregnancy, but also the HIV status. Despite many positive outcomes for those who have chosen to disclose their status to their partners, it has proven to be impossible for others who fear their boyfriends' reactions and possible rejections. Despite all this, some adolescents' pregnancies are planned. Some social issues like lack of education, unemployment, lack of social support and some benefits attached to one's HIV status and parity fuel some adolescents' desire to become pregnant. For example, if an HIV positive woman has a 'qualifying' CD4 count and a history of an opportunistic infection, she then has an AIDS diagnosis. This qualifies her for monetary and housing benefits through New York states HIV/AIDS Services Administration. If she becomes pregnant, she qualifies for a larger apartment (Childs & Maxwell, 2009; Levine, Aaron & Foster., 2006).

2.5.10 Fear of death

HIV-infected adolescents also struggle with coming to terms with an engulfing fear of death. This fear is related to the outcome of their condition. Once this is uncovered, it allows a better understanding of the patient's sexual behaviours and pregnancy-making decisions as the patient's psychic energy has been heavily invested in defending against this fear. Some

studies revealed that many HIV-infected adolescents speak of a need to leave behind a legacy, for some in the form of a healthy, HIV free child, while others are unsure of what the future has for them (Childs & Maxwell, 2009).

2.5.11 HIV positive identity

Identity development is a key psychosocial developmental task during adolescence, often based on social comparisons. Coming to terms with an HIV positive (+) identity was identified as another challenge for adolescents living with HIV. Adolescents turn to withdraw from their friends and social activities on finding out their status. They felt different from others, even though they wanted to be normal. HIV-infected adolescents often have difficulty incorporating a chronic and stigmatizing illness into a healthy identity (Coleman & Hendry, 2002; Li et al., 2010; Petersen et al., 2010).

An adolescent living with HIV often incorporate negative stigma into their sense of self, resulting in internalized stigma associated with being a member of an 'out-group'. This internalized stigma in HIV-infected adolescents may develop into 'spoiled identity'. Adolescents internalize stigma; they feel uncomfortable when people talk negatively about HIV positive people. Linked to these identity issues were concerns about relationships. Others preferred HIV positive partners because of the identity issue and disclosure (Coleman & Hendry, 2002; Petersen et al., 2010).

2.5.12 Parental mortality

Literature revealed a high burden of parental ill health and mortality, which suggest that most of the adolescents were children of HIV-infected parents. Population based studies report high rate of orphan-hood among adolescents in Southern Africa. Loss of biological parents was said to be emotionally painful for these adolescents. Adolescents reported that

the most difficult thing about their parents' death was worrying about who was going to take care of them, loss of someone who loved them and families fighting over them (Petersen et al., 2010; Shisana et al., 2005; UNAIDS, 2014).

Loss of loved ones greatly affects the functioning and outlook of HIV-infected adolescents. Not only were they dealing with the possible loss of their own life, but in the case of perinatally acquired HIV, they were also dealing with the loss of their immediate family members. Adolescents differ greatly in the manner in which they cope with loss and death depending on their attachment to the deceased, past experiences with death and developmental stage. It is common for adolescents to have delayed response to loss, especially if they are concerned about their parent's grief responses. Loss of biological parents leads to greater risk influences for emotional and behavioural problems including poverty and family disruption. Parental loss can lead to poor child mental health like depression, conduct problems and delinquency (Battles & Weiner, 2002).

2.5.13 Lack of social support

Lack of social support emerged to be another big challenge faced by HIV-infected adolescents. The secrecy behind the HIV diagnosis which is due to fear of stigma and discrimination lead to minimum social support. Stigma and discrimination continue to control the life of the HIV-infected adolescents and govern their support system. Greater social support was frequently associated with better psychological outcomes in individuals with medical conditions. Social support emerged as key to assisting adolescents to cope (Battles & Weiner, 2002; Li et al., 2010,).

Adolescents with little social support displayed either emotional problem, including suicidal thoughts, poor adherence and aggressive behaviour. Those with strong family social support appeared to cope better. Support services which help these young people cope with

being HIV positive and living with it were said to be necessary. Peer support groups have been seen to be an effective approach in other parts of the world which open dialogue about living with the virus. Support from peers and adults (parents and teachers) combined appeared to have more impact than one of them alone (parents or teachers or peers). Social support was linked with disclosure. Disclosure was seen to be related to increased social support, social self-competence and decreased behavioural problems (Battles & Weiner, 2002; Li et al., 2010).

2.5.14 Tracing

As access to HIV testing expands in many countries, thousands of young people learn that they are HIV-infected but show no signs and symptoms. These adolescents after diagnosis of HIV, they disappear without a trace and resurface when critically ill. Here the challenge was to keep these young people connected to care and support systems that can meet their needs for emotional support, counselling and prevention education while monitoring needs for medical care and nutrition interventions. This leads to delays in initiating ARV treatment which lead to high HIV morbidity and mortality. Other countries keep contact with HIV-infected adolescents who are not on treatment through post-test clubs and mobilizing support for youth-friendly HIV and AIDS treatment and care services (Shears, 2005; Wrang, 2012).

2.5.15 Transition to adult care

Successful transition of care from pediatric to adult clinic is important in maintaining optimum health. HIV-infected adolescents face same challenges faced by other chronically ill adolescents with transition to adult care. Research revealed that transition to adult care was associated with lack of communication between pediatric and adult providers. This left the adolescents to fully communicate their whole treatment history again. For HIV-infected

adolescents, describing how they acquired their disease, medication, past medical history and related events can be stressful, incomplete or inaccurate. Literature also revealed that in most cases, transition to adult from pediatric care has been guided by age limit not developmental milestones and this result in adolescents aging out of care prior to being emotionally or cognitively ready. Those with cognitive deficits may particularly have difficulties with the transition (Ross et al., 2010).

Adult care providers are said to be used to deal with routine issues of partner notification and disclosure with adults but less versed in dealing with topic for the first time with youth. Disclosure issues to friends or peers and sexual partners emerge around the same time as the transition period (Ross et al., 2010).

One of the challenges identified was developing self-care skills to manage their illness moving from the pediatric which has multidisciplinary and family-oriented care models to adult care. As in other chronic illnesses, the challenges to transitioning adolescents to adult care system were perceived autonomy and difficulty letting-go of relationships between adolescents, their families and health care providers. Adolescents who did not know their HIV status were at risk as the autonomy which is needed in adult care include knowledge of one's' HIV status. With less social support in adult care, stigma and having to address their sexuality and reproductive health were also seen as challenges. With more interest in sexual relations, HIV-infected adolescents will need assistance in handling issue of disclosure, physical and psychological safety for themselves and others (Ross et al., 2010).

2.5.16 Life constructed by the clinic

Another challenge faced by HIV-infected adolescents identified in the literature was that the HIV-infected adolescents' lives were seen to be controlled by the health facilities. Everything HIV-infected adolescents do in life needs to be made or controlled by the clinic or

health facility. These adolescents need medical check-ups, if they want to start a family, or want to be sexually active; they need to get counselling about how to do it without the risk of transmitting the HIV to both the partner and the baby (Wrang, 2012).

2.5.17 Missing school

Waiting time in the health facilities was seen be a contributing factor to school absenteeism. Health facilities were also seen to be not youth-friendly considering the fact that consultation times are in the morning when lessons are going-on. This led to adolescents missing lessons and school. HIV-infected adolescents were also missing school because of illness and clinic visits. Perinatally infected adolescents were reported sometimes to be shouldering new responsibilities when their parents get sick. These responsibilities include domestic chores such as cooking, cleaning, laundry, care-giving activities like bathing, feeding and accompanying parents for treatment. School attendance drops because labour is needed or because families cannot afford to pay school fees. Families sometimes make decisions that children should drop out of school to care for the sick parent or sibling (Hardon et al., 2006; Wrang, 2012).

2.6 Summary

Since the beginning of HIV and AIDS pandemic in mid 1980s', millions of people died and other millions are living with the HIV while others are getting infected daily worldwide. After the introduction of HAART, HIV and AIDS morbidity and mortality went down. HAART was seen as being able to reduce the ability of the HIV to replicate, hence increasing the body's immune system to defend itself against diseases. Even after the introduction of HAART, HIV and AIDS is still claiming lives of people. Reports show that different groups of people living with HIV are facing different challenges which hinder the efforts to control and manage HIV and AIDS.

Adolescents living with HIV are one group which is facing challenges in their life with HIV. Literature has revealed that both perinatally and behaviourally HIV-infected adolescents often have differing and common challenges. These challenges may include; medication non-adherence, high-risk sexual behaviours, disclosure, parenting or pregnancy, fear of death, lack of social support, loss of parent or parents or siblings, stigma and discrimination, transition from pediatric to adult care, bodily developments (illness complications), complication of HAART and/ or AIDS, HIV positive identity, tracing (lost to follow), missing school and life constructed by the health facility.

Considering the discussed challenges faced by HIV-infected adolescents, the study will use the following challenges to see if they are applicable to the HIV infected adolescents in the rural areas of Botswana: lack of social support, non-adherence, stigma and discrimination, disclosure, intimacy, missing school, HIV positive identity, tracing, transition from pediatric to adult care and complications of HAART and /or AIDS. These challenges identified, will provide the theoretical background against which to compare findings with data which will be gathered in this study. This will also assist in supplementing the interview guide and in discussion of emerging themes.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents the method by which the study will be carried out. It describes and justifies how the research questions will be answered. Included in this chapter are: definition of the research design which will be used and the reason for its use, the theory that will be guiding the research, study setting, study population, sample, ethical considerations, instrument for data collection, pilot testing, data collection procedures, trustworthiness and credibility of the research data and data analysis plan.

3.2 Research Design

Research design is the overall plan for addressing the research question and the specifications for improving the study's integrity. Research design entails defining the research problem, formulating research questions from the research problem, designing the appropriate research process, collecting data to assisit in answering the research questions, analyzing the data and reaching certain conclusions from the analyzed data hence answering the research questions. The purpose of a research design is to improve the validity of the study in examining the research problem (Burns & Grove, 2011; Polit & Beck, 2013).

3.2.1 Research questions

The research questions for this study are:

1. What are the challenges faced by HIV-infected adolescents in the rural areas?
2. Describe the challenges faced by HIV-infected adolescents in rural areas
3. How do HIV-infected adolescents cope with these challenges?

3.2.2 Research classification

Different research problems require different research methods. The classification facilitates in chosing of the appropriate research method for the particular research. Research can be classified in to purpose, process, frequency and logic (Burns & Grove, 2011; Mark, 2007; Polit & Beck, 2013).

3.2.2.1 Process

Research can be categorized according to process ie: quantitative and qualitative research (Brink, Van Der Walt & Van Rensburg, 2007; Burns & Grove, 2011; Mark, 2007; Polit & Beck, 2013).

- **Quatitative research**

Quantitative research is concerned with describing the phenomenon under study by measuring of quantity or amount and involving statistical manipulations. Data collection techniques in quantitative research would include questionnaires and actual measurements of the phenomena like weight, height and duration of projects (Brink, Van Der Walt & Van Rensburg, 2007; Burnard, Morrison & Gluyas, 2011; Burns & Grove, 2011; Mark, 2007; Polit & Beck, 2013).

- **Qualitative research**

Qualitative research is concerned with describing the phenomena in words to gain an understanding of the issues being researched within the context of the researcher. This type of research is concerned with subjective assessment of attitudes, behaviours and opinions. The goal of the qualitative research is to document and interpret as fully as possible, what is being studied from the people's point of view. Qualitative research includes the identification, study and analysis of subjective and objective data in order to know and understand the internal and

external worlds of people. A hypothesis is not tested, but the data helps to answer the research questions (Brink, Van Der Walt & Van Rensburg, 2007; Burnard, Morrison & Gluyas, 2011; Burns & Grove, 2011; Mark, 2007; Polit & Beck, 2013). This study will utilize a qualitative design to investigate the challenges faced by HIV-infected adolescents in rural areas of Botswana: the case of Kaudwane, Salajwe, Sorilatholo and Khudumelapye.

- **Reasons for using a qualitative design**

Qualitative research design develops a rich understanding of a phenomenon as it is constructed by individuals in the context of their world. Qualitative studies thoroughly describe and explain a phenomenon. This design is suitable for this research as it will thoroughly describe and explain the challenges faced by HIV- infected adolescents in rural areas. Qualitative research will guide this study with describing the challenges faced by HIV-infected adolescents in words to gain an understanding of the issue being researched (Brink, Van Der Walt & Van Rensburg, 2007; Burnard, Morrison & Gluyas, 2011; Calman, 2006; Polit & Beck, 2013).

3.2.2.2 Purpose of research

Research can also be classified according to the purpose for which it is carried out. According to purpose, the research can be exploratory, descriptive, analytic and predictive. Exploratory research is designed to gain insight in to a situation of which little is known about a phenomenon of interest. Descriptive research clearly describes the situation or behaviour at a particular time. The descriptive research may usually follow the exploratory research to describe the situation of interest. Analytical research is designed to analyse the existing data to understand the situation at hand. Predictive research is designed to determine the cause effect of some variables and predict what will happen. It involves a hypothesis and testing it statistically (Mark, 2007; Polit & Beck, 2013; Robson, 2002).

This will be an exploratory and descriptive research as it is designed to gain insight into a situation of which little is known about challenges faced by HIV-infected adolescents in rural areas in Botswana and this research also requires description of the challenges faced by HIV-infected adolescents. Analytical research will also be used to answer the research questions: 'how do HIV-infected adolescents cope with the challenges they face?'

3.2.2.3 Research frequency

Research can be classified according to how often the data is collected from the population. Depending on the frequency of data collection, research can be cross-sectional or longitudinal. Cross-sectional studies are used to examine data at one point in time with different subjects. Longitudinal studies allow the researcher to collect data at several points in time with same subjects. This will be a cross sectional study as data will be collected at one point in time which will be cheap and at the same time generating a realistic picture of what was or will be going on at a particular time (Brink, Van Der Walt & Van Rensburg, 2007; Mark, 2007).

3.2.2.4 Research logic

Research can also be classified into deductive and inductive research basing on the logic behind the research. In deductive research, expectations of hypothesis are developed to prove the hypothesis. It starts from theories to a conclusion based on data that is collected to accept or refute an idea. In an inductive research, the researcher observes carefully and/or conducts an experiment, analyses data obtained and produce new discovery or theory to explain what is happening. Personal opinions are excluded from the process to arrive at what is believed to be objective knowledge. In this research, data will be collected about challenges faced by HIV-infected adolescents and theory behind the challenges will be generated. This research will be classified as inductive research (Brink, Van Der Walt & Van

Rensburg, 2007; Burnard, Morrison & Gluyas, 2011). This inductive research will follow the principles of grounded theory.

3.3 Grounded theory

The grounded theory approach is a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon. This theory was developed in 1960's by Glaser and Strauss (as cited in Burnard, Morrison & Gluyas, 2011).

Grounded theory approach identifies concepts and the relationships between them in an inductive manner. One of the fundamental features of the grounded theory approach is that data collection, data analysis and sampling of the study participants occur simultaneously. This method involves the collection and analysis of data to generate a theory about the topic being studied. Grounded theory emphasize on human beings as active, rather than passive. This theory has been used most frequently to study areas in which little previous research has been conducted. In the context of this research study, the researcher sought to explore and describe the challenges faced by HIV-infected adolescents in rural areas. The researcher also wants to find out how these adolescents cope with these challenges and as such, grounded theory is seen to be suitable for this research (Burnard, Morrison & Gluyas, 2011; Burns & Groves, 2011; Polit & Beck, 2013).

3.3.1 Reason for using grounded theory

Grounded theory is chosen by the researcher as the appropriate method because:

- Grounded theory is suitable for study areas in which little previous research has been conducted. There is limited research on challenges faced by HIV-infected adolescents in rural areas and to my knowledge there is none in Botswana.

- Grounded theory's intention is to explore what is in the field and generate a theory that is truly grounded in the data as opposed to one that is guided by previous research.
- The results of grounded theory accurately represent real world settings because they are close to the data from which they are generated (Burnard, Morrison & Gluyas, 2011; Burns & Groves, 2011).

Grounded theory approach will be used to guide the study in answering the research questions. The research questions for this study are:

1. What are the challenges faced by HIV-infected adolescents in rural areas?
2. Describe the challenges faced by HIV-infected adolescents in rural areas.
3. How do HIV-infected adolescents cope or deal with these challenges?

The researchers must systematically collect data, categorize them and write memos, describe the central phenomena and recycle early steps. Memos are theoretical notes about the data. They link the properties and connect concepts and put together the entire theory. Observation, focus group discussion, informal interview and semi-structured interviews are used to gather data in grounded theory. This research will use focus group discussion to collect data. For grounded theory to be used as guide, the mechanism of grounded theory should be clearly defined (Burnard, Morrison & Gluyas, 2011; Burns & Groves, 2011; Chen, 2005; Polit & Beck, 2013).

3.3.2 Mechanism of grounded theory

The key concept for grounded theory approach is theoretical sensitivity. Theoretical sensitivity is the attribute of having insight and the ability to give meaning to data which is done through continous interaction with the data. In order to use grounded theory as a guide for research study, the research must emphasize on two procedures being theoretical

sampling and constant comparative method. Theoretical sampling and constant comparative method reflect cyclical processes which are flexible but ensure that the analysis is planned and well grounded in the data (Burnard, Morrison & Gluyas, 2011; Burns & Groves, 2011; Chen, 2005; Polit & Beck, 2013)

3.3.2.1 Theoretical sampling

Theoretical sampling is the joint process of data collection, coding and analysis. It is the process of data collection for generating theory whereby the analyst jointly, collects, code and analyse the data and decide upon what data to collect next and where to find it, in order to develop the theory as it emerges. There are two important mechanisms which are involved in theoretical sampling. These mechanisms are selection of groups and theoretical saturation. The selection of groups is guided by the need for theoretical development and theoretical saturation is the stage where the theorist can see that no additional data collection can further develop a category. Theoretical sampling is about emerging categories or checking the emerging conceptual framework. In grounded theory method, data collection is defined by theoretical sampling (Bowen, 2006; Glaser & Strauss, 1967). Theoretical sampling has three characteristics of grounded theory which are;

1. Theoretical sampling is an integrated process of data collection, coding and analysis where these activities occur congruently.
2. The initial data collection decisions are based on a general perspective and on a general subject or problem area rather than on a preconceived theoretical framework.
3. The proceeding of the data collection should be directed by the emerging theory (Bowen, 2006; Glaser & Strauss, 1967).

3.3.2.2 Constant comparative method

Constant comparative analysis is the process by which incidents are compared to generate and suggest categories, properties and hypothesis. Constant comparative analysis is

in four stages being; 1) comparing incidents applicable to each category, 2) integrating categories and their properties, 3) delimiting the theory and 4) writing the theory. In this process, data collection, coding and analysis are done simultaneously. Each stage is transformed into the next while the early stages remain operational simultaneously throughout the analysis until the theory emerges. In constant comparative analysis, the researcher should start with open coding until a core category emerges. Coding is the process of categorizing and sorting data. Codes are used to label, separate, compile, organize, synthesize and summarize data (Bowen, 2006; Glaser & Strauss, 1967).

3.4 Study setting

The study setting will be four ARV clinics in four rural villages. These villages will be Salajwe, Kaudwane, Sorilatholo and Khudumelapye in Kweneng-West Sub-District in Botswana. These villages have one clinic each providing primary health care services. Population of Botswana was 2 021 000 in 2013. The HIV prevalence for Kweneng-West in 2013 was 11.8% which was the lowest but one compared to other districts in Botswana (Brink, Van Der Walt & Van Rensburg, 2007 ; CSO, 2011; CSO, 2013).

3.5 Study population

The study population for this study will be HIV-infected adolescents aged between 10 and 19 years in Salajwe, Kaudwane, Sorilatholo and Khudumelapye villages. Accessible population refers to those that conform to the eligibility criteria and that are available for the study (Brink, Van Der Walt & Van Rensburg, 2007; Polit & Beck, 2013).

3.6 Sample

The sample will be obtained through convenience sampling. Convenience sampling is a non-probability sampling which entails using participants who are readily available. The

study participants will be HIV-infected adolescents. The participants will be obtained from Khudumelapye, Sorilatholo, Salajwe and Kaudwane ARV Clinics through the help of the clinics' ARV nurses. This is the most commonly used sampling method in many disciplines (Brink, Van Der Walt & Van Rensburg, 2007; Burnard, Morrison & Gluyas, 2011; Polit & Beck, 2013).

3.6.1 Sample size

Grounded theory's main aim is to gather enough data until theoretical saturation. It focuses more on the descriptive data than the number of people to recruit. Qualitative researchers have recommended sample sizes ranging from 12 to 30 for a grounded theory study. The researcher will work with an initial sample size of a minimum of 12 clients per a clinic and a maximum of 30 for the three clinics. This is because the researcher is trying to discover lot of variables in the phenomenon of interest. Theoretical sampling, which could necessitate more data collection from the same participants or from different participants, may increase the planned sample size (Guest, Bunce & Johnson, 2006).

3.6.2 Inclusion criteria

The criteria for inclusion in the study will be:

- HIV-infected adolescents aged between 10 and 19 years
- Adolescents who understand English, Setswana, Sekgalagadi
- Adolescents who have knowledge of own HIV status
- Adolescents who are not cognitively impaired

3.6.3 Exclusion criteria

The criteria for exclusion from the study will be:

- HIV negative adolescents
- HIV-infected adolescents without knowledge of own status
- Cognitively impaired adolescents

3.6.4 Recruitment of the sample

The researcher will hold meetings with the health authorities and clinics health workers to share the goals, objectives, benefits, inclusion and exclusion criteria, procedures for data collection and ask nurses and Health Education Assistants to be gatekeepers. Two recruitment strategies will be used. The researcher will obtain information on eligible clients from registry. All HIV positive adolescents in Salajwe, Kaudwane, Sorilatholo and Khudumelapye who meet the inclusion criteria will be invited to participate in the study. The researcher with the assistance of the gate keepers will also participate in the recruitment process by contacting eligible individuals per telephone together with their parents if under the age of 18 years. In the event that telephone attempts fail or the individual has no telephone, the potential participant will be invited to the study during his or her medical review at the ARV clinic. The potential participants will be given information on the purpose of the research and the method of data collection which will be focus group discussion by the researcher. Those interested will be given consent forms and those less than 18 years, assents and their parents or guardians consents to sign. The appointment date and place for interview will be scheduled at a convenient place and time. Consents will be obtained in the preferred language of the participant (Brink, Van Der Walt & Van Rensburg, 2007; Burnard, Morrison & Gluyas, 2011; Vital, 2013).

3.7 Ethical consideration

Ethics must be considered when humans are used as study participants. Care must be exercised in ensuring that the rights of those humans are protected (Polit and Beck, 2013). Permission to carry-out the study will be requested from the University of Botswana and Health Research Unit. The permission will also be sought from Kweneng West District Health Management Team (DHMT) and the facilities which will be utilized.

Those participants who will be 18 years and above will be given a consent to sign if they agree to participate and both child assent and parental or guardian consent will be obtained from those participants under 18 years. A copy of the consent and assent forms will be given to the participants. Permission to audio-tape the discussions will be sought from the participants. Participants will be given full information about the study, that is, the purpose and why they were chosen as participants. They will also be told that they have the right to refuse to participate and that they may terminate their participation at any point or refuse to give information or ask clarification about purpose of the study and that this will not disadvantage them in any way. The purpose of the study will also be explained to the participants and their parents or guardians. Only those participants who had consented to participate will participate in the study (Brink, Van Der Walt & Van Rensburg, 2007; Burnard, Morrison & Gluyas, 2011; Polit & Beck, 2013).

Anonymity will be maintained by coding the data and confidentiality will be maintained by not sharing data with people who are not part of the study. After the study is complete, all tapes and transcription notes will be destroyed after five years (Brink, Van Der Walt & Van Rensburg, 2007; Burnard, Morrison & Gluyas, 2011; Polit & Beck, 2013).

3.8 Instrument for data collection

An interview guide developed will be used as an instrument to collect data. The data collection will have two sections which will be a demographic data survey and focus group discussion. Both the demographic data questionnaire and the focus group interview guide will be developed by the researcher (Brink, Van Der Walt & Van Rensburg, 2007; Burnard, Morrison & Gluyas, 2011; Midtbø, 2012; Polit & Beck, 2013). These sections will include;

Section 1: five item demographic survey

The demographic data will include; gender, age, school participation or occupation, tribe or preferred language and primary care-giver.

Section 2: focus group discussion interview guide

The researcher will develop an interview guide from the literature reviewed. Interview guide will be used to guide the group discussions based on the research questions. The interview guide will include a range of topics including; stigma and discrimination, disclosure, HIV positive identity, transition from paediatric to adult care, coping mechanisms and complications of HAART and /or AIDS. The group discussion guide will be written in English and translated into Setswana. Setswana version will be used for collecting data (Brink, Van Der Walt & Van Rensburg, 2007; Burnard, Morrison & Gluyas, 2011; Midtbø, 2012; Polit & Beck, 2013).

3.9 Pilot testing

Study testing will be conducted on HIV-infected adolecsents in Bamalete Lutheran Hospital Infectious Disease Control unit at Ramotswa in South-East District to test various parts of the research process including consent and assent forms, interview guide, methodology and study protocol. The results of the pilot study will be used to improve the

study process, methodology and interview guide for focus group discussion basing on the results (Brink, Van Der Walt & Van Rensburg, 2007; Midtbø, 2012).

3.10 Data procedures

3.10.1 Data collection Procedure

Data can be collected from a population using interview, focus group discussion, questionnaire, field notes or observation. Observation, focus group discussion, field notes, informal interview and semi-structured interviews are used to gather data in grounded theory. Focus group discussion and field notes will be the methods of data collection for this study. Focus group discussion develops new knowledge and seeks opinions, values and beliefs in a collective context. Appointments will be made for the data collection. Two focus groups will be drawn from each location depending on age. Data collection will be done at the participants' respective clinics (Kabomo-Magowe, 2008; Li et al., 2010; Maokisa, 2011; Petersen et al., 2010).

Participants will be asked to complete demographic survey form and participate in a focus group discussion. Focus group discussion will be guided by a semi-structured interview guide. Interviews will be audio-taped with the participants' consent (Li et al., 2010; Petersen et al., 2010).

On the day of the interview, the researcher will introduce herself and purpose of the study. The participants' consents will be rechecked. The adolescents will be informed that they are free to refuse participation in the study. The participants will be told that data will be collected through focus group discussions and demographic survey. Groups will be organized by their ages into two groups. There will be the 10 to 15 years group and 16 to 19 years groups according to early and late adolescence. Each group will have six to eight participants

and each village or site will have two groups being early and late adolescence stages. The interview will be done once per group (Chen, 2005).

During the focus group discussions, the researcher will be writing extensive field notes of observations. After every discussion, the researcher will summarise the participants' responses or reflect to enhance credibility.

3.10.2 Theoretical sampling

In accordance with the mechanism of theoretical sampling, data collection after the initial stage would depend on the emergence of categories. The initial data collection will start with the data that will be collected from HIV-infected adolescents in rural areas and then identifying the emerging categories. It is hoped that the data pool will have enough data for the discovery of a grounded theory but if not, the researcher will decide upon what data to collect next and where to find it, in order to develop the theory as it emerges (Chen, 2005).

3.10.3 Data management

After the focus group discussions and survey, the recordings and questionnaires will be transcribed and saved in a laptop with a personal password which will only be known by the researcher. The laptop will always be kept in a safe place. The transcribed data will also be stored in two memory sticks which will be used as backup. These memory sticks will be stored in two safe different places. The transcribed data will not contain any names which will prevent anyone from tracing and identifying the participants. The original names will be replaced by numbers. The recordings will be erased after transcription in two to five years. The interview transcripts will be stored for two years after submission of the research project and deleted (Chen, 2005).

3.10.4 Data analysis plan

Data has to be analysed in a systematic way so that trends and patterns of relationships can be identified in order to obtain meaningful answers to research questions. The purpose of data analysis is to impose some order on a large body of information so that data can be synthesized, interpreted and communicated in a research report (Bowen, 2006; Brink, Van Der Walt & Van Rensburg, 2007).

Demographic data will be analysed to give a picture of the sample. The demographic data will be put in a table form in a frequency distribution. This information will be used in forming groups for group discussions which will be done according to age. This data will also show other categories of the sample. Demographic data will also show the quantitative representation of the sample (Brink, Van Der Walt & Van Rensburg, 2007).

Data from the group discussions will be analysed using constant comparative method. To operationalize grounded theory, research must emphasize on constant comparative analysis together with theoretical sampling. Constant comparative method is said to be in four stages which are; 1) comparing incidents applicable to each category, 2) integrating categories and their properties, 3) delimiting the theory and 4) writing the theory (Bowen, 2006).

The relationship among data collection, coding and analysis is a growing process. Coding is the process of categorizing and sorting data. The coder will be engaged. Discussions will be transcribed, translated into English and coded. The researcher and the coder will code separately. The coding process will begin with reading of the transcripts several times and listening to recordings again to check accuracy and identify themes to build categories. At the same time the researcher will analyse the data for new properties of the categories and writes memo. With more categories, the researcher will embark on constant

comparison of incidents to incidents, incidents to categories and incidents to properties. With core categories emerging, data collection, analysis and coding will focus on core categories. Coding of core categories will continue until the collection of further data and coding do not modify the categories; this is reaching theoretical saturation. Data will be scrutinized word by word so that provisional concepts and their dimensions emerge. These processes will in turn affect data collection. A conceptual framework of interrelated core concepts and their relationships will be developed. This process will continue until a theory is fully integrated (Bowen, 2006; Chen, 2005).

3.11 Trustworthiness

Qualitative researchers use trustworthiness criteria in evaluating the study's quality. This study will use trustworthiness to evaluate the study quality. Guba's model of trustworthiness will be applied to enhance trustworthiness of this research. Trustworthiness encompasses credibility, transferability, confirmability and dependability (Lincoln & Guba, 1985; Krefting, 1990).

3.11.1 Credibility

Credibility is a criterion for evaluating data quality referring to confidence in the truth of the study. Prolonged engagement and persistent observation were recommended by Lincoln and Guba as activities that make it more likely to produce credible data and interpretations. In this study the researcher will be engaged in all steps of the research process and have prolonged contact with participants from selection of participants, recruitment procedures, focus group discussions to member checking. The researcher will also ensure credibility by ensuring that adequate amount of data has been examined to support that no additional data would yield different findings. Data will be collected until theoretical saturation is reached. If after initial data collection, the theory is not discovered, the

researcher will embark on theoretical sampling until the theory emerges (Lincoln & Guba, 1985; Krefting, 1990; Polit & Beck, 2013).

3.11.2 Transferability

Transferability is the extent to which findings can be transferred to other settings. The key factor in the transferability of data is the representativeness of the sample for that particular group. For this study, the researcher will avail background information about the sample, study setting and research context to allow others to assess how transferable the findings are. For transferability judgement to take place, it is the researcher's responsibility to ensure that adequate information is available to others or to the judges (Lincoln & Guba, 1985; Krefting, 1990).

3.11.3 Dependability

This refers to the stability of data over time and over conditions. Triangulation will be used to enhance dependability. This ensures that the weakness of one method of data collection is compensated by the use of an alternative method. To overcome bias, member and peer checking techniques will be used. The coder and the researcher will code independently and discuss until consensus is reached if any disagreements. Member checking will be done by discussing the summary of the interviews with the participants to confirm that the researcher is representing their ideas correctly (Krefting, 1990; Lincoln & Guba, 1985; Polit & Beck, 2013).

3.11.4 Confirmability

Confirmability refers to the objectivity or neutrality of the data. Audit strategy is viewed as the major technique for establishing confirmability. Audit strategy describes a situation in which other researchers can clearly follow through the decision-trail used by the

investigator. This can be done by an independent coder. For this study, the independent coder will be engaged to audit the process of research, product, data, findings, interpretations and recommendations (Krefting, 1990; Lincoln & Guba, 1985).

3.12 Summary

The study will utilize a qualitative design guided by grounded theory to investigate the challenges for HIV-infected adolescents in rural areas of Botswana. Qualitative research's aim is to document and interpret as fully as possible, what is being studied from the people's point of reference. For this study, the study population will be all HIV-infected adolescents aged between 10 and 19 years in Salajwe, Kaudwane, Sorilatholo and Khudumelapye villages and these villages' catchment areas. Permission to do the study will be sort from the University of Botswana, Ministry of Health, Kweneng-West District Health Management Team and said facilities. Informed consent will be obtained from the caregivers of participants below 18 years of age and from all participants.

The sample will be obtained through convenience sampling. The data collection will have two sections which will be a demographic survey and focus group discussion. All discussions will be recorded, translated into English and transcribed. For this study, data will be analysed using constant comparative analysis. In this analysis, data will be used for the development of a general theory of challenges faced by HIV-infected adolescents in rural areas of Botswana. Demographic data will show the quantitative representation of the sample. Guba's model of trustworthiness will be applied to enhance trustworthiness of the research. Trustworthiness encompasses credibility, transferability, confirmability and dependability.

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APPENDIX 1

DEMOGRAPHIC DATA SURVEY

1. Sex _____
2. Age _____
3. School participation _____
4. Tribe or preferred language _____
5. Primary care-giver _____

APPENDIX 1

DEMOGRAPHIC DATA SURVEY: Setswana version

1. A o mosetsana kana mosimane? _____
2. Dingwaga tsa gago di kae? _____
3. O dira mophato wa bokae kana o dira eng? _____
4. O tswa mo morafeng ofe kana o rata go dirisa puo efe? _____
5. O tlhokomelwa ke mang? _____

APPENDIX 2

GROUP DISCUSSION GUIDE

1. How do you feel about HIV?
2. What kind of things make you feel good?
3. What kind of things make you feel bad?
4. What are the challenges that you face as an adolescent living with HIV?
5. How do cope or avoid these challenges?
6. Are HIV positive adolescents stigmatized and discriminated against?
7. What behaviours do you use to protect yourself from stigmatization and discrimination?
8. Is there anything in the clinic or community which help you to deal with these challenges?
9. What do you think can be put in place to assist you through these challenges?
10. Picture yourself in 10 years. What do you see?
11. How do you feel about the future?
12. What would make your life easier?
13. If you could tell everybody one message about HIV, what would it be?

APPENDIX 2

GROUP DISCUSSION GUIDE: Setswana version

1. Maikutlo a gago ke eng ka mogare wa HIV?
2. Ke dife dilo tsedi dirang gore o ikutlwe o itumetse?
3. Ke dife dilo tsedi go utlwisang botlhoko?
4. Ke dife dikgwetlho tse o kopanang le tsona ole monana yoo tshelang ka mogare wa HIV?
5. O hema jang mathata a?
6. A gona le dilo dingwe mo kokelong kana mo motseng tsedi go thusang go hema dikgwetlho tse?
7. Ke eng se se ka dirwang go hema dikgwatlho tse?
8. A banana ba ba nang le mogare ba kgethololwa?
9. O dira jang gore o seka wa kgethololwa?
10. O ipona ole fa kae, o dira eng mo ngwageng tse dilesome tsedi tlang?
11. Maikutlo a gago ke afe kana ke eng ka isago?
12. Ke eng se se ka dirang botshelo jwa gago motlhofo?
13. Fa go katwe o bolelele batho molaetsa ole mongwe ka HIV, o ka reng?

APPENDIX 3

REQUEST FOR PERMISSION TO CONDUCT THE STUDY

University of Botswana

Private Bag 0031

Gaborone

4th July 2015

Health Research Unit

Ministry of Health

Private Bag 0038

Gaborone

UFS

Head of Nursing Department

Dear Sir/Madam

RE: Permission to carry out a study titled ‘challenges faced by hiv-infected adolescents in rural areas

I am a nurse studying for Masters Degree in Community Health Nursing with the University of Botswana. As part of the requirements to obtain Masters Degree, I am to carry out a research project. I am therefore requesting permission to carry out a research project in Kudumelapye, Shorilatholo, Salajwe and Kaudwane in Kweneng West District.

It is hoped that the study will create an understanding on the challenges faced by HIV-infected adolescents in the rural areas of Botswana. The results will assist the health providers in the planning of health services for HIV-infected adolescents in rural areas.

I hope my application will be considered. Attached is the research proposal.

Yours faithfully

Matlhodi Gosa Basuhi

APPENDIX 4

UNIVERSITY OF BOTSWANA

INFORMED CONSENT FOR PARENTS OR GUARDIANS OF ADOLESCENTS PARTICIPATING IN RESEARCH

Title: Challenges faced by HIV-infected adolescent in rural areas of Botswana.

Principle Investigator: Matlhodi Gosa Basuhi

Name of Organization: University of Botswana

This Informed Consent form has two parts. These two parts are:

1. Information sheet

   This part is for information about the study. It is meant to share information with you about the study.

2. Certificate of Consent

   This part is for your signature. It is signed when you agree that your child may participate in this study.

You will be given a copy for both parts of the Informed Consent Form.

INFORMATION SHEET

Introduction

I am Matlhodi Gosa Basuhi, a student at the University of Botswana. I am doing research about adolescents in some of the clinic in your district which might help the health workers to do more to help adolescents living with HIV in rural areas.

Whenever research involves adolescents, permission has to be asked from parents or guardian. After you have understood the study and given us permission, we will ask your daughter or son for their participation as well. For us to begin the study, you both have to agree independently.

Before you decide, you can talk to anybody you trust. You need to take your time to decide on whether to grant permission or not. You do not have to decide today. Please ask me to stop and explain more where you do not understand. In case you need some clarifications during my absence, you can ask the clinic to contact the researchers for clarity. The research will only include people who choose to participate in the study. For the purpose of this study, 'your child' in this consent form refers to a minor or a person below 18 years old whom you are a legally appointed representative.

Purpose

In this study, we will talk to adolescents about challenges or problems they face as HIV-infected adolescents. This study is aimed at exploring the challenges faced by HIV-infected adolescents in your area. The study will be focusing on identifying and describing challenges faced by HIV-infected adolescents and finding out how these adolescents cope with these challenges.

Important details about the study

Group interview and survey will be used to gather information from participants. The interview and survey will take one to two hours altogether on the selected dates which will be communicated to you in advance.

Selection of Participants

We want to talk to adolescents (children aged 10 to 19 years old) who are HIV-infected. These will be adolescents from Khudumelapye, Sorilatholo, Salajwe and Kaudwane and catchment areas.

Voluntary Participation

You can say no or agree that your child can participate. All the services you and your family receive will not be affected by your decision. We know that this decision can be difficult especially when the research includes children and their HIV status. You do not have to decide today. You can tell me what you decide later. You are free to ask as many questions as you can and we will be happy to answer them.

Procedure

Your child will take part in the discussion with six to eight other HIV-infected adolescents. The children will be in separate groups according to age. The discussion will be guided by the principal researcher. The group discussion will start with the researcher making sure that the participants are comfortable. We will also invite and answer questions that they might have about the research. The discussion will include information about HIV stigma and discrimination, disclosure, social support, experiences or other challenges they face, how they conquer these challenges and what they think can be done to make life easy for them.

The discussion will take place at the local clinic office and no one else but the people who take part in the discussion and the researcher will be present. The discussions will be audio-taped but no one will be identified by name on the tape. The tapes will be kept in a safe under lock and key. The information recorded will be confidential and no one else will listen to the tapes except the researchers. The tapes will be destroyed after three months.

Your child will also fill out a questionnaire survey or the questionnaire survey will be read aloud and she or he can give the answers she or he wants to write. Included in the survey is sex or gender of the child, age, tribe or preferred language, relation to parent or guardian and occupation. The survey information will be kept confidential and no one else except the researcher will have access to the information.

Risks

There are no medical risks involved as this is not a medical study. Some topics which will be discussed might be difficult or sad to talk about, and if this happens, your child can always choose not to talk about them if he or she does not want to. Your child never has to talk about something he or she does not want to talk about.

Benefits

There may or may not be direct benefit to you and your child if you agree to participate in the study. We hope what is learnt from the study will benefit other adolescents living with HIV in the future.

Audio-taping

I request permission to audio-tape the interviews.

Reimbursement

Your child will not be provided with any payment for participating in the research, but he or she will be given P50 for transport and time lost.

Confidentiality

We will not share the information about your child with anyone outside the research team. The information collected will be kept confidential and no one else will have access to the information except the researchers. Any information about your child will be allocated a number instead of your child's name and the researcher will be the only person who knows the number and these will be kept under lock and key by the researcher.

We will ask your children not to discuss the information which was said in the group with people outside the group. However you should know that we cannot stop participants from sharing the things that should be confidential.

Sharing research findings

We will be sharing the findings of the study with the participants first and then the community at large. A report will also be written, given to the participants to share with their families and another report will be submitted to the Ministry of Health and Kweneng-West Sub-district and published so that other people interested may learn from it. The results will also be written as a report which will be part of a Masters Degree research for the principal investigator.

Right to refuse or withdraw

You may choose not to allow your child to participate in the study and your child may not choose to participate in the study. Your child is free to stop participating at any point of

the study. All the services you and your family receive will not be affected by your decision. We know that this decision can be difficult especially when the research includes children and their HIV status. You do not have to decide today. You can tell me what you have decided later. You are free to ask as many questions as you can and we will be happy to answer them.

Who to contact

If you have any questions now you may ask me and if you wish to ask later, you may contact:

NAME: Matlhodi Gosa Basuhi

ADDRESS: P O Box 1570 Gaborone

WORK TELEPHONE NO: 5381661

CELL NUMBER: 71845005

E-MAIL: gosakb@yahoo.com

APPENDIX 4

TESELETSO YA BATSADI BA BANANA BABA TSAYANG KAROLO MO PATLISISONG

SETLHOGO SA PATLISISO: Dikgwetlho tse banana ba ba nang le mogare wa HIV ba kopanang natso mo dikgaolong tsa magae mo Botswana

MMATLISISI-MOGOLO: Matlhodi Gosa Basuhi

LEPHATA: University of Botswana

Pampiri e ena le karolo tse pedi. Dikarolo tse ke:

Karolo ya ntlha

Karolo ya ntlha e bua ka thuto-patlisiso e. E diretswe go gofa lesedi ka thuto-patlisiso e.

Karolo ya bobedi

E ke setlankana sa tetlelelo. O baya mononwa wa gago fa o dumalana gore ngwana wa gago o ka tsaya karolo mo thuto-patlisisong e.

O tla fiwa moriti wa dipampiri tse.

TLHALOSO KA THUTO-PATLISISO

Ketapele

Ke bidiwa Matlhodi Gosa Basuhi. Ke moithuti ko University ya Botswana. Ke dira patlisiso mo dikokelwaneng mo kgaolong ya lona tsedi ka thusang badiri ba tsa botsogo go tokafatsa matshelo le botsogo ba banana ba ba tshelang ka mogare wa HIV mo dikgaolong. Fa go dirwa thuto-patlisiso mo bananeng, tetla e kopiwa mo botsading. Fa le sena go tlhaloganya le bo le re fa tetla, re kopa tetla gape ko bananeng go tsa karolo mo thuto-patlisisong. Go simolola thuto-patlisiso, le tshwanetse gore le bo lere file tetla lotlhe ka bobedi.

Pele o tsaya tshwetso, o ka bua le mongwe yo o mo tshepang. O tlhokana le nako go tsaya tshwetso gore fa tetla kana go sa re fe tetla. Ga o patelesege go tsaya tshwetso gompieno. Fa gona le seo sa se tlhaloganyeng, nkemisa o botse. Fa o ka nna le dipotso ke seo, o ka kopa kokelwana go itshwaraganya le rona gogo tlhalosetsa. Patlisiso e tla akaretsa banana ba ba letleletsweng ebile ba letlile go tsaya karolo. Mo patlisisong e, lefoko ‘ngwana wa gago’ le le mo lokwalong la tetlelelo, le raya motho wa dingwaga tsedi kafa tlase ga lesome le borobabobedi yoo kafa tlase ga tlhokomelo ya gago kafa molaong.

Maikaelelo a thuto-patlisiso

Patlisiso e, e itebagantse le go batlisisa dikgwetlho tse banana ba ba tshelang le mogare wa HIV ba ba nnang mo dikgaolong tsa tengnyanateng ba kopanang le tsone mo botshelong. Patlisiso e itebagantse gape le go batlisisa gore banana ba, ba fenya jang kana ba feta jang mo dikgwetlhong tse.

Dintlha tsa botlhokwa tsa thuto-patlisiso

Thuto-patlisiso e, e tla dirisa dipuisanyo mo ditlhopheng go kgobokanya dintlha tsa botlhokwa. Dipuisanyo tse, ditla tsaya oura ele nngwe kgotsa tse pedi fela mo letsatsing lele tla le bolelelwang go sale gale.

Tlhopho ya go tsaya karolo

Re batla go bua le banana ba dingwaga tse 10 goya ko go 19, ba ba tshelang ka mogare wa HIV. Banana ba, ke ba ba nnang ko Khudumelapye, Sorilatholo, Salajwe le Kaudwane le metsana ee welang ka fa tlasa ga metse e.

Ithaopo ya motsayakarolo

O ka letla ngwana wa gago kana wa seka wa mo letla go tsaya karolo mo patlisisong e. Dithuso tsotlhe tse o ntseng o difiwa mo kokelong ga dina go amega ka gope. Re lemogile gore tshwetso e, e ka nna thata, bogolo jang ta e akaretsa banana le seemo sa bone sa mogare wa HIV. Ga o patelesege go tsaya tshwetso gompieno, o ka mpolelela tshwetso ya gago moragonyana. O letlelesega go botsa dipotso mme re tla araba.

Tsela ya go batlisisa

Ngwana wa gago otla tsenelela dipuisanyo le banana ba bangwe bale barataro goya ko go borobabobedi ba ba tshelang le mogare wa HIV. Bana batla kgaoganngwa ka ditlhopha goya ka matsalo a bone. Puisano etla etelelwa pele ke mmatlisisi. Puisanyo etla akaretse dintlha di tshwanang le kgethololo, kitsiso ya seemo sa mogare, thotloetso, itemogelo le dikgwetlho tse dingwe tse ba kopanang natso, kafa ba difenyang ka teng le kafa ba akanyang gore ba ka thusiwa ka teng gore botshelo bo tokafale.

Puisanyo e, etla nnela ko kokelwaneng ee mo motseng mme go tla bo gose ope ko ntleng ga batsayakarolo fela. Puisano etla gatisiwa mme gago ope yoo tla itsiweng ka leina mo kgatisong. Kgatiso etla bewa mo sebolokelong se se lotlelwang. Se se gatisitsweng, e tla nna sephiri se se reediwang ke mmatlisisi-mogolo fela. Kgatiso e tla senngwa morago ga kgwedi tse tharo. Ngwana wa gago gape otla tlatsa pampitshana ya gore ke mong, dingwaga di kae, o bala bokae ko sekolong kana o dira kae/eng.

Borai

Ga gona borai bope mo go tseyeng karolo. Dintlha dingwe tsedi tla buisanngwang di ka nna tsa utlwisa botlhoko, mme fa se se dirafala, ngwana ona le tetla ya go sa bue ka tsone fa a sa batle.

Poelo

Go ka nna ga seka ga nna le dipoelo mo go wena kana ngwana wa gago fa a tsenelela patlisiso e. Re solofela gore se se ithutilweng mo patlisisong e, setla sologela molemo banana ba ba tshelang ka mogare wa HIV ba ba mo pakeng ee tlang.

Tuelo

Ngwana wa gago ga a na go duelelwa go tsaya karolo mo patlisisong, mme otla fiwa P50 wa sepalamo le nako e a e dirisitseng kwano.

Kgatiso

Ke kopa tetla ya go gatisa potsolotso.

Sephiri

Se re tsileng go se buisanya le kana ka ngwana wa gago se tsile go felela mo go rona, eseng ope yo eseng wa lekoko la thuto-patlisiso e. Dikgang tsotlhe ka ngwana wa gago ditla fiwa nomore gona le leina la gagwe mme mmatlisisi etla nna ene fela yoo itseng nomore eo.

Re tla kopa bana ba lona gore ba seka ba tsaya dikgang tsedi tla buisanngwang mo ditlhopheng go di isa ko go ba ba seng mo patlisisong e. Go ntleng le go buisana le bona ka gosa ise dikgang kwa ntle ga ditlhopha, le tshwanetse go itse gore gare kake ra ba tshwara gore ba seka ba dira jalo.

Pego ka maduo a patlisiso

Maduo a patlisiso e atla begelwa banana ba baneng ba tsaya karolo ele pego ee kwadilweng gore ba e kopanele le ba malapa a bone. Pego e nngwe e tla neelwa ba Lephata la Botsogo le dikokelwane tsa banana ba tswang mo go tsone. Pego enngwe ee kwadilweng etla neelwa ba University ya Botswana e le bontlha bongwe ba dithuto tsa mmatlisisi-mogolo.

Tshwanelo yago gana kana go ikgogela-morago

O na le tshwanelo ya go tlhopha gore ngwana wa gago a seka a tsaya karolo kana a tseye karolo mo patlisisong e. Ngwana wa gago le ene o na le tshwanelo ya go tlhopha go tsaya karolo kana go gana go tsaya karolo mo patlisisong e. Se o se tlhophileng kgotsa se ngwana wa gago a se tlhophileng ga sena go ama ka fa o ntseng o fiwa ditirelo tsa botsogo ka teng le ba lapa la gago. Ngwana wa gago ona le tshwanno ya go ikgogela morago mo thuto-patlisisong fa sa battle go tswelela nayo. Re lemogile gore tshwetso e ka nna thata bogolo jang fa patlisiso e ama monana le seemo sa gagwe sa mogare wa HIV. Ga o tlamege go tsaya tshwetso gompieno. O ka mpolelela tshwetso ya gago moragonyana. O letlelelwa go botsa dipotso mme retla araba ka boitumelo.

O ka bona mang fa ona le dipotso?

LEINA: Matlhodi Gosa Basuhi

POSO: P.O.Box 1570 Gaborone

MOGALA:

- Wa tiro: 5381661
- Wa letheka: 71845005

E-MAIL: gosakb@yahoo.com

APPENDIX 4a

CERTIFICATE OF CONSENT

Parent or guardian

I have been asked to give consent for my child _____ to participate in this research study which will involve survey and group discussion. I have read or the information about the research study was read to me. I had the opportunity to ask questions and any question that I asked was answered to my satisfaction. I consent voluntarily for my child to participant in this study.

Print Name of Parent or Guardian _____

Signature of Parent or Guardian _____ Or Right Thumb

Relationship to Subject _____

Date _____

Witness

This signature must be present if the consent was read to the signatory at any manner.

Print Name of Witness _____

Signature of Witness _____

Date _____

Statement by the researcher or person taking consent

I certify that I have explained to the above individual the nature, purpose, potential benefits and possible risks involved in the study. I have answered any questions raised and witnessed the above signature.

Print Name of Researcher or Person taking consent _____

Signature of Researcher or Person taking consent _____

Date _____

APPENDIX 4a

SETLANKANA SA TETLELELO

Motsadi kana motlhokomedi

Ke kopilwe go letlelela ngwanake _____

go tsaya karolo mo patlisisong ya puisanyo ya ditlhopha. Ke badile/ ke baletswe thulagayo ya thuto-patlisiso e. Ke nnele le sebaka sa go botsa dipotso, mme di arabilwe mo go kgotsofatsang. Ke ithaopa go letlelela ngwanake go tsaya karolo mo patlisisong e

Leina la motsadi/motlhokomedi _____.

Monwana wa motsadi/motlhokomedi _____Kana monwana wa moja

Kanamo ya gago le monana _____

Letsatsi _____.

Mosupi

Monwana o tshwanetse go nna teng fa motsadi/motlhokomedi a ne a balelwa thulaganyo ya thuto-patlisiso e.

Leina la mosupi _____.

Monwana wa mosupi _____.

Letsatsi _____.

Mmatlisisi

Ke supa gore ke tlhaloseditse motsadi/motlhokomedi ka tshimologo, mosola, dipoelo le ditlamorago tsa thuto-patlisiso e. Ke arabile dipotso tsotlhe tse di boditsweng. Ke bone motsadi/motlhokomedi a baya monwana.

Leina la mmatlisisi _____.

Sekano sa mmatlisisi _____.

Letsatsi _____

APPENDIX 5

UNIVERSITY OF BOTSWANA

INFORMED CONSENT FOR PARTICIPATING ADOLESCENTS WHO ARE 18 YEARS AND ABOVE

TITLE: Challenges faced by HIV-infected adolescents in rural areas of Botswana

PRINCIPAL RESEARCHER: Matlhodi Gosa Basuhi

NAME OF ORGANIZATION: University of Botswana

This form has two parts being which are;

Part 1: Information Sheet

This part gives you information about the study

Part 2: Certificate of Consent

This part is where you sign if you agree to participate.

You will be given a copy of the full Informed Consent Form.

INFORMATION SHEET

Introduction

I am Matlhodi Gosa Basuhi, a student at the University of Botswana. I am doing research on adolescents in some of the clinics in your district. We would like to know the challenges faced by HIV-infected adolescents and how adolescents cope with these challenges. You do not have to take part in the research if you do not want to.

I am giving you information and inviting you to take part in this research. You may discuss anything in this paper with anyone you trust and feel comfortable to talk to. You do not have to give the answer now, you can decide after you have talked it over. If there is something that you do not understand, please ask me anytime and I will gladly clarify. In case you need some clarification during my absence, you can ask the clinic to contact us to help you. The research will only include people who choose to participate in the study.

Purpose of the research

We want to find better ways of assisting HIV-infected adolescents to overcome the challenges they face in rural areas.

Reason for my participation

We will like to learn from you the challenges or obstacles you face when living with HIV. We will also like to know how you cope to overcome these challenges. This can help HIV-infected adolescents to live a better life in the future.

Selection of Participants

This study is for adolescents (children from 10 years to 19 years of age) who are HIVinfected and live in Khudumelapye, Sorilatholo, Salajwe and Kaudwane and the villages'catchment areas. Adolescents who are mentally incapacitated will not be included.

Voluntary Participation

You can agree or not agree to participate. All the services you and your family receive will not be affected by your decision. We know that the decision can be difficult especially when the research includes your HIV status. You do not have to decide today. You can tell me what you have decided later. You are free to ask as many questions as you can and we will be happy to answer them.

Procedure

If you choose to participate, you will take part in the discussion with six to eight other adolescents. You will be in separate groups according to age. The discussion will be guided by the researcher. The discussion will include information about HIV stigma and discrimination, status disclosure, social support, experiences or other challenges you face, how you conquer these challenges and what you think can be done to make life easy for you.

The discussion will take place at the local clinic and no one else will be allowed but the people who take part in the discussion and the researcher. The discussions will be audio-taped but no one will be identified by name in the tape. The tapes will be kept in a safe under lock and key. The information recorded will be confidential and no one else except the principal researchers will have access to keys. The tape will be destroyed after three months.

You will also fill out a survey questionnaire. Included in the survey is sex or gender, age, tribe or preferred language, relation to guardian and occupation. The survey information

will be kept confidential and no one else except the principal researcher will have access to the information.

Risks

There are no medical risks involved as this is not a medical study. Some topics which will be discussed might be difficult or sad to talk about, and if this happens, you can always choose not to talk if you do not want to talk about it. If you experience any discomfort during the interview, you will be refered to the counsellor in your respective clinic.

Potential benefits

There may or may not be direct benefit to you if you agree to participate in the study. We hope what will be learnt from the study will benefit other adolescents living with HIV in the future.

Audio-taping

I request permission to audio-tape the interviews.

Reimbursement

You will not be provided with any payment for participating in the research, but you will be given P50 for transport and time lost.

Protection of confidentiality

We will not share the information about you with anyone outside the research team. The information collected will be kept confidential and no one else will have access to the information except the researchers. Any information about you will be given a number instead of your name and the researcher will be the only person who knows the number and these will be kept under lock and key by the researcher.

We will ask you not to discuss the information which was said in the group with people outside the group. However you should know that we cannot stop participants from sharing the things that should be confidential.

Sharing research findings

We will be sharing the findings of the study with the participants. A report will also be written, given to the participants to share with their families and another report given to the Ministry of Health, Kweneng West Sub-district and Khudumelapye , Sorilatholo, Salajwe and Kaudwane clinics. This report will also be published so that other people interested may learn from it. Another written report will be given to the University of Botswana as part of the partial fulfilment of her studies.

Right to refuse or withdraw

You may choose not to participate in the study at any point in time. Your decision to participate and not to participate will not affect the treatment and any rights you have in the facility and your family. You are free to stop participating at any point of the study.

Who to contact

If you have any questions now you may ask me and if you wish to ask later, you may contact:

NAME: Malhodi Gosa Basuhi

ADDRESS: P O Box 1570 Gaborone

TELEPHONE NO.:

- Work phone number 5381661
- Cell number 71845005

E-MAIL: gosakb@yahoo.com

APPENDIX 5

UNIVERSITY YA BOTSWANA

TESELETSO YA GO TSAYA KAROLO MO PATLISISONG YA BANANA BA DINGWAGA TSE 18 LE GO FETA

SETLHOGO: Dikgwetlho tse banana ba ba tshelang ka mogare wa HIV ba kopanang natso mo dikgaolong tsa magae a tengnyanateng mo Botswana

MMATLISISI-MOGOLO: Matlhodi Gosa Basuhi

LEPHATA: University of Botswana

Pampiri e ena le karolo tse pedi. Dikarolo tse ke:

Karolo ya ntlha

Karolo ya ntlha e bua ka patlisiso e. E diretswe go gofa lesedi ka patlisiso e.

Karolo ya bobedi

E ke setlankana sa tetlelelo. O baya monowana wa gago fa o dumalana le go tsaya karolo mo patlisisong e.

O tla fiwa moriti wa dipampiri tse.

TLHALOSO YA PATLISISO

Ketapele

Ke bidiwa Matlhodi Gosa Basuhi. Ke tsena moithuti ko University ya Botswana. Ke dira patlisiso mo bananeng mo kgaolong ya lona. Ke eletsa go itse dikgwetlho tse banana ba ba tshelang le mogare wa HIV ba nnang le tsone le gore ba dira jang go fenya dikgwetlho tse. Patlisiso e e ka thusa badiri ba tsa botsogo go tokafatsa matshelo le botsogo ba banana ba ba tshelang le mogare wa HIV mo dikgaolong. Fa go dirwa patlisiso mo bathong, tetla e kopiwa mo go bone pele go simololwa. Fa le sena go tlhalosetswa le bo le tlhaloganya le bo le re fa tetla, ke gone re ka simololang patlisiso.Ke a lo itsise e bile ke a lo laletsa go tsaya karolo mo patlisisong e.

Pele o tsaya tshwetso, o ka bua le mongwe yo o mo tshepang ka se se mo pampiring e. O tlhokana le nako go tsaya tshwetso gore fa tetla kana go sa re fe tetla. Ga o patelesege go refa karabo jaanong. Fa gona le sengwe se o sa se tlhaloganyeng, nkemisa o botse. Fa o ka nna le dipotso ke seo, o ka kopa ba kokelwana go itshwaraganya le rona gogo tlhalosetsa. Patlisiso e tla akaretsa banana ba ba letlileng go tsaya karolo.

Maikaelelo a patlisiso

Re batlisisa methale ee botoka go thusa banana tshelang le mogare wa HIV go fenya dikgwetlho tse ba nnang le tsone kwa dikgaolong tsa magae.

Botlhokwa ba patlisiso

Patlisiso e, e itebagantse le go batlisisa dikgwetlho tse banana ba ba tshelang le mogare wa HIV ba ba nna mo dikgaolong tse ba kopanang le tsone mo botshelong. Patlisiso e itebagantse gape le go batlisisa gore banana ba, ba fenya jang kana ba feta jang mo

dikgwetlhong tse, ebile la eletsa go thusiwa jang go tokafatsa seemo ka na go fedisa dikgwetlho.

Mabaka a go tsaya karolo ga gago

Re batla go ithuta mo go wena dikgwetlho tseo lebaganang le tsone fa o tshela le mogare wa HIV. Se seka thusa banana ba ba tshelang le mogare wa HIV go tshela botshelo jo bo botoka mo isagong.

Tlhopho ya ba tsaya karolo

Re batla go bua le banana ba dingwaga tse 10 goya ko go 19, ba ba tshelang le mogare wa HIV. Banana ba, ke ba ba nnang ko Khudumelapye, Sorilatholo, Salajwe le Kaudwane le metsana ee welang ka fa tlasa ga magae a. Banana ba ba nang le bogole ba tlhaloganyo ga ba na go akarediwa mo patlisisong e.

Ithaopo ya motsayakarolo

O ka tlhopha go tsaya karolo kana wa tlhopha go sa tseye karolo mo patlisisong e. Dithuso tsotlhe tse o ntseng o difiwa mo kokelong ga dina go amega ka gope. Re tlhaloganya gore go tsaya tshwetso go ka nna thata, bogolo jang fa patlisiso e akaretsa seemo sag ago sa mogare wa HIV. Ga o patalesege go tsaya tshwetso gompieno. O katla wa mpolelela tshwetso ya gago moragonyana. O letlelesega go botsa dipotso mme re tla araba.

Tsela ya go batlisisa

Fa o dumela go tsaya karolo, otla tsenelela dipuisanyo le banana ba bangwe bale barataro goya ko go borobabobedi ba ba tshelang le mogare wa HIV. Lo tla kgaoganngwa ka ditlhopha goya ka matsalo a lona. Puisano etla etelelwa pele ke mmatlisisi. Puisanyo etla akaretsa dintlha di tshwana le kgetholoolo, kitsiso ya seemo sa mogare, thotloetso, itemogelo

le dikgwetlho tse dingwe tse banana ba kopanang natso, kafa ba difenyang ka teng le kafa ba akanyang gore ba ka thusiwa ka teng gore botshelo bo tokafale.

Puisanyo e, etla nnela ko kokelwaneng ee mo motseng mme go tla bo gose ope ko ntleng ga batsayakarolo fela. Puisano etla gatisiwa mme gago ope yoo tla itsiweng ka leina mo kgatisong. Kgatiso etla bewa mo sebolokelong se se lotlelwang. Se se gatisitsweng, e tla nna sephiri se se reediwang ke mmatlisisi-mogolo fela. Kgatiso e tla senngwa morago ga kgwedi tse tharo. O tla tlatsa pampitshana ya gore o mong, dingwaga di kae, o bala bokae ko sekolong kana o dira kae/eng, gore o tswa mo morafeng ofe le gore o rata go bua puo efe.

Borai ba go tsaya karolo mo patlisisong

Ga gona borai bope ba bongaka. Dintlha dingwe tsere tla buisanyang ka tsone di ka nna tsa utlwisa botlhoko, mme fa se se dirafala, ona le tetla ya go sa bui ka tsone fa osa batle. Fa osa tseege sentle mo maikutlong mabapi le potsolotso,o tla fetisediwa kwa go ba tshidilomaikutlo ba kokelwana ya gago.

Poelo

Go ka nna ga seka ga nna le dipoelo mo go wena fa o tsenelela patlisiso e. Re solofela gore se se tla ithutiwang mo patlisisong, setla sologela molemo banana ba ba tshelang ka mogare wa HIV ba ba tswang ko tlase kana mo nakong e e tlang.

Tuelo

Ga o na go duelelwa go tsaya karolo mo thuto-patlisisong, mme otla fiwa P50 wa sepalamo le nako e a e dirisitseng kwano.

Kgatiso

Ke kopa tetla ya go datisa puisanyo.

□□□ □

Pabalesego ya se mmotsoloswa a se neilweng

Se re tsileng go se buisanya se tsile go felela mogo rona, eseng ope yo eseng wa lekoko la patlisiso e. Dikgang tsotlhe ka ga gago di tla fiwa nomore gona le leina la gago mme mmatlisisi etla nna ene fela yoo itseng nomore eo mme ditla lotlelelwa mo sebolokelong ke mmatlisisi.

Re tla le kopa gore lo seka lwa tsaya dikgang tsedi tla buisanwang mo ditlhopheng go di ise ko go ba ba seng mo patlisisong e. Go ntleng le go buisana le lona letshwanetse go itse gore gare kake ra le tshwara gore ba seka la dira jalo.

Pego ka maduo a thuto-patlisiso

Maduo a patlisiso e, a tla fiwa banana ba baneng ba tsaya karolo. Pego e nngwe ee kwadilweng banana ba batsaya karolo batla e neelwa go e buisa le ba malapa a bone. Pego e nngwe e tla neelwa ba Lephata la Botsogo le dikokelwane tsa banana ba tswang mo go tsone. Pego enngwe ee kwadilweng etla neelwa ba University ya Botswana e le bontlha bongwe ba dithuto tsa mmatlisisimogolo.

Tshwanelo yago gana kana go ikgogela-morago

O na le tshwanelo ya go tlhopha gore o seka wa tsaya karolo kana o tseye karolo mo thuto-patlisisong. Se o se tlhophileng ga sena go ama ka fa o ntseng o fiwa ditirelo tsa botsogo ka teng le ba lapa la gago. Ona le tshwanelo ya go ikgogela morago mo thuto-patlisisong fa o sa batle go tswelela nayo.

Fa o na le dipotso ka nako efe fela ka patlisiso, o ka itshwaraganya le:

LEINA: Matlhodi Gosa Basuhi

POSO: P.O.Box 1570 Gaborone

□□□ □

MOGALA:

- wa ko tirong 5381661
- wa letheka 71845005

E-MAIL: gosakb@yahoo.com

APPENDIX 5a

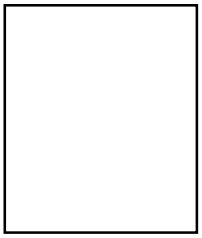
CERTIFICATE OF CONSENT

Participant

I _____ confirm that the information about this research has been explained to me. I understand that I can withdraw to participate in this research study which will involve survey and group discussion at anytime. I have read or the information about the research study was read to me. I had the opportunity to ask questions and any question that I asked was answered to my satisfaction. I consent voluntarily to participate as a participant in this study.

Print Name of Adolescent _____

Signature of Adolescent _____ Or Right Thumb



Date _____

Witness

Print Name of Witness _____

Signature of Witness _____

Date _____

Statement by the researcher

I certify that I have explained to the above individual the nature, purpose, potential benefits and possible risks involved in the study. I have answered any questions raised and witnessed the above signature.

Print Name of researcher or person taking consent _____

Signature of researcher or person taking consent _____

Date _____

APPENDIX 5a

SETLANKANA SA TETLELELO

Motsayakarolo

Ke le _____ke netefatsa gore ke tlhaloseditswe ka patlisiso e. Ke tlhaloganya gore ke kgona go ikgogela morago mo patlisisong e ka nako nngwe le nngwe. Ke badile/ ke baletswe thulagayo ya patlisiso e. Ke nnile le sebaka sa go botsa dipotso, mme di arabilwe mo go kgotsofatsang. Ke ithaopela go nna mo tsaya-karolo mo patlisisong e.

Leina la monana _____.

Sekano sa monana _____Kana monwana wa moja

Letsatsi _____.

Mosupi

Leina la mosupi _____.

Sekano sa mosupi _____.

Letsatsi _____.

Maikano a mmatlisisi

Ke supa gore ke tlhaloseditse monana ka tshimologo, mosola, dipoelo le ditlamorago tsa thuto-patlisiso e. Ke arabile dipotso tsotlhe tse di boditsweng. Ke bone monana a baya monwana.

Leina la mmatlisisi _____.

Sekano sa mmatlisisi _____.

Letsatsi _____

APPENDIX 6

UNIVERSITY OF BOTSWANA

ASSENT FORM FOR ADOLESCENTS UNDER 18 YEARS PARTICIPATING IN THE RESEARCH STUDY

TITLE: challenges faced by HIV-infected adolescents in rural areas

NAME OF PRINCIPAL RESEARCHER: Matlhodi Gosa Basuhi

NAME OF ORGANIZATION: University of Botswana

This form has two parts which are;

Part 1: Information Sheet

This part gives you information about the study

Part 2: Certificate of Assent

This part is where you sign if you agree to participate.

You will be given a copy of the full Informed Assent Form.

INFORMATION SHEET

Introduction

I am Matlhodi Gosa Basuhi, a student at the University of Botswana. I am doing research on adolescents in some of the clinics in your district. We would like to know the challenges faced by HIV-infected adolescents and how adolescents cope with these challenges. You do not have to take part in the research if you do not want to.

I am giving you information and inviting you to take part in this research. You may discuss anything in this paper with anyone you trust and feel comfortable to talk to. You do not have to give the answer now, you can decide after you have talked it over. If there is something that you do not understand, please ask me anytime and I will gladly clarify. In case you need some clarification during my absence, you can ask the clinic to contact us to help you. The research will only include people who choose to participate in the study.

Purpose of the research

I want to find better ways of assisting HIV-infected adolescents to overcome the challenges they face in rural areas.

Reason for my participation

I will like to learn from you the challenges or obstacles you face when living with HIV. We will also like to know how you cope to overcome these challenges. This can help HIV-infected adolescents to live a better life in the future.

Selection of Participants

This study is for adolescents (children from 10 years to 19 years of age) who are HIV-infected and live in Khudumelapye, Sorilatholo, Salajwe and Kaudwane or these villages' catchment areas. Adolescents who are mentally incapacitated will not be included.

Voluntary Participation

You can agree or not agree to participate. All the services you and your family receive will not be affected by your decision. We know that the decision can be difficult especially when the research includes your HIV status. You do not have to decide today. You can tell me what you have decided later. You are free to ask as many questions as you can and we will be happy to answer them.

Procedure

If you choose to participate, you will take part in the discussion with six to eight other adolescents. You will be in separate groups according to age. The discussion will be guided by the researcher. The discussion will include information about HIV stigma and discrimination, status disclosure, social support, experiences or other challenges you face, how you conquer these challenges and what you think can be done to make life easy for you.

The discussion will take place at the local clinic and no one else will be allowed but the people who take part in the discussion and the researcher. The discussions will be audio-taped but no one will be identified by name in the tape. The tapes will be kept in a safe under lock and key. The information recorded will be confidential and no one else except the principal researchers will have access to keys. The tape will be destroyed after three months.

You will also fill out a survey questionnaire. Included in the survey is sex or gender, age, tribe or preferred language, relation to guardian and occupation. The survey information

will be kept confidential and no one else except the principal researcher will have access to the information.

Risks

There are no medical risks involved as this is not a medical study. Some topics which will be discussed might be difficult or sad to talk about, and if this happens, you can always choose not to talk if you do not want to talk about it. If you experience any discomfort during the interview, you will be refered to the counsellor in your respective clinic.

Benefits

There may or may not be direct benefit to you if you agree to participate in the study. We hope what will be learnt from the study will benefit other adolescents living with HIV in the future.

Audio-taping

I request permission to audio-tape the interviews.

Reimbursement

You will not be provided with any payment for participating in the research, but you will be given P50 for transport and time lost.

Protection of confidential information

We will not share the information about you with anyone outside the research team. The information collected will be kept confidential and no one else will have access to the information except the researchers. Any information about you will be given a number instead of your name and the researcher will be the only person who knows the number and these will be kept under lock and key by the researcher.

We will ask you not to discuss the information which was said in the group with people outside the group. However you should know that we cannot stop participants from sharing the things that should be confidential.

Sharing research findings

We will be sharing the findings of the study with the participants. A report will also be written, given to the participants to share with their families and another report given to the Ministry of Health, Kweneng West Sub-district and Khudumelapye , Sorilatholo, Salajwe and Kaudwane clinics. This report will also be published so that other people interested may learn from it. Another written report will be given to the University of Botswana as part of the partial fulfilment of her studies.

Right to refuse or withdraw

You may choose not to participate in the study at any point in time. Your decision to participate and not to participate will not affect the treatment and any rights you have in the facility and your family. You are free to stop participating at any point of the study.

Who to contact

If you have any questions now you may ask me and if you wish to ask later, you may contact:

NAME: Matlhodi Gosa Basuhi

ADDRESS: P O Box 1570 Gaborone

TELEPHONE NO.:

- work phone number 5381661
- cell number 71845005

E-MAIL: gosakb@yahoo.com

APPENDIX 6

UNIVERSITY YA BOTSWANA

TESELETSO YA GO TSAYA KAROLO MO PATLISISONG YA BANANA BA DINGWAGA TSEDI FA TLASE GA 18

SETLHOGO: Dikgwetlho tse banana ba ba tshelang ka mogare wa HIV ba kopanang natso mo dikgaolong tsa magae a tengnyanateng mo Botswana

MMATLISISI-MOGOLO: Matlhodi Gosa Basuhi

LEPHATA: University of Botswana

Pampiri e ena le karolo tse pedi. Dikarolo tse ke:

Karolo ya ntlha

Karolo ya ntlha e bua ka thuto-patlisiso e. E diretswe go gofa lesedi ka thuto-patlisiso e.

Karolo ya bobedi

E ke setlankana sa tetlelelo. O baya sekano sa gago fa o dumalana go tsaya karolo mo thuto-patlisisong e.

O tla fiwa moriti wa dipampiri tse.

TLHALOSO KA THUTO-PATLISISO

Ketapele

Ke bidiwa Matlhodi Gosa Basuhi. Ke tsena moithuti ko University ya Botswana. Ke dira patlisiso mo bananeng mo kgaolong ya lona. Ke eletsa go itse dikgwetlho tse banana ba ba tshelang le mogare wa HIV ba nnang le tsone le gore ba dira jang go fenya dikgwetlho tse. Patlisiso e e ka thusa badiri ba tsa botsogo go tokafatsa matshelo le botsogo ba banana ba ba tshelang le mogare wa HIV mo dikgaolong. Fa go dirwa patlisiso mo bathong, tetla e kopiwa mo go bone pele go simololwa. Fa le sena go tlhalosetswa le bo le tlhaloganya le bo le re fa tetla, ke gone re ka simololang patlisiso.Ke a lo itsise e bile ke a lo laletsa go tsaya karolo mo patlisisong e.

Pele o tsaya tshwetso, o ka bua le mongwe yo o mo tshepang ka se se mo pampiring e. O tlhokana le nako go tsaya tshwetso gore fa tetla kana go sa re fe tetla. Ga o patelesege go refa karabo jaanong. Fa gona le sengwe se o sa se tlhaloganyeng, nkemisa o botse. Fa o ka nna le dipotso ke seo, o ka kopa ba kokelwana go itshwaraganya le rona gogo tlhalosetsa. Patlisiso e tla akaretsa banana ba ba letlileng go tsaya karolo.

Maikaelelo a patlisiso

Re batlisisa methale ee botoka go thusa banana tshelang le mogare wa HIV go fenya dikgwetlho tse ba nnang le tsone kwa dikgaolong tsa magae.

Botlhokwa ba patlisiso

Patlisiso e, e itebagantse le go batlisisa dikgwetlho tse banana ba ba tshelang le mogare wa HIV ba ba nna mo dikgaolong tse ba kopanang le tsone mo botshelong. Patlisiso e itebagantse gape le go batlisisa gore banana ba, ba fenya jang kana ba feta jang mo

dikgwetlhong tse, ebile la eletsa go thusiwa jang go tokafatsa seemo ka na go fedisa dikgwetlho.

Mabaka a go tsaya karolo ga gago

Re batla go ithuta mo go wena dikgwetlho tseo lebaganang le tsone fa o tshela le mogare wa HIV. Se seka thusa banana ba ba tshelang le mogare wa HIV go tshela botshelo jo bo botoka mo isagong.

Tlhopho ya ba tsaya karolo

Re batla go bua le banana ba dingwaga tse 10 goya ko go 19, ba ba tshelang le mogare wa HIV. Banana ba, ke ba ba nnang ko Khudumelapye, Sorilatholo, Salajwe le Kaudwane le metsana ee welang ka fa tlasa ga magae a. Banana ba ba nang le bogole ba tlhaloganyo ga ba na go akarediwa mo patlisisong e.

Ithaopo ya motsayakarolo

O ka tlhopha go tsaya karolo kana wa tlhopha go sa tseye karolo mo patlisisong e. Dithuso tsotlhe tse o ntseng o difiwa mo kokelong ga dina go amega ka gope. Re tlhaloganya gore go tsaya tshwetso go ka nna thata, bogolo jang fa patlisiso e akaretsa seemo sag ago sa mogare wa HIV. Ga o patalesege go tsaya tshwetso gompieno. O katla wa mpolelela tshwetso ya gago moragonyana. O letlelesega go botsa dipotso mme re tla araba.

Tsela ya go batlisisa

Fa o dumela go tsaya karolo, otla tsenelela dipuisanyo le banana ba bangwe bale barataro goya ko go borobabobedi ba ba tshelang le mogare wa HIV. Lo tla kgaoganngwa ka ditlhopha goya ka matsalo a lona. Puisano etla etelelwa pele ke mmatlisisi. Puisanyo etla akaretsa dintlha di tshwana le kgetholoto, kitsiso ya seemo sa mogare, thotloetso, itemogelo

le dikgwetlho tse dingwe tse banana ba kopanang natso, kafa ba difenyang ka teng le kafa ba akanyang gore ba ka thusiwa ka teng gore botshelo bo tokafale.

Puisanyo e, etla nnela ko kokelwaneng ee mo motseng mme go tla bo gose ope ko ntleng ga batsayakarolo fela. Puisano etla gatisiwa mme gago ope yoo tla itsiweng ka leina mo kgatisong. Kgatiso etla bewa mo sebolokelong se se lotlelwang. Se se gatisitsweng, e tla nna sephiri se se reediwang ke mmatlisisi-mogolo fela. Kgatiso e tla senngwa morago ga kgwedi tse tharo. O tla tlatsa pampitshana ya gore o mong, dingwaga di kae, o bala bokae ko sekolong kana o dira kae/eng, gore o tswa mo morafeng ofe le gore o rata go bua puo efe.

Borai ba go tsaya karolo mo patlisisong

Ga gona borai bope ba bongaka. Dintlha dingwe tsere tla buisanyang ka tsone di ka nna tsa utlwisa botlhoko, mme fa se se dirafala, ona le tetla ya go sa bui ka tsone fa osa batle. Fa osa tseege sentle mo maikutlong mabapi le potsolotso,o tla fetisediwa kwa go ba tshidilomaikutlo ba kokelwana ya gago.

Poelo

Go ka nna ga seka ga nna le dipoelo mo go wena fa o tsenelela patlisiso e. Re solofela gore se se tla ithutiwang mo patlisisong, setla sologela molemo banana ba ba tshelang ka mogare wa HIV ba ba tswang ko tlase kana mo nakong e e tlang.

Kgatiso

Ke kopa tetla ya go gatisa puisanyo.

Tuelo

Ga o na go duelelwa go tsaya karolo mo thuto-patlisisong, mme otla fiwa P50 wa sepalamo le nako e a e dirisitseng kwano.

□□□□ □

Pabalesego ya se mmotsoloswa a se neilweng

Se re tsileng go se buisanya se tsile go felela mogo rona, eseng ope yo eseng wa lekoko la patlisiso e. Dikgang tsotlhe ka ga gago di tla fiwa nomore gona le leina la gago mme mmatlisisi etla nna ene fela yoo itseng nomore eo mme ditla lotlelelwa mo sebolokelong ke mmatlisisi.

Re tla le kopa gore lo seka lwa tsaya dikgang tsedi tla buisanwang mo ditlhopheng go di ise ko go ba ba seng mo patlisisong e. Go ntleng le go buisana le lona letshwanetse go itse gore gare kake ra le tshwara gore ba seka la dira jalo.

Pego ka maduo a thuto-patlisiso

Maduo a patlisiso e, a tla fiwa banana ba baneng ba tsaya karolo. Pego e nngwe ee kwadilweng banana ba batsaya karolo batla e neelwa go e buisa le ba malapa a bone. Pego e nngwe e tla neelwa ba Lephata la Botsogo le dikokelwane tsa banana ba tswang mo go tsone. Pego enngwe ee kwadilweng etla neelwa ba University ya Botswana e le bontlha bongwe ba dithuto tsa mmatlisisimogolo.

Tshwanno yago gana kana go ikgogela-morago

O na le tshwanelo ya go tlhopha gore o seka wa tsaya karolo kana o tseye karolo mo thuto-patlisisong. Se o se tlhophileng ga sena go ama ka fa o ntseng o fiwa ditirelo tsa botsogo ka teng le ba lapa la gago. Ona le tshwanelo ya go ikgogela morago mo thuto-patlisisong fa o sa batle go tswelela nayo.

Fa o na le dipotso ka nako efe fela ka patlisiso, o ka itshwaraganya le:

LEINA: Matlhodi Gosa Basuhi

POSO: P.O.Box 1570 Gaborone

□□□□ □

MOGALA:

- wa ko tirong 5381661
- wa letheka 71845005

E-MAIL: gosakb@yahoo.com

APPENDIX 6a

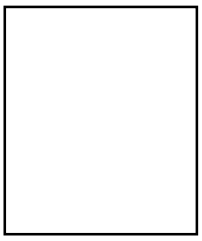
CERTIFICATE OF ASSENT

Participant

I _____ confirm that the information about this research has been explained to my parents or guardian. He or she agreed that I may participate if I want. I understand that I can withdraw to participate in this research study which will involve survey and group discussion at anytime. I have read or the information about the research study was read to me. I had the opportunity to ask questions and any question that I asked was answered to my satisfaction. I consent voluntarily to participate as a participant in this study.

Print Name of Adolescent _____

Signature of Adolescent _____ Or Right Thumb



Date _____

Witness

Print Name of Witness _____

Signature of Witness _____

Date _____

Statement by the researcher or person taking assent

I certify that I have explained to the above individual the nature, purpose, potential benefits and possible risks involved in the study. I have answered any questions raised and witnessed the above signature.

Print Name of researcher or person taking assent _____

Signature of researcher or person taking assent _____

Date _____

APPENDIX 6a

SETLANKANA SA TETLELELO

Motsaya-karolo

Ke le _____ke netefatsa gore ke tlhaloseditswe ka patlisiso e. Ke tlhaloganya gore ke kgona go ikgogela morago mo patlisisong e ka nako nngwe le nngwe. Ke badile/ ke baletswe thulagayo ya patlisiso e. Ke nnile le sebaka sa go botsa dipotso, mme di arabilwe mo go kgotsofatsang. Motsadi kana motlhokomedi wama o tlhaloseditswe patlisiso e. Ke ithaopela go nna mo tsaya-karolo mo patlisisong e.

Leina la monana _____.

Sekano sa monana _____Kana monwana wa moja

Letsatsi _____.

Mosupi

Leina la mosupi _____.

Sekano sa mosupi _____.

Letsatsi _____.

Mmatlisisi

Ke supa gore ke tlhaloseditse monana ka tshimologo, mosola, dipoelo le ditlamorago tsa thuto-patlisiso e. Ke arabile dipotso tsotlhe tse di boditsweng. Motsadi kana motlhokomedi o itse ka thuto-patlisiso e. Ke bone monana a baya monwana.

Leina la mmatlisisi _____.

Sekano sa mmatlisisi _____.

Letsatsi _____

*(*www.who.int/rpc/**research**_ethics/**informed_consent**/en/)