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KwaDlangezwa

With the title:

MENTAL HEALTH STATUS OF SCHOOL GOING ADOLESCENTS ON ANTIRETROVIRAL TREATMENT IN AMAJUBA DISTRICT, KWAZULU-NATAL.

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DECLARATION

I, Zinandi Ziyanda Zipho-zethu declare that this dissertation is the product of my own work and effort. I have, to the best of my knowledge and belief, acknowledged all sources of information in line with normal academic conventions.

Zinandi Z.Z. Nyasulu

DEDICATION

“No weapon that is formed against thee shall prosper, and every tongue that shall rise against thee in judgment thou shalt condemn. This is the heritage of the servants of the Lord, and their righteousness is of me, saith the Lord.”- King James Bible

I dedicate this dissertation to all the people living with HIV and AIDS particularly the adolescents who are still battling with this diagnosis. Yes, the weapon was formed but it shall not prosper. Keep going strong and most importantly keep a positive mind. Lastly, I dedicate my hard work to my late mother Lungile, Rebecca, Early-Rose Nyasulu I wouldn’t have survived the challenges if it wasn’t for her belief in me and the words of encouragement she always instilled in me while I was growing up.

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ABSTRACT

The aim of this study was to assess the mental health status of school going adolescents on ART. The objectives of the study being to establish the status of mental health before and after these adolescents are placed on ART.

A literature study was done in order to determine the feasibility of the study and in order to strengthen the need for such information to be known. A qualitative approach was used so as to gain insight into the topic. Data was collected using face to face interviews and an interview guide was prepared to guide the discussions between the researcher and the participants. The data collected was thematically analysed and the results were presented using the research questions and the themes that emerged in answering those questions. Themes and sub-themes that emerged included compliance; fear of disclosing; normalisation of life with HIV; acceptance and support from family; fear of rejection, stigma and discrimination; institutional support; morally judged.

Since participants were young when they tested mental health changes occurred once their status was disclosed to them. The adolescents have unresolved mental health issues and which become unknown to the healthcare workers due to ineffective communication. Participants were still preoccupied with the thought that they will be on ARVs for the rest of their lives. Key problems faced by the adolescents included preoccupation about the future, fear of stigma and discrimination and reject from society. There were no feelings of anger towards their caregivers once their status was disclosed to them. Only feelings of fear and confusion were raised which were quickly addressed by caregivers. Recommendations were included to address the concerns highlighted in the study and these included a need to address factors such as disclosure, stigma and discrimination as these directly and indirectly have an impact on the mental health of HIV positive adolescents and follow-up research needs to be done to document the lives of adolescents post admission in the ART programme.

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ABBREVIATIONS AND ACRONYMS

HIV: Human-Immuno-Deficiency Virus

AIDS: Acquired-Immuno-Deficiency Syndrome

ARV: Antiretroviral

ART: Antiretroviral Treatment

WHO: World Health Organization

CD4: Cluster of Differentiation

VCT: Voluntary HIV Counselling and Testing

CHAPTER 1

1.1 INTRODUCTION

Health, as defined by the World Health Organization, is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. Health is also viewed as being related to the promotion of well-being, the prevention of mental disorders and the treatment and rehabilitation of people affected by mental disorders.

It appears easy to assess physical well-being by merely taking health status measurements of the body. Blood pressure, temperature, and cholesterol levels are all precise means by which we can tell if the physical components of the body are healthy. However, mental and social components of health are so much more challenging to assess. Thoughts and perceptions of internal states are subjective and difficult to measure.

Mental health, as defined by the Surgeon General's Report on Mental Health (2002), refers to the successful performance of mental function resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and cope with adversity. In other words, it is the psychological well-being and satisfactory adjustment to society and to the ordinary demands life brings us. It is easy for one to put on a façade and pretend to be mentally sound or satisfied with life’s toils.

Having had exposure in the field of HIV/AIDS, the researcher had noticed that great strides have been made in increasing access to HIV medical treatment and care for children and adolescents, the emotional impact of HIV on the other hand seems to have been neglected. Medical treatment should however be complemented with psychosocial support.

School going adolescents who are on ART seem not to receive that support from the school environment. The manner in which psychosocial support in general and counselling in particular, has been long conceptualised as a form of imparting information to patients rather than engage in relationships within which to influence behavioural or change in perception.

In South Africa, the impact of HIV has been increased by other social challenges such as poverty and the socio-economic imbalances that already exist in diverse communities. These challenges have increased the physical and emotional vulnerability of women and children. Most adolescents have to look after their HIV infected parents and try to concentrate at school while taking care of their own emotional and physical challenges.

Most people view negative changes in mental health as something far from them. They do take into account minor mental health changes such as stress and anxiety but never consider the severity or dimensional aspects of mental health as a whole. It would be considered normal though not to dwell in such thoughts as we go on our daily activities. There are though, stressors in our daily functioning which bring about sudden changes in our level of distress and adjustment.

Young people seem to be the fastest growing age group of HIV positive individuals. They make up a segment of the population that is vulnerable to HIV as they are particularly affected in terms of transmission, vulnerability and impact. Most adolescents who acquire HIV are infected through sexual risk behaviours and most than others through mother to child transmission.

The rise of teenage pregnancy rates in schools is evidence that most adolescents engage in unprotected sex or risky sexual behaviours. Most of these adolescents are recently infected and unaware of their HIV infection status. Those who are on treatment are unaware of the reasons why they are taking treatment and may engage in unprotected sex without the knowledge that they are spreading the virus. Infected adolescents seem to be at a greater risk than non-infected adolescents of experiencing negative changes in their mental health.

Even though communities at large have been well educated about HIV/AIDS some individuals still perceive it as a deadly virus and as a taboo subject, making it harder for others who test positive to accept their newly learnt HIV status, this leading to difficulties when the need arises to take ARVs. Other infected adolescents may be fine with being HIV positive but have issues of stigma in the school environment and society at large and fear of disclosure to their peers or educators. There is therefore a greater need for psychosocial support services. Fewer psychological services are available for those who seek help.

Motivation for this study stemmed from research (South African HIV Clinician Society, 2013) showing the impact of mental health disorders such as depression on the health of adolescents on ARVs. The study reveals that up to 25% of people living with HIV/AIDS are thought to suffer from some form of depression during the course of their illness. Mental disorders are also found to be highly prevalent among people living with HIV/AIDS, even mild depression can lead to erratic adherence, poor care management and ultimately to more serious outcomes. Feelings of depression, social withdrawal, loneliness, and anger are common among youths struggling to cope with HIV.

1.2. LITERATURE REVIEW

According to the South African HIV Clinicians Society (2013), there is no health without mental health. This in turn means that for an individual to function holistically in all aspects of life they will need to be in a good state of well-being, physically and mentally. Mental disorders are highly prevalent among people living with HIV/AIDS, with major depressive disorders occurring almost twice as frequently among this group than in the general population.

Anderson and Seedat (2009) mention that although progress has been made concerning the launch of the National Antiretroviral Programme in April 2004 in providing medical treatment for people living with HIV/AIDS, their psychosocial needs have not been equally provided for.

A more prominent role is needed for mental health interventions in global HIV/AIDS initiatives. Significant numbers of infected people have or develop mental health problems, and this often adversely impacts on the treatment and adherence. Integration between psychiatric and psychosocial interventions should benefit both the mental and the physical health of people living with HIV (Freeman, Patel, Collins & Bertolote, 2005). The article also supports looking at different aspects that touch on HIV and intervention strategies.

Living with a chronic illness like HIV is of daily concern among infected adolescents and they face the challenges of adapting their lives to live with a chronic illness whilst continuing to achieve or meet social expectations which include high academic achievement, being economically independent, having intimate relationships, assessing risks, protecting others and adhering to treatment.

According to the Department of Health children and adolescents are particularly vulnerable to distress caused by a multitude of factors, which include the virus itself, loss of loved ones and fear of rejection and isolation as a result of stigma and discrimination. Psychological stressors such as loss of parents or family members, social stigma, isolation, or fear related to disclosure might also contribute to poor school performance (Benton, 2011).

Research findings (Menon, Glazebrook, Ngoma, 2009) show that factors leading to the vulnerability of young people include lack of knowledge about HIV and AIDS, lack of education and life skills, poor access to health services and commodities, early sexual debut, early marriage, sexual coercion and violence, trafficking and growing up without parents or other forms of protection from exploitation and abuse.

Abrahams & Jewkes (2012) mentioned in their findings that although stigma was still part of people's lives, it didn't dominate their social interactions and most resisted the stigma and sort to regain normality. All participants in their study except a few were concerned about people's perceptions of their HIV status. Of the 21 participants in Cape Town 15 had disclosed to their partners and for some females relationships continued but for a few they ended and most of them decided not to disclose when entering new relationships.

Evidence of stigma decline has however been reported from studies including the South African HIV study (Shisana, Rehle, Simonyi, Parker, Zuma, Bhana, Connolly, Jooste, Pillay, Mbhele, Managa, Ramlagan, Zungu-Dirwayi, Louw, van Wyk, Tamasane, Petros, Freeman, Tshose, Letlape, Naidoo, Henda, Mqeketo, Prince, Shaun, 2005) which reported a decline between 2003 and 2005, improved treatment and care being cited as contributing to the decline.

Several studies have shown a clear association between cognitive, psychosocial and behavioural problems in HIV infected adolescents with substance abuse, sexual risk activities and poor adherence to ART (Chandwani, Koenig, Sill, Abramowitz, Conner, D’Angelo, 2012)

Participants from a study on psychosocial revealed that symptoms of distress were ostensibly related to their HIV status. Decreased levels of energy, feeling everything is an effort, and feelings of hopelessness were reported. Psychiatric disorders that can be diagnosed and psychological distress may have a negative effect on quality of life, family functioning, adherence to ARV treatment and adherence to infant-feeding guidelines among new mothers (Kagee and Martin 2012).

Previous research has revealed that people living with HIV/AIDS stressed the lack of information about HIV/AIDS as a problem. People are aware of this disease but have misconceptions about it. In addition, people's negative attitudes towards and the high rate of refusal to assist them at health care institutions along with the discrimination of experienced in society, the mental health of people living with HIV/AIDS can be seriously harmed (Stvilia, Badridze, Geleishvili, 2008).

Officials in the current healthcare system of Georgia do not recognise the need for psychosocial services for people living with HIV/AIDS. There are no governmental policies, documents or programs which address the link between HIV and mental health issues (Stvlia, Badridze, Geleishvili, 2008).

Through counselling, clients in recovery from risky behaviours often discover and begin to heal underlying psychological wounds they attempted to mask through risky behaviour. Counselling explores feelings, motivations, behavioural patterns, interpersonal relationships, and patterns of thinking over time (Acuff, Archambcault, Greenberg, Hoeltzel, McDaniel, Meyer, Parker, Parga, Phillen, Ronhovde, Saldarriaga, Smith, Stroff, Wagner, 1999).

The surveyed literature was helpful in the analysis of data and in developing research instruments. They were chosen because of their relevancy with the concerns the researcher had in the research study.

1.3. PROBLEM STATEMENT

Almost every person faces mental health issues at some point of their life. Major stresses like the death of a loved one, job loss or divorce can have a major impact on mental health. Having a serious illness like HIV can be another source of stress for some. (South African HIV Clinician Society, December, 2013)

Mental health can be an issue in adolescents who are not aware of their status and are on a road of finding out. Once they test and their status turns out to be positive, a change occurs in their mental health. This is due to the preconceived thoughts about the period of infection, the WHO clinical stage they are in, as prescribed by the World Health Organisation (World Health Organisation, 2013) and starting treatment.

Infected individuals and those who have started their treatment deal with a vast number of issues which affect the self. Those being issues of denial, disclosure and psychosocial issues like that of stigma and discrimination. All of which have an impact on the mental health status. In children and adolescents the experiences are worsened as most infections were due to mother-to-child transmissions.

Adolescents who are HIV positive are flooded with challenges of the adolescent stage, together with a chronic illness, which may place various restrictions on their lifestyle. All of which may not only have a negative impact on their social life part also academically. They therefore have unique psychosocial needs and particular mental health issues.

If we still see ARVs and a proper diet as the only solution in fighting the spread of the virus or lowering the viral load, then we are still looking at a rise of people dying of AIDS or HIV related infections.

HIV/AIDS patients with mental health issues such as depression are less likely to adhere to their medication. This resulting in the failure of the viral load to decline and leading to the resistance of the virus towards ARVs thereby diminish the possibilities of effective treatment in the future.

This study therefore proposed to investigate why, despite government efforts there is still a rise in mental health issues among adolescents infected with HIV/AIDS. This study further attempted to provide answers to the following questions:

- Are there differences in the mental health status before and after being enrolled in the antiretroviral therapy (ART) programme?
- What are the different perspectives regarding ART among school going adolescents on ARVs?
- Are there key problems experienced by adolescents on ART?

- Are there differences to the family dynamics?
- Does disclosing the HIV status affect the relations with significant others?

1.4. AIM OF THE STUDY

The study aims to explore the mental health status of adolescents on antiretroviral treatment (ART).

1.4.1. Objectives

The study was guided by the following research objectives:

Overarching objective

- To establish the pre and post enrolment mental health status of adolescents who are on antiretroviral treatment.

Secondary objectives

- To assess the adolescents’ perspectives regarding antiretroviral therapy (ART).
- To examine the key problems they experience.
- To identify their family dynamics.
- To determine if disclosing their HIV status affects the relations with the significant others.

1.5. RESEARCH ASSUMPTIONS

1. There will be differences in the mental health status of adolescents before and after being enrolled into the antiretroviral therapy programme.
2. There will be different perspectives regarding antiretroviral therapy (ART) among school going adolescents on ARVs.
3. There will be key problems experienced by adolescents on ARVs.
4. Being on ARVs will affect the family dynamics of infected adolescents.
5. Disclosing the HIV status will affect the relations with significant others.

1.6. INTENDED CONTRIBUTIONS TO THE BODY OF KNOWLEDGE

Given its nature, the study will make a worthwhile and different contribution to the field of HIV/AIDS research, health and psychology. It will also assist healthcare workers working within the field of HIV/AIDS to also be aware of complexities of the mental health of patients and its impact on treatment and care.

1.7. RESEARCH METHODOLOGY

This study utilised qualitative research methods where it relied mostly on individual interviews with adolescents who are on ART to provide the necessary information for achieving the study objectives. Terre Blanche, Durrheim & Painter(2006) define qualitative methods as, allowing the researcher to study selected issues in depth, openness, and detail as the researcher identifies and attempts to understand the categories of information that emerge from the data.

1.71. Sampling

The study was conducted in a health facility based in Amajuba district, KwaZulu-Natal. This study employed purposive sampling method which means that sampling depended not only on availability and willingness to participate but also that cases that are typical of the population were selected. The target sample was comprised of HIV positive learners who are on antiretrovirals (ARVs). The researcher particularly focused on learners from grade seven (7) to grade twelve (12), ranged from 13 to 19 years old. This type of group consisted of people who did not know each other in the normal course of their lives but share a similar type of experience.

1.7.2. Study criteria

This study was carried out through conducting in-depth individual interviews with males and females. A study guide was prepared and used to guide the discussion which was held with the research participants. The discussions were conducted in the research site where a conducive venue was assigned to the researcher. The research guide comprised of open-ended interviews to facilitate discussion. An audio device to record the discussion was used. Ethical considerations were maintained during data collection.

Guardians and parents of patients participating in the study provided written consent. Study participants were offered a copy of the consent form to read along with the researcher and assent. The area is predominantly a Zulu speaking community therefore consent forms were available in English and in isiZulu, the local language. Consent forms were translated and checked for quality through back translating to English after the first translation.

1.7.3. Data handling and analysis

Researcher notes and audio records are kept in a lockable cabinet which will be accessed by only the researcher. Audio tapes were transcribed and translated into English. Audio files were saved in a password protected folder which will only be accessible to the researcher. All names of the participants were changed to pseudonyms for anonymity. Data was thematically coded to prepare for analysis. The report was produced from the data collected and analysed.

1.8. ETHICAL CONSIDERATIONS

The researcher complied with the laws and ethical standards of research where research was planned and conducted in a manner that was consistent with the law and internationally acceptable standards governing research with human participants.

The researcher requested for written institutional approval before conducting the study. In her request the researcher provided accurate information about the nature of the research.

The research was conducted in accordance with the research protocol approved by the institution.

A language that is understandable by the participants was used in obtaining informed consent. Since this was a written informed consent, it included clearly the nature of the research.

Participants were informed that they were free to withdraw from the research at any time. Informed consent on the basis of recording as being part of the research instruments was also obtained. Participants were also assured on issues of confidentiality during and after the research in record keeping.

The researcher also had to provide prompt opportunities for participants to obtain relevant information about the nature, results and conclusions of the research and maybe correct any misconceptions that participants may have.

In reporting research results no data was fabricated nor was there any falsification of results of the study, data references, claims or research findings. If the researcher does discover errors in already published data of this research steps to correct such errors in a correction, retraction, or other appropriate means of publication will be taken.

The researcher referenced the authors of any resource material used so as to avoid plagiarism.

After the research findings have been published the researcher will not withhold the data on which the conclusions have been based from other professionals who might need it for re-analysis. The researcher will however, protect the identity of the participants by use of pseudonyms.

1.9. DISSEMINATION OF THE STUDY

This study will be disseminated through seminar presentations, publications of peer reviewed articles in accredited journals of mental health and HIV/AIDS. It is also the researcher’s wish to write articles or a journal based on the findings of this research study.

1.10. DEFINITION OF KEY TERMS/CONCEPTS

A definition of the terms used in this study is important to be included by the researcher so the readers can have a clear understanding of the terms/concepts used throughout the study. These are explained here under:

Mental health: mental health includes an individual’s emotional, psychological, and also their social well-being.

Adolescents: An adolescent is a young person who is changing from being a child to an adult.

Adolescence: The term adolescence refers to a transitional period of physical and psychological development that generally occurs during the time from puberty to adulthood (Rice & Dolgin, 2002).

HIV: HIV is a virus that slowly attacks the immune system. It destroys the white blood cells and makes copies of itself inside them (Healthline, 2014).

AIDS: AIDS is a syndrome that is caused by the HI virus. This is when the individual's immune system is too weak to fight off infections. It is the last stage of infection (Healthline, 2014).

CD4 count: This term refers to the number T-helper cells found in a certain amount of blood. If it drops below 200 the individual is said to have full blown AIDS (Healthline, 2014).

Viral load: The viral load is used as a term to describe the amount of HIV in an individual's blood. The higher the viral load the lesser the CD4 count becomes, making the person weaker.

ARVs: These are drugs used to suppress the effects of HIV (AIDS Resource Center, 2016).

ART: This term in turn is used to define the anti HIV treatment which uses a combination of ARVs (AIDS Resource Center, 2016).

1.11. Summary

This chapter has given attention to the layout of the problem that has led the researcher to want to pursue the topic further. After analysis of the problem the aim and objectives of the study were given. The following chapter will give attention to relevant literature to this study.

CHAPTER 2

LITERATURE REVIEW

2.1. Introduction

This chapter discusses the literature relevant to the study, looking at some of the theories that shape the key issues of the study objectives. The chapter also covers the issue of mental health as a whole and mental health with regard to adolescents who are HIV positive and those that are already on antiretroviral treatment (ART). The chapter further covers key problems experienced by adolescents in general and those who are on ART. Literature and findings from previous and current research relevant to this study is also included.

2.2. Theoretical Framework

This study is informed by the Systems Theory, Ecological Systems Theory, and Cognitive Behavioural Therapy.

2.2.1 Systems Theory

Anderson, Carter, & Louw (1999) defines the system as an organised whole which is made up of components that interact in a way that is distinct from their interaction with other entities and which endures over some period of time.

The systems approach attempts to view the world in terms of integrated systems; it focuses attention on the whole and as well as on the complex interrelationships among its constituent parts. According to Anderson, Carter, & Louw (1999) Systems theory is a way of elaborating increasingly complex systems across a continuum that encompasses the person-in-environment. The Systems theory also enables us to understand the components and dynamics of client systems in order to interpret problems and develop balanced intervention strategies, with the goal of enhancing a fit enough relationship between individuals and their environments.

Kuhn (1974) explains that knowing one part of a system enables us to know something about another part. Kuhn's model stresses that there are certain elements that move a system towards equilibrium. Communication and transaction provide the vehicle for a system to achieve equilibrium.

It is through collaborative relationships with other community-based services and programmes that gaps can be addressed to help provide a comprehensive approach to adolescents' health care. The mental health of adolescents should not necessarily be one dimensional especially because the adolescent belongs to a set of systems which have a direct and an indirect impact on their lives.

2.2.2 Ecosystems Theory

The ecological systems theory holds that we encounter different environments throughout our lifespan that may influence our behaviour in varying degrees. Bronfenbrenner in his Ecological Systems Theory argues that the child is embedded in multiple layers of contexts that influence his or her development (Bronfenbrenner, 1979). Bronfenbrenner proposed that human development is influenced by factors operating at different systems levels and within a broad, ecological structure. These different levels exert reciprocal influences on one another. These ecosystems which significantly affect the interactions of the individual in their environment are namely, the microsystem, mesosystem, exosystem, and the macrosystem.

Ecological Systems Theory suggests that the micro-, meso-, exo- and macro-systems impact the child in different ways with the mutual influence on the child strongest at the micro level (Bronfenbrenner, 1979).

The micro system's setting is the direct environment the individual has in their lives. This includes; family, friends, classmates, teachers, neighbours and other people who have a direct contact with the individual. It contains factors within an individual's immediate environment. These factors directly affect the individual, and, in turn, may be affected by the individual (Bronfenbrenner, 1979).

The mesosystem involves the relationship between the microsystems in an individual's life. It is the connection between the microstructures which means that as an example ones family experience may be related to one's school experience. If a child, for example, is neglected by his parents, he may have a low chance of developing a positive attitude towards his teachers. The child may also feel awkward in the presence of peers and may resort to withdraw from a group of classmates.

The exosystem refers to structures that have an impact on the child's mesosystem and therefore have ripple effects on the child. It is a setting in which there is a link between the context wherein the person does not have any active role and the context wherein the individual is actively participating (Bronfenbrenner, 1979, p.25). It includes all external networks, such as community structures and local educational, medical, employment and communication systems, which influence the microsystem.

The macrosystem setting refers to those structures that have cascading influence on the child although they are far from the child. An example of those may be government policies, cultural values, political philosophies, economic patterns, and social conditions (Paquettte & Ryan, n.d). All settings at each level operate within a cultural context. A child, his or her parents, the school, or the parent's workplace are all part of a large cultural context. Members of a cultural group share a common identity, heritage, and values. The macrosystem evolves overtime, because each successive generation may change the macrosystem, leading to their development in a unique macrosystem (Kail, R.V. & Cavanaugh, J.C., 2010).

The chronosystem is defined as a patterning of environmental events and transitions over the life course, as well as sociohistorical circumstances. Over the years, through medical research, mother to child transmission of the humane immuno virus has been prevented through the use of prophylactic treatment by the mother during the pregnancy stage. Even though this may not prove to be of benefit to the already infected adolescent it could also be seen as a prevention of having more children being exposed to the virus. An improvement in one system draws back to the balance of the systems in order to prove beneficial to the individual belonging to the system.

Adolescents' social worlds extends to more than their families to include peers, other respected adults in the community and celebrities on social media who may become important role models.

2.2.3. Cognitive Behavioural Theory

Cognitive therapy is a type of psychotherapy which was developed by American psychiatrist Aaron T. Beck. It is based on the cognitive model, which states that thoughts, feelings and behaviour are all connected. The model further states that individuals can move toward overcoming difficulties and meeting their goals by identifying and changing unhelpful or inaccurate thinking, problematic behaviour, and distressing emotional responses. It involves the individual working collaboratively with the therapist to develop skills for testing and modifying beliefs, identifying distorted thinking, relating to others in different ways, and changing behaviours (J. Beck, 2008).

In their guide on mental health care for people living with or affected by HIV/AIDS Acuff, Archambcault, Greenberg, Hoeltzel, McDaniel, Meyer, Parker, Parga, Phillen, Ronhovde, Saldarriaga, Smith, Stroff and Wagner (1999) discovered that through counselling, clients in recovery from risky behaviours often discover and begin to heal underlying psychological wounds they attempted to mask through risky behaviour. Counselling explores motivations, behavioural patterns, interpersonal relationships, and patterns of thinking over time.

According to Beck’s theory of the causes of depression, depressed people acquire a negative schema of the world in childhood and adolescence. Adolescents who experience depression acquire this negative schema earlier. The theory further holds that depressed people have negative thoughts about themselves, their experiences in the world, and the future.

Living with HIV is of daily concern among infected adolescents and they face the challenges of adapting their lives to live with a chronic illness whilst continuing to achieve or meet social expectations which include high academic achievement, being economically independent, having intimate relationships, assessing risks, protecting others and adhering to treatment.

Benton (2011) cited the Department of Health, which states that children and adolescents are particularly vulnerable to distress caused by a multitude of factors, which include the virus itself, loss of loved ones and fear of rejection and isolation as a result of stigma and discrimination. Psychological stressors such as loss of parents or family members, social stigma, isolation, or fear related to disclosure might also contribute to poor school performance.

2.3. Mental health status of adolescents

In responding to the question which seeks to understand why it is often the case that for many mental disorders, symptoms first emerge during adolescence and young adulthood, the National Institute of Mental Health (2011) argued that this question informed several studies of brain development from infancy to adulthood. They further argue that scientists increasingly view mental illnesses as developmental disorders that have their roots in the processes involved in how the brain matures. They further state that the capacity for learning at this age [adolescence], an expanding social life, and an urge for exploration and limit testing may all, to some extent, be reflections of age-related biology (National Institute of Mental Health, 2011).

Understanding the changes taking place in the brain at this age presents an opportunity to intervene early in mental illnesses that have their onset at this age. Research findings on the brain may also serve to help adults understand the importance of creating an environment in which adolescents can explore and experiment while helping them avoid behaviour that is destructive to themselves and others National Institute of Mental Health (2011).

Chandwani, Koenig, Sill, Abramowitz, Conner and D’angelo (2012) reveal that several studies have shown a clear association between cognitive, psychosocial and behavioural problems in HIV infected adolescents with substance abuse, sexual risk activities and poor adherence to ART.

In support of the arguments of this study the South African HIV Clinicians Society (2013), states that there is no health without mental health. This means that for an individual to function holistically in all aspects of life they will need to be in a good state of well-being, physically and mentally. Mental disorders are highly prevalent among people living with HIV/AIDS, with major depressive disorders occurring almost twice as frequently among this group than in the general population.

Mental health problems place youth at increased risk for poor psychological adaptation throughout childhood, adolescence and adulthood (Reef, Diamantopoulou, van Meurs, Verhulst, van der Ende, 2009). This is why the researcher saw it essential to explore the psychological needs of HIV positive adolescents, as addressing mental health problems at an early age might decrease the risk of having more young people suffer from psychologically related problems and not being able to keep a low viral load.

According to the World Health Organisation (2013) many mental health problems emerge in late childhood and early adolescence. Recent studies done under the WHO have identified mental health problems, depression in particular, as the largest cause of the burden of disease among young people.

Mental health problems among children with perinatal HIV infection have been described prior to and during the highly active antiretroviral therapy era. Yet child, caregiver and socio-demographic factors associated with mental health problems are not fully understood.

Prevalence and types of problems vary due to assessment and sampling methodologies, but rates of mental health problems in both perinatal HIV-infected and perinatal HIV-exposed but uninfected are higher than expected relative to the general US youth population (Bauman L.J., Silver E.J., Draimin B.H., Hudis J.,2007)

The growing number of uninfected youth with perinatal HIV and ARV exposure provides a strong public health mandate to monitor the development of these children and routinely assess their mental health needs. Appropriate diagnosis and intervention are crucial since untreated mental health problems often lead to co-morbidities, including school failure, juvenile crime, substance use, HIV infection, unintentional injuries, violence, and increased mortality, including suicide.

Poor mental health can have an effect on the wider health and development of adolescents. Poor mental health is associated with several health and social outcomes such as alcohol abuse, tobacco and illicit substance use, adolescent pregnancy, school dropout and delinquent behaviours. There is growing consensus that healthy development during childhood and adolescence contributes to good mental health and can prevent mental health problems. Stivilia, Badridze, Geleishvili (2008) in their journal article reveal that officials in the current healthcare system of Georgia do not recognise the need for psychosocial services for people living with

HIV/AIDS. There are no governmental policies, documents or programs which address the link between HIV and mental health issues.

While early diagnosis and treatment of mental health problems are necessary, prevention of mental health problems in families affected by HIV is also an important goal. Health care providers, psychologists, psychiatrists and social workers are positioned to lead efforts that will ultimately foster resilience and reduce intergenerational transmission of psychopathology in families affected by HIV, through culturally sensitive, individualized and targeted mentoring, parenting support, and peer and group support. A number of family-based interventions have been developed for children infected and affected by HIV and may be appropriate models that could be incorporated into health care programs that serve HIV affected adults and youth (McKay M., Block M., Mellins C.A., Traube D., Brackis-Cottt E, Minott D, Abrams E.J., 2006).

2.4. Pre and post enrolment mental health status

Participants from a study by Kagee and Martin (2010) on psychosocial issues revealed that symptoms of distress were ostensibly related to their HIV status. Decreased levels of energy, feeling everything is an effort, and feelings of hopelessness were reported. Psychiatric disorders that can be diagnosed and psychological distress may have a negative effect on quality of life, family functioning, adherence to ARV treatment and adherence to infant-feeding guidelines among new mothers.

Through different research articles it has become evident that mental illness can take many forms, especially in adolescents as they go through emotional, social and physical changes. Adolescents living with HIV experience numerous psychosocial stressors over an extended period of time.

These may be related to the initial diagnosis and disclosure of their HIV status; the emotional and financial strain of long-term care and adherence to treatment. They might further have to cope with stigma and discrimination; distrust of health care providers; fear and experience of legal consequences and abuse; bereavement related to the death of loved ones or apprehension about their own possible death and concerns around emerging sexuality and desire for relationships and families of their own. These concerns may bring about doubt and fear for adolescents to enrol in the ART programme or even adhere to treatment.

Likewise to the researcher's concern Siegel K. & Lekas H.M. (2002) state that it can never be easy for adolescents to accept their HIV status, because in addition to changes and conflicts inherent to the age itself, having a chronic condition intensifies such conflicts that reflect on their social environment, daily activities, sexuality and relationships with other people, generating physical and psychological limitations. They further state that these limitations become more severe especially because the disease is incurable, infectious and transmitted by the mother, which, in the case of HIV/AIDS, is routinely stigmatised and treated with discrimination and prejudice.

Kourrouski & Lima (2009) in their study report reference Moreira and Cunha (2003) who also adds that adolescents with HIV/AIDS experience challenges related to their status namely: a complex therapeutic regime; periodic medical visits; a large number of medications with unpleasant flavours and side effects in addition to hospitalisation in the case of intercurrences. Yet, many of these adolescents do not understand such measures since the diagnosis is not disclosed to them.

2.5. Adolescents' perspectives on ART

Freeman, Patel, Collins and Bertolote (2005) in their article concluded that a more prominent role is needed for mental health interventions in global HIV/AIDS initiatives. Significant numbers of infected people have or develop mental health problems, and this often adversely impacts on the treatment and adherence. Integration between psychiatric and psychosocial interventions should benefit both the mental and the physical health of people living with HIV. The article also supports looking at different aspects that touch on HIV and intervention strategies.

As stated earlier by the researcher, Anderson and Seedat (2009) mention that although progress has been made concerning the launch of the National Antiretroviral Programme in providing medical treatment for people living with HIV/AIDS, their psychosocial needs have not been equally provided for.

In their report on barriers to medication adherence in HIV infected children and youth, Buchanan, Montepiedra, Sirois, Kammerer, Garvie and Storm (2012) concluded that lifestyle barriers such as forgetting, worrying about disclosure of HIV status, falling asleep before taking ART, being away from home, busy and varied schedules including school attendance are common to resource-rich and resource-limited settings.

Garvie, Flynn, Belzer, Britto, Hu and Graham (2011) found that medication related barriers are also common in perinatal HIV (PHIV) infected adolescents and include treatment fatigue, complexity of regimens including pill burden and dosing frequency.

In their journal article on HIV-positive youths' perceptions of HIV treatment Veinot, Flicker, Skinner, McClelland, Saulner and Read (2006) show that poor treatment knowledge and understanding of the benefits of taking ART as a non-curative intervention may impact adherence. Adolescents may also be emotionally unprepared for ART, particularly if they have been newly diagnosed or recently disclosed to. In fact, non-disclosure of HIV status to HIV infected adolescents by caregivers may impact adherence, particularly when adolescents begin to question their ART regimen and express regimen fatigue (Merzel, Van Devanter and Irvine, 2008).

Battles & Wiener (2002) in their article show that a high prevalence of PHIV-infected adolescents who have experienced the loss of a primary caregiver, and parents who have survived frequently all, show, in the long run, depressive symptoms and psychological distress which may impact adherence. Mellins & Ehrhardt in their article on families affected by paediatric acquired immunodeficiency syndrome report the same.

Adolescents experiencing adherence problems most commonly use withdrawal and passive emotional regulation and less commonly use problem solving or social support as coping mechanisms, possibly because of fear of stigma or unwanted disclosure. A passive coping style is also associated with depression and poorer psychological adjustment (Orban, Stein, Koenig, Conner, Rexhouse and Lewis, 2010).

In their investigation on the prevalence and interactions of patient-related risks for nonadherence to ART Rudy, Murphy, Harris, Muenz and Ellen (2010) found that adolescents who experience problems such as lack of medical insurance, problems with work or school, concerns about dealing with family and looking after children, housing instability, lack of transportation to clinic visits or to obtain medications, may have lower adherence.

Agwu and Fairlie (2013) concluded that the relative lack of healthcare professionals (medical care providers, support staff, psychologists, social workers and counsellors) experienced in adolescent healthcare management may further impact the adherence counselling and support needed for PHIV-infected adolescents in resource limited settings.

2.6. Problems experienced by adolescents

According to the American Academy of Child and Adolescent Psychiatry (AACAP, 2003) the adolescent years are a time of transition from childhood into adulthood. Adolescents often struggle with being dependent on their parents while having a strong desire to be independent. They may also feel overwhelmed by the emotional and physical changes they are going through.

At the same time, the Botswana: Baylor International Pediatric AIDS Initiative (BIPAI,2012) also state that adolescents may be facing a number of pressures from friends to fit in and from parents and other adults to do well in school or activities like sports or part-time jobs. The adolescent years are important as it is where the child starts to assert his or her individuality.

For any person adolescence is a challenging time and this is even more so for adolescents living with HIV (Kerrissey, 2008). Research findings by Menon, Glazebrook, Ngoma (2009) show that factors leading to the vulnerability of young people include lack of knowledge about HIV/AIDS, lack of education and life skills, poor access to health services and commodities, early sexual debut, early marriage, sexual coercion and violence, trafficking and growing up without parents or other forms of protection from exploitation and abuse.

Several studies have shown a clear association between cognitive, psychosocial and behavioural problems in HIV infected adolescents with substance abuse, sexual risk activities and poor adherence to ART (Chandwani, Koenig, Sill, Abramowitz, Conner, D’Angelo, 2012).

The World Health Organization (2008) state that the degree and impact of mental health problems on the lives of adolescents varies and can also range from mild to severe or acute to chronic. The organization further states that the most common mental health problems experienced by adolescents are depression and anxiety disorders. The most prevalent of those mental health issues being behavioural and psychiatric problems such as attention deficit hyperactivity disorder. In this regard the organization advocates that health workers therefore need to have the competencies to relate to young people, to detect these mental health problems early. Furthermore they need to provide treatments which include counseling, cognitive-behavioural therapy and psychotropic medication, where appropriate.

The London: National Children's Bureau (2012) also state that for many adolescents living with HIV, the clinic is the only place in which they can openly talk about their status and ask questions which they may be uncomfortable to address with their friends or family members. Health care providers remain the integral part for positive living and they can only do this best when they understand and address the complex psychosocial, physical and other support needs of their adolescent patients who are living with HIV. Enhancing adolescents with problem-solving skills, social skills can help prevent mental health problems namely; conduct disorders, anxiety, depression, eating disorders and other risk behaviours which relate to sexual behaviour, substance abuse and violent behaviour.

According to World Health Organization (2014) one's physical, mental health, emotional life and social life (relationships, attitudes, school, peers and community) all affect psychosocial well-being. Adolescents living with HIV are further affected by the pressure for seeking independence and self-management, understanding the dynamics around stigma, vulnerabilities linked to being orphans, poverty, illness and abuse, coping with death and bereavement, educational challenges and disclosure to others for emotional and practical support. It is therefore essential to provide psychosocial support to adolescents living with HIV.

In their study, Mavhu, Berwick, Chirawu, Makamba, Copas, Dirawo, Willis, Araya, Abas, Corbett, Mungofa, Laver and Cowan (2013) on enhancing psychosocial support for HIV positive adolescents, state that such psychosocial support could also assist to prevent adolescents living with HIV from adopting risk-associated behaviours or from developing more severe mental health problems. They further state that caregivers could also benefit from this support that acknowledges the stress they are under and validates their concerns about their children while informing them about how to cope with the adolescent's developmental and health needs.

According to Meyersfeld and Vujovic (2012) almost all adolescents need support in coping with developmental issues, such as independence, seeking for acceptance among peers and learning to navigate their emerging sexuality and new intimate relationships. They further state that adolescents living with HIV may experience additional HIV- related stressors and with most cases, additional vulnerabilities and challenges. Therefore, limiting confidentiality to only the most intimate health issues dampens adolescents' hope for seeking preventive care and counselling before problems even occur.

2.7. Family dynamics experienced by adolescents on ART with regards to disclosure

Abrahams & Jewkes (2012) mentioned in their findings that although stigma was still part of people's lives, it didn't dominate their social interactions and most resisted the stigma and sort to regain normality. All participants in their study except a few were concerned about people's perceptions of their HIV status. Of the 21 participants in Cape Town 15 had disclosed to their partners and for some females, relationships continued but for a few they ended and most of them decided not to disclose when entering new relationships.

Being open to others about their status was a coping strategy mentioned several times by participants in a study conducted by Mills, Nachega, and Bangsberg in 2006. However some participants reported their families as showing little or no support. When the participants disclosed their status to their families, they reacted differently, depending on the families' level of knowledge and awareness of HIV/AIDS. They found also that interacting with other positive persons or forming support groups was another coping strategy.

Previous research by Stivilia, Badridze and Geleishvili (2008) has revealed that people living with HIV/AIDS stressed the lack of information about HIV/AIDS as a problem. They found that people are aware of this disease but have misconceptions about it. In addition, people’s negative attitudes towards and the high refusal to assist them at health care institutions along with the discrimination experienced in society, the mental health of people living with HIV/AIDS can be seriously harmed.

Ayres and Franca-Junior (2006) in their study found that fear of prejudice and discrimination tend to lead people with HIV/AIDS to adjourn disclosure, and this decision affects access to health care and sexual, social, family and educational life.

In 2000 NEPAIDS also concluded that discrimination alone can cause people to isolate themselves and might become another factor hindering medication adherence (NEPAIDS 2000).

Findings in a study by Nyongea, Mtenga, Henning, Franzeck, Glass, Letang, Tanner, Geubbels (2015) that investigated determinants on ARV adherence among HIV positive children and teenagers, indicate that amongst other things, being unaware of their HIV status were seen to be barriers for optimal adherence. They further add that to achieve optimal adherence, strategies aimed at targeting the caregivers, the school environment and the health system need to be designed.

In a study by Kidia, Mupambireyi, Cluver, Ndhlovu, Borok & Ferrand (2014) on HIV status disclosure to perinatally-infected adolescents in Zimbabwe, the results indicated that most adolescents preferred disclosure to take place in the presence of health care workers at the clinic. The reason for this preference was because it gave them access to correct information as well as an environment that made test results seem more credible. Participants further expressed that they were able to share their experiences with their peers at the clinic (2014).

Mavhu *et al.* (2013) agree that psychosocial support can help patients as well as their caregivers feel more confident in themselves and their coping skills. This support can increase patients’ understanding and acceptance of comprehensive HIV care and support services, promote adherence to treatment, and further equip them with skills to make informed secondary prevention decisions.

2.8 Summary

Few studies in South Africa exist on the mental health of HIV positive adolescents even though that is the case the studies that do exist do indicate that there is no health without mental health. Since the adolescence stage is filled with major emotional and physical changes the mental health status of HIV positive adolescents cannot be detached from their overall health status. Most studies affirm that most adolescents may have issues of fear of stigma, discrimination thus lessening chances of disclosure to friends and other members of society. Though this may be the case more studies indicate that disclosure to family members and disclosure from family members increases support and adherence.

CHAPTER 3

RESEARCH METHODOLOGY

3.1. Introduction

Methodology can be best described as a system of methods used in a particular discipline to gain access to information. Henning, Rensburg, Smit, (2004) describe methodology as a coherent group of methods that balance one another and have the ability to deliver data and findings that will reflect the research questions and suit the researcher's purpose. The previous chapter has considered different research results and conclusions from different provinces and countries with regard to the researcher's area of concern. This chapter aims to cover the research process followed to investigate the research questions. The specific research questions were formulated in Chapter one. As previously stated the researcher is interested in finding answers to the following research questions:

- Are there differences in the mental health status before and after being enrolled in the antiretroviral therapy (ART) programme?
- What are the different perspectives regarding ART among school going adolescents on ARVs?
- Are there key problems experienced by adolescents on ART?
- Are there differences to the family dynamics?
- Does disclosing the HIV status affect the relations with significant others?

The primary focus of this chapter is on the procedures followed before the study could commence, the research design, sampling method applied, data collection techniques and the method for analysis.

3.2. Preparations before the study commenced

A feasibility analysis was done by the researcher in order to determine whether the topic of research was viable or not. The researcher had to ensure whether the topic was worth pursuing or not. Through the literature reviewed in chapter 2, the researcher discovered that several studies have been made on adolescents and most indicate that, as many theorists have noted, the adolescence period is focused on identity formation and this is where most are adolescents may struggle with achieving a dignified identity. This is also a period marked by physical and sexual development. Adolescents at this stage tend to want to explore their world. With these findings the researcher was curious to find out how HIV positive adolescents handle the difficulties and/or challenges of overcoming such a stage and at the same time having to deal with their HIV diagnosis.

Findings in Benton's study (2011) indicate that adolescents are particularly vulnerable to destress caused by multitude of reasons and these include the virus itself, loss of loved ones, fear of rejection and isolation as a result of stigma and discrimination. Psychological stressors such as loss of parents or family members, social stigma, isolation, or fear related to disclosure might also contribute to poor school performance. This was supported by Menon, Glazebrook & Ngoma (2009) whose research findings indicate that factors leading to the vulnerability of young people may include lack of knowledge about HIV and AIDS, lack of education and life skills, poor access to health services and commodities, any sexual debut, any marriage, sexual coercion and violence, trafficking and growing up without parents or other forms of protection from exploitation and abuse.

These findings inspired the researcher to explore the mental health of these adolescents as there were a few studies done on the mental health status of HIV positive adolescence, especially studies focusing on adolescents in South Africa. The researcher explored this topic with her supervisor who in turn worked with the researcher to unfold the plan of action in exploring this topic. The researcher was also familiar with interviewing HIV positive individuals; this experience was gained in a research study which the researcher was involved in.

The study explored the side effects of ARVs on HIV positive individuals. This experience made the researcher aware that people living with HIV were willing to have their stories heard by the public. This gave the researcher confidence that the adolescents aimed for this study would also be willing to be interviewed in order to give their insight on living with HIV. The researcher was also familiar with the proceedings followed at the research site as she was previously employed as a HIV/AIDS lay counsellor there; all that was left was for the researcher to enquire about the procedures to be followed in order to conduct research at the site. For permission to conduct the study the researcher was told by the clinic manager to contact the main hospital which the intended site was under. The hospital was contacted in order to secure an appointment with the hospital manager who was the relevant person for permission to be granted. A verbal agreement was given by the manager while awaiting the relevant letter from the researcher.

The topic for the study was then sent to the University of Zululand Research and Ethics Committee (UZREC) for approval. Once approved, the researcher proceeded with the writing of the proposal. The proposal was then sent to the committee for ethical clearance. Regular consultations were done with the supervisor for progress on the proposal. Permission letters to be sent to the relevant gatekeepers were then drafted and approved by the supervisor. The permission letter was then sent through to the hospital and then permission was granted by the hospital for the researcher to conduct the study at the selected site. Ethical clearance was then granted by the ethics committee and a visit was then paid to the site by the researcher with a plan and programme of action.

3.3. Research Design

The research design is of paramount importance because it has a bearing on the reliability of the research findings arrived at and as such constitutes the firm foundation of the entire structure of the research work. Kothari (2004) in his describes the research design as a conceptual structure within which research is based. He further explains that the design is a blueprint for the collection, measurement and analysis of data.

The research design stands as a strategic framework for action and a bridge between research questions and the execution of the research (Terre Blanche, Durrheim & Painter, 2006). It is a plan that guides the whole process of the research and its purpose. As the purpose of this study is to explore the mental health of adolescents on antiretroviral treatment, a more detailed design had to be utilised so as to informatively capture the experiences of such adolescents. In this study, the researcher used an exploratory research design. The researcher opted for this design as explained here under:

3.3.1 Exploratory research

The Collins English Dictionary for Advanced Learners (2001) defines exploratory actions as being done in order to discover something or to learn the truth about something, as is the aim of the study. According to Burns and Grove (2003) exploratory research is conducted to gain new insights, discover new ideas and/or as a means to increase knowledge on a phenomenon.

The researcher chose to use the exploratory method in this study to gain new insights and increase knowledge in the field of HIV research and also in the field of mental health, particularly the mental health of adolescents living with the human immuno virus. In using the exploratory method the researcher enters the research site with curiosity from the point of not knowing and to provide new data regarding the phenomenon in the context (Creswell, 2003). In exploratory research everything about the phenomenon is of importance.

A qualitative research design was chosen by the researcher due to the nature of the study and proposed objectives.

3.3.2. Characteristics of qualitative research

According to Melendez (2011) a unique attribute of qualitative research is that it promotes a more diverse reaction from those previously asked or researched. This is so as the human behaviour is taken more into consideration than is metrics or numbers. According to Hanson, Balmer, Giardino (2011) a qualitative study is concerned with the point of view of the individual under study.

Another attribute mentioned by Melendez (2011) is that qualitative research causes the variable sampling to be much smaller to work with than the larger and more composite samples used in quantitative researches.

The purpose for selecting this type of research design was due to the fact that the research questions for this study could not be addressed or answered using quantitative methods. As already indicated, the purpose for the research questions is to gain insight into the topic on which there is limited literature, especially in the South African context. The character of the study required access to personal experiences of individuals who are considered to be vulnerable and this information could not just be acquired through a questionnaire with pre-established or set answer categories as is in a quantitative research design. Qualitative designs seem to be personal in nature and are not centred on measures or variables. Maudsley (2011) states that qualitative research methods explore, describe, generate theory, especially for uncertain and less popular concepts; sensitive and socially dependent concepts; and complex human intentions and motivations.

In addition, qualitative research focuses on understanding the whole, which is consistent with some of the philosophy of psychology. Qualitative methods of research appear to be more effective methods of investigating emotional responses than quantitative methods of research.

3.4. Research Setting

The study is contextually based in Amajuba District, KwaZulu-Natal. The study was conducted in a health facility in one of the towns which falls under Amajuba District. The health facility falls under one of the largest hospitals in the area. This chosen site is a primary health care facility which provides HIV/AIDS and TB related treatment. They provide HIV counselling and testing and, where necessary, they perform further tests to determine the CD4 count and viral load. Additionally, the facility is an accredited antiretroviral treatment site. They also organise referrals for people with mental health issues. All these services are free of charge.

Moreover, this facility was chosen by the researcher due to the fact that it is based in a community which is rated to have the most underprivileged families. The researcher was therefore, interested more in investigating the mental health issues faced by HIV infected adolescents on ART, who are raised in such circumstances.

3.5. The study population and sample

According to Burns and Grove (2003), the population includes all elements that meet certain criteria for inclusion in a study. For the purpose of this study the population consisted of school going adolescents who are HIV positive and on antiretroviral treatment living in the Amajuba District, who utilise one of the clinics in the area as their health facility, so as to provide the necessary information for achieving the study objectives.

The researcher had initially opted for 20 participants for the study sample but due to issues of consent the researcher remained with only 6 participants who were willing to participate in the study. The size of the sample proved to be optimum for the researcher. Kothari (2004) defines an optimum sample as one which fulfils the requirements of efficiency, representativeness, reliability and flexibility. The researcher particularly focused on learners from grade seven (7) to grade twelve (12) ranged from 13 to 19 years old. This type of group consists of people who do not know each other in the normal course of their lives but share a similar type of experience.

A non-probability purposive sampling technique was used by the researcher due to the fact that information-rich participants were required. Sampling also depended not only on availability and willingness to participate but also that cases that are typical of the target population were selected. Lincoln and Guba (1985) mentioned that purposeful sampling is characteristic of qualitative enquiry and is based on informational and not statistical purposes. Its purpose is to maximize information and not to facilitate mere generalizations. Patient Advocates (PA) working at the selected site helped in getting the participants needed in the study. Each PA is allocated a number of patients who are on antiretroviral treatment to do follow-up. The duty of the patient advocates is to make sure that clients abide to their clinic appointments and also adhere to their treatment. This made it easy for the researcher to get the required participants.

According to the ethical guidelines for good practice with regards to HIV (HPCSA, 2007), children who are 12 years and above can consent for themselves in this study, children who were below 18 years old were given consent forms to assent and for their parents/caregivers to give consent. The reason the researcher did that was to follow the ethical guidelines in research. The study consisted of 4 male participants and 2 female participants. The participants also had to be mentally sound and mature in order to assent to participation. The patient advocates helped in that regard as they knew the participants more on a clinical level than the researcher did.

3.6. Data Collection Procedures

The World Health Organization (2016) emphasises that awareness of existing national and/or regional health research guidelines is important as these may set out specific anticipations to protect the interests and well-being of participants, their communities and lastly, the national health research system. The researcher is also required to consult national and/or regional research institutions on any proposed human subject research which will take place within their boundaries (WHO, 2016).

In keeping with the above, the researcher contacted the Department of Health to seek permission to conduct the study in one of their clinics and was referred to the research department. The proposal for the study had to be forwarded to the department for ethical reasons on the side of the department. Once the proposal was received and approved a permission letter was forwarded to the researcher. The researcher then had to forward the letter to the relevant hospital which the clinic was under. The matron in charge of the clinic then communicated with the head of the clinic to grant the researcher access to the required participants. The researcher was then introduced to the patient advocates as they would make tracking down the participants easier.

The Patient Advocates (PAs) were informed in detail about the study so as to let the participants know what the study objectives were and that their involvement in the study was to be voluntary. The response received from the PAs informed the researcher that all the 6 adolescents who were chosen and present at the site wanted to be part of the study.

3.6.1. Instrumentation

The study was carried out through the use of face to face interviews. An interview guide was prepared by the researcher and used to guide the discussion between the researcher and the participants. The use of questionnaires was avoided because as much as they have their advantages of requiring less time and energy for the administration, the participants might not reflect their true opinions but might answer what they think might delight the researcher and valuable information may be lost as answers are usually brief and not well thought of.

The interview guide was prepared both in English and isiZulu as prescribed (UNIZULU Ethics Guide, 2014) in order to cater for all client needs. The instrument was designed in such a way as to get knowledge and an insight from the participants regarding their health living with HIV/AIDS. The researcher collected data through interviews and used the data instruments together with the procedures in preparation for analysis.

3.6.2. Interviews as a method of data collection

In this study the information was collected through in-depth one-on-one interviews conducted by the researcher herself. Questions for the interview were compiled by the researcher guided by the objectives and questions of the study. The interviews were unstructured in order for the researcher to be able to ask probing questions as a result this led to the participants to disclose enlightening information. While the general topic of mental health was common in all questions, the interview guide allowed the researcher to be flexible and responsive to unanticipated paths and findings during the interview. The interviews took place at the research site where a conducive venue was assigned by the site manager to the researcher. The venue ensured privacy for confidentiality purposes.

Permission was granted from the participants to have the interviews recorded for quality purposes. A consent form with this sub-section was signed by the participants. The recorded transcripts were then transcribed for analysis purposes.

The interviews were 15-20 minutes long and resulted in transcripts averaging from 8-12 pages and that resulting to about 72 pages of interview data. Interviews with the adolescents provided a basis for understanding the research concerns from the perspectives of the individuals directly involved.

3.7. Quality and Trustworthiness of the study

A fundamental concern in any research study is to integrate appropriate mechanisms that assure the researcher and the reader of the quality of the research, its process and its findings. Quantitative methods employ the criteria of reliability and validity and qualitative constructs correspond with of quantitative methods. This study addressed quality in terms of trustworthiness related to this criteria: credibility (internal validity), dependability (reliability), transferability (external validity), confirmability and confirmability (objectivity).

3.7.1. Credibility

Credibility deals with how congruent the findings are with reality. The adoption of research methods that are well established in qualitative research was undertaken by the researcher. The correct operational methods were used in that multiple sources of data were used, these were: interviews, data transcripts, researcher's notes and observations. A review of literature about existing theories and findings was considered. Development of an early familiarity of the organisation was shown in that the researcher had worked in the research site before so she understood the procedures or culture followed in the site and also some of the contextual disadvantages of clients. This experience however did not influence the judgement of the researcher or the responses of the clients. In her working experience the researcher had a chance to engage with informants who had similar experiences as the study participants.

Trustworthiness was further ensured by the researcher by the use of triangulation. This was done by the use of a variety of informants. In this process individual viewpoints and experiences can be verified against others and ultimately, a rich picture of the experiences, attitudes, needs and behaviour of those under study may be constructed based on the contributions of a range of people. Each participant was given an opportunity to refuse to participate in the study. This was done to ensure that the data collection procedure involves those who are willing to participate freely. To further ensure credibility the researcher made clear to participants that they have the right to withdraw from the study at any point.

3.7.2. Transferability

Transferability is used in qualitative research to demonstrate the probability that the research findings have meaning to others in similar situations (Streubert & Carpenter 1995). According to Bitsch (2005) the researcher can facilitate transferability judgment through thick descriptions and purposeful sampling. In this study the researcher gave a detailed description of the enquiry and the participants were purposefully selected. Creswell (2003), claims that the comprehensive description of the participants' experiences by the researcher, may enable the reader to transfer the information to other settings with a similar context.

3.7.3. Dependability

Dependability is defined by most researchers as challenging due to the fact that the researcher should strive to enable a future investigator to repeat the study (Shenton 2004). It is the stability of the research findings over time (Bitsch, 2005). Throughout the chapters of the research project, there was constant interaction with the supervisor for external checking of the research, which is the same process as interrater reliability in quantitative research (Creswell, 2003).

Krefting (1991) as referenced by Anney (2014), explain that dependability can be established by using peer examination. They further explain that during this process the researcher discusses his or her research process and findings with neutral colleagues, who are either doing qualitative research or have experience in qualitative research methods. Peer examination assists the researcher to be honest about his/her study. Peers will then contribute to the researcher's deeper reflexive analysis. A contribution by Silverman (2000) is that the interpretation of transcribed data may be less reliable than other forms of data because some researchers may fail to transcribe crucial information, such as pauses and overlaps or sighs. In avoidance of this the researcher used a skilled person to transcribe the interviews, who was able to pay close attention to every detail of the interview to ensure dependability. The researcher then rechecked the transcription against the original interviews and thus accounted for transcription reliability.

3.7.4. Confirmability

Tobin & Begley (2004) describe confirmability as being concerned with establishing that the data and interpretations of findings are not figments of the researcher's imagination, but are clearly derived from the data.

Studies suggest that confirmability in qualitative research can be achieved through an audit trail, reflexive journal and triangulation (Bowen, 2009). The audit trail allows any observer to trace the course of the research step by step through the decisions made and procedures described. The researcher achieved this by supplying evidence in terms of literature review, interviews, permission letters and research instruments used to conduct the study. According to Krefting (1991), reflexivity is an assessment of the influence of the researcher’s own background, perception and interests on the qualitative research process. In a research study the researcher is part of and not separated from the phenomenon which is under study. The researcher has to adopt an emic approach. In this study the researcher explored her personal feelings and experiences that might influence the influence the study and then integrated this understanding into the study in order to promote objectivity (Burns & Grove, 2003). Analysing the researcher’s experience made her aware of possible biases and preconceived ideas. Bracketing, which is defined as the process of holding assumptions and presuppositions in suspension in order to improve the rigour of the research (Holloway, 2005) was applied by the researcher. Bracketing is crucial because it allows the researcher to be neutral. This further allowed the researcher to be open-minded when approaching the phenomenon and avoidance of being bias or making unwarranted assumptions about the participants.

3.8. Ethical Considerations

In this study the researcher complied with the laws and ethical standards of research where research will be planned and conducted in a manner that is consistent with the law and internationally acceptable standards governing research with human participants. Ethical approval for this study was obtained from the University of Zululand Research and Ethics Committee (UZREC) at the University of Zululand, approval number (see Annexure B).

In advance, the researcher requested for a written institutional approval for conducting the study. In the request the researcher provided accurate information about the nature of the research. A written permission to conduct the research was obtained from the Department of Health. When the permission was granted, the written permission from the department had to be forwarded to the hospital which the selected site operated under. The researcher had to then take the letter to the matron in charge of the site who then imparted the message to the manager of the clinic that was the selected site. The research was conducted in accordance with the research protocol approved by the institution.

The researcher used a language that is understandable to the participants in obtaining informed consent. Informed consent on the basis of a recorder as being part of the research instruments was obtained. The nature of the study was also clearly stipulated. Consent was obtained from the participants before the interviews. The participants were informed of their rights to voluntarily consent or decline to participate, and to withdraw participation at any time without any penalties.

The participants were informed by the researcher about the purpose of the study, the procedures that would be used to collect the data, and guaranteed that there were no potential risks or costs involved. The participants were assured on issues of confidentiality during the research and after the research in terms of record keeping.

The researcher will have to provide a prompt opportunity for participants to obtain relevant information about the nature, results and conclusions of the research and maybe correct any misconceptions that participants may have.

In reporting research results no data shall be fabricated or falsification of results of the study, data references, claims or research findings. If the researcher discovers errors in already published data of the study, steps will be taken to correct such errors in a correction, retraction, or other appropriate means of publication.

The researcher has referenced the authors of any resource material used as to avoid plagiarism.

After the research findings have been published the researcher will not withhold the data on which the conclusions have been based from other professionals who might need it for re-analysis. The researcher will however, protect the identity of the participants by use of pseudonyms.

3.9. Data Analysis

3.9.1. Introduction

The purpose for analysing data is to extract information from data and make it accessible to other readers. Lacey, Anne, Luff and Donna (2001) state that, the analysis of qualitative data usually goes through some or all of the following stages:

- Acquainting oneself with the data through review, reading and listening, etc.
- Transcription of audio recorded material
- Organisation and coding of data for easy retrieval and identification

- Anonymising of sensitive data
- Identification of themes

3.9.2. Type of Analysis

The information from the interview scripts was analysed using thematic method of analysis. The data analysis was iterative with data collection. Thematic analysis focuses on identification, analysis, and also reporting themes within data (Braun & Clarke, 2006). It is a type of qualitative analysis. They further state that a thematic analysis of the data is done throughout the coding process and as themes are established they are clustered into categories that are discernible from each other for mutual exclusivity (Braun & Clarke, 2006). Thematic analysis is considered the most appropriate for any study that seeks to discover in a way of using interpretations (Alhojailan, 2012). This type of analysis is consistent with the researcher's study design which uses exploratory actions in order to discover something or to learn the truth about something. In this study the focus was to understand and explicate the mental health status of adolescents on ARVs.

3.9.3. Data Analysis Process

Although this was a time consuming process, the richness of the information obtained from each interview warranted such an effort. Verbatim transcription was essential to get the participants' exact words related to their experiences as adolescents on antiretroviral treatment. The audio recordings were transcribed and translated into English so as to follow for an interpretative analysis of the data (Braun & Clarke, 2006). The process of transcription allowed the researcher to make sense of which data will be useful in the analysis process. The data was then read repeatedly in order for the researcher to be familiar with the information contained in the data. During the reading process notes for codes were generated as patterns were observed in the data. Through open coding, common themes of everyday life were identified and examined in relation to the context, meanings, and circumstances of being an adolescent living with HIV and AIDs.

There were precise patterns that seemed to be repeatedly coming out from data. Through deep searching the researcher was then able to identify themes from the codes. To ensure that the themes were mutually exclusive they were categorised and in that process sub-themes were also identified. Coherence in the themes was given much attention by the researcher by reviewing them repeatedly across the whole data set. Themes were named and those found to be identical were combined, labelled and given a specific definition for each and how they relate to each research question. The relationship between the themes and the research questions was shown throughout the analysis.

3.10. Conclusion

The purpose of this chapter was to clarify the research methodology of this study. The following were also presented: the sample selection, the procedure used in designing the instrument and collecting the data. Furthermore an explanation of the statistical procedures used to analyse the data was made. This chapter has also attempted to provide a step by step process of how the study was undertaken.

CHAPTER 4

ANALYSIS AND PRESENTATION OF STUDY FINDINGS

4.1. INTRODUCTION

The following chapter introduces and presents the findings of the study. As the researcher mentioned in the previous chapter that thematic analysis will be used in analysing data, these findings are categorised according to the themes and sub-themes that emerged from the analysis of data. The study's research questions asked in Chapter 1 and revisited in in each chapter will receive special attention in Chapter 4 as answers help us make meaning of findings and whether the study yielded positive or negative outcomes. In some cases affirmative answers to questions suggest a positive outcome and a negative response suggest a negative and risky outcome. The findings are guided and mostly influenced by the aim of the study and questions of the study. The first part of the chapter will give a brief background information of the participants under study, thereafter the major themes with their sub-themes will be discussed.

4.2. BRIEF BACKGROUND HISTORY OF THE PARTICIPANTS

A summary of each participant's background information will be provided here under. Pseudonyms were used in order to protect the identity of each participant. Information is reported according to the time of data collection.

4.2.1. Participant 1- Sakhile

Sakhile is a 13 year old male and in grade eight. They are six in his family and all family members know of his HIV status. Sakhile learnt of his status in 2013 when they were taken as a school to circumcise. At the time he was still in Primary school. He was enrolled in the ART programme immediately after being diagnosed.

4.2.2. Participant 2- Simiso

Simiso is an 18 year old male and is in grade eleven. He lives with his aunt, grandmother, two of his sisters, his uncle, his niece and nephew and lastly his cousin. He learnt of his HIV status when he was in grade nine and he has been taking ARVs for three years now. Almost all his family members know of his HIV status.

4.2.3. Participant 3- Phila

Phila is a 14 year old male doing grade eight. He lives with his sister, brother and his nieces and nephews. His mom passed away in 2005 and he tested HIV positive in 2007 and was enrolled in the ART programme that year.

4.2.4. Participant 4- Mbali

Mbali is a 19 year old female who is in grade 12. She lives with her aunt, her sister and her aunt's three children. She was enrolled in the ART programme in 2007; it has been nine years since she has been on the programme.

4.2.5. Participant 5- Nokuphila

Nokuphila is a 15 year old female who is in grade 9. She lives with her grandmother, uncle and her brother. She learnt of her HIV status at a very young age and does not quite remember when she started taking ARVs but she does know that it was still at a very tender age.

4.2.6. Participant 6- Mbuso

Mbuso is a 14 year old male who is in grade 8. He lives with his mother, grandparents, great-grandmother and his aunt. In 2008 he learnt of his HIV status and was put on ARVs and around that time again he was diagnosed with epilepsy. He is currently on ARVs and epilepsy medication. He only comprehended that he was on ARVs in 2011.

4.3 DISCUSSION OF RESULTS

The research questions were used to give the analysis and discussion of results as indicated here under:

4.3.1. QUESTION 1: What are participants' views regarding ARVs?

The purpose of the question was to find out the participants' views or perspectives on ARVs. From the answers given the researcher concluded that the participants' view on taking the ARVs was not a personal decision that would improve the quality of life after infection. Instead they saw ARVs as an either do or die type of a relationship. The meaning of HIV and AIDS though known was misleading as most participants saw it as compliance without the benefits of support and /or counselling which although available was limited and disjointed. The themes that emerged in the responses of the above research question are discussed here under:

4.3.1.1. THEME 1: COMPLIANCE

Compliance can be defined as the act of obeying an order or request. In a medical context, compliance can also be referred to as adherence. Compliance explains the extent to which patients follow medical advice.

All participants were still very young when they learnt of their HIV positive diagnosis, for some even the day they tested and events leading to them joining the ART programme is a vivid memory.

> *“I was still naïve at that time. I only thought about everything now that I’m older”* -Participant 6
>
> *“Mmm…it’s just that I was still very young but I remember that I was very sick and it was after my mom had died.”*-Participant 4

They all report that at that time they had no idea what they were being told, those that knew also did not know the implications of such a diagnosis (P4). When asked what they did after disclosure, participants said that they listened and complied with that which they were told by their parents, caregiver and health professional. Responses from participants gave the picture that since they were young at that time, nothing much was explained to them and that they were not given that opportunity to enquire further.

> “I *(stutters) I also did not know (stutters) I was just told after my mom’s death… then I started ARVs”*- Participant 3

When asked what type of advice they were given during counselling, this was the response: “*for me to do right and take my pills on time.”*

None of the respondents were given advice about where to go to when faced with emotional issues arising from their newly found HIV diagnosis, the theme of compliance is what is mostly highlighted.

> *"I accepted but…there was that thing…of being scared, of fear and a lot of crying."*- Participant 2

The researcher's question and concern in the study is who addresses these feelings of fear and these emotions. Even now as they grow older and comprehend their situation, no issues are addressed, compliance again supersedes emotional well-being. Counselling that addresses psychological issues during monthly clinic visits was not highlighted.

> *"No, I just take my pills and go."*- Participant 2

Participant 6 still could clearly relate all the events that led him to test. Yet when asked how he felt when his status was disclosed to him this was response: *"mmh…I was clueless at the time…I only thought about everything now that I have grown…"* instead of compliance making them more conscious of their status it is leading them to deny their true feelings about their diagnosis, how they feel and more oblivious of their emotions. Participant 6 only understood that he was taking ARVs 3 years after disclosure.

4.3.1.2. Sub-theme- Treatment perceived as the only way to a healthy life

When asked if any side effects were felt when starting treatment this was the response:

> *"It was difficult, I thought about a lot of things, especially why this was happening to me but that is over now."*- Participant 2

The researcher enquired about the physical aspects and yet the participant gave a response that highlighted the emotional aspects. So as much as their adhering to treatment and their clinical requirements, emotions still seem to be acknowledged and then supressed. The question is for how long can these feelings be supressed? Participant 6 said that even though he had no idea of what treatment he was taking and for what reasons, once he realised, he did not want to stress much about it because he saw that he was healthy.

When participant 1 was asked to give a brief background about his life, who he lives with and so on this was his response:

> *"My life is right, ever since I took treatment because I had once lost a lot of weight then once I took treatment my weight picked up."*- Participant 1.

He gave a background of his life only after the above response. This signified how much value the treatment has in his life. Participant 6 also was on ARV treatment without his knowledge. He later said that he knows that if he takes ARVs his CD4 count was going to increase. *"For me to do well and adhere to treatment."* was the response participant 3 gave when asked about what she was told during post counselling. Participant 4 has been on ARV treatment for almost nine years and she mentions that when she started treatment she gained a lot of weight especially around the upper body. These bodily changes did not stop her from adhering to treatment nor did it change the way she perceived ARVs.

Adhering to treatment and complying with the regulations of the clinic seemed to be of importance for all participants. What was captured the most in the participants' responses when questions were raised about procedures followed when adhering to treatment was that, participants were not granted the chance to ask questions regarding treatment. Additionally, they were also not given the chance to raise any concerns. Participants seemed to subserviently agree to adhere to their treatment and hardly reported physical and emotional concerns. Participant 1 as noted earlier displayed such behaviour.

> *"I just collect my treatment and leave"* – Participant 2

Participant 2 also added that most of the times he is at school and cannot find the time to come to the clinic to address his concerns. In their report on barriers to medication adherence in HIV infected children and youth, Buchanan et al. (2012) concluded that lifestyle barriers such as forgetting, worrying about disclosure of HIV status, falling asleep before taking ART, being away from home, busy and varied schedules including school attendance are common to resource-rich and resource-limited settings.

Before being enrolled in the programme clients have to attend adherence classes where they are given a brief education on what it means to be HIV positive and how to practice adherence. Questions on emotional wellness seemed to be overshadowed by the clients' compliance to treatment. Responses from participants indicated that communication in the health facility was more treatment-focused. Participants were asked if taking ARVs did not stress them in any way and this was the response:

> *"No, because I was told the time and now that I have a phone I can check the time for myself and take pills."*- Participant 3.

Adherence counselling entails more than just receiving treatment but it is where clients can shed their emotional burden as well. Communication seems to be one-sided and procedural which may be the reason why these adolescents highlight nothing else than just to comply to treatment in order to live longer. The concern of the researcher here is that adhering to treatment alone does not increase the CD4 count but it takes the overall well-being of the individual to stay completely healthy as a HIV positive individual. Time constraints and lack of privacy in the health facility also contribute to this type of interaction.

Health professionals are always in a rush to finish servicing all clients by the end of the day which may limit the time for proper counselling. This contributes negatively to the client's proper understanding of HIV/AIDs and what it means to be on treatment. It is of a greater concern for adolescents because most of them learn of their status when they are older and that is also when they are told about the medication they are taking. A platform of enquiry should be given to these adolescents to address any form of confusion, denial, stigma or discrimination. Furthermore, to address all the issues surrounded by disclosure and taking treatment. This is strongly highlighted by the researcher because most participants mentioned that they did not remember what was said in the adherence classes as they were still young and most of them had a family attend the classes for them while attending school. The researcher enquired from one of the participants how they have received the news now that they are fully aware of their clinical diagnosis and this was her response:

> *"Yes, I asked myself why me because out of all my mother's children I was the only one who was infected then I just accepted that* (paused) *ya."*- Participant 4

> *"I thought they were for the illness (epileptic fits) that I was admitted for in hospital…I did get advice but did not take it seriously."* – Participant 6

During the enquiry phase he continued to say that he did not experience any side effects and that is when he decided not to stress much about it. Only one participant acknowledged that it does not take adhering to treatment only to benefit you once you are HIV positive but it also takes a healthy lifestyle.

> *"If I take my pills I know that my CD4 count will increase. Again in order for my CD4 count to increase properly I need to eat healthy things."* – Participant 5

4.3.2. QUESTION 2: What problems do the adolescents experience as a result of HIV and ARVs?

The adolescence stage is marked by great changes for the adolescents. These changes do not only include physical changes but these changes also include emotional, cognitive and interpersonal changes. Through the changes problems in relations within the family may occur, additionally adolescents may have issues of identity within their social circles.

From research articles gathered the researcher concluded that these changes mentioned above might be more overwhelming for HIV positive adolescents on ARVs. The researcher was then interested in finding out the key problems experienced by these adolescents. Responses from the participants indicated that all the participants seem to come from a system that lacks a fully functioning family structure. Most of the participants don't have mothers and stay with caregivers such as older siblings, aunts, grandmothers, etc., only one participant reported to still have a mother and a father figure was not mentioned. Additionally responses from participants indicate that the adolescents were perinatally infected with HIV. Furthermore the lack of adequate knowledge regarding their status and lack of proper counselling and support that speaks to their experiences was also noted. These factors seem to bring about problems of denial, disclosure, fear of rejection, stigma and discrimination among these adolescents. The themes noted under emerged from the responses given from this question.

4.3.2.1. THEME 2: NORMALISATION OF LIFE WITH HIV

This theme was chosen on the fact that all the participants seem to have accommodated their HIV diagnosis into their lives and have chosen to live a normal life. Responses on disclosure reveal a need to own the virus and no need to share their experience was noted. Being infected has not affected their future plans nor has it affected their school performance. The participants seem to have chosen to disregard being diagnosed with HIV as a death sentence and instead have chosen to comply with their treatment and making taking it a normalised routine. The researcher will briefly break down this theme and link it to the concept of mental health in terms of normalisation versus denial.

4.3.2.1.1. Sub-theme: Fear of disclosing

All participants tested positive at a young age and were accompanied by close family members who served as guardians as most of the adolescents under study had lost their biological mothers due to HIV related illnesses. This type of situation did not allow the adolescents to choose who they disclose their status to. Since that was a situation beyond their control the adolescents seem to have decided to choose another level of privacy. They seem to have chosen for their status to be known only by the family members that were present during testing. Once their clinical diagnosis was disclosed to them they decided to remain silent to other close and not so close family members, friends and other community members.

> *“My aunt is the one who found out I had this disease…I won’t involve the rest of the family because I don’t think any of them know.”* – Participant 4

This type or level of privacy did not, according to the participants, come across as a form of fear of being known but as a choice of accommodating HIV in their lives and not disclosing to anyone. Participant 6’s family knows of his status but he has chosen not to tell his friends or his girlfriend. He later said that being on ARVs did not affect him in any way.

> *“I saw that nothing has changed life is still the same as before.”*

Participant 2 has a friend who is also on ARVs and within their circle of friends they have chosen not to disclose their status.

> *“We hide it…we have kept it a secret with my friend and we give each other signals when it is time to take our treatment because we take them at the same time.”*

In summary, disclosure to these adolescents is not used as a form of coping strategy instead they prefer to live their normal lives without letting anyone know of their status and the fact that they are on ARVs. This is contrary to HIV positive adults as most of them find disclosure as breaking free from self-stigmatisation and discrimination or unnecessary gossip. In their study Abrahams and Jewkes (2012) give an account of a woman who fell victim of discrimination, stigma and gossip around her community, while in her ill state she asked her mother to put a chair in the middle of the road around her neighbourhood and she got a chance to disclose her status and also encourage people to test and practice safe sex.

Participant 5 mentioned that his immediate family knows and then he further says that: *“I don’t know maybe others know as well…I don’t know who but news have a way of reaching people without anyone telling them.”*

From the responses gathered it seems like these participants choose not to disclose so they can live a normal life and be treated normally and on the other hand they choose not to disclose because of the fear of discrimination or reject. Participant 1 tested in 2013 where they were taken as a school to circumcise and that is where he tested HIV positive. He decided to tell his whole family as he was confident that he did not get the virus through his negligence as he was not yet sexually active.

> *“Keeping secrets does not help in any way because once they find out that you are on ARVs they will quarrel with you.”*-Participant 1

> *“Not even my friends…it’s just that my friends eish, I don’t see them as people I can have a future with, who I can talk to about everything. I don’t see a need to tell about my status.”* – Participant 4

> *“No because you will never know, they might put it on Facebook.”* – Participant 5

On their disclosure to their family members the study findings reveal that participants report that life is normal and they are not treated any differently. Findings from other studies however reveal that a passive coping style as the one that has been chosen by these participants is also associated with depression and poorer psychological adjustment (Orban, Stein, Koenig, Conner, Rexhouse and Lewis, 2010).

4.3.2.1.2. Sub-theme: Acceptance

Being infected with HIV has not introduced any abnormalities in the participants' lives. Participants asserted that they were not different or unusual from other adolescents. Below are extracts which confirm that being HIV positive did not change the daily routine and future plans of participants.

> *"I can say that my life is normal, it is the same like any other person."* – Participant 1

> *"I want to be a policeman and then have a house to stay in…then fix my home."* – Participant 2

> *"Yes nothing has changed…I don't see anything that has changed because what I have planned to do I will still do and I want to work on TV and radio. There are HIV positive individuals on TV and I think I will be one of them and even disclose my status."*-Participant 4

> *"I want to finish school so that I can be able to go to university so that I can study and work."* – Participant 5

Participant 5 further said that:

> *"I am fine because I am well; I take my ARVs I am living well."*

> *"I go and dance with my friends."* –Participant 6

Affirmations of normality were strong indications of the way in which HIV had been accommodated into the lives of these adolescents.

> *"I see myself in the near future talking about HIV… I want to go to school and give advice to school children about it."* –Participant 4

Contrary to that there is though that seed of fear and preoccupation about the future:

> *"I sometimes think about the future and ask myself what I will do, who I will marry…"* – Participant 4

The participants also dismissed any notions that being on ARVs has an impact on their school life. When asked if they can fully concentrate in school this was the response from participants:

> *"Yes very much so."* –Participant 2
>
> *"No it has never I pass very well."* –Participant 1

One participant mentioned that when they first took ARVs they experienced a lot of drowsiness but it did not occur in school, it only occurred at home. He would just fall asleep. As much as the participant tried to normalise the situation, the researcher noted that the participant experienced such a side effect only in the home environment and not at school, taking into consideration that at that time he was taking his pills twice a day. One participant mentioned that fetching her treatment disturbs her studies because sometimes she has to be absent from school in order to fetch her treatment since the clinic no longer allows other people to fetch the treatment for them.

In terms of disclosure and discrimination at school, findings indicated that only one participant indicated that there might be teachers who are aware of his HIV status and that is because there is a section in the school admission form that requires them to disclose their status. The findings further indicate that with that fact the participant has never experienced any discrimination or special treatment amongst the educators or classmates. Participant 5 revealed that she sometimes comes across her schoolmates in the clinic and when they enquire about what she is doing in the VCT/ARV section she just tells them that she is visiting one of the staff members. She further mentioned that this lowers her self-esteem because she wonders what questions they have in their mind about her.

Under this theme the findings reveal that being on ARVs has not made these adolescents lose hope about any future prospects. Instead they tried to show the researcher that they live a normal life and are still hopeful about their lives regardless of their status. It was noted though by the researcher that despite the efforts of the participants of trying to normalise their lives a bit of denial and fear seem to be slightly evident and this might be the trigger of mental health changes in the adolescents' lives.

> *"I need to find out if I have finished doing my matric will I be able to get employment if I am in **this kind of a situation**."* -Participant 1

> *"I sometimes stress and ask myself when will ever finish taking these pills…but my grandmother told me that I will take them until I die."*-Participant 5

This is the same participant who had said: *"I don't stress at all because I am alive it is good now that I am taking pills I enjoy living."*

These findings are consistent with the study findings by Garvie et al. (2011) who found that medication related barriers are also common in perinatal HIV (PHIV) infected adolescents and include treatment fatigue, complexity of regimens including pill burden and dosing frequency. This reveals the consistent shift in the mental health as these adolescents live by constantly counselling themselves to better health including better mental health.

4.3.2.1.3. Sub-theme: Fear of rejection, stigma and discrimination

The researcher noticed that the participants were well aware of the stigma surrounding HIV. This realisation might have an influence on decisions around disclosure and the support system they choose for the future.

> *"No when there are people around I hide them."*-Participant 3

> *"I take them when there is no one around, only when I'm alone or when I'm with my family… It is difficult to take them in the presence of other people "*-Participant 1

> *"They usually call me at home…but when I am with my close family I take them from the cupboard which I keep them in."* –Participant 6

> *"When I am visiting other family members I usually go outside to take them."*-Participant 4

> *"Me and my friend keep it a secret from our other friends then we signal each other when it is time to take our treatment."*-Participant 2

Findings from this study further indicate that the fears of disclosure and stigma are only confined to being morally judged but it is also encompassed by the fear of rejection. Three of the participants had concerns about possibilities of being rejected or stigmatised by their current and future partners, especially with regard to being intimate. Siegel K. & Lekas H.M. (2002) state that it can never be easy for adolescents to accept their HIV status, because in addition to changes and conflicts inherent to the age itself, having a chronic condition intensifies such conflicts that reflect on their social environment, daily activities, sexuality and relationships with other people, generating physical and psychological limitations. They further state that these limitations become more severe especially because the disease is incurable, infectious and transmitted by the mother, which, in the case of HIV/AIDS, is routinely stigmatised and treated with discrimination and prejudice.

Below are quotations that provide examples of the above mentioned statement:

> *"No we have never talked about it."*-Participant 6
>
> *"I would have a problem in being in an intimate relationship…I would have sex but not that much…the reason for that is maybe…maybe I will infect him."*-Participant 5
>
> *"…* (sighs) *eish I don't know with that regard I am still not sure. I normally tell myself that eish even when I'm having a heart to heart with my sister; I tell her that I will never have sex with anyone."*-Participant 4

When asked if this has got anything to do with her status this is what she said:

> *"Yes maybe because boys nowadays eish…I want someone who will understand me."*-Participant 4
>
> *"If I get married how will my partner feel about my status?"*-Participant 6

It was evident in some cases that this fear of stigma and rejection occurred also in their social circles. In almost all cases it seemed to be an internalised type of stigma which was exacerbated by the participants' self-esteem to an extent that some adolescents choose not to socialise in order to avoid being discriminated or stigmatised. According to Beck's theory (2008) on some of the attributes to depression, depressed people acquire a negative schema of the world in childhood and adolescence. Adolescents who experience depression acquire this negative schema earlier. The theory further holds that depressed people have negative thoughts about themselves, their experiences in the world, and the future.

> *"Before starting treatment I expected that I was going to be different."*- Participant 2

When asked if he faced any discrimination within the facility and community at large this was the above participant's response:

> *"No not really but I normally don't talk to anyone, I just keep quiet."*-Participant 2

> *"One girl saw me attending the adherence classes while she was passing by…but I don't know if she told anyone or not…but I think she did not say anything but even if she did they would not approach me and ask me."*- Participant 2

> *"Sometimes I would ask myself if someone had to walk in how I would explain me being in the clinic."*- Participant 3

> *"No I don't have any friends…I don't have much of a reason but I am still going to have them…I still want to differentiate between good and bad friends. I want to see the type of lifestyle they have."*-Participant 1

> *"I would not want my friends to know because they might expose me on Facebook."*-Participant 4

In the findings discovered above none of the discussed responses indicated poor adherence. Most studies reveal that a lot of factors contribute to non-adherence especially among HIV positive adolescents, those factors being non-disclosure, fear of rejection, stigma, discrimination and lack of trust. As is the report on barriers to medication adherence in HIV infected children and youth by Buchanan *et.al* (2012), which concluded that lifestyle barriers such as forgetting, worrying about disclosure of HIV status, falling asleep before taking ART, being away from home, busy and varied schedules including school attendance are common to resource-rich and resource-limited settings. In their journal article on HIV-positive youths' perceptions of HIV treatment Veinot, Flicker, Skinner, McClelland, Saulner and Read (2006) show that poor treatment knowledge and understanding of the benefits of taking ART as a non-curative intervention may impact adherence.

4.3.3. Question 3: Are there differences to the family dynamics and does disclosing the HIV status affect the relations with significant others?

The researcher here was interested in finding out if any changes occurred within the household now that the status of the adolescents was known. Furthermore the researcher was interested to know if disclosure affects the relations with significant others. As noted earlier the adolescents under study have chosen to have their status known only by their close family members so the research study wanted to investigate if this disclosure had affected the relations with these significant others.

4.3.3.1. THEME 3- ACCEPTANCE AND SUPPORT FROM FAMILY

Findings have shown that by disclosing their status to their family and/or having their family members tell them of their status and reason for taking chronic medication, the adolescents give way to an even greater emotional and social support as they live with HIV/AIDs and it also helps to adopt a sense of trust among the family members. According to Lemme (2015), disclosure to family forms an important role to cope with the stress of living with a chronic illness as well as trying to maintain trust and mutual respect within the family. In their study Abrahams and Jewkes (2013) found that participants who disclosed to their family described receiving great support from them and nobody abandoned or rejected them. Studies by Merzel, Van Devanter and Irvine (2008) indicate that adolescents may also be emotionally unprepared for ART, particularly if they have been newly diagnosed or recently disclosed to. In fact, non-disclosure of HIV status to HIV infected adolescents by caregivers may impact adherence, particularly when adolescents begin to question their ART regimen and express regimen fatigue.

Below are references which confirm that, indeed feelings of acceptance and support from the family and disclosure plays a huge role in the participants' lives.

> *"My grandmother attended classes for me and yes when we were home she explained everything to me. When I was a bit grown up she explained to me what I had and how I should take my pills. All my family members know I'm taking ARVs and they have not changed their attitude towards me, they freely talk about it around the house."* – Participant 5
>
> *"If there is something troubling me I talk to my mom"*…*I take my medication when there is no one around or when I'm only with my family."* – Participant 1
>
> *"I was with my aunt when I tested we got home and told my grandmother…no nothing has changed things are still as normal as before…they are used to it we talk about anything."*- Participant 2
>
> *"It is at home where they know about my status*…*they tell me when it is time to take my medication…when they suspect something is wrong with my adherence they count the pills for me…if I don't have my phone with me my brother reminds me."*- Participant 3
>
> *"At home they all know about my status and they all remind me when it is time to take my medication…my mom used to accompany me to fetch my treatment but now I fetch them alone."*- Participant 6

Bronfenbrenner's ecological perspective explains how family support is a microsystem which plays a very important role in the lives of these HIV positive adolescents and his theory further emphasises the importance of a good, positive relationship between the systems for the benefit of the well-being of the individual in the mesosystem.

Findings from this study are contrary to that of Brown, BeLue and Airhihenbuwa (2010) who indicated that family relations do not always represent the type of emotional support and physical care that HIV infected individuals require. Mburu, Ram, Oxenham, Haamujompa, Lorpenda, Ferguson (2014) in their research findings indicated that unconditional love and support from family were amount to influence positive adherence. They further state that the support from family heightened the drive of HIV infected adolescents, strengthened their minds and enhanced their self-worth and this also showed them that they still have a position in society. Here under are themes that emerged from responses to the above mentioned question that give an indication that these adolescents may not have any other existing support structure either then their family.

4.3.3.1.2. Sub-theme: Institutional support

Lemme, 2015 cites Peterson, Bhana, Myeza, Alicea, John, Holst, McKay, Mellins (2010) and Botswana Balor Children's Centre of Excellence (2012) who highlight that the supply of services from health facilities such as counselling services, acts as a mediator in a number of issues faced by HIV infected adolescents. Research findings in this study showed that the clinic providing services for the participants was not youth friendly. Adherence and supportive counselling is only done during the first few weeks when the clients are being enrolled in the ART programme.

> *"I was told to do right and adhere to my treatment and to always take them on time."* -Participant 3
>
> *"I got counselled but did not take it seriously at that time."*-Participant 6
>
> *"I went there and they told us we had to check and they said we had to attend adherence classes. I couldn't because I was still in school so my aunt attended for me. She showed me how the treatment works and what happens if you default."*- Participant 2
>
> *"I was taken to the clinic where they tested me then the day came for adherence classes I was then told that since my CD4 count is low I was going to take ARVs."* –Participant 1

Most participants revealed that they either keep their troubles to themselves or talk to their Patient Advocates (PAs). None of the participants mentioned receiving proper adherence counselling from a healthcare worker. The World Health Organization (2008) state that the degree and impact of mental health problems on the lives of adolescents varies and can also range from mild to severe or acute to chronic. The organization further states that the most common mental health problems experienced by adolescents are depression and anxiety disorders. The most prevalent of those mental health issues being behavioural and psychiatric problems such as attention deficit hyperactivity disorder. In this regard the organization advocates that health workers therefore need to have the competencies to relate to young people, to detect these mental health problems early. Furthermore they need to provide treatments which include counseling, cognitive-behavioural therapy and psychotropic medication, where appropriate.

Participant 1 mentioned that he sometimes takes his pills on an empty stomach and when the researcher enquired if he mentions this when he fetches his treatment this was his response:

> *"Only my PA knows."*
>
> *"I normally talk to my PA and if she is not around I go back home with whatever issue I had."* -Participant 5

Participant 2 mentioned that when he started treatment he had a lot of concerns but could not talk to anyone about them because most of the time he is at school. When he does get time he just collects his treatment and leaves. Agwu and Fairlie (2013) concluded that the relative lack of healthcare professionals (medical care providers, support staff, psychologists, social workers and counsellors) experienced in adolescent healthcare management may further impact the adherence counselling and support needed for PHIV-infected adolescents in resource limited settings. Furthermore to support the researcher's findings, in their guide on mental health care for people living with or affected by HIV/AIDS Acuff, Archambcault, Greenberg, Hoeltzel, McDaniel, Meyer *et al* (1999) discovered that through counselling, clients in recovery from risky behaviours often discover and begin to heal underlying psychological wounds they attempted to mask through risky behaviour. Counselling explores feelings, motivations, behavioural patterns, interpersonal relationships, and patterns of thinking over time.

Participant 3 did however mention the point of receiving adherence counselling but in their conversation with the healthcare worker only the physical well-being is covered and emotional constraints are never discussed.

> *"No they have never asked me about how I'm feeling emotionally…*(sighs) *no there has been a time…maybe before but now I just take my medication and leave."*-Participant 3

4.3.3.1.3. Sub-theme: Morally judged

Another factor which is also identified is that as much as some participants don't make much of a big deal in fetching their treatment they do however feel stigmatised when they are awaiting their turn in the clinic. References will be made below which give a clear indication that some of the adolescents feel as if they are being morally judged by the older people in the clinic:

> *"It happened once I was seen by people who know me and I asked myself what they were thinking."*-Participant 2

> *"No there is nothing much but I can see sometimes that I'm the only school child all the other people are adults and they are older…so I often see that eish I'm the only one who is young here."*-Participant 4

> *"Sometimes I would ask myself what I would do if someone I know walked in, what would I say*."-Participant 6

Contrary to that participant 3 had this to say:

> *"No I don't feel ashamed because I know that we all have come for one thing."*

Findings from this study also reveal that the lack of privacy or youth friendly services encumbers effective communication and also caused patients to experience psychological distress due to feelings of stigmatisation. Moreover this could also be due to the fact that at the time of this research the VCT/ARV section was secluded from other services offered at the clinic which means that when one enters that section for whatever consultation people would automatically know that they are there because they are HIV positive and/or on ARV treatment. The London: National Children's Bureau (2012) also state that for many adolescents living with HIV, the clinic is the only place in which they can openly talk about their status and ask questions which they may be uncomfortable to address with their friends or family members.

> *"It is sometimes a problem because a lot of people here are old and they look down on you if you are a child who has come to fetch ARVs…but I kind of accept the situation because there is nothing much I can do about it."* – Participant 1

The theme of trying to normalise life comes up now and again because as much as this affects them it is still a condition which they have to accept and live with unless systems change and become youth friendly.

4.4. Conclusion

The above chapter provided a detailed discussion on the results of the study. The core focus of the study was to explore the mental health status of HIV positive adolescents on ARVs. The study explored the different factors that come up in the life of an adolescent on ARVs as they develop in society and within their family. The major themes that emerged from the data included compliance, normalisation of life with HIV, acceptance and support from family, fear of reject, stigma and discrimination. Internalised stigma and discrimination and lack of trust in friends seemed to be the possible factors contributing to mental health changes. The lack of time and privacy and discrimination in the health facility also emerged as contributing factors to mental health changes. All participants seemed to go through the same mental health changes of constant worry and preoccupations about the future. The changes varied with every factor that they were faced with in their journey of living with HIV. The next chapter will discuss the conclusions drawn from the entire study, the recommendations and limitations will also be highlighted.

CHAPTER 5

CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

5.1. Introduction

In this chapter, the relationship between the study questions and the findings of the study will be discussed. Relevant literature will also be used to elaborate this relationship. This will be done with keeping in line with the aim of the study, objectives, summary of conclusions, strengths, limitations and recommendations. The strengths and limitations together with the recommendations will be presented.

5.2. Summary of Conclusions

The study was designed to explore the mental health status of adolescents on antiretroviral treatment (ART). The researcher's concern was based on finding out the emotional path that HIV positive adolescents go through from the time they are tested, to the time their status is disclosed to them, to the time they are put on ARVs and their journey thus far. Just as the physical well-being is mostly emphasised in our health system, the concern of the researcher lies mostly on the mental well-being of the adolescents.

5.2.1. Are there differences in the mental health status before and after being enrolled in the antiretroviral therapy programme?

Information gathered revealed that the study participants were still very young when they tested for HIV. Only one participant voluntarily tested and even though it was on prerequisites for circumcision. Since they tested at a young age they could not really comprehend what was happening to them. They were in an earlier developmental phase when they may not have been able to adequately process and understand what was happening to them. Furthermore three of them were very sick when they tested. Mental health changes seem to have occurred once their HIV status was disclosed to them. As much as they try to live normal lives they still question their future. The researcher observed that as much as the participants tried to normalise their current condition, their body language during the interviews and part of their responses told another story. Participants would sigh, stutter or smile nervously even after rapport with the researcher was well established. These came across as a façade put on by the participants or a defence mechanism in order to hide their true emotions. In their guide on mental health care for people living with or affected by HIV/AIDS Acuff *et al.* (1999) discovered that through counselling, clients in recovery from risky behaviours often discover and begin to heal underlying psychological wounds they attempted to mask through risky behaviour. Counselling explores feelings, motivations, behavioural patterns, interpersonal relationships, and patterns of thinking over time. In their responses feelings of constant anxiety, depression and hopelessness were picked up by the researcher. Tanney, Naar-King, MacDonnel (2011) stated that HIV positive adolescents might be at risk of experiencing mental illness and in that way centres providing care to them should routinely screen for mental health disorders.

It became evident that the adolescents have unresolved mental health issues and which become unknown to the healthcare workers due to ineffective communication. Kuhn (1974) explains that knowing one part of a system enables us to know something about another part. Kuhn's model stresses that there are certain elements that move a system towards equilibrium. Communication and transaction provide the vehicle for a system to achieve equilibrium.

It is through collaborative relationships with other community-based services and programmes that gaps can be addressed to help provide a comprehensive approach to adolescents' health care. The mental health of adolescents should not necessarily be one dimensional especially because the adolescent belongs to a set of systems which have a direct and an indirect impact on their lives.

According to Beck (2008) individuals can move toward overcoming difficulties and meeting their goals by identifying and changing unhelpful or inaccurate thinking, problematic behaviour, and distressing emotional responses. It involves the individual working collaboratively with the therapist to develop skills for testing and modifying beliefs, identifying distorted thinking, relating to others in different ways, and changing behaviours. Now since these adolescents depend on the free healthcare system for their well-being it is the only system apart from the family system that can help them address issues leading to mental health changes. The researcher identified that what is worse about these adolescents is that they don't even have friends that they trust who they can confide in. most of them are dependent on their family members and their PAs for emotional support. During the process of concluding the study the researcher learnt that PAs were no longer available in the clinic which leaves wondering as to who is now available for the emotional needs of these adolescents in the health care system.

5.2.2. Are there different perspectives regarding ART?

The current study discovered that the majority of the participants in this study started ARVs at a young age and most of them discovered later into their adolescent life the reason for taking this chronic medication. In their article on HIV positive youths' perceptions of HIV treatment Veinot *et al.* (2006) show that poor treatment knowledge and understanding of the benefits of taking ART as a non-curative intervention may impact adherence. Adolescents may also be emotionally unprepared for ART, particularly if they have been newly diagnosed or recently disclosed to. In fact, non-disclosure of HIV status to HIV infected adolescents by caregivers may impact adherence, particularly when adolescents begin to question their ART regimen and express regimen fatigue (Merzel, Van Devanter and Irvine, 2008).

Study findings indicate that the participants were still preoccupied with the thought that they will be on ARVs for the rest of their lives. Through the compliance theme participants showed that they have decided to comply with the treatment requirements and to practice adherence. It also emerged that the participants were convinced and had accepted that ARVs were their ticket to a healthy, long life. In the normalisation of life with HIV theme some participants expressed how they sometimes stress about the thought of being on ARVs for the rest of their lives.

> *"I sometimes stress and ask myself when will ever finish taking these pills…but my grandmother told me that I will take them until I die."*-Participant 5

This is consistent with the findings by Garvie et al. (2011) who found that medication related barriers are also common in perinatal HIV (PHIV) infected adolescents and include treatment fatigue, complexity of regimens including pill burden and dosing frequency.

As much as the adolescents reported to adhere to their treatment, the researcher gathered from observations of the participants' body language during their responses that this might not be completely true in most cases. It was also evident that most adolescents depended on family support in order to adhere fully to their treatment. Institutional preaching on treatment adherence also aided the adolescents in adhering to their treatment.

Another important factor that also emerged amongst the participants was that sometimes fetching their treatment during monthly visits disturbs them in their studies as they have to be absent from school in most of those visits.

Feelings of being morally judged by adults at the clinic were also expressed by the participants. In their study Agwu and Fairlie (2013) indicate that for healthcare workers caring for adolescents it is crucial to understand that for the success of treatment, the adolescent needs to be managed as a whole within their context and moreover it is important to provide adolescents with psychosocial support which includes creating a non-stigmatising or discriminatory environment which will help them to conquer challenges which may confront them in this journey. Kamau, Kuria, Mathai, Atwoli and Kangethe (2012), in agreement with Tanney et al*.* (2011) when these centres routinely screen for mental health disorders, intervention should be provided early before the condition worsens as these disorders play a significant role in non-adherence to ARVs.

5.2.3. Are there key problems experienced by adolescents on ART?

The Botswana: Baylor International Paediatric AIDS Initiative (BIPAI, 2012) state that the adolescent years are important as it is where the child starts to assert his or her individuality. Adolescents may be facing a number of pressures from friends to fit in and from parents and other adults to do well in school or activities like sports or part-time jobs. Consistent to that Kerrissey (2008) states that for any person adolescence is a challenging time and this is even more so for adolescents living with HIV.

Research findings from this study indicate that key problems faced by the adolescents included preoccupation about the future, fear of stigma and discrimination and reject from society. Participants expressed how they sometimes worry about the future, whether they will be employed or not as they are HIV positive, whether or not they will marry and how their partners might feel about their HIV positive status. Most participants expressed fear of forming close friendships or intimate relationships in avoidance of reject and being stigmatised or discriminated against. Kagee , Remien, Berkman, Hoffman, Campos and Swartz (2011) state that negative stigma and labelling attached to being HIV positive, have made HIV positive adolescents to be selective about revealing their diagnosis to family and friends. Little mention was made about the treatment or HIV status causing any scholastic difficulties accept for the concern of sometimes missing class due to monthly clinic visits.

5.2.4. Are there differences in the family dynamics?

The researcher was curious to know whether or not there were any changes in the home environment with the knowledge of the adolescents' HIV status. That is because according to Rajaraman, Earle and Heymann (2008) families are the ones which most of the time take care of the millions of HIV infected and affected in Africa. Most of the participants indicated that the home environment contributed to feelings of stigma or discrimination. Instead participants reported that it is at home where they feel mostly comfortable about their HIV status and it is where they receive most emotional support. Additionally, it is at home where adherence to treatment is mostly highlighted as most family members serve to remind the participants of the time to take their treatment.

Participants also did not report any feelings of anger towards their caregivers once their HIV status was disclosed to them. Only feelings of fear and confusion were raised and those were quickly addressed by caregivers. Findings from other studies done by Arrive, Dicks, Ambghar, Aka, Dior *et al.* (2012), indicate that while disclosure is important for secondary prevention of HIV transmission, it may elevate emotional and behavioural disorders and also familial conflicts. Additionally they state that anger in some cases may lead the adolescents to be less adherent and may want to punish their parents as to why this happened to them.

5.2.5. Does disclosing the HIV status affect the relations with significant others?

Study findings indicate that the participants were comfortable with the fact that only their close family knew of their HIV diagnosis. Participants expressed discomfort and fear in having to disclose their status to friends or their partners.

> *"Not even my friends…it's just that my friends eish, I don't see them as people I can have a future with, who I can talk to about everything. I don't see a need to tell about my status."* – Participant 4
>
> *"No because you will never know, they might put it on Facebook."* – Participant 5

They further stated that the knowledge of their status by their family members did not affect their relationship. Findings in a study by Nyongea *et al.* (2015) that investigated determinants on ARV adherence among HIV positive children and teenagers indicate that amongst other things, being unaware of their HIV status was seen to be barriers for optimal adherence. They further add that to achieve optimal adherence, strategies aimed at targeting the caregivers, the school environment and the health system need to be designed.

Another factor that emanated from the study was that participants were not treated any differently from other family members within the home. Ayres *et al.* (2006) in their study found that fear of prejudice and discrimination tend to lead people with HIV/AIDS to adjourn disclosure, and this decision affects access to health care and sexual, social and educational life.

5.3. Implications of the study

Mental health remains an important factor in adolescence living with HIV and on ARVs. A healthy mental status allows the adolescents to foster resilience by applying protective mechanisms that can enable them to maintain secure attachments and access the appropriate social support. Interaction of the systems is essential in order to enhance development. The exosystem refers to structures that have an impact on the child's mesosystem and therefore have ripple effects on the child. It is a setting in which there is a link between the context wherein the person does not have any active role and the context wherein the individual is actively participating (Bronfenbrenner, 1979, p.25). It includes all external networks, such as community structures and local educational, medical, employment and communication systems, which influence the microsystem.

The findings strongly imply that services need to improve for the mental well-being of younger patients, institutional support is highly needed.

Five out of six participants tested at a young age and were unaware of the reasons for testing. One participant that was aware claimed that he was never sexually active, therefore the findings entail that most adolescents who are infected with HIV were infected through mother to child transmission amongst other ways. It was evident in the study that this did not deter the adolescents from achieving proper adherence. The above factor did not however deter the participants from questioning the reason why the virus chose them.

> *"Yes, I asked myself why me because out of all my mother's children I was the only one who was infected then I just accepted that* (paused) *ya."*-Participant 4
>
> *"If I get married how will my partner feel about my status?"*-Participant 6

The study findings further imply that the adolescents use different strategies as coping mechanisms; most of them choose support from family, speaking to their PAs and keeping quiet about their status to friends and other family members as a strategy. These findings strongly imply that a lot still needs to be done with relation to stigma especially internalised stigma that constantly haunts these adolescents.

5.4. Limitations of the study

Limitations that were identified in the study were mostly due to the study design and others were independent of it.

- The researcher had chosen an exploratory research design an one of the limitations of this design is that findings could be susceptible to substantial interpreter bias.
- The sample size is another limitation that was identified. Using modest samples may not always be a representative of the study population at large.

- Observation of participants could have been made a major subject in order for the researcher to pick up more cues that could be indicative of the participants' mental health status.
- The lack of South African literature that looks at the mental health status of adolescents on ARVs proved to be a contextual limitation. The literature used was mainly European or from other African countries therefore as the researcher I had to remain aware of the differences in contexts of the studies conducted. This therefore posed as a challenge to not have a template to compare and contrast my findings to.

5.5. Recommendations

Recommendations are mainly based on the findings of the study. These recommendations point to different possibilities for future research and possible directives.

- More research on HIV positive youth needs to be conducted in South Arica as most studies done are mostly focused on HIV positive adults.
- In past studies it is evident that studies focus on the period after diagnosis, there is less focus on mental health.
- Support structures that will be formed by a strong collaboration between healthcare workers and caregivers and that will cater especially for concerns brought forward by HIV positive youth are vital. These support structures should include more youth friendly approaches in the healthcare system.
- The researcher noticed that the participants were not sometimes honest in some responses therefore in future research the healthcare workers and even the caregivers can be included as study participants in order to strengthen the findings.
- Lastly municipality offices should update statistics on their different sections of each area that they serve as the researcher failed to get updated statistics on the area of focus for the study. These are important in order to identify areas in our community that have a high prevalence of cases of concern that are in need of interventions.
- Part of the recommendations during the course of the study would be to do away with the segregation of the VCT/ARV section within health facilities but

the researcher later made a follow-up into that and found that this was no longer a factor in the clinic. HIV positive patients seeking to fetch their medication now fall under the chronic section that caters for all chronic patients within the health facility.

5.6. Conclusion

In spite of the limitations that were identified in this study, the study did however; identify important factors that exist in our healthcare system. Much still needs to be done in order to address factors such as disclosure, stigma and discrimination as these directly and indirectly have an impact on the mental health of HIV positive adolescents. Complete treatment adherence does not necessarily imply a healthy mental status. Follow-up research needs to be done to document the lives of adolescents post admission in the ART programme. A positive mental health status goes a long way in sustaining life and promotion of health.

REFERENCES

Abrahams, N., & Jewkes, R. (2012). Managing and resisting stigma: a qualitative study among people living with HIV in South Africa. Journal of the International AIDS Society.Vol 15.

Acuff, C., Archambcault, J., Greenberg, B., Hoeltzel, J., McDaniel, J.S., Meyer, P., Parker, C.et al. (1999). Mental Health Care for People Living with or Affected by HIV/AIDS. A Practical Guide. America: Department of Health and Human Services.

Agwu, A.L. & Fairlie, L. (2013). Antiretroviral treatment, management challenges and outcomes in perinatally HIV-infected adolescents. Journal of the International AIDS Society, 16(1): 1-13

AIDS Resource Center. Retrieved November, 2016, from www.etharc.org

Alhojailan, M.I. (2012). Thematic analysis: A critical review of its process and evaluation. West East Journal of Social Sciences, 1(1), 39-47

American Academy of Child and Adolescent Psychiatry (AACAP). Retrieved 2016, from http://www.aacap.org/publications/factsfam/develop.htm

Anderson, L.S., Seedat, S. (2009). Mental health services for HIV/AIDS patients are long overdue [Abstract]. South Mental Health Journal, 11,796.

Anderson, R.E., Carter, I., & Lowe, G.R. (1999). Human behavior in the social environment 5th ed. New York: Aldine de Grugter.

Anney,V.N. (2014). Ensuring the Quality of the Findings of Qualitative Research: Looking at Trustworthiness Criteria. Journal of Emerging Trends in Educational Research and Policy Studies (JETERAPS) 5(2): 272-281

Arrive, E., Dicks, F., Ambghar, H., Aka, A.E., Dior, Bouah, B., Traore, M., et. al (2012). HIV status disclosure and retention in care in HIV-infected adolescents on antiretroviral therapy (ART) in West Africa. PLos ONE 7(3):1-8

Ayres, J.R.C. & Franca I. Jr. (2006). Adolescent Health. 2nd ed. Brazil: Hucitec; 2000: 66-85.

Bauman L.J., Silver E.J., Draimin B.H., Hudis J. (2007). Children of mothers with HIV/AIDS: Unmet needs for mental health services. Pediatrics. 2007; 7: 39-54.

Battles, H.B. & Wiener, L.S. (2002). From adolescence through young adulthood: psychosocial adjustment associated with long-term survival of HIV. Journal of Adolescent Health,30,161-168.

Beck, J. (2008). Questions and Answers about Cognitive Therapy. Beck Institute for Cognitive Therapy and Research.

Benton, T.D. (2011). Psychiatric considerations in children and adolescents with HIV/AIDS. Pediatric clinics of North America, vol.58, 989-1002.

Bitsch,V. (2005). Qualitative Research: A Grounded Theory Example and Evaluation Criteria. Journal of Agribusiness,23.

Botswana: Baylor International Pediatric AIDS Initiative (2012). Retrieved May, 20, 2016 from www.bipai.org

Bowen, A.G. (2009). Document Analysis as a Qualitative Research Method. Qualitative Research Journal, vol.9, no. 2

Branfenbrenner, U. (1979). The Ecology of Human Development: Experiments by Nature and Design. Harvard University Press, Cambridge, Massachusetts.

Braun, V & Clarke, V. (2006) Using Thematic Analysis in Psychology. Qualitative Research in Psychology, 3 (2), 77-101.

Brown, D.C., BeLue, R., Airhihenbuwa, C.O. (2010). HIV and AIDS related stigma in the context of family support and race in the South Africa. Ethnicity and health, 15(5): 441-458.

Buchanan, A.L., Montepiedra, G., Sirois, P.A., Kammerer, B., GarvieP.A., Storm, D.S. Barriers to medication adherence in HIV-infected children and youth based on self and caregiver report. Pediatrics. 2012; 129(5).

Burns, N. & Grove, S.K. (2003). Understanding nursing research. 3rd ed. Philadelphia: Saunders Company.

Chandwani, S., Koenig, L.J., Sill, A.M., Abramowitz, S., Conner, L.C. & D'Angelo, L. 2012. Predictors of antiretroviral medication adherence among a diverse cohort of adolescents with HIV. The journal of adolescent health: official publication of the Society for Adolescent Medicine, 51, 242-51.

Collins, C., Marin, S.F., Shriver, M.D., Coates, T.J. (2000). Designing Primary Prevention for People Living with HIV/AIDS. San Fransisco: University of California

Collins English Dictionary for Advanced Learners (2001). Retrieved from http://m.harpercollins.co.uk

Consolidated Guideline on the use of antiretroviral drugs for treating and preventing HIV infection. (2013). Malaysia: World Health Organisation. Retrieved March 03, 2014, from www.who.int/hiv/pub/guidelines/arv2013/en

Creswell, J.W. (2003). Research design: Qualitative, quantitative, and mixed method approaches. Thousand Oaks, Calif: Sage Publications.

Freeman, M., Patel, V., Collins, P., & Bertolote, J. (2005). Integrating mental health in global initiatives for HIV/AIDS. British Journal of Psychiatry, vol. 187, 1-3.

Garvie, P.A., Flynn, P.M., Belzer, M, Britto, P., Hu, C., Graham B. Gaur AH. Psychological factors, beliefs about medication, and adherence of youth with human immunodeficiency virus in a multisite directly observed therapy pilot study. Journal of Adolescent Health. 201; 48(6):637-640.

Hanson, J. L., Balmer, D.F., Giardino, A.P.(2011). Qualitative research methods for medical educators. Academic Pediatrics, 11(5),375-386.

Healthline (2014). The effects of HIV on the body. Retrieved 2016 from www.avert.org

Henning, E., Rensburg, V., Smit, B. (2004). Finding your way in qualitative research. Pretoria: Van Schaik.

Holloway, I. (2005). Qualitative research in health care, Maidenhead: Open University Press.

Kagee, A. (2013). Addressing psychosocial problems among persons living with HIV. Stellenbosch University.

Kagee, A., Martin, L. (2010). Symptoms of depression and anxiety among a sample of South African patients living with HIV. AIDS Care 22(2): 159-165.

Kail, R. V., & Cavanaugh, J. C. (2010). The Study of Human Development. Human Development: A Life-span View (5th ed.). Belmont, CA: Wadsworth Cengage Learning.

Kerrissey, M. (2008). Adolescents Living with HIV in Uganda: Factors Affecting Disclosure, Adherence and Prevention. JCRC, Uganda.

Kidia, K.K., Mupambireyi, Z.,Cluver, L., Ndhlovu, C.E., Borok, M., Ferrand, R.A. (2014). HIV Status Disclosure to Perinatally-Infected dolescents in Zimbabwe: A Qualitative Study of Adolescent and Healhcare Worker Perspectives. PLoS ONE 9(1): e87322.

Kothari, C.R. (2004). Research Methodology: Methods and Techniques. Second Revised Edition. New Age International.

Kourrouski, A., Lima, M. (2009). Treatment adherence: the experience of adolescents with HIV/AIDS. Retrieved from http://dx.doi.org/10.1590/S0104-11692009000600004

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. The American Journal of Occupational Therapy, 43(3),214.

Kuhn, A. 1974. The Logic of Social Systems. San Francisco: Jossey-Bass

Lacey, Anne, Luff & Donna (2001). “Qualitative Data Analysis.” Leicester: United Kingdom Trent Focus for Research and Development in Primary Health Care.

Lemme, T.A. (2015). Barriers to highly active antiretroviral therapy amongst HIV-infected adolescents in a government hospital in Botswana. Masters mini-dissertation. University of Pretoria

Lincoln, Y.S. & Guba, E.G. (1985). Naturalistic Inquiry. Newbury Park, CA: Sage Publications.

Maree, K. (2007). First Steps in Research. Pretoria: Van Schaik Publishers.

Maudsley, G. (2011). Nixing it but not mixed-up: Mixed methods research in medical education (a critical narrative review). Medical Teacher,33, e92-e104.

Mavhu, W., Berwick, J., Chirawu, P., Makamba, M., Copas, A., Dirawo, J., Willis, N., Araya, R., Abas, M.A., Corbett, E.L., Mungofa, S., Laver, S.M., Cowan, F.M. (2013). Enhancing psychological support for HIV positive adolescents in Harare, Zimbabwe. Zimbabwe AIDS Prevention Project. University of Zimbabwe College of Health Sciences, Harare, Zimbabwe.

Mburu, G., Ram, M., Oxenham, D. ,Haamujompa, C., Lorpenda, K., Ferguson, L. (2014. Responding to adolescents living with HIV in Zambia: A social ecology approach. Children and Youth Services, 45(1): 9-17.

McKay M., Block M., Mellins C.A., Traube D., Brackis-Cottt E, Minott D, Abrams E.J. (2006). Adapting a family-based HIV prevention program for HIV-infected adolescents and their families: Youth, families and healthcare providers coming together to address complex needs. Social work in Mental Health.

Melendez, A. (2011). Characteristics of Qualitative Research. Retrieved June, 2013 from www.brighthubpm.com

Mellins, C.A., Ehrhardt, A.A. (1994). Families affected by pediatric acquired immunodefiency syndrome: sources of stress and coping. Journal of Developmental & Behavioral Pediatrics. PubMed

Menon, A., Glazebrook, C., Ngoma, M.S. (2009). Mental Health of HIV Positive Adolescents in Zambia. Medical Journal of Zambia, vol. 36, 4.

Mental health (2011). National Institute of Mental Health. Retrieved April, 14, 2016 from http://www.nimh.nih.gov

Merzel, c., VanDevanter, N., Irvine, M. Adherence to antiretroviral therapy among older children and adolescents with HIV: a qualitative study of psychosocial contexts. AIDS Patient Care and STDs. 2008,22:977-987.doi:10.1089/apc.2008.0048

Meyersfeld, S. & Vujovic, M. (2012). Sexual and ReproductiveHealth and Life-skills. Anova Health Institute.

Mills, E.J., Nachega, J.B., Bangsberg, D.R. (2006). A systematic review of developed and developing nation patient-reported barriers and facilitators. PloS Med;3(11):2039-2064.

Nyongea, D., Mtenga, S., Henning, L., Franzeck, F.C., Glass, T.R., Letang, E., Tanner, M., Geubbels, E. (2015). Determinants of antiretroviral adherence among HIV positive children and teenagers in rural Tanzania: a mixed methods study. BMC Infectious Diseases.

Olley, B. (2006). "Psychological distress in the first year after diagnosis of HIV infection among women in South Africa." African Journal of AIDS Research, vol. 5, no.3, 207-215.

Olley, B., Sededat, S., & Stein, D. (2006). Persistence of psychiatric disorders in a cohort of HIV/AIDS patients in South Africa: a 6 month follow-up study. Journal of Psychotic Research, vol. 61, 479-484.

Paquette, D. & Ryan, J. (n.d). Bronfenbrenner's ecological systems theory. Retrieved May,20,2015,from http://64.233.183.104/search?q=GhdZQiGraEJ:pt3.nl.edu/paquetteryanwebquest.pdf

Orban, L.A., Stein, R., Koenig, J.K., Conner, C.L., Rexhouse, L.E., Lewis, V.J. (2010).Coping strategies of adolescents living with HIV: disease-specific stressors and response. AIDS care, 22(4):420-430.

Reef, J., Diamantopoulou. S., van Meurs, I., Verhulst, F., & van der Ende, J. (2009). Child to adult continuities of psychopathology :A 24-year follow-up. Acta Psychiatrica Scandinavica, 120, 230-238.

Rice, P.F. & Dolgin, K.G. (2002). Adolescent, The: Development, Relationships, and Culture, 12th ed. Ohio Wesleyan University.

Rudy, B.I., Murphy, D.A., Harris, D.R., Muenz, L., Ellen, J. (2010). Patient Risks to Antiretroviral Therapy among HIV-infected Youth in the United States: A study of Prevalence and Interactions. AIDS Patient Care and STDs 23(3): 185-194

Schoeman, J., (2008, March). Support groups in HIV and Mental illness. HEARD. Retrieved February 18, 2014 from http://www.heard.org.za/support-groups-within-the-hiv-and-mental-health-services-are-they-sufficient

Sexual and reproductive health for young HIV positive adolescents: The club concept in support groups. Johannesburg: Anova Health Institute; 2011.

Shenton, A.K. (2004). Information-seeking research in schools: opportunities and pitfalls. Retrieved in 2015 from www.emeraldinsight.com

Shisana, O., Rehle, T., Simbayi, L., Parker, L., Zuma, K., Bhana, A., Connolly, C., Jooste, S., Pillay, V., Mbhele, N., Managa, A., Ramlagan, S., Zungu-Dirwayi, N., Louw, J., van Wyk, B., Tamasane, T., Petros, G., Freeman, M., Kelly, K., Tshose, P., Letlape, L., Naidoo, E., Henda, N., Mqeketo, A., Prince, B., Shaun, Y., 2005. South African National HIV prevalence, HIV incidence, behaviour and communication survey. HSRC Press: Cape Town.

Siegal, K. & Lekas, H.M. (2002). AIDS as a chronic illness: psychosocial implications. Center for the Psychological Study of Health & Illness, Mailman School of Public Health, Columbia University, New York, 10032, USA.

Silverman, D. (2000). Doing qualitative research: A practical handbook. Thousand Oaks, CA:Sage.

Southern African HIV Clinicians Society (2013). Management of mental health disorders in HIV positive patients. G. Johsson [Guideline]. Johannesburg

Streubert, H.J, Carpenter, D.R. (1995). Qualitative research in Nursing: Advancing the Humanist Imperative. Philadelphia: Lippincott.

Stigma Project (2007). Final Report: The Influence of Stigma on Access to Health Services by Persons with HIV illness. Alberta. Retrieved April, 04, 2014 from www.thestigmaproject.org/

Terre, B. M., Durrheim, K., & Painter, D. (Eds.) (2006). Research in Practic Applied methods for the social sciences. Cape Town: University of Cape Town Press.

The Mental Health and HIV/AIDS Georgia Expert Centre. (2008). Mental Health Issues and support structures concerning people living with HIV/AIDS in Georgia. Retrieved from www.bemonidrug.org.ge/

Tobin, GA & Begley, C.M. (2004). Journal of Advanced Nursing 48(4, 388-396). Methodological rigour within a qualitative framework.

World Health Organization. Comprehensive Mental Action Plan 2013-2020. Geneva: World Health Organization, 2013.

World Health Organization. Research Ethics Review Committee (WHO ERC).

The Process of Obtaining Informed Consent. Retrieved 2016 from http://www.who.INT/RPC/RESEARCH-ETHICS

University of Zululand
Private bag x1001
KWADLANGEZWA
3886

21 October 2014

The Manager
Madadeni Hospital
P/Bag X6642
Newcastle
2940

Dear Sir/Madam

PERMISSION TO CONDUCT RESEARCH: MENTAL HEALTH STATUS OF SCHOOL GOING ADOLESCENTS ON ANTIRETROVIRAL THERAPY ON MADADENI, AMAJUBA DISTRICT, KWAZULU-NATAL

I request permission to conduct research in your health facility. This research project is titled, **Mental Health Status of School going Adolescents on Antiretroviral Therapy in Madadeni, Amajuba District, KwaZulu-Natal**. I am doing a research study to learn about the mental health status of school going adolescents on antiretroviral therapy (ART) in this health facility. The study is supported by the University of Zululand (UniZulu), Department of Educational Psychology and Special Education. We are conducting the study in the health facility based in Amajuba district in KwaZulu-Natal, South Africa. Most health centers in Amajuba district are enrolling HIV positive patients on antiretroviral therapy (ART). We are exploring the mental health status of adults on antiretroviral therapy in this health facility.

I, the researcher, will be undertaking study activities in your health facility. We will interview 28 patients from this health facility to learn about patients' perspectives and experiences with ART. Finally, 1 focus group discussion will be conducted with 6-8 patients. In order not to disrupt service provision in the site, these interviews will be held at times convenient to patients and service providers.

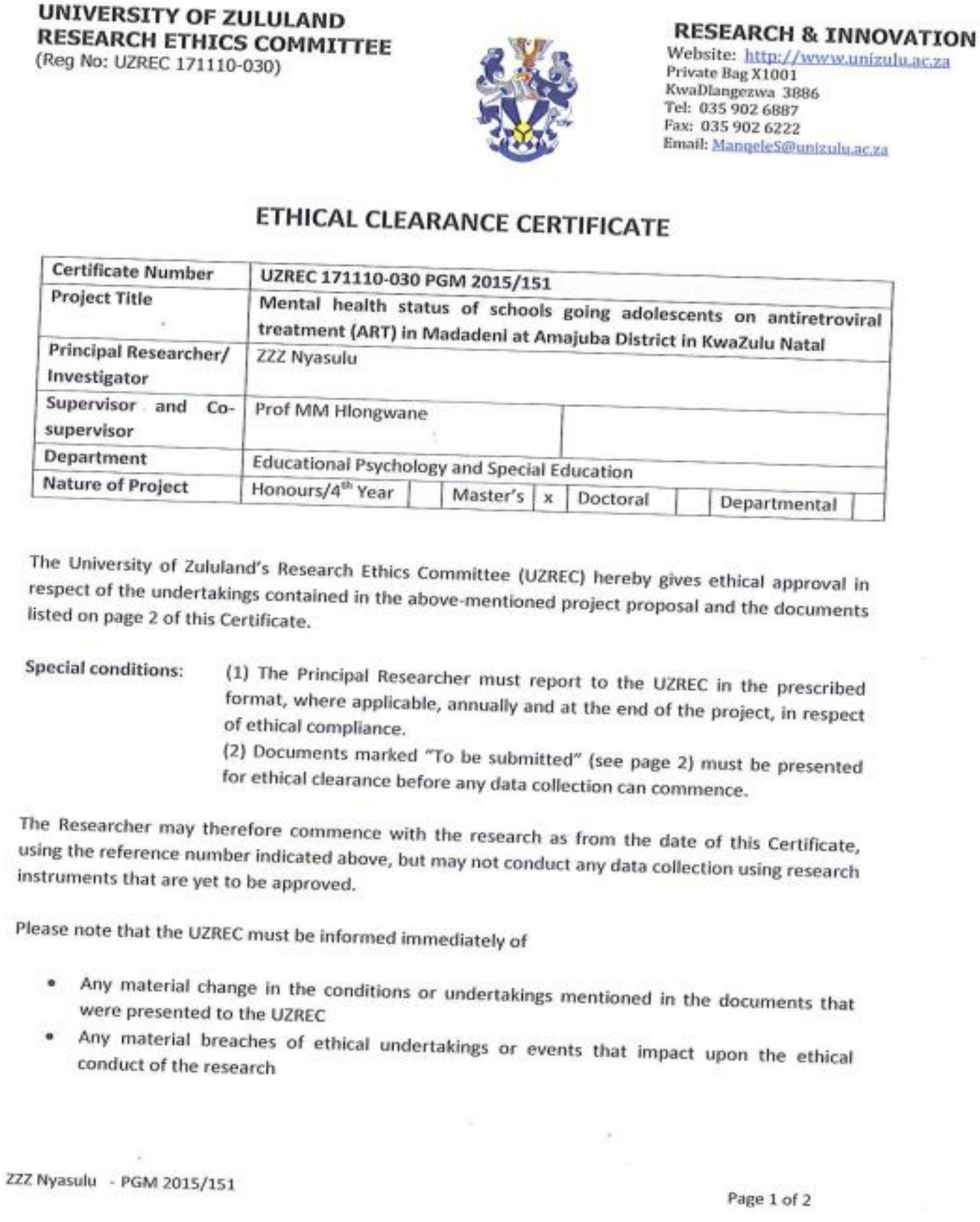
Should my request meet your favourable consideration, kindly respond by sending me a letter stating that your facility grants me permission to conduct research mentioned above. This letter will be submitted to the Research Board of the University of Zululand as one of the requirements for the committee to process research ethical approvals. The study will start as soon as I am granted permission to access the research site.

Kindly contact me if you have any questions or require more information.

Yours sincerely

____

Miss Zinandi Ziyanda Zipho-zethu Nyasulu
Masters Student, University of Zululand (UniZulu)
zinandin@yahoo.com
Department of Educational Psychology and Special Education



UNIVERSITY OF ZULULAND
RESEARCH ETHICS COMMITTEE
(Reg No: UZREC 171110-030)

RESEARCH & INNOVATION
Website: http://www.unizulu.ac.za
Private Bag X1001
KwaDlangezwa 3886
Tel: 035 902 6887
Fax: 035 902 6222
Email: MangeleS@unizulu.ac.za

ETHICAL CLEARANCE CERTIFICATE

Certificate Number	**UZREC 171110-030 PGM 2015/151**
Project Title	**Mental health status of schools going adolescents on antiretroviral treatment (ART) in Madadeni at Amajuba District in KwaZulu Natal**
Principal Researcher/ Investigator	ZZZ Nyasulu
Supervisor and Co-supervisor	Prof MM Hlongwane
Department	Educational Psychology and Special Education
Nature of Project	Honours/4th Year ☐ Master's x Doctoral ☐ Departmental ☐

The University of Zululand's Research Ethics Committee (UZREC) hereby gives ethical approval in respect of the undertakings contained in the above-mentioned project proposal and the documents listed on page 2 of this Certificate.

Special conditions: (1) The Principal Researcher must report to the UZREC in the prescribed format, where applicable, annually and at the end of the project, in respect of ethical compliance.

(2) Documents marked "To be submitted" (see page 2) must be presented for ethical clearance before any data collection can commence.

The Researcher may therefore commence with the research as from the date of this Certificate, using the reference number indicated above, but may not conduct any data collection using research instruments that are yet to be approved.

Please note that the UZREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the documents that were presented to the UZREC
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Health Research & Knowledge Management sub-component
10 – 103 Natalia Building, 330 Langalibalele Street
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www.kznhealth.gov.za

Reference : HRKM197/15
NHRD Ref.: KZ_2015RP57_295
Enquiries : Ms G Khumalo
Telephone : 033 – 395 3189

Dear Ms Z Nyasulu

Subject: Approval of a Research Proposal

1. The research proposal titled **'Mental health status of school going adolescents on antiretroviral treatment (ART) in Madadeni at Amajuba District in KwaZulu-Natal'** was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

The proposal is hereby **approved** for research to be undertaken at Madadeni Hospital.

2. You are requested to take note of the following:
   a. Make the necessary arrangement with the identified facility before commencing with your research project.
   b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Ms G Khumalo on 033-395 3189.

Yours Sincerely

Dr E Lutge
Chairperson, Health Research Committee
Date: 19/08/15

uMnyango Wezempilo, Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

Consent Form – Patient Interview

Mental Health Status of School going Adolescents on Antiretroviral Therapy on Madadeni, Amajuba District, KwaZulu-Natal

A. PURPOSE

Hello, my name is Zinandi Nyasulu; I am a Masters student studying at the University of Zululand (UniZulu).

We are doing a research study to learn about the mental health status of school going adolescents on antiretroviral therapy in this health facility. The study is supported by the University of Zululand, Department of Educational Psychology and Special Education. We are conducting the study in the health facility based in Amajuba district in KwaZulu-Natal, South Africa. Most health centers in Amajuba district are enrolling HIV positive patients on antiretroviral therapy (ART). We are exploring the mental health status of school going adolescents on antiretroviral therapy in this health facility. We will interview patients from this health facility to learn about patients' perspectives and experiences with ART. We would like to invite you to participate in this interview because you are receiving health service from this facility. We would like to get your thoughts, perspectives and/or experiences with ART. Your thoughts can help us to offer better services in the future.

B. PROCEDURES

If you agree to be in this study, you will be asked to answer some questions about the services you received today. This will take about 30-45 minutes of your time.

C. DISCOMFORTS AND RISKS

There are no physical risks to you by participating in this interview. However, some questions are sensitive and may be hard to talk about; they may make you feel uncomfortable or embarrassed. These include questions about your knowledge of HIV. Doing this interview is VOLUNTARY. You have the right to refuse to answer any question. You can end the interview at any time. You can refuse to answer a question or refuse to participate at any time. If you do not answer a question or want to end the interview, there will not be any penalty to you. This will not affect the medical care that you receive. Your name will not be attached to your answers.

D. BENEFITS

You may benefit from the opportunity to discuss the interview content, including your opinions about the mental health issues and to gain further information about antiretroviral therapy following the interview. The information you give us may help us offer better services at this health facility.

E. COMPENSATION

You will not receive any compensation for the time you spend taking part in the interview.

F. PERSONS TO CONTACT

If you have any questions now, please ask me. If you have any questions in the future, there is someone that you can contact.

If you have any concerns about your rights in this study and or if you feel that you have been harmed by or have questions about this study, please contact my supervisor, Prof. M.M. Hlongwane at **(035) 9026237**.

G. CONFIDENTIALITY STATEMENT

What you tell us is confidential. Efforts will be made to protect your privacy. No one except me and the research staff will have access to your interview and this information will not be traceable to you, because we are not collecting any of your personal contact information (not your name, phone number or address). Your interview will have a code number. Your name will not be on this interview or in any report about this study. Answers to questions regarding possible illegal behavior will be held in strict confidence. All information will be kept in a locked file cabinet and will not be available to others. There will be no way to connect any of your answers with your name.

H. RIGHT TO REFUSE OR WITHDRAW

Doing this interview is VOLUNTARY. You have the right to refuse to answer any question. You can end the interview at any time. You can refuse to answer a question or refuse to participate at any time. If you do not answer a question or want to end the interview, there will not be any penalty to you. This will not affect the medical care that you receive. Your name will not be attached to your answers.

I. AGREEMENT

Do you have any questions?

Interviewer: Answer the participant's questions about the interview before proceeding to the next question.

You have read or had read to you the explanation of this study. You have been given a copy of this form. You have had your questions answered. You have the right to refuse participation.

I am going to ask for your consent to participate in this interview. Do you agree to take part in the interview?

Participant consents to the following:
(Check one)

☐ Taking part in the interview
☐ Declined participation

I have fully explained to the participant the nature and purpose of the procedures described above and the risks involved in its performance. I have asked if any questions have arisen regarding the procedures and have answered these questions to the best of my ability. By signing this form I am agreeing to participate in the interview and for the audio recording to be done during the interview.

Signature of parent/guardian: ____________________

Signature of participant (assent): __________________

Researcher's Signature: ________________________
Date: _______________

Ifomu lokuvuma – Ingxoxo nesiguli

Ukuma kwesimo sempilo yengqondo yezingane zesikole abadla umshanguzo wesandulela ngculazi Madadeni, kusifunda saseAmajuba, KwaZulu-Natal.

A. INHLOSO

Sawubona, igama lami ngingu Zinandi Nyasulu; ngingumfundi we Masters esikhungweni sezemfundo esiphezulu sase Zululand (UniZulu).

Senza ucwaningo ukwazi kabanzi ngokuma kwempilo yengqondo yezingane zesikole abadla umshanguzo wesandulela ngculazi. Lolu cwaningo luxhaswe ngezimali yiHealth Research Council yasesikhungweni sezemfundo esiphakeme sase Zululand.Lolu cwaningo lwenziwa esikhungweni sezempilo esikusifunda saseAmajuba,saKwaZulu Natal, eNingizimu neAfrica. Izikhungo zempilo eziningi zifaka iziguli ezinesandulela ngculazi ohlelweni lokuqala imshanguzo yesandulela ngculazi.Sihlola kabanzi ngokuma kwempilo yengqondo yezingane zesikole abadla umshanguzo wesandulela ngculazi abakulesikhungo sezempilo. Sizoxoxisana neziguli ezelashwa kulesikhungo ukuthola uvo nesipiliyoni sabo ngohlelo lwemshanguzo yesandulela ngculazi.Siyakumemaukuba ubambe iqhaza kulengxoxo ngoba njengengxenye yokuvakashela kwakho kulesikhungo sezempilo namuhla ulutholile usizo lwezempilo.Sithanda ukuzwa imicabango, uvo nesipiliyoni sakho ngohlelo lomshanguzo wesandulela ngculazi. Imibono yakho ingasisiza ukuba sinikeze usizo olungcono kakhulu ngokuzayo.

C. OKUZOKWENZIWA

Uma uvuma ukuba kulolu cwaningo, uzocelwa ukuba uphendule imibuzo mayelana nosizo olutholile namuhla. Lokhu kuzothatha imizuzu engu 30-45yesikhathi sakho.

D. UKUNGAKHULULEKI NOBUNGOZI

Abukho ukungozi obuphathekayo obungakwehlela ngokubamba kwakho iqhaza kule ngxoxo. Inxoxo yethu izoqoshwa ukuze izohlaziywa kahle umcwaningi, unelungelo lokunqaba ukuthi iqoshwe kepha okumele ukwazi ukuthi ekuqoshweni kwayo izolalelwa umcwaningi nomlekeleli womcwaningi kuphela.Nokho-ke,eminye imibuzo mide futhi ibucayi futhi kungenzeka kube lukhuni ukukhuluma ngayo; ingakwenza uzizwe ungakhululekile noma ube namahloni. Lokhu kubandakanya imibuzo mayelana nolwazi lwakho ngegciwane lesandulela ngculazi nomlando wakho kwezocansi.Ukuba kulengxoxo KUNGOKOKUZINIKELA. Unelungelo lokwenqaba ukuphendula noma yimuphi umbuzo. Ungayimisa lengxoxo nganoma yisiphi isikhathi futhi uzokwedluliselwa kumeluleki uma lolo sizo uludinga. Ungenqaba ukuphendula umbuzo noma ukubambiqhaza nganoma yisiphi isikhathi. Uma wenqaba ukuphendula umbuzo noma uyeka ukubambiqhaza engxoxweni, angeke ujeziswe ngalokho. Lokho ngeke kube namthelela osizweni lwezempilo olutholayo. Igama lakho angeke limbandakanywe nezimpendulo zakho.

D. IMIHLOMULO

Ungahlomula ngokuthola ithuba lokukhuluma ngezinto eziphethwe yile ngxoxo kubandakanya imibono yakho ngosizo lwezempilo ozitholayo emtholampilo nokuzuza ulwazi oluthe xaxa ngesimo sengqondo nolwazi ngokulashwa ngemishanguzo yesandulela ngculazi emva kwengxoxo.Ulwazi ozosinika lona luzosisiza ukuthi sinikeze usizo olungcono kulesi sikhungo.

E. OZOKUPHIWA

Akukho ozophiwa khona ngesikhathi sakho ozosichitha ubambe iqhaza kule ngxoxo.

F. ONGABATHINTA

Singathanda ukuba siyiphendule yonke imibuzo yakho. Uma unemibuzo njengamanje, sicela uyibuze. Uma kunemibuzo oba nayo ngokuzayo, kunabantu abambalwa ongathintana nabo.

Uma unokungeneliseki mayelana namalungelo akho kulolu cwaningo noma uzwa ukuthi uzwiswe ubuhlungu noma unemibuzo mayelana nalolu cwaningo, sicela uthintane noMphathi wami uProf. M.M. Hlongwane kulenombolo **(035) 9026237**.

G. UKUGCINWA KWEMFIHLO

Konke ozositshela kona kuyimfihlo. Iyokwenziwa imizamo yokuvikela imfihlo yakho. Akekho noyedwa, ngaphandle kwabasebenzi balolu cwaningo kanye nabasemnyangweni kazwelonke wezempilo oyofinyelela kulengxoxo yakhofuthi lolulwazi angeke lubandakanywe nawe, ngoba asiyithathi imininingwane ekuchazayo (hhayi igama lakho, inombolo yocingo nomaikheli). Le ngxoxo yakho iyoba nenombolo eyikhodi. Igama lakho angeke libe kule ngxoxo noma kunoma ngabe yimuphi umbiko ozobhalwa mayelana nalolu cwaningo. Izimpendulo zemibuzo mayelana nezenzo ezingekho emthethweni zizogcinwa ziyimfihlo. Yonke imininingwane echazayo iyogcinwa ekhabetheni elihluthulelwayo futhi angeke ivuleleke kwabanye. Angeke ibe khona indlela yokuxhumanisa izimpendulo zakho negama lakho.

H. ILUNGELO LOKWENQABA NOKUYEKA UKUBAMBA IQHAZA

Ukuba kulengxoxo KUNGOKOKUZINIKELA. Unelongelo lokwenqaba ukuphendula noma yimuphi umbuzo.Ungayimisa lengxoxo nganoma yisiphi isikhathi.Ungenqaba ukuphendula umbuzo noma ukubambiqhaza nganoma yisiphi isikhathi. Uma wenqaba ukuphendula umbuzo noma uyeka ukubambiqhaza engxoxweni, angeke ujeziswe ngalokho. Lokho ngeke kube namthelela osizweni lwezempilo olutholayo. Igama lakho angeke limbandakanywe nezimpendulo zakho.

I. ISIVUMELWANO

Ngabe unayo imibuzo?

Obuzayo: Phendula imibuzo yobambiqhaza mayelana nnengxoxo ngaphambi kokudlulela embuzweni olandelayo.

Uyifundile noma ufundelwe incazelo ngalolu cwaningo. Unikiwe ikhophi yaleli fomu. Iphenduliwe imibuzo yakho. Unelungelo lokwenqaba ukubamba iqhaza.

Ngizocela ukuba unginike imvume yokuba ubambe iqhaza kule ngxoxo. Ngabe uyavuma yini ukubamba iqhaza kule ngxoxo?

Obambiqhaza uvuma lokhu okulandelayo:

(Khetha kube kunye)

- ☐ Ukubambiqhaza engxoxweni
- ☐ Wenqabile ukubambiqhaza

Ngichazile kabanzi kobambiqhaza isimo nenhloso yesikwenzayo okuchazwe ngenhla nobungozi obungenzeka uma kwenziwa. Ngibuzile ukuba ikhona imibuzo evelile mayelana nendlela okuzokwenziwa ngayo ngayiphendula leyo mibuzo ngokusemandleni ami onke. Ngokusayina leli fomu ngiyavuma ukuthi ukubambiqhaza kule ngxoxo nokuqoshwa.

Usuku: ________________Isiginesha yomzali/umbheki:________________

Isiginesha yobuzwayo (assent): __________________________

Isiginesha yobuzayo: ________________________

ART PATIENT CONVERSATION GUIDE (ENGLISH VERSION)

A) Personal history/ Personal circumstances

Please tell me about how your life is going these days: where you live, with whom, your work, your relatives, etc.

(Conversation check points)

- Living situation
- Family and friends
- Participation in groups and associations
- Education
- Plans for the future

B) Daily life/ Daily routine

Please tell me about what you do on a daily basis to earn living, hobbies, means of entertainment, how often you visit others, etc.

Please tell me what happened yesterday.

(Conversation check points)

- Daily activities
- Social gatherings
- Alcohol consumption
- school
- Diet
- Travel
- Obtaining food to eat on a regular basis

C) Learning about their HIV status

Please tell me about the circumstances that led you to get tested for HIV for the first time: where, when and how it happened.

Was everything explained well to you?

How has not knowing your status affected your life as a whole?

(Conversation check points)

- Where and when they were tested
- Advice they were given when they received results
- Who knows about their HIV status
- How they learned and why they were told

D) Enrollment into the ART programme

Please give us the full details of how you joined the ART programme; how you heard about it, what were your expectations and how it has been to you ever since you've started, etc.

(Conversation checkpoints)

- How they heard about the programme
- Expectations of ART
- How they entered into the programme
- How long they have been in the programme

E) ARV intake procedure

Could you please tell me about the procedure you follow when taking your medication: where do you get them, how often do you take them and how often do you fetch them, is there anyone who accompanies you, etc.

(Conversation check points)

- Specifics of taking the treatment
- Who knows about their taking of ARVs
- How they learned and if they were told, why were they told?
- How do they collect the drugs and how often do they collect them.
- Do they experience any discrimination once they are in the facility or outside the facility?
- How often do they meet with counsellors at the facility

F) Ways they have found to help them take their treatment

It is of interest to hear about the ways you use to remember taking your treatment, and if you still adhere to the treatment or have you stopped taking it. How has it been for you?

(Conversation check points)

- Other people who assist them
- Getting the necessary food
- Keeping their taking of ARVs a secret
- Things they have tried to help them which have failed

G) Effects on them of taking the treatment

Once you had started treatment how did the ARVs affect you and your life as a whole?

Have there been any major changes in your life or your family? Please specify.

(Conversation check points)

- Their health
- Their thinking process
- Their schedule
- Their social relations
- Their sexual relations
- Their daily activities

H) Circumstances that have made it difficult to take treatment regularly

Are there things that make it difficult to take the treatment regularly?

(Conversation check points)

- Disclosing to others that they take ARVs
- Are they able to remember the time for taking their treatment?
- Are they free to take their treatment in front of others?
- Lack of knowledge of what not adhering can do to the system.

Thank you very much for your time. Is there anything you feel I have left out or just anything that you feel I should know?

ART PATIENT CONVERSATION GUIDE (isiZulu VERSION)

IMIBUZO NEZIHLOKO NGEZIGULI ZE ART

A) Umlando ngawe

Ngicela ungitshele ukuthi impilo yakho ihamba kanjani kulezizinsuku: uhlala kuphi; nobani; umsebenzi wakho;izihlobo zakho njalonjalo.

(Okumele kuvele enxoxweni)

- Isimo senhlalo
- Umndeni nabangani
- Ukubamba iqhaza emaqenjini nasezinhlanganweni
- Imfundo
- Izinhlelo noma amaqhinga ngekusasa

B) Impilo yansukuzonke

Ngicela ungitshela ngokuthi wenzani usuku nosuku ukuziphilisa; ukuchitha iskhathi uzithokozisa ; ukuvakasha nokunye njalonjalo.

Ngicela ungitshela ukuthi kwenzakaleni izolo.

(Okumele kuvele enxoxweni)

- Imisebenzi yansuku zonke
- Ukuhlangana ngobungani
- Ukuphuza amanzi aponjwayo/ ukucisha ukoma
- Isikolo
- Izinhlelo zokudla
- Ukuhamba
- Ukuthola ukudla okudla nsukuzonke

C) Ukwazi ngesimo sabo segciwane lesandulela ngculazi

Ngicela ungitshele ngesimo noma izimo ezikudonsele ekutheni uhlolelwe isandulela ngculazi okokuqala: kuphi futhi nini, ingabe kwenzeka kanjani.

(Okumele kuvele enxoxweni)

- Kwakukuphi futhi kwakuyinini behlolwa igciwane
- Izeluleko abazithola ngenkathi bemukela imiphumela
- Ubani owaziyo ngesimo sabo ngegciwane
- Bazi kanjani futhi batshelelwani labo
- Isimo somqondo saba njani mhla bezwa

D) Ukungeniswa kuloluhlelo lwe ART

Ngicela usitshela ngokuphelele ukuthi wangena kanjani kuloluhlelo lwe ART: wazi kanjani ngalo noma wezwa kanjani ngalo, yini owawuyilindele , kwabanjani kuwena, njalonjalo.

(Okumele kuvele enxoxweni)

- Bezwa kanjani ngohlelo
- Okulindelekile nge ART
- Bangena kanjani ohlelweni
- Sekuyisikhathi esingakanani beyinxenye yohlelo

E) Inqubo yokuthatha ama ARV

Bengisacela ungitshela uhlelo noma inqubo oyilandelayo uma uthatha umshanguzo wakho; uwuthola kuphi; uvame ukuwathatha kanjani futhi uvame ukuwalanda kawungakhi ; ukhona yini okuphelezelayo uma uyowalanda, njalonjalo, uyakuthokozela yini ukuwulanda.

(Okumele kuvele enxoxweni)

- Imigomo yokuphuza umshanguzo
- Ubani owaziyo ngokudla kwabo imishanguzo
- Bazi kanjani labo bantu, ubani owabazisa futhi baziselwani
- Ingabe bayilanda kanjani futhi nini imishanguzo
- Ingabe bayabhekani yini nobandlululo uma sebephakathi noma bengaphandle kwesikhungo abalashwa kuso.
- Bavame ukuhlangana nini nabaluleki bezempilo basesikhungweni, bayakubika yini ukukhathazeka uma kukhona

F) Izindlela abazitholile zokubasiza ekuthatheni imishanguzo

Ngingathanda ukwazi ngezindlela ozisebenzisayo zokuthi ukhumbule futhi uqhubeke ukuthatha imishanguzo yakho; nokuthi usayiphuza ngohlelo yini noma awusayithathi nhlobo.

(Okumele kuvele enxoxweni)

- Abanye abantu ababasizayo
- Ukuthola ukudla okudingekayo
- Ukufihla kwabanye ukuthi bathatha imishanguzo
- Izinto abazizamile ukuzisiza ngazo, zanga phumelela

G) Imithelela yokuthatha imishanguzo

Mhla uqala ukuthatha imishanguzo ngendlela ngabe yakuphatha kanjani noma abanjani kuwe futhi nasempilweni yakho iphelele?

(Okumele kuvele enxoxweni)

- Impilo yabo
- Indlela/ Isimo sokucabanga
- Ngohlelo lwabo lansukuzonke
- Ngobudlelwane babo nabantu noma umphakathi
- Ngobudlelwane babo ngokocansi
- Imisebenzi yabo yansukuzonke

H) Izimo ezike zenza kwabanzima ukuthatha imishanguzo ngokujwayelekile

Zikhona yini izinto noma izimo ezenza kubenzima ukuthatha imishanguzo ngokujwayelekile?

(Okumele kuvele enxoxweni)

- Ukwazi kwabanye ukuthi bathatha imishanguzo
- Bayakwazi yini ukukhumbula isikhathi sokuthatha amaphilisi
- Ingabe bakhululekile ukuthatha imshanguzo yabo phambi kwabantu.

- Ukungabi nalwazi lokuthi ukungawuthathi ngendlela umshanguzo kungenzani emzimbeni.

Ngiyabonga kakhulu ngesikhathi sakho. Ingabe kukhona yini ocabanga ukuthi ngikushiyile noma ocabanga ukuthi kufanele ngikwazi?